

Vulnerable groups and access to health care: a critical interpretive review

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Executive summary

Aim of the review

We report a critical interpretive review of access to health care by vulnerable groups. An interpretive synthesis does not simply produce a summary of the evidence; it interprets it in ways that are insightful and useful. Our aim was to produce *theory*: a logical, plausible and useful explanation, grounded in a comprehensive but not exhaustive body of evidence, about access to health care.

Methodology

We developed a new methodology, with its origins in meta-ethnography, in order to conduct the review. This methodology, which we termed 'critical interpretive synthesis' starts with a fuzzy and tentatively defined phenomenon; conducts extensive though not exhaustive searching; strategically samples from the literature; conducts appraisal and critique of the included papers and, through a process similar to primary qualitative research, aims to produce a theoretical output in the form of *synthesising argument*.

Findings

- Precise definitions of access to health care and equity of access have remained elusive. It has proved even more difficult to operationalise these for purposes of research.
- The practical consequence of problems of defining and measuring access is a set of methodological, conceptual, and theoretical problems in investigating access, and in investigating the extent to which access is equitable in particular.
- Studies of utilisation and receipt of health care show some evidence of distinctive patterning according to age, gender, socio-economic advantage and ethnicity, but the data remain difficult to interpret and inconclusive. For example the evidence does not consistently point to poorer access for socio-economically disadvantaged people, even when need is accounted for: some studies even suggest that there is a pro-poor bias in the NHS.
- The most useful way of understanding access to health care is in terms of 'candidacy'. **Candidacy** describes the ways in which people's eligibility for medical attention and intervention is jointly negotiated between individuals and health services. Candidacy is a dynamic and contingent process, constantly being defined and re-defined through interactions between individuals and professionals, and managed in the context of operating conditions, including the biography of the relationship between patients and staff, the typifications staff use in categorising people and diseases, availability of resources, local pressures, and policy imperatives.

- Cultural expectations affect people's help-seeking. For example expectations of what is gender-appropriate may deter men from seeking help, while those living in conditions of socio-economic disadvantage or older people may 'normalise' symptoms with reference to those around them.
- People's preferences for particular forms of services, and their perceptions of the quality of services, influence their willingness to use services. People are especially unwilling to use services that they perceive to be of poor quality or to be hostile to them.
- People need to be able to identify and evaluate their symptoms and to negotiate routes to health care, and these tasks may require particular sets of competencies and resources that may be patterned by age, gender, social class, or ethnicity.
- Ability to attend health services may depend on being able to make arrangements – for example in relation to language, transport, and care of others – that may make using health services more difficult for some groups. The help available for making such arrangements is variable.
- There has been an effort to ensure that health services are not over-burdened by people seeking help for minor, self-limiting illnesses. The moral character that has been imposed on help-seeking as a result has made people highly sensitive to the demands on professional time.
- Services can be conceptualised in terms of how **porous** or **permeable** they are. High permeability services are those that are most comfortable for people to use, that demand the fewest qualifications for candidacy, and that require less work. Services that are less permeable require much more work in order to gain a point of entry and sustain engagement with the service.
- Health care organisations often rely implicitly on an 'ideal user', who is able to match the precise set of competencies and resources to the way in which the service is intended to be used by providers, and whose preferences are in line with the way the service is organised and delivered.
- Cultural dissonance – discord between the cultural norms of health care organisations and their imagined ideal user – creates low permeability. People of minority ethnicity may become alienated from organisations that appear to stereotype them or treat them with a lack of sensitivity, though the direct evidence of interactions between minority users and providers is lacking.
- Lack of capacity, variations in quality, differences in resource allocation and features of service configuration, including geographical patterning and concentration of services, all create access-disadvantaged groups, but the effects of increasing capacity are not well understood.

- Dedicated services for specific conditions or specific patient groups have been evaluated in several settings, and while they appear to be popular with patients, require more comprehensive evaluation, particularly as to their system-level effects.
- People in more deprived circumstances do show a readiness to consult, but are more likely to manage health as a series of minor and major crises, rather than treating diseases as requiring maintenance and prevention. This is likely to be linked to the normalisation of ill-health in more deprived communities as well as the range of resources people are required to mobilise to use services.
- Using health services requires considerable work on the part of people. People have to mobilise a range of resources, including knowledge and information resources, social, language and support resources, and practical resources. There is evidence that socio-economically deprived people, older people, and people of minority ethnicity may be disadvantaged in their access to these resources.
- Provision of language and interpreting services is variable and patchy, and causes difficulty for people who cannot speak English.
- Having to co-ordinate aspects of candidacy through organisational turbulence and fragmented boundaries poses considerable challenges and drains resources.
- Being a resident of a nursing or residential home is a barrier to accessing both mainstream and specialist NHS services.
- By putting in an appearance at health services, people are making a claim to candidacy for medical attention or intervention. However, their ability to make presentations that allow their candidacy to be judged appropriately is variable.
- Health professionals are required to make 'adjudications' based on their judgements of health needs. There is concern that the ways in which adjudications are made by health professionals may disadvantage people of minority ethnicity, different genders, older people, and socio-economically disadvantaged people. Adjudications are made in the context of operating conditions, including scarcity of resources.
- Health professionals may make offers of health care to people, based on their adjudications of people's candidacy. People may therefore choose to decline offers made by health services, but this important aspect of access has been relatively little studied.
- There is also need for caution and attention to the unwanted consequences of identifying and making offers to people on the basis of assumptions about 'unmet need'.

Conclusions

A focus on candidacy helps to identify where and when people are vulnerable: at the stage of recognising and acting on candidacy, in navigating routes to enter and sustain engagement with services; in the ways they present at services; in the ways in which claims to candidacy are judged and adjudicated; in the offers that are made to them; and in their willingness or ability to accept or reject those offers. It also helps to recognize the influence of 'operating conditions' in the form of wider contexts. Particular groups may experience amplified vulnerabilities in relation to some aspects of candidacy.

Recommendations for future research

Research is needed across the entire range of candidacy issues. Areas that are particularly under-researched include: whether the amount of work people have to do to use health services varies systematically between different groups; how practitioners make judgements and categorisations of people's eligibility for health care; whether evidence-based guidelines tend to disadvantage particular groups through their specification of eligibility criteria; exploration of whether 'acceptance' by patients of offers made by practitioners varies between different groups, and why; research on the impact of dedicated services, and evaluations of anti-discrimination interventions.

Recommendations for policy and practice

- Information resources about illness should be available in forms that people can find and use readily, but it should also be accepted that educational interventions are likely to have only limited impact in altering help-seeking behaviour, and only then for specified conditions.
- Simplistic assumptions about 'deficits' in people's knowledge should be avoided. The potential for interventions aimed at promoting 'appropriate' help-seeking to discourage 'appropriate' help-seeking, by imposing a moral character on using health services, needs to be recognised.
- The proliferation of organisational forms in the NHS needs to be managed carefully to avoid creating risks for candidacy.
- High levels of non-attendance at services should be treated as a signal of low permeability i.e. a service that is difficult for people to use. Services should assess the extent to which there is social, ethnic, gender, or age patterning of non-attendance and investigate (probably using qualitative methods) reasons for these.
- Services need to establish how much work people have to do, how many resources they need to mobilise in order to use them, and how comfortable people feel about using services. This may be achieved by audits where users are asked about, for example,

transport, workplace and childcare arrangements and arrangements for accompaniment or language.

- Services, particularly those that offer preventive or health-maintaining care, need to evaluate how they can make themselves most congruent with the ways in which potentially vulnerable groups tend to use health care.
- Practitioners need to be reflexive (i.e. engage in critical self-reflection) and be explicit about how they respond to presentations and make adjudications about people; and they need to identify the heuristics (rules of thumb) they use in assessing people's eligibility for particular services.
- It will also be important to recognise the team-based nature of many decision-making processes, and to understand the contributions that different members of the team make, as well as how the patient's view is incorporated in the negotiations.
- The impact on equity of evidence-based guidelines on managing health conditions should be assessed.
- The debate about whether there should be specialised services for particular groups has not yet been resolved. Any evaluation of specialised services needs to pay careful attention to the unwanted effects of specialised services.

The Report

Section 1 Introduction and methodology

1.1 Introduction

The literature in the area of access to health care is large, diverse, and complex. It includes empirical work using both qualitative and quantitative methods (and a diversity of approaches within these two broad methodologies); editorial or speculative comment and theoretical work; case studies and case reports; evaluative, epidemiological, trial, descriptive, sociological, psychological, management, and economics papers, as well as policy documents and political statements. Many of the literatures on access are very large – for example, a systematic review of ethnicity and health service access in London identified over 2,000 relevant papers (Atkinson *et al.* 2001). In addition, there are substantial adjunct literatures that are important in explaining access. For example, there are large literatures on quality in health care, priority-setting, and patient satisfaction, all relevant to access. 'Access' itself has not been consistently defined or operationalised across the field. The challenge in producing a review of such an amorphous evidence base is to assemble the findings into a form that is useful in informing policy and that is empirically and theoretically grounded (Dixon-Woods and Fitzpatrick 2001).

In this *section* we explain the background to the methodology we developed and used for conducting a review of the literature on access to health care by vulnerable groups. We show that we aimed not to conduct a systematic review, but an interpretive review of a comprehensive (though not exhaustive) body of relevant literature. The aims of an interpretive review are to produce a critical overview of the evidence in a particular area, and to produce theory (i.e. an insightful and useful way of understanding a phenomenon which can be used to inform policy, practice, and future research).

1.2 Interpretive and aggregative reviews

Noblit and Hare (1988), in their pioneering book, introduced the useful distinction between *integrative* and *interpretive* reviews. They suggest that *integrative* reviews are rooted in the positivist paradigm, involve techniques such as meta-analysis, are concerned with assembling and pooling data, and require a basic comparability between phenomena so that the data can be *aggregated* for analysis. *Interpretive* reviews, on the other hand, see the essential tasks of synthesis as involving both induction and interpretation, and are concerned not to predict but to 'anticipate' what might be involved in analogous situations and to understand how things connect and interact. While the distinction

between integrative and interpretive review is very important and informative, we wish to elaborate on Noblit and Hare's original conceptualisation.

First, we propose replacing the term 'integrative' with the term 'aggregative', as we feel this is less prone to causing confusion. We further suggest that *aggregative* syntheses have two defining characteristics: first, a focus on *summarising data*, and second, an assumption that the concepts (or variables) under which those data are to be summarised are largely secure and well specified. For example, in an aggregative synthesis of interventions to improve uptake of breast-feeding, key concepts (intervention, uptake, breast-feeding) would be defined at an early stage in the synthesis and would effectively form the categories under which the data extracted from any empirical studies are to be summarised. This summary might be achieved through pooling of the data, using techniques such as meta-analysis, or less formally, through techniques such as providing a descriptive account of the data (often referred to as a narrative review). It is important not to exaggerate how secure such categories might be, of course: there may be debates within and external to a review team about the properties of categories – for example whether 'breast-feeding' should be defined only as exclusive breast-feeding and over what duration. However, the primary focus of an aggregative synthesis is not on the development of concepts, or their specification. This does not, of course, prevent aggregative syntheses from fulfilling theoretical or interpretive functions – indeed Noblit and Hare argue that all types of syntheses involve interpretation. The kinds of theory that aggregative syntheses may be especially likely to produce will often be theories of causality.

In an *interpretive* synthesis, the primary concern is with the development of concepts and theories that integrate those concepts. An interpretive synthesis will therefore avoid specifying concepts in advance of the synthesis; in contrast with an aggregative synthesis, it will avoid fixing the meaning of those concepts at an early stage, as one of its key aims is to generate those concepts. The analysis that yields the synthesis is conceptual in process and output, and the product is not aggregations of data, but theory. However, as with primary qualitative research, an interpretive synthesis does not float free of any empirical anchor: it must be grounded in the data reported in the studies included in the review. It is also important to stress that *interpretive* syntheses should not be limited to qualitative primary studies.

We report here an interpretive review of access to health care by vulnerable groups. The focus is on the development of concepts and theory grounded in empirical evidence, rather than on producing summaries of data. The choice of an interpretive synthesis approach has several implications for the review methodology, relating to the

formulation of the review question, the searching and selection of evidence, and the methods for synthesis.

We report an interpretive synthesis of access to health care by vulnerable groups. The aim of an interpretive synthesis is not simply to produce a summary of the evidence, but to interpret it in ways that are insightful and useful.

1.3 Practical constraints

This project had a timescale of 18 months and was intended to be conducted using meta-ethnography techniques (Noblit and Hare, 1988). Meta-ethnography is still an emerging methodology, and, prior to this project, had previously only been used with small sets of papers, and only on papers that were qualitative. What we were attempting to do using meta-ethnography – synthesise a large and diverse literature, incorporating many different paper types, in a relatively unfocused area – posed considerable challenges. We therefore had to undertake methodological work to ensure that we had a workable research process through which the review could be controlled.

We invested four months in a pilot exercise, scoping study, and development of procedures and systems for managing the project. This included a full work-up of a demonstration meta-ethnography on help-seeking in relation to children to test out procedures and processes, develop a methodology, and train the review team in its use. The pilot exercise also led to us making a number of pragmatic decisions about searching and selection of papers.

Following the pilot phase, we were left with 14 months to develop a general synthesis of the literature on access of health care, and syntheses for each of the five areas identified in our original application to the Department of Health: access to health care by socio-economically disadvantaged people, by people from minority ethnic groups, by people of both genders, by children and young people, and by older people. This meant that there was a maximum of nine to ten weeks available for each of these six areas (general plus five specific groups) in which to conduct searches, screen abstracts, obtain papers, screen for relevance, appraise papers, undertake data extraction, develop a synthesis, conduct quality checks, write up, and coordinate with the other syntheses. These constraints resulted in a number of pragmatic decisions, as we describe below.

1.4 Meta-ethnography

First proposed by Noblit and Hare (1988), meta-ethnography, as originally proposed, involves three major strategies:

1. **Reciprocal translational analysis.** The key metaphors, themes, or concepts in each study are identified. An attempt is then made to translate the concepts into each other. Judgements about the ability of the concept of one study to capture concepts from others are based on attributes of the themes themselves, including cogency, economy, and scope. The concept that is 'most adequate' is chosen.

2. **Refutational synthesis.** The key metaphors, themes or concepts in each study are identified, and contradictions between the reports are characterised. The 'refutations' are examined and an attempt made to explain them.

3. **Lines-of-argument synthesis** involves building a general interpretation grounded in the findings of the separate studies. In a process that can be likened to the constant comparison method for primary studies, the themes or categories that are most powerful in representing the entire dataset are identified by constant comparisons between individual accounts.

Meta-ethnography as originally proposed, however, is solely a method for synthesis, and offers little guidance on how to formulate questions for review, how to identify, appraise, and select studies for inclusion in a review, or on the procedures for conducting a synthesis. Though growing in popularity, there are, as mentioned earlier, relatively few worked examples of meta-ethnographies. All have involved small or very small numbers of studies in highly focused areas, and all have synthesised qualitative studies only. Nelson (2002) describes using meta-ethnography to synthesise 12 studies on mothering other-than-normal children. Beck (2000a) reports using meta-ethnography techniques to synthesise the findings of six qualitative studies on mothering of multiples and 18 qualitative studies on post-natal depression (Beck, 2000b). There additionally appears to be a small body of papers that has used Noblit and Hare's proposals informally (e.g. Cook *et al.*, 2001).

Recent years have seen attempts to develop and specify some of the methodology for meta-ethnography. Paterson *et al.* (1998) report what appears to be the largest meta-ethnography to date, involving the synthesis of 43 qualitative studies of the lived experience of diabetes, but their methods are not well documented. Britten *et al.* (2002) do offer a well-documented demonstration meta-ethnography to synthesise four papers on the meanings of medicines. They identified the key concepts in each paper and the main explanation or theory arising from each paper. In developing the grid, Britten and colleagues built on Schutz's (1962) notions of 'orders' of constructs. Schutz used 'first order construct' to refer to the everyday understandings of ordinary people and the term 'second order construct' to refer to the constructs of the social sciences. The explanations and theories used by authors in the original studies could therefore be seen as second order interpretations. Britten and colleagues used lines-of-argument synthesis to develop what they call

'third order interpretations'. These third order interpretations built on the explanations and interpretations of the constituent studies, and were at the same time consistent with the original results and also extended beyond them. They argue that these third order interpretations justify the claim that meta-ethnography achieves more than a traditional literature review, and also note that the process of qualitative synthesis cannot be reduced to a set of mechanistic tasks.

Campbell *et al* (2003), with the same team as Britten *et al* (2002), offer a similarly detailed and well-documented evaluation of meta-ethnography through a demonstration synthesis of papers on lay experiences of diabetes and diabetes care. Campbell and colleagues purposively sampled ten papers, which varied in terms of country of study, ethnic groups studied, and qualitative approaches employed. The papers were appraised using an adapted form of the Critical Appraisal Skills Programme (CASP) checklist, and seven papers were judged to be suitable for inclusion in the review after this process. Lists of the papers' findings were generated, using the authors' terms and concepts, and the 'key concepts were identified. A systematic search for the presence or absence of these concepts in all seven papers was then undertaken, in keeping with the requirements of reciprocal translational analysis. A higher-order analysis was then achieved through lines-of-argument synthesis, and allowed the identification and characterisation of what the authors call 'strategic non-compliance'. Third order constructs, and in particular the notion of 'achieving a balance' were found to be very important in explaining people's experiences of diabetes, but were not evident in the primary studies.

In this review we have built upon and adapted the methodological advances of Britten, Campbell and colleagues to adapt meta-ethnography as a methodology for synthesising a large and diverse literature. This has involved making a number of methodological innovations, relating to the synthesis of diverse evidence, the priority given to lines-of-argument synthesis, formulating the review question, searching, sampling, appraisal, data extraction, and use of software. These processes are summarised in Box 1.1. Because some of these processes are quite distinct from other approaches to meta-ethnography, we felt it was no longer appropriate to retain the term 'meta-ethnography' for what we did. In other areas of qualitative methodology where variants of particular approaches, such as grounded theory, are rife, it has proved unhelpful to continue to label new methodologies which have developed out of original approaches using the same name. We have termed our new approach 'critical interpretive synthesis'.

Box 1.1 Methods for critical interpretive review of access to health care by vulnerable groups

1. Our interpretive synthesis did not start with a precisely formulated question, but with a set of guided topics. The principal aim of the review was deemed to be the development of a synthesising argument – a coherent and integrated set of synthesising concepts.
2. Sets of papers were identified through a range of searching strategies, yielding a sample of potentially relevant papers that were screened for relevance.
3. Relevant papers formed the sampling frame. Sampling aimed to produce a representative sample of the literature.
4. Papers selected to form the sample for inclusion in the review were further screened to confirm relevance and to ensure that they were not fatally flawed, using five simple criteria.
5. Data were extracted using a pro-forma (with some exceptions).
6. Detailed analysis of data was undertaken to identify themes and generate categories.
7. Categories, with explicit specifications, were programmed into QSR N5. Data indexed using these categories, but categories modified iteratively in response to data.
8. Further theoretical sampling of the literature was undertaken to extend, confirm, and challenge the analysis.
9. The synthesising argument was generated through explicit integration of themes, and is therefore grounded in the evidence but produces a distinct interpretation.

1.4.1 Using critical interpretive synthesis to synthesise diverse evidence

Synthesising diverse forms of evidence

Meta-ethnography has previously been used only to synthesise qualitative studies. Our first innovation was to synthesise a diverse body of evidence, rather than limiting application of the methodology to the synthesis of qualitative studies only. We argue that interpretive syntheses should be able to synthesise evidence produced by any methodology, since theory-building need not, and indeed should not, be based only on one form of evidence. Indeed, Glaser and Strauss (1967), in their seminal text, include an (often forgotten) *section* on the use of quantitative data for theory-building.

It is worth noting that there is a body of argument against the secondary use of qualitative research. The argument rests primarily on

the epistemological and ontological commitments that are assumed to underlie qualitative research, and in particular the inviolable relationship between the researcher, the data, and its interpretation. Qualitative researchers tend to emphasise the importance of their relationships with research participants and of taking into account the context in which data were collected, and these are usually inaccessible to the secondary analyst (Fielding and Fielding 2000). Qualitative studies, it is therefore suggested, are unsuitable for 'summing up' (Sandelowski *et al.*, 1997). However, Barbour (1998) points out that qualitative researchers use contradictory evidence collected within a single method to explore the boundaries of emergent typologies or theoretical explanations, and that it is therefore acceptable to analyse data from different sources together to focus on contradictions and exceptions in developing, expanding, or reformulating theories. We have accepted this argument.

Lines-of-argument synthesis

Lines-of-argument (LOA) synthesis is the interpretive output of a meta-ethnography, and involves processes similar to the constant comparative method (Glaser and Strauss, 1967) used in primary qualitative research. We wish to introduce a number of terms and methodological concepts that we have developed to explain how lines-of-argument synthesis can be used in the synthesis of a large and diverse literature.

We suggest that the output of an LOA synthesis is a *synthesising argument*. This synthesising argument integrates evidence from across the studies in the review into a coherent theoretical framework comprising a network of constructs and the relationships between them. Its function is to provide more insightful, formalised, and generalisable ways of understanding a phenomenon. Synthesising arguments, we suggest, may operate at a fairly low level of theoretical abstraction, for example in the form of a taxonomy. Synthesising arguments may also operate at the level of mid-range theory (McKenna 1997). Mid-range theories are moderately abstract and inclusive, balancing the need for precision with the need to be sufficiently abstract, and can lead to the derivation of testable hypotheses.

A synthesising argument is produced through detailed analysis of the evidence included in the review, analogous to the analysis undertaken in primary qualitative research. We further suggest that a synthesising argument may require the generation of what we call *synthetic constructs*. These are concepts that are produced through analysis of the evidence: the products are the result of a transformation of the underlying evidence into a new conceptual form. Synthetic constructs are grounded in the evidence, but result from an interpretation of that evidence, and allow the possibility of several disparate aspects of a phenomenon to be unified in a more useful and explanatory way. For

example, we will suggest in this report that 'candidacy' is a core synthetic construct allowing issues of access to be better understood. Synthetic constructs are also *synthesising constructs* – they are constructs that can be used to categorise evidence, including evidence that has previously been categorised in a different way.

Britten (2002) and Campbell (2003) would use the term 'third order construct' to refer to what we have called a 'synthetic construct'. We suggest that 'synthetic construct' is a more useful term, not only because it is more explicit, but also because we suggest that a *synthesising argument* may not need to consist solely of synthetic constructs, as their model seems to imply. Instead, we suggest, synthesising arguments may explicitly link both synthetic constructs (which may be necessary to properly represent some aspects of a phenomenon) but also 'found' or 'second order' constructs that are already reported in the literature. A synthesising argument might therefore integrate a synthetic construct such as 'candidacy' with an existing construct such as 'identity'. However, this existing construct may be pressed to serve synthesising functions, by being used to code evidence that previously was not categorised using such a construct. It is therefore also a *synthesising construct*, in the same way that synthetic constructs are also synthesising constructs.

We also suggest that what Noblit and Hare (1988) call 'refutational synthesis' are best conducted as part of the analysis that produces the synthesising argument. Few published meta-ethnographies have in fact reported separate refutational synthesis. It is, we suggest, much more productive instead to consider contradictions in the evidence in the course of producing the synthesising argument, in the same way as deviant or negative cases would be considered as part of the analysis that produces the theoretical output in primary research. This consideration is part of the 'critical' element of a critical interpretive synthesis.

This brings us to an important additional element of producing a synthesising argument: the need, when conducting the analysis, to consider and reflect on the credibility of the evidence. Clearly, credibility depends on the quality of the research and its reporting, but also depends on currency – the extent to which findings remain true over time. We sampled papers back to 1985, covering almost 20 years of research. However, the evolution of the National Health Service over this time, and wider social changes, mean that extreme caution is required in interpreting the continuing validity and relevance of some research. For example Bowler's (1993) study, based on data collected in the 1980s, should not be read as continuing evidence of racism in the NHS (though more recent evidence might be). This paper, moreover, demonstrates a number of methodological shortcomings. We discuss later our decision to exclude only those papers that we deemed to be fatally flawed in terms of methodological quality. This meant that we included a large number of papers that might, under

stricter conditions, have been excluded from the review, but which we felt were important in terms of their theoretical contribution, or in terms of demonstrating the breadth of evidence considered in the construction of particular categories, or in terms of providing a more comprehensive summary of the evidence. In developing our synthesising argument, therefore, we were critical of the evidence included in our review, both in terms of judging the quality of papers on their own terms, but also in the wider context of how they contributed to a broader understanding of access.

To summarise, we suggest that the output of an LOA synthesis is a *synthesising argument*, best understood as a coherent and integrated set of *synthesising constructs*, which may themselves be *synthetic constructs* or *found constructs*. Synthesising arguments must be grounded in the evidence included in the review, and their claims should be consistent with the empirical observations reported in that evidence. Synthesising arguments may operate at several levels, including at the level of taxonomy and mid-range theory. The credibility of the evidence, including contradictions between studies, should be considered as part of the analysis that produces the synthesising argument, so that the interpretation of the evidence is explicitly critical.

Reciprocal translational analysis and refutational synthesis

Reciprocal translational analysis (RTA), a key strategy in meta-ethnography, involves the identification of what Noblit and Hare call 'metaphors' but later researchers have called 'key concepts' across studies, and then selecting the concept that best 'fits', in terms of allowing these concepts to be translated into one another.

Over the course of this project, we became increasingly doubtful about the value of RTA as a synthetic strategy, particularly for a large set of papers addressing a relatively unfocused question (as in access to health care by vulnerable groups). First, the main product of an RTA is a list of commonly studied themes, in which the themes that appear to be most inclusive appear on the list. It provides primarily a demonstration of the extent to which concepts reported in papers are 'translatable' into each other, but offers little in the way of insight, and to a large extent dampens rather than promotes the interpretive exercise. Put simply, such an analysis does not take one very far in understanding a phenomenon; it provides only a summary in terms that have already been used in the literature, and the extent to which demonstrating 'reciprocity' between the various terms and concepts is a useful exercise is questionable. Second, there are considerable methodological problems in trying to apply RTA across a large set of papers, in part, as we report below, because of the issues in formulating a review question and determining on which set of papers an RTA should be conducted.

We began by attempting to conduct RTA on the papers in our review, and developed a set of procedures to govern this, including use of Excel spreadsheets. However, over time, as we began to develop what we saw as more useful synthesising arguments as the product of our analysis, we began to treat RTA very much as a stage, similar to that of open coding in primary research, on the way to conducting an interpretive synthesis.

Reciprocal translational analysis is one of the principal strategies of meta-ethnography. We did not consider reciprocal translational analysis to be a useful strategy for our review. Our primary output is lines-of-argument synthesis.

Formulating the review question

Traditional systematic review methodology (e.g. NHS CRD, 2001) has emphasised the need for review questions to be precisely formulated. Whether one should start with an *a priori* definition of a phenomenon for purposes of review is therefore an important question, not least because of its practical implications. A tightly focused research question allows the parameters of the review to be identified and the study selection criteria to be defined in advance. This in turn limits the amount of evidence required to address the review question. This strategy is highly successful when it is possible to start with a narrowly defined research question in which the phenomenon of interest, the populations, interventions, and outcomes are all well specified. It does, however, involve trade-offs: the more narrow and tightly focused a research question is, the less likely it is to allow an inclusive and iterative approach to the identification and incorporation of evidence. Tightly focused questions may be most suitable for *aggregative* reviews, where there is a need to summarise data under well-defined categories that can be pre-specified.

In the case of access to health care by vulnerable groups, it was not possible to satisfy the criteria necessary for an aggregative review, because of problems in specifying in advance either the research question or the categories under which the data could be summarised. We have therefore chosen to accept Jensen and Allen's (1996) argument that where the identification of the phenomenon of interest is not straightforward, the definitions of the phenomenon may emerge from the data (i.e. the empirical papers considered in our review) as they do in primary research. Indeed, as will be evident in Sections Two to Eight, one of the outputs of our synthesis is what we believe to be a more useful conceptualisation of 'access to health care'.

This is not to say, however, that we did not have a review question, only that it was, as Greenhalgh *et al.* (2004) describe, tentative, fuzzy and contested at the outset of the project. We began with the definition of access proposed by the NCCSDO Scoping Exercise Report on access to health care (Gulliford *et al.* 2001). Access is broadly

described here as relating to need, provision and utilisation of health services, and concerns the processes through which entry into the health system occurs. A distinction is made between 'having access' – utilisation of services is hypothetically possible in that the given service and pathways to that service exist and are available, and 'gaining access' – actually making use of the service or achieving entry. *Vulnerable groups* were identified as those who are potentially at risk of poorer access by virtue of their known or hypothesised vulnerabilities (Rogers 1997). We focused particularly on whether access to health care was mediated by socio-economic disadvantage, ethnicity, age (older people and children), and gender. The SDO scoping report on access to health care, together with a scoping and pilot exercise carried out by our own review team, identified four topics around which this review was initially organised (Gulliford *et al.* 2001):

1. How does help-seeking behaviour affect access to healthcare?
2. How does provision of services affect access to healthcare?
3. What organisational features of health services affect access to healthcare?
4. How can access to healthcare be improved?

Our pilot exercise included an attempt to apply the meta-ethnography approach to a sample of papers on access to health care by children. It became apparent following this exercise that it was necessary to produce a general synthesis in taxonomic form of the evidence on access to health care (reported in Section 2 of this report) and then to customise in a more theoretically sophisticated way for each of the groups (Sections 3 to 8).

To address *general* issues of access to health care, we conducted syntheses (Section 2) on the four key topics (help-seeking, provision, organisational features, and interventions and policies to improve access) identified in the scoping report. For each of these topics, teams of at least two individuals worked independently. The team approach allowed a number of quality checks, described below, to be built into the process. We attempted to produce reciprocal translational analyses (RTAs) for each *topic*, but remained dissatisfied with these, for the reasons described earlier. RTA requires a reasonably small set of papers, otherwise the task becomes practically unfeasible. However, setting the boundaries of the papers to be included in each set by any technique (including that of using *topic*) seemed artificial, and, eventually, unhelpful.

On completion of the synthesis for each of the four topics, we integrated these to produce a general synthesis of the evidence on access to health care. As reported in Section 2, this synthesis is largely a taxonomy, producing themes that could be re-assembled and re-interpreted to enable the customised interpretations for specific

groups. More sophisticated interpretive syntheses were then for each of the groups of interest (men/women; children; older people; members of ethnic minorities; and the socio-economically disadvantaged) were undertaken. Again, these analyses were carried out in multidisciplinary teams.

1.4.2 Searching the literature

Traditional systematic review methodology has emphasised the need, as discussed above, for a well-defined and narrowly focused research question. It has also traditionally encouraged limiting the review to particular types of study – for example randomised controlled trials. For purposes of this review, we decided to include all types of evidence relevant to access to health care by vulnerable groups. This decision posed a number of challenges in terms of searching for the evidence. First, it meant that we were likely to have difficulties in identifying all papers that were relevant, but also that we were likely to identify large amounts of literature that would be irrelevant or only marginally relevant. Second, it meant that we were likely to identify a very sizeable literature that would exceed our capacity to synthesise it. Our searching strategies, therefore, need to be understood in the context of our sampling strategies, described later.

The purpose of the searching phase of the study was to identify potentially relevant papers or 'candidate studies' order to provide a sampling frame. The searching phase aimed:

- to produce a sampling frame of potentially relevant evidence
- to classify the evidence into study or paper type
- to produce an initial classification of the evidence according *topic* and *group*

We piloted the use of a highly structured search strategy but, like Greenhalgh *et al.* (2004) found that this risked missing relevant materials. We then developed a more organic process that fitted better with the emergent and exploratory nature of the review questions. Given the diversity of the evidence and the requirements of the theoretical sampling approach described below, we refined the basic search strategy as we progressed through the project. This combined a number of strategies:

- searching of electronic databases
- searching websites
- reference chaining
- contacts with experts

Searching of electronic databases

Computerised, manual, and reference list searches in the English-language literatures of nursing, medicine, sociology, and psychology

was undertaken. The electronic databases searched included are listed in Box 1.2

Box 1.2 Electronic databases searched

1. Medline
2. PubMed (using 'related articles') facility
3. Embase
4. Science Citation Index (Web of Science)
5. Social Sciences Citation Index (Web of Science)
6. Sociological Abstracts
7. Applied Social Sciences Index & Abstracts (ASSIA)
8. Cumulative Index to Nursing and Allied Health Literature (CINAHL)
9. British Nursing Index (BNI)
10. PsychLIT
11. PsycINFO
12. Health Management Database (HMIC)
13. Ethnic Health File
14. International Bibliography of the Social Sciences
15. Cochrane Library
16. Database of Abstracts of Reviews of Effectiveness (DARE)

A combined approach to strategies for searching electronic literature databases was adopted, involving searches using the following:

1. Thesaurus terms (terms relating to access formally indexed on databases)
2. A free text natural language approach
3. Citation or 'school of thought' approach (e.g. using key authors in the field such as Zola).

Examples of free text search terms used can be found in Appendix 1A. These were developed from brainstorming among members of the research team, from terms used in key articles (e.g. 'inverse care law'), agency websites and documents on the topic of access, and the search strategies used by Goddard and Smith in their 1998 review of equity of access to health care .

Searching was conducted initially for *general* articles relating to access to health care. Subsequent searching focused on the key *topics* (help-seeking, provision and availability, organisation, policies and interventions) and *groups* (children, older people, men and women, minority ethnic groups and the socially and economically disadvantaged). See Appendix 1B for examples of terms used for topic

and group searches. A total of ten different searches were carried out across *each* of the electronic databases listed in Table 1.2, generating thousands of potentially relevant hits. However, there was a high degree of overlap across these searches, with the same articles being retrieved over and over again. We used the reference management software Procite to handle all the articles and deal with the huge number of duplicates, and to code articles according to their source and topic / group of relevance.

Website searching

We searched the websites below to identify documents relevant to our review questions:

- Association of Public Health Observatories (www.pho.org.uk)
- British Medical Association (www.bma.org.uk)
- Department of Health (www.dh.gov.uk)
- Institute of Education and Social Science Research Unit (www.ioewebserver.ioe.ac.uk)
- National Electronic Library for Health (www.nelh.nhs.uk)
- NHS Modernisation Changing Workforce Programme (www.modern.nhs.uk)
- Social Policy and Research Unit, York (www.york.ac.uk/inst/spru)
- The Audit Commission (www.audit-commission.gov.uk)
- The Institute of Child Health (www.ich.ucl.ac.uk/ich)
- The Kings Fund (www.kingsfund.org.uk)
- The National Children's Bureau (www.ncb.org.uk)
- The Picker Institute (www.pickereurope.org/index.htm)

Reference chaining

We used a 'snowballing' approach to the analysis of reference lists in selected relevant articles, using these lists to generate further lists of potentially relevant articles.

Contact with experts

We wrote to selected experts, identified from published papers, to seek advice on any relevant materials.

Questionnaire survey

In addition to the strategies described above, we had also planned to conduct a questionnaire survey of voluntary organisations and relevant agencies to identify additional relevant exercises. Our pilot exercise showed that organisations found replying to requests about

potentially relevant literature burdensome, that response was poor, and that many of the materials we were being referred to had already been identified by other means, particularly via internet searching. We initially decided to defer conducting the survey until the review was more advanced. However, later in the review process it was evident that the volume of material identified by other means was enormous, and our sampling strategy meant that it was possible that even if organisations went to the trouble of responding to our questionnaire, the materials they identified for us would not be included in the synthesis. We decided that such a survey would be unlikely to be productive, and would not be an appropriate investment of resources.

Managing the searching

Given the huge number of items retrieved using our search strategies, it was necessary to conduct an initial screening of papers. Papers excluded at this stage were only those deemed to be completely irrelevant to the topic of access or the vulnerable groups. Papers were excluded based on the following criteria:

- Non-English language articles.
- Papers immediately apparent as completely not relevant e.g. not related to humans.
- Papers published prior to 1985, unless deemed to be key papers on theoretical grounds.

All articles deemed potentially relevant that were identified in relation to each topic and vulnerable group were imported into *separate* Procite databases. All articles were labelled according to the source, which originally identified them (e.g. Medline) before being moved to a single Procite database in order to remove duplicates. Further Procite databases were created for each of the *topics* (help-seeking, provision and availability, organisational features, and policies and interventions) and the *groups* of interest (children, older people, men and women, minority ethnic groups and socially and economically disadvantaged groups).

Abstracts of papers were screened for relevance using the following questions:

1. Does the title/abstract where available make it immediately obvious that the paper is irrelevant? (If YES, no further assessment is made)
2. Does the paper refer to access and related issues?
3. Does the paper refer to one of the groups chosen for the review?
4. Does the paper have any link with the review topic that could be useful?
5. Is the paper anachronistic?

Where no clear information regarding the type, source or content of the paper was obvious from the title or abstract, or there was uncertainty about the relevance of the paper, it was retained on the principle that we should err on the side of inclusion. The remaining articles after the second phase of screening for each topic and group formed the list of potentially relevant articles to be sampled for inclusion in the review, and formed the 'R' list – the sampling frame of our review. All articles sampled were moved to one single Procite database and given a unique identifier number.

We used a range of strategies to identify potentially relevant papers for inclusion in our review, and conducted two stages of screening for relevance to construct a sampling frame of relevant articles.

1.4.3 Selecting papers for inclusion in the review

The papers deemed to be potentially relevant following abstract screening formed what we called the 'R' list – the sampling frame for the review, and were stored on a Procite database together with bibliographic details. An 'R' list was created for the 'general' category and for each of the groups of interest, with some overlap between the 'R' lists where papers were relevant across several groups.

Determination of quality

Once papers had been selected from the 'R' list for potential inclusion in the review, they underwent a further assessment of relevance and quality. In conducting this review, we prioritised papers that appeared to be relevant, rather than prioritising studies of a particular study type or that met particular methodological standards. We might therefore be said to be prioritising 'signal' (likely relevance) over 'noise' (the inverse of methodological quality), as is suggested by Edwards *et al.* (2000) when approaching a review of a diffuse topic area such as ours.

The issue of how or whether to appraise papers for inclusion in a review has received a great deal of attention, but, particularly for interpretive syntheses, there is little sign of an emergent consensus. Some argue that formal appraisals of quality may not be necessary at all: Sandelowski *et al.* (1997) argue that papers should not be excluded for reasons of quality, particularly where this might result in synthesisers discounting important studies for the sake of 'surface mistakes', and argues that synthesisers have to be 'connoisseurs' to be able to distinguish between these surface mistakes and mistakes so fatal that they invalidate the findings. Jensen and Allen (1996) appear to concur with this, suggesting data 'germane to the purpose of the investigation' is likely to be excluded if studies are eliminated based on scientific merit. Some reviewers have chosen not to appraise the papers (e.g. Garcia *et al.* 2002).

Notwithstanding this debate, we considered it important that very poor quality research was not included in the review. However, there were considerable difficulties in identifying a means of appraising quality across the wide range of study designs we have included in our review. While there are some widely accepted checklists for appraising quantitative study designs such as randomised controlled trials and case control studies, there is little agreement on how to appraise qualitative studies (Dixon-Woods *et al.* 2004; NHS Centre for Reviews and Dissemination 2001). Several published qualitative syntheses have used quality criteria to judge the quality of papers for inclusion, though perhaps unsurprisingly, the same criteria have not been used. Paterson, Thorne and Lewis (1998) used five criteria: explicit purpose; sampling and interpretation of findings guided by theoretical framework; clear inclusion and exclusion criteria; findings given alternative explanations; and sufficient detail to allow replication. Barroso and Powell-Cope (2000), in their meta-synthesis of studies of living with HIV infection, guide assessments along the following criteria: descriptive vividness; methodological congruence; analytical precision; theoretical connectedness; and heuristic relevance. Campbell *et al.* (2003) used an approach modelled on the CASP checklist for qualitative research.

We felt it important that a low threshold be applied to maximise the inclusion and contribution of a wide variety of papers at the level of *concepts*. We therefore decided that only papers that were deemed to be fatally flawed would be excluded from the review. To identify these weak papers, we decided to use the following criteria, adapted from those proposed by the National Electronic Library for Health for the evaluation of qualitative research, to inform expert judgements on the quality of the papers. These criteria were used for assessing *all* empirical papers, regardless of study type.

- Are the aims and objectives of the research clearly stated?
- Is the research design clearly specified and appropriate for the aims and objectives of the research?
- Do the researchers provide a clear account of the process by which their findings were produced?
- Do the researchers display enough data to support their interpretations and conclusions?
- Is the method of analysis appropriate and adequately explicated?

Decisions about relevance and quality were recorded on an Access database, and for each topic and group, a small sample of decisions about relevance and quality was reviewed, facilitated by working in teams.

We used five simple criteria to judge whether papers were fatally flawed. Only papers deemed fatally flawed were excluded.

1.4.4 Sampling

As discussed above, one strategy for limiting the number of papers to be included in a review is to focus the question very narrowly and / or to limit the papers to be included to particular study types. We did not have a narrowly focused question, and we chose to include all study types. An alternative strategy was necessary to limit the number of papers to be included in our review, bearing in mind that as an interpretive synthesis, the focus was on the development of concepts and theory rather than on exhaustive summary of all data. Schreiber *et al.* (1997) suggest drawing on the sampling techniques of primary qualitative research, arguing that the principles guiding the theoretical sampling technique depend on the research questions, the desired end product, and the ontological and epistemological framework of the analysis. In primary research, theoretical sampling is conducted with a view towards the evolving theoretical development of the concepts. Theoretical saturation is considered to be reached when new data do not seem to amend the theoretical categories of the analysis, either to extend or contradict them (Strauss and Corbin, 1990).

Using this approach in the reviewing of evidence would suggest that including *all* papers meeting the review criteria, as required under traditional systematic review procedures, would be potentially redundant: accumulation of papers could stop once reviewers were satisfied that sufficient data existed for each category generated by the review. Booth (2001) argues that this approach would be consistent with the forms of sampling used in primary research, suggesting that:

'If we think of the papers in a qualitative review as being "informants" then we seek to identify specific groups of papers that possess characteristics that are relevant to the phenomenon being studied. We aim to include a wide range of types of papers (i.e. reflecting as many of the themes or schools of thought as possible) and, preferably to select "key informants" (i.e. papers that lead us to important sources of knowledge in the form of additional citations).[...] Once a particular theme has been identified further occurrences of this theme are only of interest in strictly quantitative terms unless they expand on or modify an already-identified theme.'

Booth further points out that quantitative researchers are also currently seeking to establish a law of diminishing returns beyond which there is little benefit in further searching. In utilising such an approach, Paterson and Thorne (2001) suggest that there must be a sufficient number of studies to answer the question and allow comparisons among selected dimensions and constructs.

We decided on a purposive sampling approach to selecting papers for inclusion in our review. *Maximum Variation* sampling was used initially to sample different study types so that different paper types – primary qualitative, primary quantitative, mixed method, editorial, review and theoretical - were represented within the review. We sought to include

a range of papers on the basis of paper type, theoretical stance and specific subject analysed / addressed. Sampling initially focused on empirical reports in order to establish the basic thematic framework. *Intensity and typical case* sampling was also undertaken to highlight papers identified as key to the topic of interest. Later in the review process, *theoretical* sampling was adopted to add test and elaborate the emerging analysis. Theoretical sampling allowed a dynamic interaction between the analysis and the evidence. Sampling was conducted on the basis of abstracts. Each abstract was screened to determine whether it was likely to contribute to the emerging analysis.

In the event, sampling, while purposive, was constrained by important practical limitations. Our pilot study revealed that the processes involved in the review would be laborious and time-consuming and that, within the time and resources available, we could expect to synthesise approximately 200 papers for the general review. We would also expect to synthesise an initial set of about 30-40 papers for each of the groups, and to engage in additional theoretical sampling to extend, challenge, or confirm our analysis for each of these groups.

Sampling of papers was necessary because of the large volume of relevant literature. We used a range of strategies to select a representative sample of the literature.

1.4.5 Data extraction

A data-extraction pro-forma was devised to assist in systematically identifying the participant demographics, methods of data collection, methods of data analysis and major findings of each paper. These were assembled onto a matrix using Access software (Appendix 1C).

We extracted and summarised the 'key concepts' in each paper. A title was given to each key concept based on the terms used in the paper itself. A summary of the material in the paper relating to this was then extracted. A sample of data extraction was checked for accuracy and completeness for each topic and group, again facilitated by working in teams. The checking was done by comparing extracted themes with the original papers. Practically, however, it proved impossible to conduct this form of data extraction on very large documents, including books and large reports. We therefore summarised these documents more informally 'off-line'. In the later stages of the project, when we engaged in theoretical sampling of additional papers to ensure that our review was more comprehensive and that we were closer to theoretical saturation, we also used this strategy on some shorter papers in the interests of speed and efficiency.

Data extraction was facilitated by use of a pro-forma for most papers included in the review. Large reports and some papers selected later in the process through theoretical sampling were summarised less formally.

1.4.6 Synthesis

We earlier described our primary approach to synthesis: the generation of synthesising arguments that would integrate synthetic and found constructs to produce an interpretation of the evidence on access to health care by vulnerable groups. We produced a largely taxonomic synthesis of the general literature on access to health care (reported in Section 2), which does include some examples of synthetic constructs. In the interpretive syntheses reported in Sections 3 to 8 (one for each group), we move to a more sophisticated analysis, customised for each group.

Our analysis was similar to that undertaken in primary qualitative research. We began with detailed inspection of the data in the papers, gradually identifying themes that were recurring within the data. We then generated themes which helped to explain the phenomena being described in the literature, constantly comparing the theoretical structures we were developing against the data in the papers, and attempting to specify the categories of our analysis and the relationships between them. To facilitate the process of identifying patterns, themes, and categories across the large volumes of text-based data in our study, we used QSR N5 software. However, it is important to note that, as with any qualitative analysis, full transparency is not possible because of the creative, interpretive processes involved.

Synthesis was achieved through processes similar to those used in primary qualitative research, and QSR N5 qualitative analysis software was used to facilitate the process.

1.5 Conclusions

This report will give an account of an interpretive synthesis of access to health care by vulnerable groups, specifically people who are socio-economically disadvantaged, people of minority ethnicity, older people, children and young people, and an investigation of the effects of gender. Building on, but innovating with, the methodology of meta-ethnography, its primary aim is to produce a synthesising argument for each of these five areas, as well as to produce a synthesis of the evidence on access to health care generally. Such a synthesis will aim to produce useful and insightful explanations into the phenomenon of access to health care, rather than a straightforward summary.

We had to make a number of innovations to adapt the methodology of meta-ethnography for this synthesis, which aimed essentially to produce six syntheses – one general synthesis and one for each of the groups in the study – in an 18 month period. We termed our new methodology 'critical interpretive synthesis'.

Our synthesis did not start with a precisely formulated question, as we wished the definition of the phenomenon to emerge from our analysis.

However, we did begin with a guided set of topics which had been generated by the previous SDO scoping study on access to health care. We aimed initially to produce a general synthesis of the evidence on access to health care in taxonomic form, and then to produce a more sophisticated analysis customised for each of the groups in our review.

We used a range of searching strategies to identify relevant papers, but with a very amorphous research area it was very difficult to set the limits of the searching precisely. We used an iterative and creative approach to searching in addition to using formal search strategies. We developed a list of potentially relevant articles which we regarded as our sampling frame. The potentially relevant literature in this area, including the literature on the five groups we had chosen to study, was enormous, and given that we had chosen not to exclude studies by study design, we needed to limit the number of papers to be included in the review. We therefore used a purposive sampling strategy to select papers, initially selecting a set of papers and then engaging in theoretical sampling to extend, confirm, or challenge the analysis. We believe this strategy allowed us to produce a synthesis of a broadly representative set of papers.

Papers selected for inclusion in the review were screened to confirm relevance and were screened for quality using five simple questions adapted from the National Electronic Library for Health. These questions were used to make a guided judgement about whether or not the paper was fatally flawed. Only papers that were deemed fatally flawed or genuinely irrelevant were excluded from the review.

Data were extracted from papers using a standardised pro-forma. The data were extracted under thematic headings derived from the papers themselves, and a sample of these was checked to ensure accuracy. It was not possible to undertake this laborious and time-consuming process for large reports and for some papers selected later for inclusion through the theoretical sampling process, and these were instead summarised off-line. Data extraction reports were imported into QSR N5 software to facilitate analysis, and in particular the systematic indexing of data to the categories generated through the analysis.

Through detailed analysis of the data, and repeated comparisons across the papers, we generated a set of themes with category specifications that were explicitly linked. This synthesising argument is similar, but distinctive, for each of the groups in our analysis, and goes beyond what is reported in the original papers.

Section 2 Access to health care – a general synthesis

2.1 Introduction

In this *section* we present a summary of the general access to health care literature. Our analysis in this section is largely at the level of taxonomy. We propose what we believe to be useful ways of organising and categorising the literature. Some of the categories we propose are synthetic, in the sense that they represent new conceptual products. However, many categories in this *section* will also be those found extant in the literature. In the later *sections*, we begin to develop what we believe to be more explanatory approaches to understanding access to health care by specific groups.

For purposes of this general overview, we started with the four topics identified by the Service Delivery Organisation (SDO) scoping report on access to health care (Gulliford *et al.*, 2001) together with our own scoping and pilot exercise, as a general framework:

1. How does help-seeking behaviour affect access to healthcare?
2. How does provision of services affect access to healthcare?
3. What organisational features of health services affect access to healthcare?
4. How can access to healthcare be improved?

Details of the papers included in the review in this *section* can be found in the table at Appendix 2A.

2.2 Theory in relation to access

Recent years have seen several attempts to analyse and specify what is meant by 'access to health care', and more precisely, what is meant by 'equitable access' to health care (Cuyler, 2001; Cuyler and Wagstaff, 1993; Dixon *et al.*, 2003; Chang, 2002). We do not propose to synthesise these here, but it is useful to outline some of the main issues.

Gulliford (2003) argues that rather than being explicit, clear, static and consistent, equity principles in the NHS tend to be implicit, vague, changing and inconsistent. Attempts to clarify concepts of equity have been a long-standing feature of moral and political discourse, but the operationalisation of 'equity' and 'need' for the purposes of research has remained difficult (Smaje 1998). Raine *et al.* (2003) agree with many others when they argue that the need for health care depends on the ability to benefit from health care use. A number of writers distinguish between horizontal and vertical equity in relation to need. Horizontal equity refers to the principle that people with equal needs

should be treated equally, while vertical equity refers to the principle that people with greater need should receive more care. In practice, utilisation has been used in many studies as a proxy for access but, as our later analysis will demonstrate, this has been deeply problematic.

The practical consequence of the problems of defining and measuring access is a set of methodological, conceptual, and theoretical problems in investigating access, and in investigating the extent to which access is equitable in particular. We hope to move towards resolving some of these problems in the analyses of the evidence on access by potentially vulnerable groups that we present in the later *sections*.

Our analysis below is organised around the following themes:

- 2.2.1 Theme 1: Help-seeking
- 2.2.2 Theme 2
- 2.2.2 Theme 2: Provision and availability of services
- 2.2.3 Theme 3: Organisational features of health services
- 2.2.4 Theme 4: Policy, service developments, and interventions to improve access

2.2.1 Theme 1: Help-seeking

It is clear that neither service availability nor the presence or absence of symptoms of illness is sufficient to explain use of services. A service may be available but not be used, or may be used in a way in which it is not intended; people may seek help for some problems but not others, and may seek help in ways that do not reflect the intended provision of services. The SDO scoping report identified a mismatch between professional expectations and patients' needs and patterns of uptake of services (Gulliford *et al.*, 2001).

Morgan (2003) described problems of delay and non-uptake of health services that appear to be linked to underlying structures of social deprivation and membership of specific cultural groups, and the problems of apparent; over-utilisation' or 'inappropriate' use of some services. Morgan identified four broad types of explanations for help-seeking:

- *Individualistic* approaches derived from social-psychological research and focusing on individuals' attributes and the cognitive processes that underlie decision-making.
- *Social barrier approaches* that focus on the social and situational forces, including economic factors, organisational and medical care factors, knowledge, beliefs and roles, that function to prompt or delay help-seeking.

- *Patient-oriented approaches* that focus on how people make sense of and response to various types of body changes within the framework of their 'lay' knowledge and
- *The social strategy approach*, which focuses on sees health care decisions as embedded in social processes and strongly influenced by networks and contexts of time and place.

Our analysis suggests that the assumptions that underlie these various approaches have influenced the kinds of research questions posed by empirical studies in the field, as well as methods of data collection and the types of conclusions drawn.

Our lines-of-argument synthesis generated two synthesising constructs that appear to explain help-seeking behaviour:

- Resources available to people.
- Service and user discordance.

Resources available to people

Our analysis suggests that resources of information, knowledge and beliefs, confidence in self-diagnosis and self-management, and practical resources, powerfully influence people's ability to manage, make decisions, and execute help-seeking actions in relation to health and illness. We generated the following themes around which our summary of the evidence on resources are organised:

- Information, knowledge and beliefs.
- Confidence in self-diagnosis and self-management.
-
- Social support.
- Advocates.
-
- Practical resources.
-
- Psychological resources.

Information, knowledge and beliefs

We analysed articles that demonstrated the role of information and knowledge about health issues as an important resource in mediating individuals' decisions to seek health care and their help-seeking behaviour. This resource refers to information and knowledge of all kinds. For example, related to types and symptoms of illness; availability and appropriate use of services; gaining a diagnosis and managing conditions. It is a key influence on people's interaction with health services and health management strategies, affecting their

classification of health problems, their evaluation of the seriousness of the problem, and choice of service to address the problem (Milewa *et al.*, 2000; Haylock *et al.*, 1993; Jacobson *et al.*, 2001; Kai, 1996a; Kai, 1996b; Shaw *et al.*, 2001; Sheikh and Ogden, 1998; Stallard and Lenton, 1992; Stevenson *et al.*, 2003; Tod *et al.*, 2001; Whitehead and Gosling, 2003; Paterson and Britten, 2000; Bond *et al.*, 2000; Somerset *et al.*, 1999; McKee and Waghorn, 2000; Cragg *et al.*, 1994; Baker *et al.*, 1999; Carter *et al.*, 2002; McIntosh and Shaw, 2003; Neal and Linnane, 2002; Cromerty, 1996; Chapple *et al.*, 2001; De Nooijer *et al.*, 2001; Anderson *et al.*, 1997).

Lack of information thwarts people from using services in the way that would most benefit them at every stage of their interaction with health services. Lack of knowledge of services was found to be a key problem in several studies (Neal and Linnane, 2002; Jacobson *et al.*, 2001), and medical knowledge is important in knowing when to initiate help-seeking (Kai, 1996a; Shaw *et al.*, 2001; Sheikh and Ogden, 1998; Tod *et al.*, 2001; Neal and Linnane, 2002; De Nooijer *et al.*, 2001). For example, Kai (1996a) found that parents wanted to know more about symptoms and management of conditions such as meningitis. One parent in this study noted:

'It's the not knowing what it could be – how to tell – that's what panics me, if I was told what to do, shown what to do and how to do it, I would feel I could manage much better.'

Perceptions of the extent to which problems can or will be addressed by health services also exert influences on help-seeking. Bebbington *et al.*, (2000) show that there are high levels of under-consultation for mental health problems because of beliefs about the extent to which services can help.

Papers also emphasised difficulties in accessing appropriate information resources for managing illness after diagnosis and the consequences of this for help-seeking (Carter *et al.*, 2002; Stallard and Lenton, 1992; Paterson and Britten, 2000; Bond *et al.*, 2000; Somerset *et al.*, 1999; Haylock *et al.*, 1993). For example, a study of patients suffering from back pain found that they received very little and sometimes conflicting information from their GP, and were often forced into seeking information elsewhere (McIntosh and Shaw, 2003). McKee and Waghorn (2000) reported that patients were dissatisfied with the help they received from non-medical staff, who were often reluctant to provide information and support. Somerset *et al.*, (1999) found that patients with a serious condition had little confidence in their General Practitioner's (GP) specialist knowledge of their condition, and wanted to be referred to a specialist as quickly as possible. Such findings suggest that help-seeking behaviour may be influenced by perceived deficits in care, and that patients may engage in compensatory help-seeking strategies to gain the services they need. It is also evident that potentially stigmatising conditions,

including mental health problems, may also present later or less frequently to health services.

Confidence in self-diagnosis and self-management

Our analysis identified the synthesising construct of *confidence* as a key resource in help-seeking. We characterised confidence as individuals' perceptions of their ability to manage a health problem, including the extent to which people feel they can diagnose and manage a problem alone or need to seek medical help. Evidence in articles that we analysed emphasised the role of confidence in self-diagnosis and self-management in people's decisions to seek help (Fiorentino *et al.*, 1998; Milewa *et al.*, 2000; Hopton *et al.*, 1996; Houston and Pickering, 2000; Kai, 1996a; Kai, 1996b; Klasen and Goodman, 2000; Martin *et al.*, 1991; Pattenden *et al.*, 2002; Barker *et al.*, 1990; Richardson and Rabiee, 2001; Shaw *et al.*, 2001; Sheikh and Ogden, 1998; Shipman *et al.*, 2001; Stevenson *et al.*, 2003; Tod *et al.*, 2001; Rogers *et al.*, 1999a; Walsh, 1995; Skeate *et al.*, 2002; Paterson and Britten, 2000; Stoddart *et al.*, 2003; Somerset *et al.*, 1999; Morris *et al.*, 2001; Carter *et al.*, 2002; Cornford *et al.*, 1993; De Nooijer *et al.*, 2001; Dixon-Woods *et al.*, 2001; Anderson *et al.*, 1997; Edwards and Pill, 1996)

This work indicates that many symptoms are managed without recourse to professional help. A questionnaire study of 1,972 people attending general practice found that 25 per cent of patients had tried to treat themselves, and only consulted their GP when this failed, or when their symptoms worsened or had begun to affect their day-to-day living (Martin *et al.*, 1991). These findings are repeated in other studies (Shaw *et al.*, 2001). Individuals may decide to seek professional medical help if they lack confidence in diagnosing and managing their medical problem themselves. This appeared to be pronounced in certain groups, particularly, as will be discussed in more detail later, in relation to help-seeking on behalf of children (Cornford *et al.*, 1993; Hopton *et al.*, 1996; Kai, 1996a; Kai, 1996b; Houston and Pickering, 2000; Carter *et al.*, 2002).

Social support

We analysed papers that referred to the significance of social and professional support in help-seeking and management of illness (Fiorentino *et al.*, 1998; Freeman, 1999; Haylock *et al.*, 1993; Milewa *et al.*, 2000; Houston and Pickering, 2000; Kai, 1996a; Kai, 1996b; Martin *et al.*, 1991; Pattenden *et al.*, 2002; Barker *et al.*, 1990; Richardson and Rabiee, 2001; Shaw *et al.*, 2001; Stallard and Lenton, 1992; Olsson and Hansagi, 2001; Walsh, 1995; Bebbington *et al.*, 2000; Paterson and Britten, 2000; Gravelle and Sutton, 2001; McKee and Waghorn, 2000; Baker *et al.*, 1999; Tarrant *et al.*, 2003; Carter *et al.*, 2002; Neal and Linnane, 2002; Cornford and Cornford, 1999; Cromerty, 1996; De Nooijer *et al.*, 2001).

Social network analysis has emphasised the importance of interpersonal networks that link people in ways that allow them to cope with routine and extraordinary circumstances, including links with others who may be of use. There was evidence that individuals relied heavily on informal social support from friends and family, and that this strongly influenced help-seeking (Houston and Pickering, 2000; Kai, 1996a; Kai, 1996b; Richardson and Rabiee, 2001; Milewa *et al.*, 2000; Barker *et al.*, 1990; Pattenden *et al.*, 2002; Walsh, 1995; Cornford and Cornford, 1999). Advice is often sought from friends, family and the community pharmacy before seeking help from a doctor. For example, 71 per cent patients (n=365) interviewed by Cornford and Cornford (1999) reported that the role of lay conversations, especially conversations with partners, was important or very important in informing their decision to seek help. People sought advice, reassurance and support from these conversations, often in the form of practical help with transport and childcare.

The competence and sensitivity of lay referral networks, and their ability to legitimise help-seeking, are likely to influence the quality of advice given. A study of decision-making for acute myocardial infarction suggests that the influence of others on decision-making is vital (Pattenden *et al.*, 2002). This study reported that it was common for someone other than the patient to recognise that something was wrong and phone emergency services, serving to relieve patients of a sense of guilt and the obligation of making a fuss. Walsh *et al.*, (1995) found that 128 out of 200 patients attending Accident and Emergency (A&E) were advised to do so by others, including friends, relations, colleagues and health professionals. However, despite the clear importance of such lay referral systems, they have been relatively little studied in the UK (Freidson, 1961; Kleinman, 1980).

Advocates

Advocacy, where a third party takes responsibility on behalf of people for assisting in the negotiation of services and may be active in seeking solutions to problems or take up roles that the individual is unable to assume, was identified as a specific form of social support in papers that we analysed (Milewa *et al.*, 2000; Kai, 1996a; Kai, 1996b; Klasen and Goodman, 2000; Pattenden *et al.*, 2002; Barker *et al.*, 1990; Richardson and Rabiee, 2001; Sayal *et al.*, 2002; Shaw *et al.*, 2001; Sheikh and Ogden, 1998; Shipman *et al.*, 2001; Tod *et al.*, 2001; Whitehead and Gosling, 2003; Rogers *et al.*, 1999a; Olsson and Hansagi, 2001; Walsh, 1995; Skeate *et al.*, 2002; Somerset *et al.*, 1999; Burgess *et al.*, 1998; Carter *et al.*, 2002; Carter and Bannon, 1997; Charlton *et al.*, 1991; Churchill *et al.*, 2000; Cornford, 1998; Cromerty, 1996; Chapple *et al.*, 2001; De Nooijer *et al.*, 2001; Dixon-Woods *et al.*, 2001; Donovan *et al.*, 1997; Charles-Jones *et al.*, 2003; Feder *et al.*, 1993). Advocacy may take many forms, including acting as an intermediary or broker between individuals and health services through, for example, providing language support.

Relationship between perceived need and service use

Perceived need was identified as having a strong impact on decision to seek help and uptake of services in papers that we analysed (Milewa *et al.*, 2000; Houston and Pickering, 2000; Kai, 1996a; Kai, 1996b; Martin *et al.*, 1991; Baker and Hann, 2001; Pattenden *et al.*, 2002; Peay and Peay, 1998; Barker *et al.*, 1990; Richardson and Rabiee, 2001; Sayal *et al.*, 2002; Shaw *et al.*, 2001; Shipman *et al.*, 2001; Smaje and Grand, 1997; Smith *et al.*, 2001; Tod *et al.*, 2001; Whitehead and Gosling, 2003; Black *et al.*, 1995; Rogers *et al.*, 1999a; Olsson and Hansagi, 2001; Walsh, 1995; Bebbington *et al.*, 2000; Talley *et al.*, 1997; Paterson and Britten, 2000; Stoddart *et al.*, 2003; Williams *et al.*, 2000; Goyder *et al.*, 1996; Bowling *et al.*, 1987; Reid *et al.*, 1999; Somerset *et al.*, 1999; van Doorslaer *et al.*, 2000; Blatchford *et al.*, *et al.*, 1999; Cragg *et al.*, 1994; Lattimer *et al.*, 1998; Shipman *et al.*, 2000; Bowling and Redfern, 2000; Bowman *et al.*, 2001; Kinnersley *et al.*, 2000; Cornford *et al.*, 1993; Neal and Linnane, 2002; Cornford, 1998; De Nooijer *et al.*, 2001; Dixon-Woods *et al.*, 2001; Anderson *et al.*, 1997; Drummond *et al.*, 2000; Edwards and Pill, 1996; Anie *et al.*, 2002). Perceptions of severity of illness were reported to be among the strongest predictors of help-seeking (Houston and Pickering, 2000; Martin *et al.*, 1991; Peay and Peay, 1998; Barker *et al.*, 1990; Richardson and Rabiee, 2001; Sayal *et al.*, 2002; Smaje and Grand, 1997; Smith *et al.*, 2001; Rogers *et al.*, 1999a; Olsson and Hansagi, 2001; Walsh, 1995; Bebbington *et al.*, 2000; Talley *et al.*, 1997; Cornford, 1998; De Nooijer *et al.*, 2001; Dixon-Woods *et al.*, 2001; Drummond *et al.*, 2000; Edwards and Pill, 1996). Even in cases where people delayed help-seeking, worsening of symptoms and impact on quality of life eventually led to contact with health services (Shaw *et al.*, 2001; Tod *et al.*, 2001; Whitehead and Gosling, 2003; Neal and Linnane, 2002; Cornford, 1998). By contrast, the interpretation of symptoms as not serious posed strong barriers to help-seeking (Pattenden *et al.*, 2002; Tod *et al.*, 2001; Rogers *et al.*, 1999a; Neal and Linnane, 2002; Cornford, 1998).

Practical resources

Our analysis of papers identified practical resources as a potential barrier to seeking medical help (Field and Briggs, 2001; Freeman, 1999; Gardner and Chapple, 1999; Klasen and Goodman, 2000; Shipman *et al.*, 2001; Stevenson *et al.*, 2003; Tod *et al.*, 2001; Walsh, 1995; Stoddart *et al.*, 2003; Jones and Bentham, 1997; Lundberg *et al.*, 1998; Reid and Todd, 1989; Cragg *et al.*, 1994; Shipman *et al.*, 2000; Carter and Bannon, 1997; Cornford and Cornford, 1999; McKinley and Roberts, 2001; Anderson *et al.*, 1997). The kinds of practical issues that affect individuals' ability to seek care include physical distance and access to transport (Field and Briggs, 2001; Jones and Bentham, 1997; Reid and Todd, 1989; Cragg *et al.*, 1994), costs of using health care (Stevenson *et al.*, 2003) and arranging

childcare and time off work (Shipman *et al.*, 2000; Shipman *et al.*, 2001).

Access to the practical resources necessary to access health care may be very complex, and not a simple function of any single factor. For example, access to a car may be very important in negotiating a route to health services, but the relationship between distance and use of services is not a straightforward linear relationship. Field and Briggs (2001) found a general distance decay effect for general practice, but this was mediated by effects of socio-economic status. The more socially and economically disadvantaged were more likely to live in city centres and the more affluent to live in more rural areas with access to a car. Those living in the intermediate areas (four to five miles away) were most likely to rely on public transport and to experience difficulties with physical access.

We analysed papers that refer to the financial costs incurred by people when they attempt to access services (Field and Briggs, 2001; Shipman *et al.*, 2001; Stevenson *et al.*, 2003; Blair *et al.*, 1997; Dossetor *et al.*, 1999; Lundberg *et al.*, 1998; Ryan *et al.*, 2000; Hirst *et al.*, 1998). Cost may arise directly, in the form, for example, of prescription charges or fees (Stevenson *et al.*, 2003; Lundberg *et al.*, 1998); or indirectly, in the form, for example, of costs of transport to health care centres or loss of income while attending for health care (Field and Briggs, 2001; Shipman *et al.*, 2001; Ryan *et al.*, 2000).

Psychological resources

We analysed papers relating to psychological influences on help-seeking behaviour (Field and Briggs, 2001; Freeman, 1999; Houston and Pickering, 2000; Jacobson *et al.*, 2001; Klasen and Goodman, 2000; Pattenden *et al.*, 2002; Richardson and Rabiee, 2001; Shaw *et al.*, 2001; Sheikh and Ogden, 1998; Tod *et al.*, 2001; Walsh, 1995; Churchill *et al.*, 2000; Neal and Linnane, 2002; De Nooijer *et al.*, 2001; Donovan *et al.*, 1997). Embarrassment is an important example of a psychological issue common to eight of the studies in this category (Churchill *et al.*, 2000; Donovan *et al.*, 1997; Jacobson *et al.*, 2001; Richardson and Rabiee, 2001; Neal and Linnane, 2002; Pattenden *et al.*, 2002; Sheikh and Ogden, 1998; Shaw *et al.*, 2001). Four studies related to embarrassment felt by young people about going to see a health professional (Churchill *et al.*, 2000; Donovan *et al.*, 1997; Jacobson *et al.*, 2001; Richardson and Rabiee, 2001). A study by Neal and Linnane (2002) found that people suffering from incontinence were deterred from seeking medical help because they were embarrassed by their symptoms and did not feel comfortable discussing them with a GP.

Fear was identified as another psychological barrier to help-seeking in six papers (Freeman, 1999; Pattenden *et al.*, 2002; Shaw *et al.*, 2001; Sheikh and Ogden, 1998; Tod *et al.*, 2001; Walsh, 1995). Fear is associated with uncertainty about what might happen, and anxiety; for

example about invasive examinations and treatments. All participants (n=14) in a qualitative study named fear as a factor obstructing their use of health services for angina (Tod *et al.*, 2001). Walsh's (1995) survey of 200 A&E attenders reported that fear of the unknown and anxiety about their condition and disruptions to their life led to delays.

Service and user discordance

We explored the concept of discordance between services and potential users through the following themes generated by our analysis:

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- Medically defined appropriateness.
- Perceptions of availability and quality.
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- Identity.
-
- Presentation skills.
-
- Power and disempowerment.
-
- Help-seeking dilemmas.

Medically defined appropriateness

A long history of studies around 'appropriateness' of help-seeking behaviour has traditionally emphasised biomedical definitions of 'appropriateness' (Murphy, 1998). Judgements of 'appropriateness' of attendance have traditionally reflected professional attitudes. Qualitative studies, particularly in the area of A&E attendance, have emphasised the moral dimensions of staff judgements about patients. Jeffrey's (1979) classic study showed how staff in A&E classified patients into a number of categories, including 'rubbish' – problems uninteresting or unworthy of medical attention. As we discuss below, research with users of services, on the other hand, has shown that they are very sensitive to the issue of 'appropriateness' and fear of felt or enacted criticism by health service staff may play a very constraining role in decisions about help-seeking. Many people recognise the moral dimension of their behaviour and the impact that 'inappropriate' attendance may have on staff workload and on the access of others (e.g. Cornford *et al.*, 1993; Houston and Pickering, 2000; Kai, 1996a; Stevenson *et al.*, 2003).

Discordance of perspectives was also demonstrated in studies that showed conflict over the definition and management of a problem as a

medical issue. The struggle between perspectives may be played out in conditions of hostility – for example when there is an active conflict over whether a problem requires medical intervention and in what form – or less dramatically, in passivity and failure to initiate the action that might deliver the best medical outcome. For example, Klasen and Goodman (2000) found that parents and doctors were at odds in their interpretation of hyperactivity as a legitimate health problem. Parents wanted to ‘medicalise’ the problem and were keen to be given a diagnosis as a label for the problem in order to make sense of it and treat it. GPs believed that parents wanted to define hyperactivity as a medical problem as a way for them to deal with possible shortcomings in parenting.

By contrast, other studies show how some problems may not be identified by people as medical problems, when they would be seen by health professionals as serious medical problems requiring intervention. Pattenden and colleagues (2002) found that patients delayed in seeking emergency help for acute myocardial infarction due to confusion over symptoms. Many of the participants interviewed did not believe that their symptoms were sufficiently severe, and misinterpreted their symptoms as angina or indigestion or felt they were protected by lifestyle factors.

Identity

Our analysis of studies on help-seeking produced ‘identity’ as a synthetic construct that helped to link and explain findings across a large number of studies of help-seeking. Issues related to identity were identified as important influences on help-seeking behaviour in papers that we analysed (Gardner and Chapple, 1999; Hopton *et al.*, 1996; Houston and Pickering, 2000; Jacobson *et al.*, 2001; Kai, 1996a; Kai, 1996b; Klasen and Goodman, 2000; Pattenden *et al.*, 2002; O’Cathain *et al.*, 2000; Richardson and Rabiee, 2001; Stevenson *et al.*, 2003; Tod *et al.*, 2001; Whitehead and Gosling, 2003; Rogers *et al.*, 1999a; Olsson and Hansagi, 2001; Churchill *et al.*, 2000; Cornford *et al.*, 1993; Cornford and Cornford, 1999; Cromerty, 1996; Charles-Jones *et al.*, 2003; Dixon-Woods *et al.*, 2001). Identity as an individual’s sense of self, is made meaningful in their interactions with others. Individuals are motivated by a need for ‘confirmation’ or approval of their self and so act in such a way as to protect their identity (Laing, 1988). Identity has, of course, become a major theme in sociological and cultural research, and recent work has demonstrated its utility in the health field. Coyle (1999) for example, emphasised the significance of identity in her analysis of patients’ accounts of dissatisfaction with health services. Negative perceptions and experiences are regarded as threats to personal identity and included: not being treated as a human being; being stereotyped by doctors; having little power to assert one’s personal identity; health problems being treated without seeking insight into the patient’s subjective experience; and feeling devalued.

We identified issues relating to identity as barriers to help-seeking and accessing health care, particularly in the context of conflict in lay and medical perspectives and the resources available to people. People may be highly sensitive to perceptions of their behaviour by professionals and others. Many help-seeking studies show that people's fear of identity threats influences their decisions to seek help for medical problems and their interaction with health services. Their need to protect their identity – as rational, non-neurotic, non-hypochondriacal, responsible users of health services – may mean that they delay help-seeking (Cornford *et al.*, 1993; Houston and Pickering, 2000; Kai, 1996a). The importance of identity as an issue in help-seeking is illustrated in evidence reporting the relief that some patients feel when they receive a diagnosis – even quite a devastating one such as cancer – because it vindicates earlier help-seeking (Hopton *et al.*, 1996; Houston and Pickering, 2000; Klasen and Goodman, 2000; O'Cathain *et al.*, 2000; Whitehead and Gosling, 2003). In a study of NHS Direct service users, O'Cathain *et al.*, (2000) reported that users felt reassured from the advice given by NHS Direct nurses as it gave confirmation that they were right to consult the service and needed treatment.

Perceptions of availability and quality

A body of evidence describes patients' perceptions of adequacy and quality of provision. Issues relating to waiting emerged as an important theme in our analysis of articles on capacity in the NHS: having to wait for an appointment and perceptions of length of wait inhibit people's actual and perceived ability to access health care.

We analysed articles that reported on the relationship between service use and perceived quality of care (Milewa *et al.*, 2000; Haylock *et al.*, 1993; Jacobson *et al.*, 2001; O'Cathain *et al.*, 2000; Whitehead and Gosling, 2003; Rogers *et al.*, 1999a; Olsson and Hansagi, 2001; Walsh, 1995; Paterson and Britten, 2000; Bond *et al.*, 2000; Campbell *et al.*, 2001a; Bowling *et al.*, 1987; Dale *et al.*, 1996; Cragg *et al.*, 1994; Baker *et al.*, 1999; Murphy *et al.*, 1996; Shipman *et al.*, 2000; McKinley and Roberts, 2001; Stern and Brown, 1994; Richards *et al.*, 1998; Tarrant *et al.*, 2003; Harrison *et al.*, 1996; Carter *et al.*, 2002; Grant *et al.*, 2002; Churchill *et al.*, 2000; Neal and Linnane, 2002; Cromerty, 1996; McKinley and Roberts, 2001; Dixon-Woods *et al.*, 2001; Donovan *et al.*, 1997; Drummond *et al.*, 2000; Feder *et al.*, 1993). People reported dissatisfaction with a range of different services and services providers, including pharmacists (Milewa *et al.*, 2000); health visitors (Haylock *et al.*, 1993); psychiatric care (Olsson and Hansagi, 2001) and NHS Direct (Grant *et al.*, 2002). Dissatisfaction with general practice is associated with delays, perceived incompetence and lack of information and advice (McKinley *et al.*, 1997; Dixon-Woods *et al.*, 2001; Cromerty, 1996; Neal and Linnane, 2002; Carter *et al.*, 2002; Stern and Brown, 1994).

Perceived poor quality of care may help to explain people's decisions to seek help in ways that are not considered appropriate by service providers. Bowling *et al.*, (1987) found that dissatisfaction with GP services is among the reasons given for bypassing the GP and going straight to A&E, a finding repeated in other studies (Rogers *et al.*, 1999b).

Presentation skills

Analysis of our sample of papers indicates that people's interpersonal and language skills, and in particular their ability to articulate their health problem and conduct consultations, may mediate access to care. Issues of communication were addressed in many articles that we reviewed (Gardner and Chapple, 1999; Jacobson *et al.*, 2001; Richardson and Rabiee, 2001; Shaw *et al.*, 2001; Stallard and Lenton, 1992; Stevenson *et al.*, 2003; Tod *et al.*, 2001; Whitehead and Gosling, 2003; Karim *et al.*, 2000; Somerset *et al.*, 1999; Baines *et al.*, 1998; McKee and Waghorn, 2000; Baker *et al.*, 1999; Carter *et al.*, 2002; Churchill *et al.*, 2000; Chapple *et al.*, 2001).

Issues of people's presentation skills arise once a point of entry, or 'access-entry', has been gained. Difficulties in the consultation can lead to problems in gaining access to appropriate diagnosis, referral, and treatment – or problems of 'in-system' access are reported in the literature (Rosen *et al.*, 2001). Eight articles referred to the importance of interactions with health professionals in gaining diagnoses that would allow progression within the system (Klasen and Goodman, 2000; Whitehead and Gosling, 2003; McKee and Waghorn, 2000; Baker *et al.*, 1999; Dixon-Woods *et al.*, 2001; Kai, 1996a; Cornford *et al.*, 1993; Cromerty, 1996). For example, Baker *et al.*, (1999) reported that some patients felt the doctor was not listening to them or involving them in the decision-making process about their illness, and this inhibited sustained engagement with health services.

A study of reporting of urinary symptoms revealed the difficulty people had in reporting symptoms to their doctor (Shaw *et al.*, 2001). Patients were very sensitive to the doctor's reaction: patients would often mention urinary symptoms in the context of consulting for something else. If the doctor did not pick up on it, patients could interpret this as meaning there was no treatment available. Embarrassment and / or fear prevented patients from mentioning it again. Patients were very responsive to the doctor's approach and could be easily encouraged or discouraged from consulting. Further evidence of the sensitivity of people to professional perceptions of help-seeking is found in the Stevenson *et al.* study (2003), which found that patients withheld information from their GP that they feared their GP would deem inappropriate action.

Power and disempowerment

Our analysis identified issues of power as key influences on help-seeking behaviour. Disempowerment refers to the phenomenon of people feeling inhibited in seeking help by their felt position of power relative to those providing services (Hopton *et al.*, 1996; Houston and Pickering, 2000; Jacobson *et al.*, 2001; Kai, 1996a; Kai, 1996b; Pattenden *et al.*, 2002; Richardson and Rabiee, 2001; Whitehead and Gosling, 2003; Olsson and Hansagi, 2001; Somerset *et al.*, 1999; Morris *et al.*, 2001; Baker *et al.*, 1999; McIntosh and Shaw, 2003; Cromerty, 1996; Donovan *et al.*, 1997; Charles-Jones *et al.*, 2003). These studies were largely based on qualitative interviews investigating patient experiences of using health care. Descriptions of feelings such as lack of confidence (Hopton *et al.*, 1996), lack of choice (Kai, 1996b) and being made to feel incompetent (Klasen and Goodman, 2000) were linked to a common experience of disempowerment.

Olsson and Hansagi (2001) report that resigning to symptoms and seeking professional help signifies the relinquishing of power over the symptoms and a threat to individuals' personal autonomy and ability to cope with their health problem. They interviewed ten patients who attended Stockholm's emergency department and found that disempowerment had a strong influence on patients' behaviour and interactions with health services. Feelings of inferiority associated with the need for frequent medical attention were reported among participants in this study. One patient, for example, reported that she was aware that the staff's judgements about the urgency of her case might differ from her own, leaving her feeling disrespected and ashamed.

There is some evidence to suggest that medical discourses around 'appropriateness' may, perhaps unintentionally, disempower patients. In a questionnaire study of 447 GPs' attitudes towards minor ailments, 61.6 per cent of GPs agreed that encouraging patients to self-manage and use over the counter remedies would 'empower' people to self-manage in the future (Morris *et al.*, 2001). Other work has identified the political and professional capture of discourses around 'empowerment' and 'what is best for the patient' as a means of justifying the organisation of services in ways that best suit professional views of what services should provide (Charles-Jones *et al.*, 2003). However, these discourses may function to sensitise patients to the demands on professional time and discourage them from help-seeking, rather than to promote more 'appropriate' help-seeking. Cromerty (1996) found, in their qualitative study of 18 general practice patients, that patients were sensitive to their perception of the doctor's attitude, and often felt that their problem was trivialised or that they had wasted the doctor's time. Patients in this study were concerned about a perceived lack of time in the consultation and often limited its length out of a sense of guilt.

Help-seeking dilemmas

Discordance between provider and user perspectives can result in help-seeking dilemmas: people have to seek a balance between the available resources, motivations, facilitators, and barriers (Houston and Pickering, 2000; Kai, 1996a; Whitehead and Gosling, 2003; Shaw *et al.*, 2001; Sheikh and Ogden, 1998; Pattenden *et al.*, 2002; Rogers *et al.*, 1999a). People may, for example, be concerned that their symptoms are not worthy of investigation and that they might be deemed neurotic and paranoid by health professionals, and on the other hand be concerned that symptoms could be serious and require early detection. Consultation may occur only when the latter concerns outweigh the former.

Rogers *et al.* (1999a) found that perceptions of rationing in health care led to dilemmas about whether or not to consult. Patients felt that GPs were oversubscribed, so consultations would be rushed and short, and that they were unlikely to be referred on to secondary care due to lack of resources. Seven participants were fearful that they would be removed from the practice list if they attended too frequently and became expensive. Patients voiced concerns about appropriate use of services. In response to these beliefs, patients did not want to 'bother' the doctor or consult for minor ailments, instead self-rationing their service use. Another response was for patients to adapt or curtail their health problem to fit in with their perceived length of time the doctor had to see them.

Summary: Help-seeking

Help-seeking behaviour is strongly influenced by the resources available to people. People need to be able to identify and evaluate their symptoms and to negotiate routes to health care, and these tasks may require particular sets of competencies that may be socially or culturally patterned. People need to have access to information and knowledge in order to feel confident in managing health problems, and may rely on forms of social support, including lay referral systems and various forms of advocacy, to inform decision-making in relation to help-seeking. They may be inhibited in their help-seeking by a range of practical problems, from car-parking through to childcare, and may also experience social and psychological deterrents. Perceived deficits of care may prompt further compensatory forms of help-seeking. Access to resources is likely to reflect patterns of social advantage, but all patients, regardless of social position, may be affected by issues of resources.

Our analysis suggests that discordance between medical / service and lay / user perspectives, including differences in definitions and perceptions of health and illness, and what constitutes a health problem and how it should be managed, can operate as barriers both to gaining a point of entry to health services and continued progression within services. There has been, on one hand, an effort to ensure that health services are not overburdened by people seeking help for minor, self-limiting illnesses. On the other hand, this has made people highly sensitive to the demands on professional time and created dilemmas because of the moral character that has been imposed on help-seeking. People often experience uncertainty about help-seeking and may experience key uncertainties about how to match their perceived health needs with the service best suited to dealing with it.

Gatekeepers to services exist at several levels and in several forms. Discordance between medical and lay perspectives about help-seeking is common, and fear of identity threats, may encourage unpredictable forms of help-seeking. People may be keen to protect their status as reasonable, non-demanding individuals in their use of health care, or may use other strategies to protect their identity in their help-seeking behaviour. Patients sometimes feel that they are rendered powerless in their ability to define problems or initiate the actions they feel to be appropriate to address these problems. There is a widely reported feeling that lay knowledge is undervalued. Professional responses to help-seeking may have a powerful influence on future patterns of help-seeking behaviour.

2.2.2 Theme 2: Provision and availability of services

Access to health care is clearly dependent on the availability and provision, or adequate supply in an appropriate configuration, of health services. In general, because the NHS is free at the point of use, it avoids the main financial barriers to access that exist in other countries. Nonetheless, differing patterns of provision will affect the

extent to which services are available for use. Our analysis generated the following themes:

- Lack of capacity.
- Uneven service provision.
- Geographically disadvantaged communities.
- Quality of supply.

Lack of capacity

Our analysis identified lack of capacity as a significant factor affecting people's ability to access care (Fiorentino *et al.*, 1998; Haylock *et al.*, 1993; Jacobson *et al.*, 2001; Baker and Hann, 2001; Winocour *et al.*, 2002; Walsh, 1995; Nelson *et al.*, 2000; Bowling *et al.*, 1987; Campbell *et al.*, 2001a; Baines *et al.*, 1998; Gravelle and Sutton, 2001; Agarwal *et al.*, 2002; Green, 1993; Hamilton *et al.*, 1997; McKee and Waghorn, 2000; Jenkins *et al.*, 1994; Fuat *et al.*, 2003; Donovan *et al.*, 1997). There is a range of evidence reporting under-provision of general practice care according to need (Gravelle and Sutton, 2001); under provision of specialist services e.g. chronic disease management and minor surgery (Baker and Hann, 2001), and other non-clinical support services e.g. physiotherapy, speech therapy and psychological therapy (Fiorentino *et al.*, 1998; Haylock *et al.*, 1993). There is strong evidence that waiting times affect ability to access services (Richardson and Rabiee, 2001; Salisbury *et al.*, 2002; Tod *et al.*, 2001; Rogers *et al.*, 1999a; Hippisley-Cox and Pringle, 2000; Walsh, 1995; Bond *et al.*, 2000; Paterson and Britten, 2000; Miller *et al.*, 2003; Mitchell *et al.*, 2002; Nelson *et al.*, 2000; Ryan *et al.*, 2000; Baker *et al.*, 1999; Leung *et al.*, 1999; Stern and Brown, 1994; Bower *et al.*, 2003; Hackett *et al.*, 1993; Hurst *et al.*, 2000). Patient-perceived difficulties with waiting times for an appointment were reported in six studies that we analysed (Richardson and Rabiee, 2001; Tod *et al.*, 2001; Rogers *et al.*, 1999a; Walsh, 1995; Bower *et al.*, 2003; Stern and Brown, 1994). Walsh (1995) found that one of the reasons given by people attending an A&E department instead of their GP was the length of wait for a GP appointment. Stern and Brown (1994) reported evidence that too long a wait for outpatients appointments could deter people from seeking help altogether: the longer a family has to wait for an appointment, the less likely they are to actually attend the appointment.

Providers are also described as perceiving a lack of capacity in articles in our analysis (Agarwal *et al.*, 2002; Green, 1993; Hamilton *et al.*, 1997; McKee and Waghorn, 2000; Jenkins *et al.*, 1994; Fuat *et al.*, 2003). For example, Agarwal *et al.* (2002) report lack of time, space and inadequate dietetic, ophthalmology and chiropody services as important concerns of GPs. Time was also a significant factor in lack of capacity (McKee and Waghorn, 2000). Difficulty in handling demand for out-of-hours care and getting locum or deputising cover were

issues in two of these studies (Green, 1993; Hamilton *et al.*, 1997). Other issues included lack of hospital beds, inability to get an ambulance to transport patients and lack of specialist equipment (Jenkins *et al.*, 1994; Fuat *et al.*, 2003).

We do not propose, in this review, to discuss in detail issues relating to the financing of health systems as these have been extensively rehearsed elsewhere, and will instead focus on ways in which issues relating to finance appear to operate as barriers to access (Hughes, 2003). However, it is worth noting that many papers in our sample point to the limitations imposed by finite financial resources in the health service (Salisbury *et al.*, 2002; Gillam, 1992; Bond *et al.*, 2000; Blair *et al.*, 1997; Dossetor *et al.*, 1999; Hallam and Cragg, 1994; Baines *et al.*, 1998; Hirst *et al.*, 1998; Dale *et al.*, 1996; Hughes and Yule, 1992; Lack *et al.*, 2000; Murphy *et al.*, 1996; Wilkin *et al.*, 2003; Fulop *et al.*, 2002; Venning *et al.*, 2000; Miller *et al.*, 1999; Campbell *et al.*, 2003; Brogan *et al.*, 1998). For example, Baines *et al.* (1998) refer to the influence of budget in determining the volume of prescribed medication.

Uneven service provision

Differences in allocation of resources arise at several levels. We analysed papers in our sample that made reference to variations in the allocation of resources between regions and districts (Gillam, 1992; Winocour *et al.*, 2002; Langham *et al.*, 1995; Baines *et al.*, 1998; Hirst *et al.*, 1998; Gabhainn *et al.*, 2001; van Doorslaer *et al.*, 2000; Hughes and Yule, 1992; Falmer and Coutler, 1990; Adams *et al.*, 2003; Evans, 1996; Miller *et al.*, 1999). This work suggests that, at least historically, there have been variations in the supply of health services in different parts of the UK. However, problems in the evidence-base make it difficult to draw conclusive comments about the epidemiology of supply. Difficulties arise because of the number of changes in the organisation of the NHS in the last 15 years, which make comparisons over time difficult. The diversity of types of study, populations studied, and lack of consistent categories mean that it is not appropriate to carry out any meta-analysis of the quantitative data in this area. However, our analysis identified evidence of inequalities in the supply of services across areas, as well as types, of service provided, which we termed *uneven service provision*.

The evidence on service configuration and supply of health care suggests that provision is uneven. We identified a lack of consistency in service provision in different settings and geographical areas. We analysed 51 articles referring to the uneven provision of services throughout the country (Aylin *et al.*, 1996; Baker and Hann, 2001; O'Reilly *et al.*, 2001; Reading *et al.*, 1993; Salisbury *et al.*, 2002; Hippisley-Cox and Pringle, 2000; Paterson and Britten, 2000; Gillam, 1992; Haynes *et al.*, 1999; Majeed *et al.*, 1994; Miller *et al.*, 2003; Ben-Schlomo and Chaturvedi, 1995; Goyder *et al.*, 1996; Langham *et*

al., 1995; Hallam and Cragg, 1994; Nelson *et al.*, 2000; Ambery and Donald, 2000; Williams *et al.*, 2002; Jack, *et al.*, 2003; Pitchforth *et al.*, 2002; Jenkins and Campbell, 1996; Griffiths *et al.*, 1997; Reid *et al.*, 1999; Gravelle and Sutton, 2001; Hirst *et al.*, 1998; Agarwal *et al.*, 2002; Gabhainn *et al.*, 2001; Gulliford, 2002; van Doorslaer *et al.*, 2000; Perrett, 1997; Dale *et al.*, 1996; Hughes and Yule, 1992; Cragg *et al.*, 1994; Murphy *et al.*, 1996; Shipman *et al.*, 2000; Bowling and Redfern, 2000; Falmer and Coutler, 1990; Sexton *et al.*, 2000; Schneider *et al.*, 1999; Jenkins and Campbell, 1996; Bailey *et al.*, 1994; Fuat *et al.*, 2003; Kinnersley *et al.*, 2000; Venning *et al.*, 2000; Freeman and Richards, 1993; Shum *et al.*, 2000; Hughes *et al.*, 2003; Hackett *et al.*, 1993; Grant *et al.*, 2002; Hurst *et al.*, 2000; McEvoy *et al.*, 2002). We identified geographical patterning of services as one of the major contributors to inequities in the provision and availability of health care. Geographical differences in supply of services were identified in articles that we analysed (Aylin *et al.*, 1996; Lovett *et al.*, 2002; Baker and Hann, 2001; O'Reilly *et al.*, 2001; Tod *et al.*, 2001; Benzeval and Judge, 1996; Hippisley-Cox and Pringle, 2000; Haynes *et al.*, 1999; Miller *et al.*, 2003; Smiley *et al.*, 2002; Winocour *et al.*, 2002; Langham *et al.*, 1995; Hallam and Cragg, 1994; Nelson *et al.*, 2000; Ambery and Donald, 2000; Williams *et al.*, 2002; Jack *et al.*, 2003; Jenkins and Campbell, 1996; Griffiths *et al.*, 1997; Reid *et al.*, 1999; Gravelle and Sutton, 2001; Hirst *et al.*, 1998; Agarwal *et al.*, 2002; Gabhainn *et al.*, 2001; Gulliford, 2002; Bowling and Redfern, 2000; Wilkin *et al.*, 2003; Fuat *et al.*, 2003; Adams *et al.*, 2003; Hughes *et al.*, 2003; Hackett *et al.*, 1993).

Hirst *et al.* (1998) report variation in provision of nurses across the country. The nurse ratio varied more than two-fold in 1995. Thirteen of the areas of poorest provision were in the former North-West, Northern and Yorkshire Regional Health Authorities. Lower rates of practice nurse provision were associated with areas of greater healthcare needs. Similarly, Smiley and Cooper (2002) report on the 'postcode lottery' of specialist health services for people with intellectual disability in Scotland.

There has been persistent concern, reflected in 23 articles that we analysed, about inequalities in the supply and distribution of primary care supply (Aylin *et al.*, 1996; Baker and Hann, 2001; Salisbury *et al.*, 2002; Benzeval and Judge, 1996; Hippisley-Cox and Pringle, 2000; Gillam, 1992; Stoddart *et al.*, 2003; Hippisley-Cox *et al.*, 2001; Goyder *et al.*, 1996; Langham *et al.*, 1995; Hallam and Cragg, 1994; Nelson *et al.*, 2000; Jenkins and Campbell, 1996; Griffiths *et al.*, 1997; Gravelle and Sutton, 2001; Hirst *et al.*, 1998; Gabhainn *et al.*, 2001; Gulliford, 2002; Khunti *et al.*, 2001; Green, 1993; Perrett, 1997; Adams *et al.*, 2003; Venning *et al.*, 2000). The majority of this evidence comes from surveys and secondary data analysis of level of provision of particular services across the UK. The effects of different methodology on findings are evident in many of the studies (Gravelle and Sutton, 2001). Reports of variations in provision of secondary and

tertiary care services are also evident (Fiorentino *et al.*, 1998; Partridge *et al.*, 1997; Black *et al.*, 1995; Bond *et al.*, 2000; Miller *et al.*, 2003; Winocour *et al.*, 2002; Griffiths *et al.*, 1997; Sexton *et al.*, 2000; Schneider *et al.*, 1999; Hughes *et al.*, 2003).

Geographically disadvantaged communities

Analysis of the literature showed that particular forms of service configuration create access-disadvantaged groups. Some communities are disadvantaged by their location, by living, for example, in rural or deprived inner-city areas. Evidence that people were disadvantaged by the centralisation or concentration of services is found in articles that we analysed (Field and Briggs, 2001; Jones *et al.*, 1999; Lovett *et al.*, 2002; Shipman *et al.*, 2001; Hippisley-Cox and Pringle, 2000; Bain *et al.*, 2002; Baird *et al.*, 2000; Ben-Schlomo and Chaturvedi, 1995; Carlisle and Johnstone, 1998; Jones and Bentham, 1997; Ryan *et al.*, 2000; Williams *et al.*, 2002; Jack *et al.*, 2003; Campbell *et al.*, 2001b; Gabhainn *et al.*, 2001; Gulliford, 2002; Khunti *et al.*, 2001). For example, Baird *et al.* (2000) reported the role of distance from regional cancer centres as a disadvantage for certain groups. There was an average distance of 1479km travelled by the 32 rural cancer patients in this study – over 20 hours by private car. These data suggest that people living in rural areas were disadvantaged relative to people living nearer the cancer centres, creating inequities in access to treatment. Patients in a study by Bain *et al.* (2002) varied in their preference to travel to central specialist care centres. There was a perception among respondents that treatment was better in the specialist centres, but inability to travel was associated with lack of personal transport.

Evidence related to the 'distance decay effect' – the further people are located from services, the less likely they are to use them – is found in seven articles that we analysed (Field and Briggs, 2001; O'Reilly *et al.*, 2001; Ben-Schlomo and Chaturvedi, 1995; Jones and Bentham, 1997; Ambery and Donald, 2000; Cragg *et al.*, 1994; Hippisley-Cox and Pringle, 2000). Black *et al.* (1995) found large and significant variation in coronary artery bypass graft (CBAG) and percutaneous transluminal coronary angioplasty (PTCA) rates between districts. Those closer to regional centres had greater rates of treatment, explained by supply rather than demand factors. Hippisley-Cox and Pringle (2000) found lower rates of angiography among patients referred who lived furthest away from the secondary referral centre. There is some evidence that the distance decay effect is mediated by other variables (Lovett *et al.*, 2002; Haynes *et al.*, 1999). O'Reilly *et al.* (2001) found that the likelihood of seeing a GP decreases the further away the patient lives.

Quality of supply

Inequities of quality of supply have been a persistent concern, and may act as barriers to access even when nominal capacity (measured

in metrics such as number of doctors per head of population) is constant. There is a large body of evidence indicating that quality of supply of health care is variable across location and services (Agarwal *et al.*, 2002; Baines *et al.*, 1998; Blair *et al.*, 1997; Bond *et al.*, 2000; Bowman *et al.*, 2001; Campbell *et al.*, 2001a; Campbell *et al.*, 2003; Cooper *et al.*, 1998; Dunn and Pickering, 1998; Esmail *et al.*, 2000; Fiorentino *et al.*, 1998; Fuat *et al.*, 2003; Fulop *et al.*, 2002; Grant *et al.*, 2002; Green, 1993; Hamilton *et al.*, 1997; Haylock *et al.*, 1993; Hippisley-Cox *et al.*, 2001; Jenkins and Campbell, 1996; McKee and Waghorn, 2000; McKinley *et al.*, 1997; Miller *et al.*, 1999; Murphy *et al.*, 1996; Neal and Linnane, 2002; Nelson *et al.*, 2000; Shipman *et al.*, 2000; Stallard and Lenton, 1992; Tod *et al.*, 2001; Venning *et al.*, 2000; Werrett *et al.*, 2001; Wilkin *et al.*, 2003). Much of this evidence reports patients' perceptions of quality (Fiorentino *et al.*, 1998; Haylock *et al.*, 1993; Stallard and Lenton, 1992; Bond *et al.*, 2000; McKee and Waghorn, 2000; Shipman *et al.*, 2000; Fuat *et al.*, 2003; Tod *et al.*, 2001; Nelson *et al.*, 2000; 2002; McKee and Waghorn, 2000; Venning *et al.*, 2000; Neal and Linnane, 2002).

The evidence suggests a strong link between lack of capacity and quality. McKee and Waghorn (2000) report a study of consultants in an outpatient clinic which found that limited resources diminished quality. Campbell *et al.* (2001a) report shorter consultation times in smaller practices, suggesting that the number of doctors was a predictor of consultation length. Single-handed practices with larger practice lists in rural areas may be associated with poorer quality care (Jenkins and Campbell, 1996), although the evidence is not conclusive on this point: Gabhainn *et al.*'s (2001) study suggested that level of service provision was not any lower, or poorer in quality, in smaller practices.

Summary: Provision and availability of services

Variations in the supply of health services significantly affects people's opportunities to access primary, secondary and tertiary health care. Lack of capacity, variations in quality, differences in resource allocation and features of service configuration, including geographical patterning and concentration of services, all serve to create access-disadvantaged groups.

2.2.3 Theme 3: Organisational features of health services

Beech (2003) highlights the importance of organisational features of health care in determining the timeliness, availability and acceptability of health care. However, as a recent review has identified, the interaction between the discipline of organisational sociology and studies of health and illness has not been as strong as it might have been (Griffiths 2003). In our sampling of literature from the health field, we found that the impact on access is only infrequently prominent in analyses of organisation, and that where it has been

studied, the concept of 'access' is often under-theorised or incompletely operationalised. Much of the health services research literature, for example on the effects of new forms of provision, is lacking in sophistication and is often too focused on a limited range of processes and outcomes at the expense of a wider systems perspective. There has been a failure to recognise sufficiently the relationships between the various interest groups (different professional groups, managers, policy-makers, and patients) within wider institutional, organisational, and policy contexts, and how these might impact on access.

We have organised our analysis around the following themes:

- The ideal user.
- Disruptions, fragmentation and boundaries.
- Organisational forms.
- Integration and 'knock-on' effects.
- Categorisation and disposal.
- Professionals' access to resources.
- Patient preferences.

The ideal user

Our analysis suggests that many services rely on implicit assumptions about the 'ideal user' – someone who uses services precisely in the way they are intended for precisely the problems providers have identified the services as serving. The ideal user is, then, someone with the exact set of competencies and resources required to make optimal use of the service, whose characteristics and use of services has best 'fit' with health services (Dale and Dolan, 1996; Esmail *et al.*, 2000). However, different services have different ideal users, and people must be able to marshal the resources necessary to engage in services across a range of interfaces. General practice might, for example, be organised around an ideal user who is competent at judging symptoms but willing to accept medical advice and can attend promptly during surgery hours, while in-patient hospital services may have an ideal user as one who has plenty of social support and is cognitively competent.

Disruptions, fragmentation and boundaries

Our analysis suggests that complexity has emerged as a defining feature of health services, because of both historical development and the proliferation of new organisational forms. Organisational change and the introduction of new forms of provision inevitably means changes in design and work patterns within the health service. The increasingly complex configuration of health services has created composites of boundaries between the different organisations involved

in patient care. These boundaries in turn create the need for their effective management and increasing cross-boundary working by staff, raising issues of integration of services and questions about the way in which these services relate to each other. Disruptions in people's routes to and through the health care system are therefore prone to occur.

We found considerable evidence for the role of disruption in affecting access to health care (Fiorentino *et al.*, 1998; Tod *et al.*, 2001; Somerset *et al.*, 1999; Baines *et al.*, 1998; Khunti *et al.*, 2001; McKee and Waghorn, 2000; Baker *et al.*, 1999; Wilson *et al.*, 2002; Bowling and Redfern, 2000; Sexton *et al.*, 2000; Fulop *et al.*, 2002; Jenkins *et al.*, 1994; Tarrant *et al.*, 2003; Evans, 1996; Neal and Linnane, 2002). The evidence is mainly concerned with transitions between services (Fiorentino *et al.*, 1998); communication between primary, secondary and tertiary care (Somerset *et al.*, 1999; McKee and Waghorn, 2000; Bowling and Redfern, 2000; Sexton *et al.*, 2000); delays in being seen by a specialist (Baker *et al.*, 1999; Leung *et al.*, 1999; Bowling and Redfern, 2000) and other general structural features (Khunti *et al.*, 2001; Wilson *et al.*, 2002; Fulop *et al.*, 2002). In a study by Jenkins *et al.* (1994), GPs reported disruptions when arranging admissions for their patient as a result of communication breakdown. Specific communication problems experienced by GPs attempting to arrange admission for their patients included failure to obtain an answer at the switchboard; the duty doctor failing to be contacted or misdirected calls; and lengthy negotiations within the hospital.

A key contributor of the complexity of health care is the increase in inter-professional, cross-disciplinary and inter-sectoral modes of working (Fiorentino *et al.*, 1998; Tod *et al.*, 2001; Whitehead and Gosling, 2003; Bond *et al.*, 2000; Mitchell *et al.*, 2002; Hallam and Cragg, 1994; Somerset *et al.*, 1999; McKee and Waghorn, 2000; Wilson *et al.*, 2002; Werrett *et al.*, 2001; Fulop *et al.*, 2002; Schneider *et al.*, 1999; Crawford *et al.*, 2001; Rosen and Mountford, 2002; Evans, 1996; Roland and Bewley, 1992; Rosen and Pearce, 2000; Black *et al.*, 1997). Evidence refers to transition between services (Fiorentino *et al.*, 1998; Fulop *et al.*, 2002; Evans, 1996; Roland and Bewley, 1992); communication around referral processes (Tod *et al.*, 2001; Mitchell *et al.*, 2002; Somerset *et al.*, 1999; Crawford *et al.*, 2001; Rosen and Mountford, 2002); teamwork and transfer of information between colleagues (Whitehead and Gosling, 2003; Bond *et al.*, 2000; Hallam and Cragg, 1994; McKee and Waghorn, 2000; Werrett *et al.*, 2001; Schneider *et al.*, 1999; Crawford *et al.*, 2001; Black *et al.*, 1997); and trust issues between colleagues (Somerset *et al.*, 1999; Wilson *et al.*, 2002; Rosen and Pearce, 2000).

The policy emphasis on partnerships and multi-disciplinary working has created issues of managing the interfaces between individuals, services, departments and sectors. Boundaries arise between various kinds of organisations and various sectors (for example health and

social care, local strategic partnerships) and between the services provided within an organisation and between different professional and managerial groups. Issues related to management of boundaries are referred to in articles that we analysed (Fiorentino *et al.*, 1998; Salisbury *et al.*, 2002; McKee and Waghorn, 2000; Teale *et al.*, 2000; Wilson *et al.*, 2002; Werrett *et al.*, 2001; Schneider *et al.*, 1999; Evans, 1996; Miller *et al.*, 1999). Problems related to the blurring of boundaries between primary and secondary health care provision are identified in four articles (Salisbury *et al.*, 2002; Somerset *et al.*, 1999; Werrett *et al.*, 2001; Evans, 1996). The complexity of health care is also associated with a lack of common shared vocabulary and common understandings of the role, mission and boundaries of different providers. Indeed, there has been a proliferation of terms describing the services available, and this appears to have led to problems of intelligibility for patients and providers.

Strains over inter-occupational boundaries with implications for access have been reported in several studies (Svensson 1996). Somerset *et al.* (1999) report evidence for a power dynamic between GPs and consultants. GPs report that they feel an imbalance of power in their relationship with consultants when dealing with patients, with the consultants having control. Conversely, consultants felt it was the GPs who had the power once patients were discharged back to general practice. Evans (1996) found poor communication between consultants and GPs following discharge of patients back into GP care. GPs in this study identified a continuing problem in the failure of many consultants to provide timely information on discharge. Similarly, Bowling and Redfern (2000) also report poor communication between GP and hospital consultant regarding patients. GPs reported that information regarding their patients had not been relayed to them after treatment in outpatient departments. Sexton *et al.*, (2000) report poor communication between GPs, hospital and community pharmacists, particularly after regimen changes during hospital stays. In this study, 95 per cent of hospital pharmacists surveyed reporting either never involving the community pharmacist in the discharge process or doing so in less than 10 per cent of discharges. In Neal and Linnane's (2002) study, 15 per cent of GPs and 25 per cent of nurses surveyed reported having problems with accessing the incontinence service on behalf of patients. Many staff felt that they did not know whom to contact and the routes of referral were very unclear to both staff and patients.

Dodier and Camus (1998) provide a vivid explanation of the role of the hospital emergency service in what they call 'transfers of responsibility'. The emergency service is found to play three major roles: as a place for absorbing cases that have not yet been placed in the hospital but which are directed to it as the hospital's 'front door'; as a holding area for mistaken referrals and for patients who are present but not wanted by other hospital departments; and as a buffer for difficult moments of transfer from one place to another.

These kinds of strains around boundaries clearly have implications for the progression of people 'through the system' including referral patterns, non-attendance, discharge, waiting lists, and transitions between different elements of service. We analysed issues related to continuity in 15 articles included in our review (Fiorentino *et al.*, 1998; Tod *et al.*, 2001; Olsson and Hansagi, 2001; Bain *et al.*, 2002; Campbell *et al.*, 2001a; Stoddart *et al.*, 2003; Freeman and Richards, 1993; Bowling, 1996; Baker *et al.*, 1999; Tarrant *et al.*, 2003) as well as system and provider related concerns for continuity (Blair *et al.*, 1997; Hallam and Cragg, 1994; Werrett *et al.*, 2001; Tarrant *et al.*, 2003; Crawford *et al.*, 2001; Campbell *et al.*, 2003). In a study on use of A&E departments in Sweden, patients who reported being referred on for psychiatric care associated this experience with an ambiguous outcome and lack of help (Olsson and Hansagi, 2001). Once the A&E clinician had referred the patients on, they were no longer in their care, and patients then lacked a focus for care for their problem.

Organisational forms

New or alternative forms of care have been a feature of health care in the UK, perhaps particularly in the past decade. New services such as NHS Direct and rapid assessment systems for specific conditions create new management responsibilities and networks that require structural systems in order to function among a host of technical and person-related considerations. New forms of provision, such as GP co-operatives, deputising services, NHS Walk-in centres, telephone triage, all add to the complexity of the system both at the level of providers as well as at the level of potential users.

New organisational forms are identified by our analysis (Munro *et al.*, 2000; Salisbury *et al.*, 2002; Paterson and Britten, 2000; Bond *et al.*, 2000; Blair *et al.*, 1997; Dossetor *et al.*, 1999; Mitchell *et al.*, 2002; Williams *et al.*, 2000; Perrett, 1997; McKee and Waghorn, 2000; Lattimer *et al.*, 1998; Wilson *et al.*, 2002; Dunn and Pickering, 1998; Richards *et al.*, 1998; Wilkin *et al.*, 2003; Fulop *et al.*, 2002; Jennings, 1991; Bailey *et al.*, 1994; Baldock *et al.*, 2001; Hsu *et al.*, 2003; Shum *et al.*, 2000; Wooton *et al.*, 2000; Evans, 1996; Lovell *et al.*, 2003; Moore *et al.*, 2002; Rosen and Pearce, 2000; Chau *et al.*, 2003; Boghossian *et al.*, 1996; Chapple *et al.*, 2001; Dale and Dolan, 1996; Black *et al.*, 1997). We sampled articles examining NHS Direct (Munro *et al.*, 2000; Rosen and Pearce, 2000); NHS Walk-in centres (Salisbury *et al.*, 2002; Hsu *et al.*, 2003; Chapple *et al.*, 2001); outreach clinics (Bond *et al.*, 2000; Perrett, 1997; Bailey *et al.*, 1994; Black *et al.*, 1997); rapid access and open referral systems (Mitchell *et al.*, 2002; Williams *et al.*, 2000; Boghossian *et al.*, 1996; Chau *et al.*, 2003); nurse practitioner provision (Shum *et al.*, 2000; Lattimer *et al.*, 1998; Paterson and Britten, 2000; Wilson *et al.*, 2002; Moore *et al.*, 2002) and new technology (Dossetor *et al.*, 1999; McKee and Waghorn, 2000; Lattimer *et al.*, 1998; Wooton *et al.*, 2000).

The rationale behind reform of organisational forms comes from a corpus of work showing that forms of organisation have consequences for efficiency and access. A study on diabetes services suggests that poor availability of services may be linked to organisation of the practice; larger practices and those with diabetes special interest were more likely to be organised, have a re-call system and operate a mini-clinic (Khunti *et al.*, 2001). However, the motivations behind new organisational forms are not always explicit, nor are potential impact assessments generally undertaken before their introduction. Financial considerations have been identified in a number of studies as a driving factor in service provider planning and organisational change, with improvements in access either a by-product or claimed as legitimisation. Miller *et al.* (1999) theorise that reducing cost is central to the rationale for the shift towards a primary care-led health service. Bond *et al.* (2000) report one of the benefits of outreach clinics is their relative cheaper cost compared with outpatient care in hospitals. Hallam and Cragg's study (1994) reports that deputising services for out-of-hours care are cheaper than practice GPs. Murphy *et al.* (1996) reported a similar finding. On the other hand, where improvements in access might be costly, there are likely adverse influences on access. Blair *et al.* (1997) refer to the influence of financial considerations on the provision of specialist services in the community. One of the disadvantages of community-based specialist services is the inability of a specialist to serve many different practices due to travel time and costs involved.

Integration and 'knock-on' effects

Conceiving of health care at a whole system level recognises that changes in one part of the system may cause 'knock-on effects' in another part. Some 'process' approaches have sought to address these issues, including business process re-engineering, approaches which emphasise integrated care pathways and joint funding initiatives and drawing on notions of integration of services and the provision of a seamless service. Such approaches typically focus on communications between services and their interfaces; referrals between services; service mergers / concentration-dispersal of services involving economies of scale and avoidance of duplication of services (Schneider *et al.*, 1999). It is evident from the literature, however, that many initiatives have been introduced piecemeal without regard to possible 'knock on' effects within the system, and moreover have not been evaluated in ways that specifically take account of the unintended consequences of particular forms of organisation or provision in terms of access. It is also clear that the ways in which government policies are shaped in interactions with patients – how they are delivered by staff who deal with patients – has been neglected as a focus for research.

What is apparent is that changes in one part of the system may impact on other parts of the system. For example, in relation to

performance targets, if one area instigates a 'push' to achieve certain targets in their area, it may create additional intense unplanned work in an adjacent area, which that part of the system is unable to meet, resulting in the creation of a bottle-neck. Knock-on effects resulting from structural features of the health care system are referred to in seven papers that we analysed (Munro *et al.*, 2000; Williams *et al.*, 2000; McKee and Waghorn, 2000; Teale *et al.*, 2000; Hsu *et al.*, 2003; Wooton *et al.*, 2000; Charles-Jones *et al.*, 2003). The evidence suggests that changes or incentives in one part of the system may result in improved access for that service, but may in turn create demand on resources in other areas of the health service that serve to inhibit access in other ways (Williams *et al.*, 2000; Teale *et al.*, 2000; Wooton *et al.*, 2000; Charles-Jones *et al.*, 2003) as well as the impact on demand in other areas of the health service (Munro *et al.*, 2000; Somerset *et al.*, 1999; McKee and Waghorn, 2000; Hsu *et al.*, 2003).

McKee and Waghorn (2000) report in detail on 'knock-on' effects, finding that there is little recognition of the inter-relationships within the hospital and how departments influence each other's workloads. Outpatient clinics generate considerable work for other hospital departments. For example, outpatients who need radiology appointments had to rely on radiology staff to organise them, as clinic staff cannot. Even when the impact of other departments is predictable, there is no co-ordinated response. Lack of communication between clinics and hospital departments can create long waits for patients.

Categorisation and disposal

It is clear that the ways in which staff behave in organisations have key impacts on people's access to health care, and that these may affect some groups more than others. In particular, the ways in which patients are categorised by staff using heuristics such as how interesting, serious, or deserving their problem is, how well it matches to what health care staff understand their role to involve, and how it matches to staff perceptions of the appropriate allocation of resources, are important determinants of people's pathways through the health care system – or how their problem is 'disposed' (Bloor, 1976; Jeffrey, 1979; Dingwall and Murray, 1983; Hughes, 1989; Hughes and Griffiths, 1997; Latimer, 1997; Griffiths, 2001). Jeffrey's early work on casualty departments identified that staff distinguish between 'deserving' and 'undeserving' cases. Dodier and Camus (1998) show that categorisation concerns not only questions of eligibility but also the constant establishing of orders of precedence in a context where staff have to be mobilised around the flow of demand.

In categorising patients in elective situations, an observational study of the management of waiting lists found that surgical and administrative preferences were important in deciding priorities on waiting lists (Pope 1991). Reasons for treating patients might range

from case mix demands for teaching juniors, through ensuring a balanced list, to the ease with which a patient could be contacted and offered admission. Unfortunately, this seminal study, showing the non-clinical and organisational influences on access, appears not to have been replicated in more recent times and its salience today is unclear in the light of government initiatives on the management of waiting lists and computerisation.

The evidence points to the direct effects of categorisation on patients' access. Analysis suggests a relationship between diagnosis and 'system-level' access in particular. This refers to the phenomenon that services are made available once a diagnostic label has been attached to a condition: the path to treatment is opened (Gardner and Chapple, 1999; Hopton *et al.*, 1996; Klasen and Goodman, 2000; Sayal *et al.*, 2002; Whitehead and Gosling, 2003; Fuat *et al.*, 2003; Burgess *et al.*, 1998; McIntosh and Shaw, 2003; Charlton *et al.*, 1991; Fox *et al.*, 2000; McEvoy *et al.*, 2002; Dixon-Woods *et al.*, 2001; Bain *et al.* 2002). There is some evidence that if a serious condition is diagnosed, quick and easy access to treatment ensues. Bain *et al.* (2002) report patients' descriptions of GPs as gatekeepers. One patient refers to the speed with which she gained access to treatment once she had been diagnosed:

'When they first discovered I had bowel cancer that was dealt with very quickly and very efficiently through the GP here. He got me straight into (main cancer centre) and operated on.'

On the other hand, in apparently less serious or ambiguous cases where diagnosis is not easy, delays in access can occur. Gardner and Chapple (1999) found that diagnostic confusion was a barrier to referral for angina treatment. Fox *et al.* (2000) found that the diagnosis of heart failure has important implications in terms of management and prognosis.

We analysed papers that made reference to the behaviour and characteristics of health professionals as having an influence on help-seeking (Freeman, 1999; Gardner and Chapple, 1999; Milewa *et al.*, 2000; Jacobson *et al.*, 2001; Kai, 1996a; Klasen and Goodman, 2000; Martin *et al.*, 1991; Pattenden *et al.*, 2002; Peay and Peay, 1998; Richardson and Rabiee, 2001; Sayal *et al.*, 2002; Shaw *et al.*, 2001; Stallard and Lenton, 1992; Stevenson *et al.*, 2003; Tod *et al.*, 2001; Whitehead and Gosling, 2003; Majeed *et al.*, 1994; Hippisley-Cox *et al.*, 2001; Karim *et al.*, 2000; Ambery and Donald, 2000; Williams *et al.*, 2002; Bowling *et al.*, 1987; Reid *et al.*, 1999; Somerset *et al.*, 1999; Baines *et al.*, 1998; Khunti *et al.*, 2001; Morris *et al.*, 2001; Dale *et al.*, 1996; McKee and Waghorn, 2000; Baker *et al.*, 1999; Wilson *et al.*, 2002; Bowling and Redfern, 2000; Jenkins *et al.*, 1994; Dunn and Pickering, 1998; Tarrant *et al.*, 2003; Burgess *et al.*, 1998; Carter *et al.*, 2002; McIntosh and Shaw, 2003; Churchill *et al.*, 2000; Dixon-Woods *et al.*, 2001; Donovan *et al.*, 1997; Charles-Jones *et al.*, 2003). Doctors' beliefs and opinions about dealing with and referring

patients are clearly hugely influential in the progression of people through the health care system (Ambery and Donald, 2000; Somerset *et al.*, 1999; McKee and Waghorn, 2000; McIntosh and Shaw, 2003; Stevenson *et al.*, 2003; Morris *et al.*, 2001). Somerset *et al.* (1999) carried out a series of interviews with GPs, asking them to describe their views, experiences and influences on patient referral. GPs described a range of influences including their relationship and trust in the relevant consultant, patients' ability to communicate well verbally and their social status. Sayal *et al.* (2002) found that decisions to refer are not always based on clinical facts. Of the 16 GPs in this study, all of them agreed that if a parent requested a referral for their child to see a specialist for Attention Deficit and Hyperactivity Disorder (ADHD), they tended to refer. People who do not request a referral – perhaps more likely to be those who lack knowledge, confidence, or assertiveness – may therefore be disadvantaged. Similarly, more than half of the GPs in Ambery and Donald's (2000) study acknowledged that they were greatly influenced by patient and family views about the need for hospitalisation. Evidence suggesting the possibility of discrimination in the provision of services was identified (Jacobson *et al.*, 2001; Klasen and Goodman, 2000; Whitehead and Gosling, 2003; Martin *et al.*, 1991; Hippisley-Cox and Pringle, 2000; Blair *et al.*, 1997; Karim *et al.*, 2000; Smiley *et al.*, 2002; Griffiths *et al.*, 1997; Baines *et al.*, 1998; Morris *et al.*, 2001; Khunti *et al.*, 2001; Perrett, 1997; Murphy *et al.*, 1996; Hughes and Yule, 1992; McKee and Waghorn, 2000; Leung *et al.*, 1999; Fulop *et al.*, 2002; Jenkins *et al.*, 1994; Fuat *et al.*, 2003; Shum *et al.*, 2000; Carter *et al.*, 2002; Hackett *et al.*, 1993; Hurst *et al.*, 2000; McIntosh and Shaw, 2003; McEvoy *et al.*, 2002; Charles-Jones *et al.*, 2003; Freeman, 1999; Sayal *et al.*, 2002; Whitehead and Gosling, 2003; Ambery and Donald, 2000; Pitchforth *et al.*, 2002; Somerset *et al.*, 1999; Baker *et al.*, 1999; Bowling and Redfern, 2000; Bailey *et al.*, 1994; Burgess *et al.*, 1998; Grant *et al.*, 2002; Cooper *et al.*, 1998). Hippisley-Cox and Pringle suggest that there may be some under-investigation and / or treatment of patients with ischaemic heart disease from 'deprived' practices and for those from practices far from a secondary or tertiary referral centre, and propose that part of the explanation may be a result of the referral behaviour of GPs or consultant thresholds for intervention.

The influence of professional beliefs and knowledge about specific medical problems has been studied in some detail (Gardner and Chapple, 1999; Kai, 1996a; Klasen and Goodman, 2000; Peay and Peay, 1998; Sayal *et al.*, 2002; Tod *et al.*, 2001; Whitehead and Gosling, 2003; Somerset *et al.*, 1999; Morris *et al.*, 2001; Bowling and Redfern, 2000; Fuat *et al.*, 2003; Tarrant *et al.*, 2003; Burgess *et al.*, 1998; Carter *et al.*, 2002; McIntosh and Shaw, 2003; McEvoy *et al.*, 2002; Dixon-Woods *et al.*, 2001) Burgess *et al.* (1998) reported diagnostic uncertainty by both GPs and consultants as preventing referral and treatment for breast cancer. Delayed diagnosis and

uncertainty was even more pronounced in cases where women did not have a lump. Similarly, Fuat *et al.* (2003) found that doctors lacked confidence in diagnosing heart failure. Diagnosis was considered by doctors as difficult because of: the subtlety of clinical symptoms; comorbidity; time constraints; lack of availability of tests; anxiety about committing to an intensive treatment and reluctance of patients to be investigated. Knowledge and awareness of research and technology on heart failure was also reported as having an impact on likelihood of referral and treatment. Doctors' specific concerns had an impact on patient care. For example, they were reluctant to treat patients in a primary care setting due to concerns about not knowing enough about the treatment and fearing it would have adverse consequences for frail elderly patients.

McKee and Waghorn (2000) explored the problems faced by staff in organising an out-patient clinic. They reported that individual consultants' personalities and practice style had a strong influence on the management and organisations of the clinics, involving factors such as enthusiasm to work with management, preferences for working alone, resistance to change and attitudes towards risk and decision making, having an influence on the discharge of patients. Jacobson *et al.* (2001) report that support staff such as receptionists may act as gatekeepers as well as clinical staff.

Professionals' access to resources

It is also clear that categorisation occurs across boundaries in health care, with the authority, status and role of the professional acting on behalf of the patient, and the access of that professional to diagnostic and treatment resources, affecting the traversing of boundaries. Improving doctors' access to services, equipment, tests, procedures and referrals clearly assists patients' access to services, and may improve GPs' ability to manage some conditions themselves without referral to a specialist service (Bowling and Redfern, 2000). In seven studies, availability of services was related to access of services made by doctors on behalf of patients (Agarwal *et al.*, 2002; Bond *et al.*, 2000; Bowling and Redfern, 2000; Jenkins *et al.*, 1994; Fuat *et al.*, 2003; Neal and Linnane, 2002; Tod *et al.*, 2001). Neal and Linnane (2002) found that 15 per cent of nurses and 25 per cent of doctors reported problems accessing a specialist continence service in Walsall. Problems included information on the service such as who to contact and unclear routes of referral.

Patient preferences

Our analysis clearly indicates that aspects of provision interact with patient preferences to produce inequities. Evidence for the relationship between patient preferences, use, and the ways services are configured was identified by our analysis (Milewa *et al.*, 2000; Haylock *et al.*, 1993; Pattenden *et al.*, 2002; Shaw *et al.*, 2001; Rogers *et al.*,

1999a; Patterson, 1997; Stoddart *et al.*, 2003; Bain *et al.*, 2002; Bond *et al.*, 2000; Williams *et al.*, 2000; Campbell *et al.*, 2001a; Ryan *et al.*, 2000; Somerset *et al.*, 1999; Dale *et al.*, 1996; Bowling, 1996; Baker *et al.*, 1999; Wilson *et al.*, 2002; McKinley *et al.*, 1997; Freeman and Richards, 1993; Tarrant *et al.*, 2003; Bower *et al.*, 2003; Shum *et al.*, 2000; Carter and Bannon, 1997; Churchill *et al.*, 2000; Cromerty, 1996; Chapple *et al.*, 2001; Dale and Dolan, 1996). A body of research on patients' priorities in using services emphasises continuity of care and timing; preferred site and source of care; and preferences for service configuration.

There is a significant body of evidence related to the importance of seeing the same doctor and the dilemma posed when given the option of faster treatment with an unfamiliar doctor. Seeing the same doctor is identified as a strong patient preference in many studies (Stoddart *et al.*, 2003; Freeman and Richards, 1993; Bowling, 1996; Baker *et al.*, 1999; Tarrant *et al.*, 2003). However, not all patients in these studies prioritise continuity: Freeman and Richards (1993) report varying attitudes on how important it is to see the same doctor. In this study, 50 per cent of the 111 patients interviewed said it was very important to see the same doctor every time but 14 per cent said it was not important at all. Not being able to see the same doctor was associated with frustration and lack of choice. Personal continuity of care was significantly more important to patients who were older and appeared to be linked to willingness to wait. In a study by Stoddart *et al.* (2003) investigating attitudes toward continuity and getting an appointment, being seen quickly was rated as a higher priority than being seen by a known doctor for those attending for both same-day and routine appointments.

In relation to preferred site of health care, Bain *et al.* (2002) report on differential preferences for treatment at a specialist, compared with local, treatment centre. Rural patients in this study preferred to travel to specialist cancer centres for all their care. Others, who tended to be older, preferred all their treatment locally. Patients' views on this were a trade-off between some clear transportation problems and the perception of better treatment at specialist centres. Most patients accepted some degree of travelling was an inevitable part of rural life.

The evidence on the relationship between organisational characteristics and people's use of services is complex. Reid *et al.* (1999) reported that general practice characteristics explained a negligible amount of the variance in hospital admission rates; patient factors were by far the most important. Majeed *et al.* (1995) concluded that practice factors were only weakly associated with uptake of breast cancer screening; there was no significant difference between practices with or without a female partner, practice nurse, or practice manager. On the other hand Majeed *et al.* (1994), found that cervical smear uptake rates were higher in practices with at least one

female partner, in computerised practices, and with a higher number of partners.

There is also a small body of evidence looking at patient preferences and satisfaction with seeing nurse practitioners as a substitute for their usual doctor. Shum *et al.* (2000) report higher levels of satisfaction for consultations with nurse practitioners over and above GPs. However, satisfaction did not always equate with willingness to see the same type of health professional on their next consultation. Among those seen by a doctor, 47.5 per cent indicated that they would like to see a doctor again and 50.5 per cent had no preference. Among those seen by a nurse, 31.5 per cent indicated that they would like to see a doctor next time, 61 per cent had no preference. Of those seen by a nurse practitioner, only 7.5 per cent were happy to see them again. This suggests that patients favour doctors over nurse practitioners despite being happy with the service they received. GPs interviewed in a study carried out by Wilson *et al.* (2002) asserted that patients prefer seeing doctors rather than nurse practitioners for psychological reasons. GPs strongly believe that patients want to see doctors, mainly because they are seen as the appropriate person to make a diagnosis and to legitimate an illness. Somerset *et al.* (1999) provide evidence that preference for seeing a particular health professional is related to perceived severity of the condition. Patients who believed they had a serious condition felt that it was important to be referred to a consultant, feeling that the consultant had the superior knowledge and was therefore seen as the 'expert'.

Summary: Organisational features of health services

Health care organisations often rely implicitly on an 'ideal user', who is able to match the precise set of competencies and resources to the way in which the service is intended to be used by providers, and whose preferences are in line with the way the service is organised and delivered. Sustaining engagement in health care is made more difficult by the need to traverse boundaries around health care organisations. These boundaries may be created as a result of complex organisational configurations and new forms of provision, and can result in fragmentation and difficulties of coordination. Working across boundaries can mean that changes in one part of system can have 'knock-on' effects in other parts. The ways in which people are categorised and disposed in their interactions with health services exert key influences on 'in-system' access. It is clear that aspects of service provision interact with aspects of help-seeking behaviour and service use to create intensified problems of access.

2.2.4 Theme 4: Policy, service developments, and interventions to improve access

Our analysis of articles concerned with policies and interventions to improve access found that much of the published research appears to operate with poorly defined and operationalised theories of access; that many interventions and policies are not well matched to what we have identified as the major barriers to access; and that where policies and interventions have been evaluated, there is often a failure to consider these at a systems level or to consider adequately unwanted outcomes. In particular there is a failure to consider the impact of interventions for other aspects of access. A range of methods, from randomised controlled trials through to qualitative research, has been used to investigate policies and interventions to improve access, but many have failed to capture the patient's perspective, instead relying on metrics such as number of appointments. It is also clear that context is highly important, and that success of an intervention or policy in one setting with a particular group of clients may not translate well into other contexts. The importance of enthusiasm and charisma of individual staff members in the delivery of some types of interventions is, for example, a key contextual variable that may be difficult to replicate elsewhere.

Petricrew and Macintyre (undated <http://www.ukhen.org/ipeh.htm>) suggest that the reasons for the current lack of good evidence may lie in the continuing paradigm wars over the most appropriate research methods for evaluating social interventions. Community level interventions are often evaluated inappropriately, and there is a general unwillingness to seek or provide robust evidence of 'what works'. Williams and Illsley (undated <http://www.ukhen.org/ipeh.htm>)

remark that little is known about the effectiveness and costs of policy options to reduce inequity. They speculate that some of the reasons for this may be methodological difficulties (formulating issues in ways that make them empirically researchable), unwillingness to embark on this type of research, or inherent difficulties in this field. Whatever the true explanation, there is a lack of good quality evidence about policies, service developments and interventions to improve access.

We organised our analysis around the following themes:

- Organising services to respond to demands for .
- New forms and models of provision.
- Incentives to providers.
- Influencing use of services.

Organising services to respond to demands for health care

We analysed evidence about services being organised or configured to respond to demand for care in such a way as to alter access. Some of these – such as the establishment of the National Institute for Clinical Excellence, National Service Frameworks, and key targets – are clearly aimed at improving horizontal equity (equal treatment for equal need). Others such as Health Action Zones have been concerned with vertical equity – directing more resources at adversely affected groups. The evidence for changes made to health care delivery to respond to demand has been organised around the following constructs.

Uniformity versus local needs

We identified evidence in the articles we analysed of a large number of centrally planned influences on the organisation and provision of health care. A system managed from the centre may, however, be insufficiently responsive to local needs. Uniformity of provision, while addressing the issue of 'postcode lottery', may fail to address special and specific needs that exist disproportionately in some localities. There is some evidence to suggest tensions between central and locally controlled initiatives. Aims to promote partnership networking need to operate at a local level in order to succeed. However, this may be inconsistent with the government's drive to collaborate and deliver on central government targets (Glendinning *et al.*, 2002). Discussion of issues characterised by the incongruence between uniformity and local needs is found in four articles in our sample (Salisbury *et al.*, 2002; Black *et al.*, 1995; Smiley *et al.*, 2002; Fuat *et al.*, 2003).

The combined impact of centrally and locally planned provision and organisation may result in *priorities and neglects*. The introduction of forms of organisation and management may mean that some groups benefit while others are neglected (Baines *et al.*, 1998; Leung *et al.*, 1999). For example, the introduction of National Service Frameworks

may mean that services for specific groups of patients covered by the NSFs – people with coronary heart disease and diabetes – are prioritised in planning by PCTs, while other groups – those with respiratory and rheumatological conditions – are neglected.

Increasing capacity and stimulating demand

The extent to which increasing capacity can improve access and reduce inequalities and inequities in access to health care is an important and interesting question. The National Priorities and Planning Framework 2003 – 06 argues that to deliver on priority areas, it will be necessary in most cases to have additional capacity available in terms of staff, facilities, and equipment, and possibly creating new organisations to provide services and care. However, the evidence of a direct link between investment and access is relatively weak.

Increasing capacity can have the effect of exciting demand: more patients come forward and hospital referral rates continue to rise, while demand may be repressed or hidden when services are withdrawn or reconfigure. Broadly the literature suggests that the new forms of organisations have not served to reduce demand on the original modes of service delivery pre-dating them, but have generally acted to service a previously untapped demand (Bond *et al.*, 2000; Hull *et al.*, 2002; Goyder *et al.*, 1996; Goyder *et al.*, 1998; Chapman *et al.*, 2002; Hsu *et al.*, 2003; Dale *et al.*, 1996; Esmail *et al.*, 2000). We analysed five papers describing the relationship between increasing capacity and access. (Somerset *et al.*, 1999; Hirst *et al.*, 1998; Lattimer *et al.*, 1998; Roland and Bewley, 1992; Dale and Dolan, 1996). These papers appear to suggest that increasing capacity may create new forms of demand or address demand that was previously unrecognised. Dale and Dolan (1996) report that the availability of an intermediate tier of health care for minor injuries appears likely to result in increased overall workload. This issue is characterised by Morgan and Beech (1990) as the 'efficiency trap'. The authors suggest that there is little financial incentive to adopt short case and day case surgery, as they are likely to release previously suppressed demand and increase the overall throughput of patients associated with increased costs. These costs need to be balanced with the benefit of increased access and addressing previously unmet need. Rice and Smith (2001) introduce theory on supplier-induced demand: the idea that in areas of high provision of services, individuals might be induced to make more use of services than areas of lower provision; and supplier-suppressed demand: areas of low provision might put people off making more demand.

The evidence in this area is not consistent across studies and settings. Munro *et al.* (2000) found a reduction in the number of calls made to GP cooperatives in areas where NHS Direct has been introduced. Bond *et al.*, (2000) report conflicting statements from GPs about the impact

of outreach clinics on subsequent number of referrals, with some stating a decrease in referrals to outreach clinics compared with hospital clinics and others saying there had been a slight increase.

Local needs assessment, provision and organisation

It is clear that high quality data about need and demand for health are required to inform the planning and development of services to ensure access. However, as described by Hensher and Fulop (1999), the label 'health needs assessment' encompasses a wide range of activities and subject areas, while the concept of need itself is complex and often contested. They conducted a survey of 14 health authorities, analysed reports of studies, and conducted interviews with 28 staff in health authorities who were representatives of public health medicine and commissioning. They found a 'mixed scanning' model, in which certain key issues are subjected to a detailed and deliberate process of decision-making, while other areas are allowed to tick over and evolve incrementally, was in operation. However, pressures beyond the deliberate scanning process were also evident, and can play a role in highlighting issues. These include local political issues and pressure groups – a model that is more consistent with incrementalist, bargaining models of decision-making. Their study also demonstrated that analytical capacity and resources were strictly limited at the level of district health authorities. The authors concluded that needs assessment did feed into decisions and action, but a range of issues appears to exist for which needs assessment is either irrelevant or of limited value. Clearly, investigation of the extent to which these issues apply in PCT settings is required, but these findings do suggest the need for caution in assuming that service provision and organisation can be modelled as the outcome of a rational process explicitly linked to defined and well-measured needs.

Recent interest in this area has focused on the involvement of users (or potential users) in identifying need and proposing solutions (Baines *et al.*, 1998; Bowling, 1996; Crowley *et al.*, 2002; Dolan and Cookson, 2000; Chapple *et al.*, 2001; Crawford *et al.*, 2002). Crowley *et al.*'s (2002) evaluation of the community development initiative in Newcastle reports that greatest community involvement was through the process of consultation with 84 local community groups. New services that resulted from identified need in the community were: a counselling service targeting ethnic minority communities, a community family support project for isolated families, a youth project where health services are brought to marginalised young people and a project to increase local access to community care services.

However, Crowley *et al.*'s study (2002) is typical of many investigations of the effects of involving consumers in planning and development of health care, in that they are often highly descriptive, lack rigorous evaluative techniques, and are biased towards positive results. Crawford *et al.*'s (2002) review found 337 studies about

involving patients in the planning and development of health care, but 87 per cent of these did not describe the effects of involvement. Of the remaining 42 papers, 31 were case reports where project administrators commented on what the project achieved. Crawford *et al.* (2002) conclude that the effects of involving patients are likely to be complex, but are currently not well understood.

Standardisation of provision and resource allocation

While on the one hand, as described above, there is pressure to customise the provision and organisation of services in response to locally defined needs and priorities, there is countervailing pressure from the centre towards standardisation of provision and resource allocation. Performance indicators and their management and monitoring have become an increasing aspect of the whole of the public sector, and perform a number of functions in terms of demonstrating the accountability and quality of public services (Bosanquet 2003). Initiatives in the UK aimed at standardising the provision of care have included National Service Frameworks, NICE guidelines and other guidance aimed at ensuring that variations in standards and access are reduced. The National Priorities and Planning Framework 2003 - 06 sets out key targets in relation to waiting for health care in a number of areas. Additional priorities and targets have been set for cancer, coronary heart disease, mental health, older people, life chances for children, improving the patient experience, reducing health inequalities, and drug misuse. Clearly, achieving these policy targets will require considerable organisational effort. However, because of the relatively recent introduction of many of these initiatives, the empirical evidence of their impacts is still sparse.

A critique of the lack of subtlety around the notions of targets and performance management, however, is beginning to emerge. A House of Commons Public Administration Select Committee report (Wright *et al.*, 2003) has highlighted some of potential adverse effects of target-setting. They refer to the dangers of creating a measurement culture. These include lack of clarity about objectives and outcomes of this form of performance management; failure to produce equity; failure to provide a clear sense of direction and ambition to help plan resources and communicate a clear message to staff; failure to focus on delivering results; failures in reporting and monitoring; and confused accountability. The report makes an important distinction between meeting targets and delivering results, where meeting targets can subvert producing results. For example, waiting time targets for new ophthalmology outpatient appointments were achieved at the expense of cancellation and delay of follow-up. In the report, The Bristol Eye Hospital claims to have cancelled over 1000 follow-up appointments, possibly resulting in 25 cases of blindness caused by delays of up to two years. In addition to pressures to cheat in order to meet targets, other issues raised in the report include problems with cross-cutting targets in order to foster joined-up working; failure to monitor and

report adequately on targets; substituting business plans for targets and the effect on effective management; and lack of awareness of the real-world experience of trying to meet targets and the variability of best practice ability as a result of environmental factors (Wilkin *et al.*, 2003; Fuat *et al.*, 2003; Hughes *et al.*, 2003). Fuat *et al.* (2003) report on the influence of performance management initiatives filtering down into the narratives of health service practitioners. The difficulties associated with current records systems and methods for diagnosis have also been noted (Sparrow *et al.*, 2003).

It is also argued in some of the papers we analysed that the highly complex and specialised nature of much of the guidance means that only a small number of patients are affected by any single initiative, and that the scale of the task of producing guidance for all conditions, procedures and so on is enormous (Bosanquet, 2003). There is some concern that the requirement that standards set in areas covered by, for example, the National Service Frameworks, could lead to areas without standards (for example rheumatology, respiratory medicine) being neglected. Some of the emerging evidence on the impact of initiatives to improve referrals through the introduction of the 'two week rule' for cancer, suggests that these policies may increase over-referral and again have perverse effects on access. Hurst *et al.* (2000) provide some limited evidence in favour of this critique. They report a randomised controlled trial, of fast track versus six-week target waiting time in a rheumatology outpatients clinic, found that rationing by delay was not detrimental to mental or physical health. Shortening waiting times did not produce any additional health benefit.

New forms and models of provision

Our analysis has identified examples of policies, service developments and interventions of new models of service provision and their impact on access to health care. These include cross-boundary and inter-sectoral working, changes to appointments systems. The implications for access of some of the more newly introduced forms of organisation remain as yet unclear, as evaluation is still in the early stages. Munro *et al.* (2000) report that no obvious impact of NHS Direct was found to date on demand for A&E, ambulance and GP cooperative services combined. However, a more consistent effect was found on the use of GP cooperatives, suggesting that the introduction of NHS Direct served to halt the increasing use of GP cooperatives. There is some evidence that organisational changes may not deliver the improvements either in efficiency or in access that are anticipated. A study by Venning *et al.* (2000) reports that consultations with nurse practitioners are not significantly cheaper than those with carried out by GPs. Dale *et al.* (1996) in a study of patient use of minor injury clinics, report that patients chose 'appropriately' between an A&E and minor injury clinic. However, the authors suggest that availability of an intermediate tier of health care for minor injuries appears likely to result in increased workload overall. This leaves the question of the level to which the

concept of optimum 'fit' goes and therefore how 'appropriate' use is defined. There are knock-on effects to other areas of the health care system, so that even 'appropriate' use of health services can have adverse effects elsewhere in the system.

Cross-boundary and inter-sectoral collaboration

Cross-boundary and inter-sectoral collaboration has become a priority for the organisation and delivery of health care and other services. We analysed evidence that collaboration between sectors and agencies in health and social care alters access to health care (Sherwood and Lewis, 2000; Fulop *et al.*, 2002; Schneider *et al.*, 1999; Hardman, 2002; Crowley *et al.*, 2002). The evidence suggests that joint working has become a prerequisite to all major organisational changes and initiatives in recent times. Fulop *et al.* (2002) suggest that the reorganisation of NHS trusts to cover the same geographical region as the local authorities can facilitate greater integration with social services. However, many studies have lacked a direct focus on issues of access, and the benefits of inter-sectoral access in terms of improving access have remained largely asserted or inferred rather than demonstrated.

Schneider *et al.* (1999), report on a survey of a 'care programme approach' (CPA) to delivery of mental health services across all 183 NHS trusts in England. The survey involved rating the involvement of professionals from different agencies in care planning, keyworking, review and involvement of patients experiencing mental health difficulties and their carers. Ninety-five per cent of trusts reported that a tiered form of the CPA was in operation and 77 per cent of trusts had adopted 'Building Bridges' definitions. However, despite respondents stressing their efforts to promote multi-disciplinary and inter-agency partnerships, they acknowledged that there were many barriers to achieving this. Although the main elements of the CPA are well established and multi-disciplinary working is widespread, there are still significant differences among NHS trusts in the involvement of professionals, patients and carers in the various stages of care programming.

A number of studies has looked at shifts between primary and secondary care (Evans, 1996; Miller *et al.*, 1999). An evaluation by Sanderson *et al.* (2003) looks at an example of a shift from secondary to primary-care led NHS: the follow-up treatment of Ear-Nose-Throat (ENT) patients being handled by specialist GPs rather than by ENT consultants in hospital outpatient clinics. This paper looks at six pilot schemes based on the 'Action on ENT' programme to follow-up treatment for ear, nose and throat problems in the community. Those patients who were seen by the specialist GPs had relatively fewer follow-up appointments than those patients who had been seen in hospital outpatient clinics, had significantly lower non-attendance rates, were very satisfied, and had shorter waiting times. The authors

argue that for this scheme to be successful co-operation between primary and secondary care is important and it must fit in well with the strategy of the local health community.

There is some evidence that, unless carefully managed, cross-boundary working may result in forms of load-shifting that redistributes responsibilities but does not increase the capacity for meeting those responsibilities. Somerset *et al.* (1999), for example, argue that initiatives to move some responsibilities from secondary care into primary care have major implications for demand on GPs. If this is not met with the reallocation of resources to the primary care setting and an increase in capacity of GP services, the demand cannot be met and subsequently access will be inhibited.

Altering gatekeeping

Standardisation of referral guidelines is an intervention that, implemented at a policy level, could potentially ensure more consistent and equitable 'in-system' access by making gatekeeping activity more uniform. However, evidence on the impact of policies and interventions aimed at reducing variations in referrals is only now beginning to emerge. Absent from much of the research thus far has been holistic assessment of the impact of guidelines for specific conditions on the wider system, and investigation of the adverse effects for patients of 'false positive' referrals. Many of the psychological and other effects on patients might be similar to those associated with screening programmes, and it is important that they be identified and included in future evaluations. There is also an absence of research that has looked at aspects of gatekeeping behaviour that are less amenable to measurement. Earlier in this *section* we identified that the heuristics professionals use in determining referrals may draw on a wide range of resources, including judgements and intuitions that may be discriminatory in their implications. Despite a large body of work on the effects of guidelines on provider behaviour, there has been relatively little evaluation of the extent to which these 'softer' influences on behaviour might be altered.

Early research has found that GPs are generally positive about the two-week rule on referral for cancer, though they have concerns about the forms used for referral and feelings of loss of autonomy (Dodds *et al.*, 2004). There is some evidence that the introduction of the two-week rule for cancer may have had negative impacts. Failure of GPs to adhere to referral guidelines has been identified in two audits that we analysed (Coxon *et al.*, 2003; Debnath *et al.*, 2002). Cox (2004) reports a questionnaire survey of consultant dermatologists in the UK requesting views and other data on the impact of the two-week rule for skin cancer. The overall proportion of confirmed cancers in patients referred under the two-week rule was 12 per cent, but less than half, (42 per cent) of the tumours were detected by this route. The two-

week rule was perceived by dermatologists to generate a high volume of 'non-relevant' lesions and displacement of other urgent conditions.

There has been some interest in attempts to improve quality of referral or prioritisation. Bennett *et al.* (2001) report a study to compare two interventions (one a risk factor checklist, the other a training video) to reduce variations in referrals for glue ear from primary care. There was significant improvement in the quality of referrals when both interventions were used compared with one or none. However, this study did not examine whether the interventions reduced inequities in referral related to socio-economic status or ethnicity. Lack *et al.* (2000) report on the evaluation of the waiting list 'patients point' scheme for the fair management of elective inpatients and day case waiting lists. The Salisbury Priority Scoring System enables surgeons to assign relative priority to patients at the time they are placed on the waiting list for elective (inpatient or day case) health care. Points are assigned to patients to reflect the rate of progress of their disease, pain or distress, disability or dependence on others, loss of usual occupation and time already waited. Application of the points scoring scheme compared to the existing 'first come first served' orthopaedic waiting list shows that seven patients appear in the first 20 patients to be admitted under both the regimes. The Salisbury points scheme required fewer resources to treat the first 20 patients on the list (£30,254 for 20 patients) than the first come, first served scheme (£40,258 for 20 patients) and met more Salisbury-defined need. However, centrally imposed systems for managing waiting lists, which prioritise number of days on the list over clinical, psychological, and social factors, may interfere with the use and effectiveness of such a system.

Altering appointments systems

Changes to appointment systems have been identified by our analysis as one of the means by which health care organisations seek to respond to and manage demand for care. We have included evidence in this category about modifications to appointments systems, evidence about effects of particular types of appointments systems, and changes to waiting list systems. We analysed articles that refer to changes to appointment systems to manage demand and reduce waiting times (Bond *et al.*, 2000; Lack *et al.*, 2000; Mitchell *et al.*, 2002; Williams *et al.*, 2000; Jennings, 1991; Hurst *et al.*, 2000; Social Exclusion Unit, 2003). The underlying theory behind most interventions would appear to be that allowing appointments systems to be better matched to the priorities of users of services improves access.

Much of the evidence in the area of appointments systems appears to refer to local initiatives rather than initiatives driven centrally by government. An exception to this is the recent Department of Health policy of allowing patients to book their hospital appointment at a time

convenient to them, available to all by 2005. The Social Exclusion Unit (2003) report that the early evidence suggests that this form of booking may result in significant reductions in 'did not attend' rates, with obvious implications for improvements in access. The significance of 'did not attend' rates varies from setting to setting, and does appear to be linked to the ease with which patients can access services in ways and at times that suit them. This may be particularly important for highly vulnerable or potentially stigmatised groups, such as those dependent on drugs (National Treatment Agency for Substance Misuse, 2003).

Most interventions in this area have evaluated 'rapid access' or 'open access' facilities, where dedicated services are available without a lengthy waiting list system. However, few evaluations have assessed the impact of the introduction of such facilities on other services, though it is possible that they could have unwanted effects on access in other parts of the system. Mitchell *et al.* (2002) evaluated an open referral rapid access jaundice clinic, which was established by reorganising existing services and without the need for significant extra resources. The evaluation measured changes in waiting times for referral, consultation, diagnosis, treatment, length of stay in hospital and GP and patient satisfaction. GPs had easy access to the service via a 24-hour 'jaundice hotline', which enabled them to make rapid assessments of patients and refer on those they judged to require urgent treatment. Subsequent length of stay in hospital was greatly reduced as a result of this system. Patient and GP satisfaction levels were also high. In addition, the 'jaundice hotline' and open access rapid referral system significantly reduced waiting times for entry into the health care system. The authors stress that such a system can be achieved through the reorganisation of existing service provision, and need not require extra resources. However, the success of the service does depend on flexibility and teamwork among members of the primary and secondary services, and would require evaluation in other settings.

Williams *et al.* (2000) evaluated a new open-access system for follow-up appointments for patients with inflammatory bowel disease. The new system meant that patients could make follow-up appointments when ill, as opposed to having routine appointments. Patients showed a strong preference for the new system. Despite positive outcomes, including lesser costs to the patient, increased convenience and benefits to secondary resources, there are also potential negative outcomes of changes to existing systems. Patients reported problems in making urgent appointments using this new system, and there are potential dangers in relying on patients to self-initiate referral, given the barriers to help-seeking identified earlier in this *section*. This study emphasises the need for comprehensive evaluation to new systems, to ensure that new vulnerabilities are not being created.

Hurst *et al.* (2000) compare a 'fast track' referral to a rheumatology outpatient clinic in Edinburgh with the existing route to care. The 'fast track' system reduced the wait to see the consultant significantly, with 47 per cent of patients in the existing system seen within 13 weeks with a median wait of 97 days, while 98 per cent of 'fast track' patients were seen within 13 weeks with a median time of 40 days. There was no significant difference in health status between the two groups, with both groups showing significant improvement. At consultation, fewer patients in the 'fast track' were prescribed analgesics (35 per cent versus 55 per cent) or underwent laboratory tests (29 per cent versus 53 per cent). This implies reduced costs for the health service. However, the 'fast track' patients incurred higher costs in medical aids, home adaptation and medication compared with patients in the existing service. There are no available data on patient satisfaction in this study.

Alternative routes to care

We identified earlier in this report that issues of location and transport can represent major barriers to access, because of their impacts on help-seeking and less well understood distance decay effects.

Alternative routes to health care are identified in 15 papers (Munro *et al.*, 2000; Bond *et al.*, 2000; Mitchell *et al.*, 2002; Sherwood and Lewis, 2000; Chapman *et al.*, 2002; Hsu *et al.*, 2003; Hardman, 2002; Evans, 1996; Grant *et al.*, 2002; Lovell *et al.*, 2003; Moore *et al.*, 2002; Rosen and Pearce, 2000; Chau *et al.*, 2003; Fox *et al.*, 2000; Boghossian *et al.*, 1996). Substitution of *place* of care was discussed in 12 papers (Bond *et al.*, 2000; Blair *et al.*, 1997; Somerset *et al.*, 1999; Perrett, 1997; Hill and Rutter, 2001; Falmer and Coutler, 1990; Richards *et al.*, 1998; Harrison *et al.*, 1996; Bailey *et al.*, 1994; Rosen and Mountford, 2002; Dale and Dolan, 1996; Black *et al.*, 1997).

Many of these papers discuss outreach clinics as a substitute for hospital outpatient departments. Bailey *et al.* (1994) report an extensive survey and telephone interviews with hospital managers, specialists and GPs (including GP fundholders) involved with specialist outreach clinic provision in primary care. Supply of outreach clinics, their organisation and referral processes and associated benefits and problems were assessed. Comparing waiting times for different types of outreach clinics revealed that waiting times were shorter in just over half (61 out of 121) of outreach clinics compared with outpatient departments. Benefits of outreach clinics for specialists and their teams include improved communication with GPs; more relaxed patients and atmosphere and variation in work. However, a large proportion of consultants saw no perceived benefits for themselves of outreach provision. There is also some evidence, moreover, that substituting one place of care for another may have adverse effects, including adverse effects on access to health care (Bond *et al.*, 2000; Blair *et al.*, 1997; Somerset *et al.*, 1999; Richards *et al.*, 1998; Hsu *et al.*, 2003; Rosen and Mountford, 2002; Black *et al.*, 1997).

Substitution of forms of provision

We have analysed 16 papers exploring the theory that substituting one form of provision for another alters access to care (Bond *et al.*, 2000; Dossetor *et al.*, 1999; Lattimer *et al.*, 1998; Wilson *et al.*, 2002; Fulop *et al.*, 2002; Kinnersley *et al.*, 2000; Venning *et al.*, 2000; Hsu *et al.*, 2003; Harrison *et al.*, 1996; Crawford *et al.*, 2001; Shum *et al.*, 2000; Miller *et al.*, 1999; Hirst *et al.*, 1998; Lovell *et al.*, 2003; Moore *et al.*, 2002; Sanderson *et al.*, 2003). There is a significant body of articles referring to the introduction of nurse practitioners to offset demands on GPs (Wilson *et al.*, 2002; Lattimer *et al.*, 1998; Kinnersley *et al.*, 2000; Venning *et al.*, 2000; Shum *et al.*, 2000; Moore *et al.*, 2002). The evidence that substituting one form of provision for another improves access is equivocal. A study carried out by Latimer *et al.* (1997) exemplifies examples of 'freeing up' resources as a result of increased capacity and new forms of provision. The availability of nurse consultations reduced GPs workload by 50 per cent including number of home visits and out-of-hours care. Patients were also granted faster access to treatment and advice. However, it is unclear whether the time saved by GPs was reallocated to improve patients' access.

We identified a sub-section of seven articles related to substitution of forms of provision that had a negative impact on access (Wilson *et al.*, 2002; Fulop *et al.*, 2002; Venning *et al.*, 2000; Crawford *et al.*, 2001; Miller *et al.*, 1999; Hurst *et al.*, 2000; Charles-Jones *et al.*, 2003). The substitution of doctors with nurse practitioners is met with some caution on the part of GPs interviewed by Wilson *et al.* (2002). Doctors' reservations surrounded a number of issues including concern that nurses lacked the training and skills to take on the role, system constraints such as the inability of nurse practitioners to prescribe and GP views that patients will perceive the nurse practitioners not to be appropriate to make a diagnosis and legitimate their illness.

Skills substitution

New modes of work organisation within the health service have involved greater flexibilities in the deployment of staff to perform specific tasks. This often involves nurses substituting for doctors, often facilitated by the use of protocols drawn up to form an 'evidence-based' framework within which patients must be managed. We analysed evidence relating to the substitution of skills and flexible roles of health professionals (Salisbury *et al.*, 2002; Paterson and Britten, 2000; Williams *et al.*, 2000; Lattimer *et al.*, 1998; Wilson *et al.*, 2002; McKinley *et al.*, 1997; Kinnersley *et al.*, 2000; Venning *et al.*, 2000; Rosen and Mountford, 2002; Rosen and Pearce, 2000; Chapple *et al.*, 2001; Charles-Jones *et al.*, 2003). The majority of the research related to this topic focuses on the expanding role of nurses.

Rosen and Mountford (2002) describe the range of new skills being adopted by nurses in NHS Walk-in centres. They conclude that there is

no common agreement on the necessary skills, knowledge and attributes required by a Walk-in centre nurse and no standardised induction or training programmes. They assert that agreement on the competencies and role of Walk-in centre nurses is required in order to implement appropriate training and support mechanisms. There is evidence also that within organisations, the substitution of staff raises important problems of professional identity and culture, with 'tribal' and professional allegiance liable to cause disruption and disharmony (Wilson *et al.*, 2002). Clearly, there are also implications for access of these arrangements, in that potential users may be uncertain about the role, authority and competence of staff, or may experience variable standards of care.

Dedicated services

Dedicated services are aimed at improving particular services or serving particular types of patients. We have analysed evidence about the positive and negative effects of dedicated services (Goyder *et al.*, 1996; Khunti *et al.*, 2001; Hughes and Yule, 1992; Schneider *et al.*, 1999; Crawford *et al.*, 2001; Hardman, 2002; Craven *et al.*, 1994). Goyder *et al.* (1996) looked at the provision of structured diabetes care offered by some general practices in Leicestershire. Comparison of practices offering diabetes care as part of a chronic disease management programme with those not providing the service reveals that crude hospital admission rates for diabetes related illnesses are higher among those practices not adopting the disease management programme. However, when adjusted for comparative incidence of insulin dependent diabetes, the admission figures were not significantly different.

Integrated pathways

Integrated care pathways are structured multi-disciplinary task-orientated care plans that detail the essential steps in the care of patients with a specific clinical problem and describe the expected progress of the patient. Summarised by Campbell, Hotchkiss *et al.*, (1998) care pathways exist for many conditions or procedures. There were, at the time of Campbell *et al.*'s (1998) review, over 4000 references to integrated care pathways and related topics published worldwide. Most described experience and identified perceived benefits or concerns associated with their use or practical barriers to implementation. No randomised controlled trials were reported, and most reports do not provide reliable evidence. Publication bias is highly likely. Published evaluations have also failed to detail the level of input of staff time and resources invested to achieve the published outcome.

Use of new forms of technology

There has been considerable interest in the potential of new forms of technology including telemedicine, improved diagnostic or treatment

techniques in improving access (Dossetor *et al.*, 1999; Hull *et al.*, 2002; Khunti *et al.*, 2001; Harrison *et al.*, 1996; Wooton *et al.*, 2000) Dossetor *et al.* (1999) found, in a study of video-conferencing in Australia, that clinical contact through video-conferencing provides easy access to expertise without the cost and inconvenience of travel. In a similar study, Harrison *et al.* (1996) investigated whether tele-medicine could be used to improve communication between primary and secondary care.

Harrison and colleagues (1996) were interested to evaluate the potential benefits of joint tele-consulting and the extent to which it might effectively be used as an alternative to outpatient referral (Harrison *et al.* 1996). In addition, they sought to obtain an indication of its feasibility and acceptability to all the parties involved. The study involved GPs and patients from six general practices and consultants from ten hospitals. GPs and specialist were satisfied overall with the communication and information shared as a result of tele-consultations, but the specialists were critical of the technical performance, with only 54 per cent being satisfied with sound and vision. Although there was scope for technical improvement, the basic quality of the audio-visual link didn't seem to inhibit satisfactory consultations, providing a link was successfully made. The collaboration to overcome any practical problems that arose during the tele-consultations seemed to increase the rapport between the participants. Patient satisfaction levels were also high overall: 84 per cent of patients stated that after using the television link they would feel happy about using it again. Ninety-five per cent of patients felt that their experience of using the television link was positive and felt that the consultants could understand the nature of the problem. Patient also felt that they were not inhibited to say what they wanted.

There is a small amount of evidence that using new forms of technology may have adverse effects. In a randomised controlled trial comparing tele-dermatology with conventional outpatient provision of dermatological care, Wooton *et al.* (2000) found that the cost of tele-medicine per patient was higher than the conventional system, though it was suggested that this potential disadvantage is offset by the patient gains in travel costs and that cost effectiveness improves with increased use of the new system.

Incentives to providers

GPs have historically generated income via a complex system of various kinds of payments listed in the 'Red Book', a statement of fees and allowances negotiated between the Department of Health and the British Medical Association. Under this system, GPs are reimbursed on a capitation basis (for the number of patients on their lists), together with 'items of service' payments for specific activities and the costs of running their surgeries. The effects of this were intensified after the 1990 reforms, when specific financial incentives were introduced for

achieving targets in relation to health promotion. Hausman and Le Grand (1999) review how institutions should be structured so that GPs are motivated to make decisions that are both socially efficient and equitable. They argue that incentives should not be equated with material incentives, and that institutions must consider how to harness the normative and caring concerns of GPs towards the goal of achieving efficient and equitable health outcomes from limited resources, and the effects of the institutions on the distribution of motivation between caring and more self-interested concerns must be considered. They comment that it is remarkable how little hard evidence exists as to doctors' motivations with respect to the competing claims of self-interest, caring and normative commitment. It is important not to overstate the selfish motives of GPs. As Hausman and Le Grand (1999) point out, GPs' interests in neglecting patients are constrained partly by a fear of losing them and the capitation fees they bring, but probably more importantly, by strong norms governing the proper conduct of GPs, by personal ties to patients and a genuine concern for them

We analysed nine articles looking at the influence of incentives to providers on access to health care (Bond *et al.*, 2000; Baines *et al.*, 1998; Hull *et al.*, 2002; Hirst *et al.*, 1998; Khunti *et al.*, 2001; Perrett, 1997; Hughes and Yule, 1992; O'Reilly and Steele, 1998; Coleman *et al.*, 2001). There is some evidence that GPs are more likely to offer care in response to incentives such as payments, even when they are unconvinced about the appropriateness or quality of the evidence (Baines *et al.*, 1998). However, Coleman *et al.* (2001) suggest that the evidence on paying GPs for various activities is inconclusive. Lynch (1998) found that only a minority of practices maximised their income following the introduction of the 1990 contract. Targeting payments appear to have helped to improve rates of immunisation and cervical cytology, but health promotion payments were less successful (Coleman *et al.*, 2001). Coleman's own study of payments for anti-smoking advice found that payment did not change practice nurses' or GPs' behaviour; primary care staff remained resistant to raising the topic of smoking more frequently because of the risk of confrontation with patients. GPs who made the most claims, altered recording practices to document patients' smoking behaviour rather than actually changing behaviour.

The basic services provided by GPs are now referred to in policy documents as 'general medical services' (GMS). Since April 2002, policy has shifted towards a new model of primary care known as Personal Medical Services (PMS). The intention is that PMS will move the focus away from list sizes and workload volumes towards quality of care.

Influencing use of services

A body of evidence aimed at altering the ways in which people use services can be identified. This work invokes the theory that better matching of people's use of services to provision of services could improve access.

Educational interventions

As summarised by Dixon-Woods (2001), a large literature has reported efforts to use educational interventions to alter patients' help-seeking behaviour. Educational interventions to influence people's use of services are used in a variety of settings. We have included evidence in this category about explicit attempts to influence use of service through 'educational' interventions such as leaflets, poster campaigns and television advertising (Wilson *et al.*, 2002; Crawford *et al.*, 2001; McIntosh and Shaw, 2003; Boghossian *et al.*, 1996; Chapple *et al.*, 2001). Implicit in much of this work is the notion that patients need to be educated in the 'appropriate' use of the new extended range of services if they are to access them to optimum effect, both from the point of view of the patient and the staff providing the service.

We have analysed studies referring to educational interventions as a means of influencing service use (Milewa *et al.*, 2000; Hardy *et al.*, 2001; Little *et al.*, 2001; McIntosh and Shaw, 2003; Heaney *et al.*, 2001) The objective of much of this work is to reduce 'inappropriate' consultations, particularly for minor illness and particularly for children. Such work is based on a 'deficit' model of patients' beliefs about illness, where the interventions are intended to 'correct' misunderstandings about illness. As our analysis earlier in this *section* showed, deficit models are too simplistic; help-seeking is highly complex and influenced by a range of resources, only one of which is biomedically 'correct' information.

Source and type of information resources appear to be important. A questionnaire study of 495 health service users by Milewa *et al.* (2000) suggests that the provision of patient education booklet entitled *What should I do?* has a small but significant influence on appropriate self-referral for health care. However, the effect is not as strong as expected, and interviews suggested that individuals rely more heavily on what they regard as 'official' sources or 'expert' opinion from the health professionals themselves. Interview data in a study by Stevenson *et al.* (2003) also indicate that professional advice is considered more legitimate than advice from other sources.

A concern in a small number of studies was that too much information could encourage inappropriate forms of help-seeking by causing people to over-react and become anxious. Interviews with ten GPs in the Netherlands reported that lack of information can cause confusion, delay and misinterpretation of symptoms, but that too much

information can also lead to patients overreacting and being unnecessarily anxious about their symptoms being cancerous (De Nooijer *et al.*, 2001). However, there appears to be little empirical evidence to support the notion that people seek help 'inappropriately' when information is available.

Improved administration

There is some evidence that improvements in the administration of health services may improve access. Majeed *et al.* (1994) identified the significance of larger, computerised practices in having better call-recall services. They concluded that the lack of an association between the number of patients per partner and the cervical smear rate suggests that the way in which a practice organises its call-recall system is more important than list size in achieving high uptake rates.

Hardy *et al.* (2001) evaluated a system involving sending out information packs to patients in advance of their appointments in order to reduce non-attendance. The study compared intervention attendance patterns and waiting times with patterns from historic referrals. Information packs sent to patients two weeks prior to their appointment detailed when and where to come; where to park; who they will see and what to expect. In new patients who were given information before their appointment (with or without phone call) 4.6 per cent (15/325) did not turn up compared with 15 per cent (201/1336) of those who had received neither pack nor phone call ($P < 0.0001$). Of the new patients who received both information pack and phone call, 1.4 per cent (2/147) did not attend compared with 7.3 per cent (13/178) who received information but no phone call ($P < 0.01$). Hull *et al.* (2002) describe a telephone intervention to improve uptake of influenza immunisations. Their findings suggest that influenza immunisation in inner city London can be boosted by about six per cent by using a telephone call by the practice receptionist to the patient.

Charges for services

Though charging for services remains limited in the NHS, there is evidence that access to medicines in particular may be mediated by charges. A qualitative study of people who were not exempt from prescription charges found that medication costs influenced how people managed medical conditions, and that there was low awareness of pre-payment certificates (Schafheutle *et al.*, 2002). Cost was also identified as a barrier to cashing prescriptions in another qualitative study (Jones and Britten, 1998).

Summary: Policy, service developments and interventions to improve access

Generally we found that policies and interventions can be distinguished into a number of types. *Target-setting* at a policy level involves a central drive to improve access, for example a target to achieve minimum waiting times for appointments, but usually without explicit strategies on how this is to be achieved. Target-setting is becoming the subject of an emerging critique, amid concerns that it fails to deal with health care as a system with 'knock-on' effects, and risks subverting access either as a whole or as it applies to 'neglected' groups.

Organising services refers to the use of strategies focused on the organisational features of health care to improve access. Such strategies include increasing capacity, where the 'amount' of health care available is increased. However, the effects of increasing capacity are not well understood, with some evidence that increasing capacity stimulates demand and may have the perverse effect of decreasing access. There has been generally a failure to understand how changes in the organisation and delivery of services affect the micro-level interactions between professionals and patients, where issues of categorisation and disposal are played out.

Standardisation of provision has become a favoured response to evidence of variations in the provision of care, but research is only now beginning to appear on the effects of this on access. Our earlier analysis demonstrated the significance of gatekeeping by professionals at various stages in the patient's pathway through the health service, but much of the evidence thus far has focused on the effects of guidance on referrals rather than on less tangible aspects of provider behaviour. Research on changes to appointments systems appears to be promising. Most of these systems allow a greater match between how patients want to use the system and how booking is allowed. However, the effects of the universal roll-out under current government policies such as access to a GP within 48 hours and more convenient booking of appointments with hospital consultants are difficult to anticipate, as most research thus far has looked at well-defined areas with limited implications for other services.

Dedicated services for specific conditions have been evaluated in several settings, and while they appear to be popular with patients, require more evaluation as to their system-level effects. Prioritisation systems involve the use of strategies such as scoring to formalise the priority to be given to patients based on the urgency or importance of their health problems have been studied, and seem to show that access (measured by who most needs help) can be improved by such systems, but there may be corresponding reductions in access for people deemed to have lesser need. It may be increasingly difficult to implement scoring systems in the context of new policy imperatives that emphasise chronology of referral rather than urgency.

Cross-boundary and intersectoral working has been promoted as a means of improving access and quality in the health service. Again, the effects of this are still poorly understood, but one problem that is beginning to emerge concerns load-shifting between the primary and secondary care sectors. Load-shifting needs to be carefully managed if access is not to be compromised. Information for planning and user involvement in planning are important issues: good quality information on health needs

is needed to plan services, but there is relatively little evidence showing how improved health needs assessment improves access.

There is a small body of recent research on user involvement in planning services, but again it remains difficult to demonstrate direct links between user involvement and improved access. New models of provision include substitution of forms of provision, place of provision, and use of new technologies. The evidence thus far suggests that these are highly sensitive to context and required detailed system-level evaluation. We analysed evidence on the role of incentives to providers in improving access, and suggest that it is difficult to demonstrate a direct link between incentives and access. Finally, we discuss evidence about the potential adverse effects of attempts to improve access, and in particular the trade-offs between quality and access that may occur.

A second major theme of our analysis has focused on attempts to alter user behaviour to improve access. Some interventions, such as reminder systems, appear to be successful and to reduce 'did not attend' rates. Other interventions, including in particular educational interventions to influence consulting behaviour, appear to have been much less successful and may in fact intensify problems of access unless appropriately designed and based on a more sophisticated understanding of help-seeking. Transport arrangements have been identified in our earlier analysis as an important barrier, and we found evidence that policies to improve access to health care are not well delivered. There is now an emerging literature on patients' experiences of alternative pathways to care. Evidence on the impact of charges, for example for prescriptions, on access to health care, is limited.

2.3 Conclusions

In this *section* we have presented a general taxonomic framework within which the literature on access to health care can usefully be organised. This framework suggests that access to health care is highly complex, and influenced both by aspects of provider and user behaviour, but there are strong interactions between aspects of demand and aspects of supply.

Help-seeking is highly complex, and influenced by the resources, including access to forms of knowledge and information and practical and financial support, available in individuals' environments. Uncertainty is a key feature of decision-making about seeking help. There is a strong relationship between perceived need and service; people are more likely to seek help if they perceive a problem to be potentially serious, and conversely are less likely to seek help if they judge symptoms to be non-serious. The availability of forms of social support, and the competence and functioning of lay referral networks, may affect decisions to seek help and the ability to execute a decision to seek help. The extent to which people feel confident in their ability to diagnose and manage illness by themselves is important in influencing their help-seeking, and there is considerable evidence that

many health problems are managed without accessing formal health services. For some health problems, perhaps particularly those with the potential to spoil identity because they are stigmatising or embarrassing, psychological barriers may be important.

Our analysis of our sample of papers demonstrated that there are often discordances between people and services over the appropriate objects of medical attention and intervention. Services have traditionally been keen to minimise 'inappropriate' use of services, but people are often highly sensitive to the need for their use of services to be seen to be rational and appropriate, and may limit or ration their use of services in order to maintain their identity as reasonable and responsible. Dilemmas then arise which, our analysis suggests, educational leaflets aimed at encouraging 'appropriate' use may do little to resolve.

People's judgements of quality of services are important in explaining their willingness to use services and their choice of services, and if their experiences of using services are unsatisfactory, they may engage in compensatory forms of help-seeking elsewhere, or drop out of the system altogether. Considerable effort may be required to negotiate a point of entry to health services because of the complexity of the health service environment, the diversity of organisational forms, and the composites of boundaries that exist between these forms. Perversely, the increase in organisational forms aimed at improving access, including NHS Direct and NHS Walk-in centres, may increase the problems of matching perceived health needs to the appropriate health service.

Historically there have been limitations of capacity in the NHS, which have caused difficulties in access, primarily by creating long waiting times for appointments, procedures, and investigations. The extent of capacity limitation varies, and there exists what we have called 'lumpiness' in service provision. Some communities are geographically disadvantaged, though the evidence about the 'distance decay' effect is inconclusive. Limitations of capacity may cause considerable problems for individuals and professionals as they seek to co-ordinate care. There is some evidence of variations in the quality of supply, which efforts at standardisation, including National Service Frameworks and performance targets, are aiming to address. However a critique of such centrally set objectives suggests that 'pushes' in one part of the system may result in 'pulls' in another, so that, for example, one speciality area benefits while another becomes disfavoured.

Once people have gained a point of entry to services, the categorisation and disposal of their health needs depends to some extent on their ability to present in ways that health professionals find credible and legitimate, and this relies on having adequate interpersonal and language skills, and feeling sufficiently comfortable and encouraged to make potentially identity-spoiling disclosures. The

ways in which the health needs of people are categorised and disposed by health professionals are key to understanding access to treatment, investigation and referrals. Release of health service resources may be triggered by a diagnostic label, but there is evidence that decisions about diagnoses, or the investigations required to make a diagnosis, are not always made consistently or entirely on objective clinical grounds. Issues such as how interesting or deserving a case is seen to be, and perceptions of the availability of resources, may affect categorisation and disposal. Within organisations, strains over inter-occupational and inter-sectoral boundaries may create difficulties of access for people, particularly at an 'in system' level. There may also be strong effects of people's preferences on use of services and willingness to be referred, accept diagnoses, and so on.

We identified a range of service developments, policies, and interventions to improve access. Much recent effort has focused on increasing capacity in the NHS, but there is concern that increasing capacity stimulates demand, though some of this may be currently unmet need. New forms and models of service provision are also currently mostly lacking in an evidence base that might allow their effectiveness in improving access to be judged. It is important that the unanticipated and unwanted consequences of these new forms are considered in any evaluations. The effects of centrally planned targets and service structures on access are currently unknown, as research evidence is not yet available, but there are concerns that principles of uniform provision may conflict with the need to customise services for local circumstances, and that while some areas may be prioritised, others are neglected. Some effort has gone into attempting to control the gatekeeping function of GPs in particular. There is concern that initiatives such as the two week referral rule for suspected cancer may generate many false positives and divert consultant time into dealing with people who do not have cancer.

Section 3 Socio-economic disadvantage and access to health care

3.1 Introduction

In this *section* we present an interpretive synthesis of the evidence on access to health care by people in socio-economically deprived circumstances. The literature in this area is extremely large and diverse. Studies of social inequities in access to health care have used a range of variables to differentiate people's social circumstances. In addition to drawing on a wide range of empirical research, we will also draw on review papers and other documents.

3.2 Lines-of-argument synthesis

Our lines-of-argument synthesis on access to health care by people who are socio-economically disadvantaged is organised around a set of central concepts and in particular the core synthetic category of 'candidacy', which we generated through our analysis of the evidence. Appendix 3A gives details of the studies included in our synthesis.

CANDIDACY describes the ways in which people's eligibility for medical attention and intervention is jointly negotiated between individuals and health services. Candidacy is a dynamic and contingent process, constantly being defined and redefined through interactions between individuals and professionals, and managed in the context of operating conditions, including the biography of the relationship between patients and staff, the typifications staff use in categorising people and diseases, availability of resources, local pressures, and policy imperatives.

Key points in candidacy related to socio-economic disadvantage generated by our analysis:

- In most cases of help-seeking (though there are important exceptions) people come to identify and seek to present themselves as having needs (though these may not be well formulated) to which health services can respond: people thus must recognise that they are candidates for health care and act on that candidacy. It is also possible for health services to identify features of candidacy and seek to apply these to individuals – for example in the case of screening, when the normal help-seeking processes are reversed.
- **Navigation** refers to routes individuals take from identifying their candidacy to gaining a point of entry to health services. Accomplishing the work of navigation relies on a set of competencies and resources that may not be equally distributed among the population, and which may disadvantage socio-economically deprived people.

- People can penetrate, or gain a point of entry, to health services in a number of ways. We will suggest that services can be conceptualised as being surrounded by membranes that are more or less porous. More porous membranes allow people to pass through easily; services that are less permeable require much more work in order to gain a point of entry and sustain engagement with the service. More deprived people are more likely to default to highly porous services.

More porous membranes– Services that have more easily permeable membranes (for example those that do not require appointments, literacy, knowledge, or social skills) are more easily negotiated and more consistent with an impoverished environment. To a large extent, these services, which include general practice and A&E services, do not rely on judgements by health services about candidacy at an individual level.

Less porous membranes are more resistant and present more barriers, are difficult to negotiate, and require a high level of alignment with the organisational values of the services on offer. These services normally require some professional judgement of candidacy of individuals, and include outpatient appointments and procedures undertaken in hospital.

- **Presentations** refers to appearances by people at health services. Once an individual has **presented** to health services, they have asserted their candidacy as deserving of medical attention and / or intervention. They may vary in their recognition and aspirations as to the nature of that candidacy. Presentations involve people in doing work, which again requires particular sets of competencies, skills and resources, which may be variably distributed in the population. We distinguish two forms of presentation:

Appearances, in which people themselves appear before health services through a series of actions initiated (however remotely) by themselves.

Invitations, in which people respond to an invitation about candidacy from health services.

- **Adjudication** refers to professional judgements about the candidacy of the individual for intervention or service. These involve two types of judgements, but judgements are highly conditional and contingent:

Judgements about technical candidacy, in which judgements are made about the technical feasibility of providing interventions or services. People who are socio-economically disadvantaged, because of co-morbidities, later presentation, or more serious illness, may be judged to be poorer technical candidates.

Judgements about social and moral candidacy, in which judgements are made about the likely social benefits of the intervention or the moral or social worth of the candidate.

- **Conditionality** refers to adjudication and disposal being conditional on the operating conditions of services. Each stage of candidacy is likely to be influenced by the perceived or actual availability of health service resources, including issues of geographical proximity. Operating conditions may operate at the level of individual interactions – for example a professional may make an offer that is not warranted on the basis of ‘clinical’ candidacy in order to preserve the relationship with a patient. They may also operate at the level of the organisation – for example an organisation may withhold or delay offers that could be justified on the grounds of clinical candidacy because of limited resources.
- **Offers** – refers to the offer, or non-offer, of intervention or service by professionals.
- **Acceptance and receipt, resistance and rejection** – refers to the uptake of offers by individuals, or attempts to resist and reject offers.
- **Conversion** – refers to the conversion of health care into outcomes.

We suggest that most of the research on socio-economically disadvantaged people has failed adequately to distinguish these different aspects of candidacy, making the results difficult to interpret. We argue that socio-economically disadvantaged people are vulnerable at different stages of candidacy.

We organise our reporting of our synthesis around the following themes generated by our analysis of the evidence:

- 3.2.1 Theme 13.2.1 Theme 1: Construction of the problem of access to health care by socio-economically disadvantaged people.
- 3.2.2 Theme 23.2.2 Theme 2: Identification of candidacy.
- 3.2.3 Theme 33.2.3 Theme 3: Navigation.
- 3.2.4 Theme 43.2.4 Theme 4: Organisational issues in navigation.
- 3.2.5 Theme 53.2.5 Theme 5: Presentation, adjudication and offers.
- 3.2.6 Theme 63.2.6 Theme 6: Tractability: Policies, service developments and interventions to address inequity in access to .

3.2.1 Theme 1: Construction of the problem of access to health care by socio-economically disadvantaged people

Arguably, nowhere do the problems of the conceptualisation and operationalisation of access become more problematic than in the research literature on access to health care by socio-economically disadvantaged groups. The inverse care law, proposed by Tudor Hart

(1971), states that 'the availability of good medical care tends to vary inversely with the need for it in the population served'. While the inverse care law as formulated by Tudor Hart referred specifically to availability of care, it has since been used to explain any association between disadvantage and access to health care, and has operated as what Greenhalgh *et al.* (2004) have identified as a meta-narrative: a distinct research tradition invoking specific sets of 'normal science' assumptions that has developed as a storyline over time. Within this tradition, there has been ongoing concern to demonstrate that socio-economically disadvantaged people are disadvantaged in their access to health care.

Le Grand's (1978) early work continues to be cited in this respect. Summarised by Goddard and Smith (1998), this analysis combined data on General Practice (GP), outpatient and inpatient care from the 1972 General Household Survey. It concluded that the 'lower' social groups receive far less (up to 40 per cent) National Health Service (NHS) care than the 'top' groups, with the top two socio-economic groups receiving 16.8 per cent of total NHS expenditure but reporting 13.9 per cent of illnesses, while the bottom two socio-economic groups received 27.3 per cent of total NHS expenditure but reported 31.9 per cent of all illnesses. The importance of the meta-narrative of the inverse care law is demonstrated in the continued citing of this study, although the data are now more than 30 years out of date and their continued relevance can be questioned. Its methodological rigour has also been the subject of sustained critique. Pereira *et al.* (2000) point to problems with numerator / denominator bias, and a number of later papers (including some referred to later in this *section*) challenged Le Grand's findings. The key importance of this work is in providing a context for a series of studies over three decades that have attempted to assess the extent to which socially and economically deprived people might be disadvantaged in their consumption of NHS resources – in effect a quest for inequity.

The search for inequity has not been straightforward. Much of the work in the area has focused on measuring utilisation, or utilisation and 'need'. Measuring utilisation would roughly equate, in our theoretical model, to measuring the *receipt* of health care: it measures the units of health care people have actually consumed (GP consultations, procedures, and so on). It does not measure *presentations* – attempts by people to assert a claim to candidacy by presenting themselves to health services; *adjudications* (professional judgements about whether people are 'appropriate' candidates for that unit of health care); *offers* (which might be said to refer to those units of health care being made available to people); *acceptances or rejections*; or *conversions* of receipt of health care into outcomes, nor is it attentive to local operating conditions.

The conflating of these different aspects of access, or, more properly 'candidacy', in many of the studies of utilisation has made the findings

very difficult to interpret. For example, in some work it is assumed that lower rates of particular interventions mean that these interventions have not been *offered* to people. However, without knowing something about the *adjudications* (assessments of suitability for those interventions) or about rates of *acceptance* (whether people chose to have the intervention), these assumptions are not warranted.

Adding to the difficulty in interpreting the literature about utilisation are the allied problems of conceptualising and operationalising 'need'. Most studies have invoked a positivist definition of 'need', where 'need' is defined as an epidemiological or clinical construct. There is also a strong normative bias in much of the literature, in which it is assumed that people 'should' have particular forms and levels of provision. These approaches do not recognise the socially constructed nature of 'need'. Because of the continued lack of clarity about the significance of utilisation, together with methodological problems in conducting this type of research, the evidence is contradictory and difficult to interpret.

We have organised our synthesis of access to health care by socio-economically disadvantaged people around the following themes generated by our analysis:

- General practice.
- Specialist care.
- An inverse prevention law?
- Use of A&E and out-of-hours services.

General practice

Our synthesis of the evidence on access to health care suggests that issues of the availability, or supply, of services affects candidacy at every stage, but it is difficult to interpret the data on 'supply' of GPs, since some of the evidence points to large variations in the supply of GPs (number of GPs per head of population) in different areas, but at the same time about 98 per cent of the population nationally is registered with a GP.

Since the inception of the NHS there have been inequities in the number of GPs available to serve different districts (Baker and Hann, 2001; Hippisley-Cox and Pringle, 2000; Khunti *et al.*, 2001; Gillam, 1992; Majeed *et al.*, 1994a; Goyder *et al.*, 1996; Jenkins and Campbell, 1996; Benzeval and Judge, 1996). Benzeval and Judge's (1996) much cited analysis found wide variations in the numbers of GPs who were available and between those available and those who were 'needed', according to the authors' estimates of need. They showed that Cornwall and Isles of Scilly FHSA had 289 whole time equivalent GPs but based on its relative needs, this figure should, according to their analysis, be reduced by 17.5 per cent. Rotherham, on the other hand, needed a one third increase in its number of GPs. Other work has also suggested that deprived areas tend to have

proportionately fewer GPs per head of population than more advantaged areas (Gravelle and Sutton, 2001). Young and Leese (1999) report that it is deprived urban areas that have the greatest difficulties in filling GP vacancies, encouraging qualifiers to remain, and retaining new entrant principals.

Two recent studies, however, did not find evidence of under-supply of GPs in deprived areas. Baker and Hann (2001), in what appears to be the most recent analysis of supply of GPs, did not conclude that there was systematic evidence of poorer service availability in areas with higher population need, instead suggesting that the effects were localised and most predominant in London. Gulliford (2002), using data from the Department of Health's (DoH) statistical publications, found that the number of GPs ranged from 4.3 to 7.1 per 10,000 population, and showed strong univariate associations between higher supply of GPs and lower levels of deprivation, lower proportion in social class IV and V, and lower levels of limiting long-standing illness, but concluded that residual confounding can remain in any outstanding associations, and caution should be exercised in interpreting any associations as causation.

The real difficulty lies, we would suggest, in determining whether variations in supply of GPs in fact result in a socially patterned inability of people to register with a GP, or to gain a timely and high quality appointment with a GP. We did not identify any work that had directly identified this question. More work needs to be done to establish how issues of the number of GPs practising in a particular area affects people's ability to choose and use health care, and on the effects of list size and frequency of consultation on quality of care.

For the most part our analysis of the evidence suggests that, notwithstanding the variable supply of GPs, there are higher GP consultation rates among people who are socio-economically disadvantaged. Where the debate in the literature lies in relation to GP use, is in the extent to which higher GP attendance can be explained by higher rates of morbidity, and whether, if properly adjusted, GP attendance by more disadvantaged groups is in fact disproportionately low in relation to 'need'. Work by O'Donnell and Propper (1991), based on 1985 General Household survey data, examined need / utilisation ratios across self-reported morbidity groups using five income groups. They point out that morbidity is higher in the lower income groups, and that it is therefore unsurprising that their utilisation is higher. This study contradicted the earlier findings of Le Grand (1978), by suggesting that the best-off income group received approximately two thirds of the expenditure per person compared with the worst-off income group.

O'Donnell and Propper's (1991) main findings seem to be confirmed by a number of studies, many of them summarised by Goddard and Smith (1998). Higher GP consultation rates among people from more deprived social groups have been fairly consistently reported, although

many studies have been ecological. Many have not adjusted for 'need' and therefore may not have adequately adjusted for the higher levels of morbidity and serious morbidity in more deprived groups. Carlise and Johnstone (1998), for example, found that Townsend score and Jarman score were associated with higher GP consultation rates at electoral ward level, and Cook *et al.* (1990) found that the proportion of high consulters rose from 6.3 per cent in social class I to 16.1 per cent in social class V (Chi squared = 30.27, $p < 0.001$). Carr-Hill *et al.* (1996), using data from the fourth national morbidity survey for general practice, found that owner-occupiers generally consult less frequently than renters, and that deprivation in general is linked with higher consultations.

Studies that have attempted to adjust for need, usually on the basis of some estimate of morbidity, have suggested that the apparent excess of GP consultation among disadvantaged groups can be explained by higher need. Wyke *et al.* (2003) report, based on a longitudinal study involving home-based interviews, that despite strong univariate associations between socio-economic circumstances and likelihood of being a frequent consulter, no indicator of socio-economic position retained a significant association when underlying ill health was included in the analysis. A comprehensive recent analysis used pooled data from the annual Health Survey for England from 1994 to 1999 together with other data (Sutton *et al.*, 2002). This analysis suggested that social class variables are generally insignificant in explaining health service use. Low educational attainment was not negatively associated with health service use. The coefficient on the income variable was found to be insignificant for GP consultations, outpatient treatment and day case treatment. The permanently sick, the retired, and those with temporary sickness or injury were found to be more likely to use health services relative to people in paid employment. Individuals looking for paid work and those in full time education were less likely to use health services. Those looking after the home or family are more likely to see their GP and receive inpatient treatment, but less likely to receive outpatient treatment. Sutton *et al.* (2002) suggest that income, education, and economic activity drive utilisation, and that social class exerts no independent influence over and above these factors.

There is also some limited evidence from detailed studies of specific illnesses, where it may be easier to demonstrate that 'need' is similar. Macleod *et al.*'s (2000) analysis of management of cancer among women in deprived and affluent areas found that 29 per cent of women living in affluent areas consulted their GP more than once a month during the first year after diagnosis, compared with 41 per cent of women in deprived areas. This pattern of higher rates of GP consultation persisted into the second year of diagnosis.

There does, however, seem to be a distinct category of people who consult very frequently. Scaife *et al.* (2000), using a definition of

frequent attendance of 12+ consultations per year, found that patients who were most likely to be frequent attenders included those from social classes IIIM and IV/V, and those who were unemployed.

There is clearly a need to reconcile the findings of lower supply of GPs per head of population in deprived areas and the findings of higher use of GPs in these areas, though we identified little research that directly investigated the impact of apparent discordance between supply and demand. There is persistent concern that, in part because suggestions about the under-supply of GPs, people who live in deprived areas may receive poorer quality primary care (Campbell *et al.* 2001a). Baker and Hann (2001), who looked at whether there were inequities between availability of primary care services and population need, were unable to find evidence of a consistent effect of poorer service availability and need, instead concluding that there were strong local effects, but other studies have been critical of a range of aspects of primary care in deprived areas. Hippisley-Cox *et al.* (2001) report that single-handed practices were more likely to serve deprived populations, but were likely to have larger list sizes, to lack a practice nurse, and to have a higher hospital admission rate for asthma and epilepsy. Goyder *et al.* (1996) found small practice size to be associated with lack of structured general practice-based diabetes care and higher levels of deprivation. Khunti *et al.* (2001) reported that practices in more deprived areas lagged behind practices in more affluent areas in terms of access to members of the diabetes team. Perhaps a key finding, however, is Stirling *et al.*'s (2001) report that average consultation times in deprived areas were shorter than in more affluent areas, pointing to some of the direct pressures that operate in circumstances where there is high use of GP services.

Overall, the evidence would appear to suggest that socially disadvantaged people have reasonable access to general practice, at least as measured by utilisation. In the later analysis, we suggest that this is because general practice is a relatively porous service that does not impose rigid qualifications for candidacy on people who choose to use it.

Specialist care

The evidence about use of specialist services in secondary and tertiary care, including referrals, investigations, outpatient appointments and inpatient admissions, is even more equivocal and difficult to interpret than that for GP care, with variations across different specialty areas and different localities. A body of work has attempted to investigate the extent to which there is lower utilisation of procedures and investigations for socially disadvantaged people, with perhaps the greatest body of work focusing on cardiology.

The picture with regard to access to cardiac investigation and treatment is complex and confused, in part because of evidence that proximity to a major treatment centre seems to be a major

confounding variable (Black *et al.*, 1995; Hippisley-Cox and Pringle, 2000; Haynes *et al.*, 1999). Black *et al.*'s (1995) work suggested that there were variations in rates of coronary revascularisation, principally because of differences in supply of services. These included differences in levels of medical staffing, presence of a local cardiologist and distance from a specialist centre.

Other work has investigated whether people living in deprived areas have lower receipt of cardiac procedures, including revascularisation, but this has not been conclusive. Hippisley-Cox and Pringle (2000) found evidence for under-investigation and treatment for patients with ischaemic heart disease attending practices in deprived areas. People registered with practices with higher deprivation scores had lower angiography and revascularisation rates (both $p < 0.0001$) despite having a higher estimated prevalence of severe disease. This held when adjustments were made for other practice characteristics (fundholding practice area, partnership size, proximity to a secondary or tertiary referral centre). Pell *et al.* (2000) found that socio-economically deprived patients are more likely to develop CHD but are less likely to be investigated and offered surgery once it has developed. The odds ratio for deprived patients having their operation classified as urgent was 0.5 (CI 0.46 to 0.61) compared with the least deprived, after allowance for age, sex and type of operation. Socio-economically deprived patients were reported to wait on average an extra three weeks for surgery compared with the most affluent group because of being given lower priority. This study did not, however, collect information on the severity of disease or presence of co-morbidity, and it is therefore difficult to know what might have influenced the clinical decisions in this study. Payne and Saul's (1997) study in Sheffield found higher prevalence of symptoms of angina in areas with high material deprivation measured by the Townsend score, but the ratio of coronary artery revascularisation to the prevalence of symptoms varied substantially across the city and was inversely proportional to deprivation.

Other work has been unable to demonstrate inequities in access to cardiac services or has not demonstrated these consistently (Kee *et al.*, 1993; Black *et al.*, 1995a; Leung *et al.*, 1999). Black *et al.* (1995) showed that there were higher intervention rates for coronary artery bypass graft and percutaneous transluminal coronary angioplasty in more deprived areas, although they also found that districts with high levels of need (as measured by CHD mortality), made significantly less use of revascularisation services. Leung *et al.* (1999), using specific standardised criteria to review case notes of patients who underwent coronary angiography in Sunderland, reported equity of access between deprived and affluent areas when need was taken into account. Ben-Schlomo and Chaturvedi (1995) report on the relationship between ischemic heart disease (IHD), deprivation and coronary artery bypass graft (CBAG) operative rates. They found that CBAG operative rates increased linearly for women with each quartile

of deprivation, suggesting increased provision for increased need. However, for men, there was a U-shaped pattern of CBAG operative rates, with lowest provision for the second and third quartiles and a significant elevation in the fourth quartile of deprivation. The data also pointed to a relationship between distance, deprivation and CBAG rates, which explained a large amount, although not all, of the variation. The 'near' wards were significantly more deprived than the 'far' wards from the cardiothoracic unit. After adjusting for deprivation and age, the ratio of CBAG operative rates in the 'near' compared with 'far' wards was 0.65 for men and 0.55 for women. When adjusted for proximity to the cardiothoracic unit, the effect was greatest in the most deprived quartile. Ben-Schlomo and Chaturvedi's (1995) findings suggest that there is not a straightforward relationship between provision and use of services, and indeed a later comparable study by Gatrell *et al.* (2002) in North-West England, found evidence of an increase in rates of CBAG and angiography as deprivation increases.

Taken together, research on equity of utilisation in relation to cardiology does not present a consistent demonstration of inequity, and much of the work, though it continues to be widely cited, is now based on data collected up to 15 years ago. Little work has been published since the introduction of the National Service Framework (NSF) on coronary heart disease (CHD), which is likely to have altered patterns of investigation, referral and treatment, so it is unclear to what extent findings based on data collected in the early 1990s reflect current practice.

There is a smaller body of evidence in relation to socio-economic variations in access to treatment for cancer, much of it summarised by Dixon *et al.* (2003). In a Scottish study, Pitchforth *et al.* (2002) reported that those in the most deprived quartile of their study, using Deprat as an area level deprivation measure, were just over half as likely (0.55, CI 0.20-0.90) to receive chemotherapy for cancer as those in the most affluent quartile. Jack *et al.* (2003), using 1998 - 99 data from the Thames Cancer Registry, found evidence of geographical inequality. They also reported that patients who lived in health authorities with higher lung cancer incidence rates were less likely to receive any active treatment, any radiotherapy or any non-investigative surgery. The authors found that residents of a more deprived health authority area were less likely to receive chemotherapy, but acknowledged that this finding is difficult to interpret.

Pollock and Vickers' (1998) analysis of deprivation and emergency admissions for cancers of colorectum, lung and breast in South-East England, also used an ecological approach. This study found that the patients in the tenth most deprived area of their study were just over half as likely to be admitted as day cases for breast cancer compared with women from the most affluent area (OR 0.58, CI 0.50 to 0.62) and for cancer of lung, trachea or bronchus (0.50; 0.44 to 0.56), while

the odds ratio for colorectal cancer was 0.70 (0.64 to 0.76). Their analysis of the number of admissions to cancer units found that, overall, people in the most deprived decile were much less likely to be admitted (0.38, CI 0.32 to 0.45) compared with the most affluent decile, although they are as likely as to be admitted for cancer of the lung, trachea or bronchus (1.04, 0.90 to 1.21), and more likely to be admitted for breast cancer (1.21, 1.04-1.40). Pollock and Vickers (1998) found a relationship between deprivation and patients who received therapeutic or palliative surgery, with the most deprived decile less likely to have received these interventions for cancer of the lung, trachea or bronchus (0.58; 0.48-0.70) and breast cancer (0.63; 0.56-0.71). As the authors themselves conclude, it is impossible on the basis of these data to determine the explanations for these different patterns of utilisation, though they speculate that stage of presentation by patients and physician bias may be involved.

There is some limited research on possible inequities in access for conditions other than cardiovascular disease and cancer. Seymour and Garthwaite (1999) looked at men undergoing inguinal hernia surgery in Scotland over three time periods between 1982 and 1994, and found that in elective cases there were lower rates of surgery in groups with higher levels of deprivation, but the highest rates of non-elective referrals were found in the most deprived groups. Chaturvedi and Ben-Shlomo (1995) report one of the few studies to try to investigate a range of conditions. They used data from the third national general practice morbidity survey (1981 - 82) to provide an estimate of the expressed need for surgery for varicose veins, inguinal hernia, gallstones, cataract, and arthritis of the hip. They estimated social class based on occupation, and used electoral ward-based estimates of deprivation. The findings suggest different patterns for different conditions. Varicose vein consultation and operation ratios were higher with increasing deprivation, while an inverted U-shape was observed for patient consultations and operations for cataract. For hernia, gallstones and osteoarthritis, there were more consultations in lower social classes, but no corresponding trend in operations. This again is a frequently cited study, but its findings are clearly highly sensitive to the methodology used (for example it was not possible to assign a social class grouping in up to 15 per cent of cases), and its ecological design. The data were collected more than twenty years ago, though they continue to be cited as a demonstration of the inverse care law. Both of these studies illustrate the point that it is not clear what aspects of candidacy are at work here, and in particular to what extent rates of receipt reflect differing presentations, adjudications and acceptance at a variety of points in patients' careers.

An inverse prevention law?

Although, as discussed above, the evidence on utilisation of GP and specialist care is inconsistent and difficult to interpret, there is

considerable evidence that uptake of many preventive services is poorer among low-income groups. The so-called 'inverse prevention law' (Acheson 1998) proposes that communities most at risk of ill health tend to experience the least satisfactory access to the full range of preventive services. Goddard and Smith (1998) and Dixon *et al.* (2003) summarise much of the work in this vein. Health promotion claims by GPs are inversely associated with Jarman scores for deprivation (Bardsley *et al.*, 1997). Campbell *et al.* (2001b) found that deprivation predicts poorer uptake of preventive care. Screening uptake is lower in deprived areas (Majeed *et al.*, 1995; Majeed *et al.*, 1994b). A recent analysis by Baker and Middleton (2003) provides contemporary evidence of uptake of cervical cancer screening. They found that the introduction of the national screening programme in 1988 led to improvements in coverage targets, and coverage in deprived areas improved at a faster rate than in affluent areas, but inequalities in uptake of cervical screening persist. Uptake of immunisation is also socially patterned. Middleton and Baker (2003) found that mean coverage levels were two percentage points higher in the affluent areas compared with the deprived areas. Uptake of antenatal care is higher among affluent groups, a finding confirmed by the House of Commons Health Committee (2003) (Petrou *et al.*, 2001).

The issues relating to prevention are highly significant from the perspective of developing theory in relation to access to health care by socio-economically disadvantaged people. In preventive services that rely on invitations – including immunisation and screening – supply of the service does not vary greatly from locality to locality, and could be assumed to be equal. The fact that receipt of services does not match apparent availability of services tells us that other factors are at work.

Use of A&E and out-of-hours services

There is considerable evidence that use of emergency services, including A&E and out-of-hours GP services, and emergency admissions to hospital, is significantly higher among people from socio-economically disadvantaged groups (Carlisle *et al.*, 1998). Home visits by GPs are also reported to be higher, with nearly a twofold difference in age, and sex standardised home visiting ratios, between social class I and social class V. Reid *et al.* (1999) found that more deprived people are much more likely to be admitted to hospital as emergencies, but elective admissions were not affected by deprivation. Blatchford *et al.* (1999) also reported socio-economic deprivation to be strongly associated with emergency medical admission rates, with patients from the most disadvantaged category having more than double the admission rate of people from the most affluent deprivation category. Murphy (1998) reports that evidence suggesting that a high proportion (between 15 and 20 per cent) of attenders at A&E were not registered with a GP. These patients, it is suggested, probably represent a disadvantaged vulnerable group for

whom A&E acts as a safety net. However, out-of-hours primary care centres, which require travel to a specific location outside of normal surgery hours, appear to deter some people in deprived social groups. Shipman *et al.*'s (2001) study identified that these facilities may present insurmountable barriers to some, particularly in inner city areas where car ownership is low and public transport out of hours is lacking:

'I wanted a doctor to come out to see the baby but he...told me to go to primary care centre...he said "get a cab" – but I didn't have no money and went to A&E (parent of a 6 month old baby with a dry cough).'

We will later suggest that this pattern of emergency and non-elective admissions and out-of-hours use suggests that there is a tendency to manage health as a series of crises, which are addressed by accessing highly porous services.

Summary: Construction of the problem of access to health care by socio-economically disadvantaged people

The evidence about utilisation of health care by disadvantaged groups is highly complex, contradictory, and difficult to interpret. Most studies that have attempted to measure equity in access have focused on utilisation. Taken together, the studies reported here suggest that people in these groups have higher rates of GP use, they under-use preventive services, and are more likely to access emergency forms of care, including out-of-hours GPs and A&E departments. The evidence does not consistently point to poorer access for socio-economically disadvantaged people, even when need is accounted for; some studies even suggest that there is a pro-poor bias in the NHS.

There are, however, important problems with the evidence-base. We suggest that most studies have failed, in their focus on utilisation, to distinguish between different aspects of candidacy. Reports of differential rates of utilisation are in fact reports of differential rates of receipt. Receipt reflects the outcomes of processes of negotiation, presentation, adjudication and acceptance, which are dynamically jointly accomplished by people and health services. In the analysis we develop below, we suggest that services that are most porous and require less work on the part of patients to establish candidacy – such as A&E and general practice – have higher rates of use than services with less permeable membranes requiring more work to gain entry – such as specialist services – and that local operating conditions exert powerful effects at every stage.

3.2.2 Theme 2: Identification of candidacy

In this section we suggest that accomplishing access to health care requires considerable work on the part of individuals, and that the amount, difficulty and complexity of that work may operate as barriers. We suggest that social patterning of perceptions of health and health services, difficulties in marshalling the practical and social resources needed to use services, a lack of alignment between the priorities of disadvantaged people and the organisational values of

health services, conspire to create vulnerabilities for socially disadvantaged people in their negotiation of health services. We have organised our synthesis around the following themes generated by our analysis of the evidence:

- Recognition and response to symptoms: People's identification of candidacy.
-
- Readiness to consult.
- Delays and blockages in recognising or acting on candidacy.
- Identity.
- Health-maintaining behaviours.

Recognition and response to symptoms: People's identification of candidacy

How people recognise their symptoms as needing medical attention or intervention is clearly key to understanding how they assert their claim to candidacy. There is a large body of research in this area, ranging from how people deal with minor illness through to delays in presentation for serious diseases, of which we have sampled a small proportion. Our analysis suggests that people in more deprived circumstances are likely to manage health and to recognise candidacy as a series of crises. There is a tendency to seek help in response to specific events that are seen as warranting candidacy. 'Warning signs' may be downgraded in importance because of a lack of a positive conceptualisation of health, a normalisation of symptoms within deprived communities, and an inability to resource the use of services for what might initially appear to be benign symptoms. Health maintaining behaviours such as cholesterol-lowering drugs may not be consistent with a view of health as a series of crises.

Sociological work, such as Cornwell (1984) and Calnan (1987), though not formally included in our review, has long suggested that people in disadvantaged conditions may lack a positive concept of health. In brief, this work has suggested that people in more adverse social circumstances may have a more fatalistic view of control over their health, and may therefore be less inclined to take preventive action. Richards *et al.* (2002) showed, in a qualitative study of people's responses to chest pain, how participants strongly identified a 'coronary candidate' with which they had varying degrees of identification. People in the deprived area in this study reported greater exposure to ill health, allowing them to normalise their chest pain. This led to confusion with other medical conditions, and gave rise to a belief among people that they were over-using medical services. Gardner and Chapple's (1999) study identified a fatalistic view of heart disease among the deprived participants in their sample. Hunt *et al.* (2001) demonstrated social differences in lay constructions of family histories of heart disease. Working class men were the most uncertain

about whether they had a family history, and deaths were more likely to be attributed to old age at a younger age than was the case for middle class men and women.

Readiness to consult

Notwithstanding the findings that more deprived people may lack a positive concept of health, several studies have identified a readiness among more deprived groups to consult GPs with a range of symptoms. Research in Scotland found that a greater proportion of people with chest pain presented their symptoms to a GP compared with those in affluent areas (Richards *et al.*, 2000). People from more disadvantaged circumstances may be more likely to have a heightened sense of anxiety or urgency about conditions (Campbell, 1999; Wyke *et al.*, 2003). Campbell *et al.* (1999) showed that socio-economic deprivation had a significant but weak effect on perception of urgency. Alberts *et al.* (1998) explored socio-cultural variations in help-seeking behaviour and found that more educated and more professional groups were more likely to manage everyday symptoms themselves and were less likely to seek medical help (Alberts *et al.*, 1998). Professional groups were also more likely to use over-the-counter medication for common complaints such as cold and flu. Similar findings were reported in studies exploring the help-seeking behaviour of parents for their children's health conditions. Edwards and Pill (1996) found that parents from lower socio-economic groups showed less confidence in the self-management of common childhood problems such as cold, and diarrhoea but no differences in self-management of fever (Edwards and Pill, 1996). This resulted in higher GP consultations for children in deprived areas. Comparable evidence was seen in a study of traveller families and their help-seeking experiences for their children (Anderson *et al.*, 1997). Traveller parents were more concerned about keeping their children physically well and were worried about the risks of cough, colds and sickness compared with inner city, with the lowest levels of concern among affluent parents.

Evidence of variation in self-management for behavioural and psychological conditions shows a distinctive pattern. Patients from lower socio-economic groups have been found to be more likely to self-care for psychological problems and less likely to seek professional health care (Barker *et al.*, 1990). More affluent groups were less likely to cope by ignoring the problem and hoping it would go away. Parents of children from more affluent areas were less likely to report behavioural problems in their children (Edwards and Pill, 1996; Anderson *et al.*, 1997). However where there were behavioural problems, parents from more affluent areas were more likely to seek help than in the poorer group (Edwards and Pill, 1996).

Delays and blockages in recognising or acting on candidacy

There is some evidence for social class effects in asserting candidacy, in the form of research suggesting that people from deprived areas are more likely to present late with serious diseases such as cancer, though again the picture is not entirely consistent and may vary from condition to condition (Dixon *et al.*, 2003; Coleman *et al.*, 1999; Paterson *et al.*, 2002). Smith *et al.* (1994), for example, reported that anisometropic amblyopia (an asymptomatic condition affecting vision in childhood) tended to present later in children from deprived areas. Ramirez *et al.* (1999), in a systematic review of factors predicting delayed presentation of a symptomatic breast cancer, identified 27 studies that had investigated this issue, of which six met their inclusion criteria. They found insufficient evidence to support the hypothesis that delay is associated with socio-economic status. Burgess *et al.* (1998), in a study of patient and GP delay, did not find an association between delayed presentation with breast cancer and social class, but Paterson *et al.* (2002) suggested that people from more deprived areas may present at a later stage for head and neck cancers.

For particularly vulnerable people, blockages in negotiating a route to health services may exist, and they may default to the most permeable service: A&E departments. Many homeless people have difficulties in accessing care because they are not registered with a GP. Only a quarter of rough sleepers are registered with a GP, and homeless people are 40 times more likely not to be registered with a GP relative to the rest of the population. Homeless people are four times more likely than the rest of the population to use A&E services (Office of the Deputy Prime Minister, 2004). Highly mobile communities may also have difficulties in gaining entry to the health care system via GPs. In a study of travellers, Feder *et al.* (1993) reported that children did not have enough contact with a GP for their parents to be able to name their practitioner. Only 17 per cent of the parents of traveller children could name their GP compared with 90 per cent for the control families.

Identity

We identified in the general synthesis the importance of people's attempts, when help-seeking, to protect their identity. There is some evidence that deprivation may have particular types of effects on identity. A study of people's management of coronary heart disease (CHD) emphasises the strong influence of identity related to social position on help-seeking (Tod *et al.*, 2001). This study reported a strong sense of wanting to self-manage CHD among the patients interviewed, linked to cultural sentiment among the Yorkshire mining community of not talking about illness and coping with anything life brings. There was a perception that chronic illness was inevitable and people should not complain about it. The threat to the 'pit' identity

involved in seeking help presented a significant barrier to accessing treatment for CHD. 'Being blamed' by professionals emerged as an important barrier. Richards *et al.* (2002) similarly showed that among the deprived respondents, those with multiple health problems were concerned about overusing medical services as they felt they needed to protect their identity as rational, careful and responsible users. Anxiety about presenting among respondents in the deprived area was heightened by self-blame and fear that they would be chastised by their GPs for their risk behaviours.

Health-maintaining behaviours

We noted earlier that there is evidence of lower use of preventive services, including screening, among more deprived groups. Martin and Sterne (2001), analysing data on men from the Fourth National Survey of Morbidity in General Practice, looked at consultations for preventive health care, including those for vaccinations, chronic disease monitoring, and screening examinations and investigations. Consultation rates for preventive health were highest in men from social class I/II; rates in class IV/V were 37 per cent and 31 per cent lower in age groups 16-24 and 25-39 respectively. Watt (2002) summarises evidence from Scotland suggesting that treatment rates of antidepressant medication and cholesterol-lowering are lower than expected in the bottom quintile of the distribution of socio-economic status. Lower rates of use of these kinds of drugs might well produce crises – for example in the form of myocardial infarcts and strokes, or in the form of severe acute mental illness. We suggest that taking this evidence together with the evidence on emergency admissions and out-of-hours use presented earlier suggests that there is lower use of health maintaining behaviours – behaviours designed to avert crises – among more disadvantaged people.

We wish to distinguish here between *appearances* and *responses to invitations*. Forms of prevention that rely on people putting in *appearances*, such as reviews of asthma medication, are prone to the problem that people have to recognise and act on their candidacy for these services. If health care is conceived of in deprived communities as a response to crises, as we suggest, then use of health care during periods of non-crisis may appear to be an illegitimate assertion of candidacy. We also suggest that preventive services that issue *invitations* – such as screening and immunisation require people to accept that the features of candidacy identified in the invitation are legitimate and consistent with their own definitions of candidacy, and are worth resourcing in terms of the effort required to attend health services. Our analysis of the studies presented earlier suggests that illness may be understood in more deprived communities as a series of crises which allow people to assert candidacy, and invitations may not be consistent with this view of the appropriate uses to which health care can or should be put. Invitations issued to people in deprived

circumstances are, as we describe later, also prone to organisational problems.

Summary: Identification of candidacy

Our analysis and synthesis of the evidence on identification of candidacy suggests that people in more deprived circumstances do show a readiness to consult, but are more likely to manage health as a series of minor and major crises, probably linked to normalisation of health problems within disadvantaged communities, rather than treating diseases as requiring maintenance and prevention. Candidacy for health care is likely to be judged, in more deprived communities, as event-based. A specific event may be required to legitimise consultation and protect identity. Responses to invitations from services (for screening, immunisation, or other health maintaining interventions) may be less likely. Instead, there may be a tendency to wait until there is a symptom or specific problem to report, and then, to put in an appearance. As we describe below, there may also be a tendency to access very porous services such as GPs and emergency admissions.

3.2.3 Theme 3: Navigation

We identified in the general review (section 2) meta-ethnography the importance of the resources available to people in help-seeking, suggesting that resources of competence, information and knowledge, practical support, and social support may all be required to successfully negotiate health services. We suggest that there is evidence that disadvantaged people may have particular difficulty in mobilising the resources necessary to assert candidacy by putting in an appearance or responding to an invitation to health services, and may have difficulties in particular in using less permeable services. We organised our synthesis around the following themes generated by our analysis:

- Resources: Knowing where to go.
- Practical resources.
- Resources: Social networks.

Resources: Knowing where to go

Negotiation of a route to health services requires some knowledge of the services available, and this in turn demands some familiarity either at an individual level or within an individual's social network with the services on offer. There has been persistent concern that more deprived people may lack awareness of some services. Richards *et al.* (2002) identified that affluent people may know doctors and other health professionals socially, and therefore have access to shared knowledge that may be denied to people with fewer connections. People who are illiterate may find it especially difficult to access services. Anderson *et al.* (1997) found a lack of knowledge of immunisation and other preventative health services among traveller

families, who were especially disadvantaged because of their geographic mobility and generally poor health status, problems probably intensified by lower levels of literacy. The House of Commons Health Committee report on inequalities in access to maternity services (2003) similarly noted concerns that very disadvantaged groups, including recent migrants and homeless people, may lack awareness of where to get help.

Practical resources

Negotiation of a route to enter health services requires the mobilisation of a range of practical resources that may be variably available in the population. Our analysis of the literature suggests that a key practical resource that impacts on the ability to seek care for the socio-economically disadvantaged is transport (Tod *et al.*, 2001; Field and Briggs, 2001; Shipman *et al.*, 2001; Reid and Todd, 1989; Cragg *et al.*, 1994; Shipman *et al.*, 2000; Trevena *et al.*, 2003; Anderson *et al.*, 1997). As Goddard and Smith (1998) summarise, some work has suggested that people in more deprived social groups may have to make elaborate practical arrangements with friends and family to enable them to access GP services, and this dependence on 'borrowed time' may discourage use of services, though other studies have found that people from relatively deprived areas reported no greater problems in attending GP surgeries (For example Wyke *et al.*, 1992).

Perhaps the most consistent finding in the literature has related to transport. Field and Briggs (2001) highlighted that personal mobility was related to easier access to health care, with 70 per cent of car owners reporting no problems in accessing care compared with 30 per cent of non-car owners. They found a U-shaped relationship between distance from services and access to transport, with travel being the greatest hindrance for those living one to three miles away from the surgery. This fell for those living over five miles away because the distance from surgery coincided with increased likelihood of having access to a car. Research on an out-patient department in Northern Ireland showed that unemployed patients were less likely to have access to a car in order to attend hospital: 41 per cent compared with 71 per cent for those in full-time employment and 88 per cent for those patients who were self-employed (Reid and Todd, 1989). Out-of-hours primary care centres pose challenges for those with no access to a car (Cragg *et al.*, 1994; Shipman *et al.*, 2001). These centres are particularly difficult in the middle of the night when public transport is inaccessible and use of a taxi requires access to a 'phone and money (Shipman *et al.*, 2001).

Haynes *et al.* (1999) highlighted the complex interplay between distance provision and need, with greater disadvantage being found in urban areas where health facilities are concentrated. Distance from services was particularly important where public transport did not offer a convenient route to services. However, the relationship between

distance and access is not straightforward. People living in more rural areas with poorer public transport access were more likely to be of higher socio-economic status and have access to a car. More severe access issues were seen at intermediate distances where patients had to rely on public transport to get them up to four or five miles to services (Field and Briggs, 2001). Lovett *et al.* (2002) suggested that access related in complex ways to disadvantage, in that parishes close to the surgeries in travel time had poorer socio-economic characteristics, while those with apparently poorest access had less deprivation as districts. However, individual clusters of remote wards with high deprivation scores had the poorest access of them all.

Other practical resources that may impact on the ability of disadvantaged groups to negotiate health services include more rigid patterns of working life. A questionnaire study in Northamptonshire found that 13 per cent of non-manual people reported a hindrance in accessing health care due to work commitments, compared with 33 per cent of manual workers (Field and Briggs, 2001).

Resources: Social networks

In the general synthesis we suggested that access to forms of social support can mediate help-seeking behaviours in important ways. Recent work on social networks reviewed by Young (2004) suggests that social networks provide a nested middle influence between the individual and macroscopic health systems, acting as a buffer between individuals and institutions. The evidence about social networks in relation to consulting behaviour and deprivation is as yet fairly sparse. Sword (1999) summarises evidence suggesting that social networks can provide opportunities through transmission of advice and information about services as well as through provision of tangible or economic assistance; women who do not access ante-natal care are less likely to receive support from others. In Barker *et al.*'s (1990) UK study of coping and help-seeking for psychological problems, social class differences were only seen between the lowest social class group and all other groups. People in this disadvantaged group were less likely than others to think about ways of overcoming the problem or to seek help from friends and family, and were more likely to seek help from their GP. However, Cornford and Cornford (1999) in an interview study with 101 patients, did not identify social class differences in lay referral behaviour.

Summary: Navigation

Navigation of a route to enter or maintain engagement with health services requires mobilisation of a range of resources, including knowledge and information resources, social and support resources, and practical resources. There is evidence that socio-economically deprived people may be disadvantaged in their access to these resources or their ability to marshal these resources easily.

3.2.4 Theme 4: Organisational issues in navigation

We generated two themes around which to organise our synthesis of organisational issues in negotiation:

- The permeability of services.
- Turbulent organisational contexts.

The permeability of services

We suggest that many of the patterns of use we have been describing in relation to socio-economic disadvantage reflect issues in the organisation of services as much as they reflect a tendency to manage health as a series of crises on the part of disadvantaged people. We suggest that services that are well-known and easy to use are porous services. They are porous because patients require few qualifications of candidacy to use them, and because they require the mobilisation of relatively fewer resources. Services that are less permeable, however, demand qualifications (such as a referral), and also demand a high degree of cultural alignment between themselves and their users.

We suggest that services that are less permeable tend to have high levels of default by socio-economically disadvantaged people. Our analysis suggests that non-attendance is highly significant in explaining access to health care by socio-economically deprived people. A recent systematic review of non-attendance in general practice reported that patients who miss appointments tend to come from lower social classes and to live in deprived areas (George and Rubin, 2003). The link with deprivation and non-attendance also applies in secondary care and other health care settings. Non-attendance has been found by McClure *et al.* (1996) to be very high in paediatric outpatients clinic. In their study, 50 per cent of appointments were not kept in social class V compared with less than 20 per cent in social class II, even though illness were rated as more severe among non-attenders. Macleod *et al.*'s (2000) study of management of women with cancer found that significantly more patients from deprived areas failed to attend hospital appointments, though the difference was small.

Sharp and Hamilton (2002) provide an informal review of the evidence on non-attendance. They report that the main associations with hospital non-attendance are being male, youth, length of time for an appointment, and deprivation. Non-attenders are less likely to own a car, have a telephone, or be employed. Questionnaire surveys affirm the link with deprivation. The commonest reasons cited for missing an appointment, after forgetting it, are family and work commitments. People in lower paid jobs may have difficulty in arranging time off work or childcare to attend appointments. Appointment times that mean that patients are unlikely to be seen at the time they are booked intensify the difficulties for people in these groups. Goddard and Smith

(1998) summarise evidence suggesting that those from more deprived social groups face financial costs of attending which, though not sufficient to dissuade them from using services when they are ill (i.e. in response to a specific 'event'), act as a barrier to attending 'optional' services related to health promotion and health prevention. Time costs may be higher for those in manual groups because if they are not in paid employment they will not have an employer to subsidise their attendance time. Even if they are employed, they may be in the type of job where they are less likely to receive subsidies from employers. Having to travel by public transport may impose particular time costs.

George and Rubin's (2003) systematic review identifies that appointments systems can be a barrier to care. They may be especially difficult to use for members of communities in areas of social deprivation, because such systems require resources and competences that are not necessarily available. People in these groups may have less predictable, chaotic lives that are not consistent with structured systems. They conclude that non-attendance can be viewed as the manifestation of a critical level of unsuitability in the agreed arrangements for an access episode. Heath (undated) argues that all barriers to consultation should be examined to ensure that those on low incomes are not disadvantaged, suggesting that an obvious example concerns those without a 'phone, who may be easily disadvantaged if appointment systems are rigidly enforced and largely organised by telephone, or if there is increased use of e-mail. This is an important issue in the current move to ensure access to primary care, where arrangements by general practices often rely on being able to telephone the surgery during a specific period in the morning.

Services that use appointments systems rely on people having stable addresses and being able to read, and require people to present themselves in particular places at particular times. Such services include immunisation and screening programmes, outpatient clinics and elective procedures, and these, as we have already noted, have very high rates of 'default' by more deprived people. Some of this may be explained by the mobility of people in deprived populations. People who are in rented accommodation rather than owner-occupation may have much more frequent changes of address, and this puts them at risk of not receiving invitations. The Fourth National Survey of Morbidity in General Practice found that eight per cent of people registered with practices were not at their stated addresses and were not contactable (Martin and Sterne, 2001). At the more extreme end, people who are homeless or who live in travelling communities may not be sent or receive invitations to appointments at all (van Cleemput, 2000).

Our analysis also suggests that the extent to which people feel alienated from the cultural values of health services and their satisfaction with services has important impacts on which services

they choose to use. For example, in the study by Richards *et al.* (2002) participants in the deprived group were more likely to report negative experiences and lower expectations from health professionals than the affluent group. The deprived group felt that the degree of social alignment with the doctor was poor and the extent to which knowledge was shared and adequate information was supplied from the consultation was limited. The affluent group in this study was more likely to report positive experiences. Rogers *et al.* (1999) similarly report that negative experiences of quality adversely influenced patterns of use, sometimes encouraging people to withhold or delay in presenting symptoms. Services that are unattractive to people are, we argue, less porous.

We suggest that the more chaotic patterns of healthcare use among more deprived people, with high rates of use of emergency services and acute hospital admissions, illustrated earlier in our analysis, are most consistent with high use of highly porous services. For example, studies at St Mary's in Paddington reported that nine per cent of all admissions were from homeless people (Victor, 1997). Deprived people may have less control over their circumstances, and this makes their ability to attend at particular times in particular places highly contingent and dependent on the mobilisation of a wide range of resources that may be variably available. Permeable services, on the other hand, require less work from people to use them. Dodier and Camus (1998), in their French study, reported that the emergency service is used by homeless people and others because it poses least obstacles to use – it is a highly porous service in which people seek to constitute what the service will offer them; the service is relatively less able to constitute what services it will offer.

Turbulent organisational contexts

In the general synthesis in the previous section, we identified that new forms of organisation and provision in health services have created complex segmented environments and boundaries. These organisations are staffed by diverse occupational groups, each with their own cultures, internal divisions and hierarchies, and are characterised by numerous difficulties of co-ordination and management of role boundaries (Allen, 1997). Somerset *et al.* (1999) described the problems of coordinating care between GPs and hospital outpatients, highlighting difficulties in inter-professional communication and continuity. Petrou *et al.* (2001), though unable to analyse social class, identified the impact that a fragmented care delivery process has on the level of ante-natal care provided to women, with increased fragmentation leading to fewer ante-natal visits.

Though these studies do not focus specifically on issues of social disadvantage, we suggest that negotiating a patient career across these complex forms requires competence and vigilance on the part of

patients that may be especially difficult to maintain for those who are socially disadvantaged. They may be less used to or less able to co-ordinate the work of their candidacy over these multiple forms, and may be vulnerable to dropping out of the system at various stages. Again, severely deprived groups such as the homeless may be most vulnerable. Vostanis (1998) suggested that homeless families are vulnerable to problems of interagency co-ordination, and that there are often different definitions of need and statutory obligations used by agencies. The House of Commons Health Committee report on inequalities in access to maternity services (2003) also highlighted the difficulties of maintaining contact with women over multiple boundaries, quoting a witness as saying that:

'We do have a lot of problems about going across social services boundaries. If you need to be in contact with social services then once a woman moves out of one area into another that [contact] seems to break down. Unless the midwife is following that woman through, the other services do not seem to do that... you are going to lose women if they do not have the confidence to keep in touch with the midwife or the services they are getting.'

Summary: Organisational issues in negotiation

Socio-economically deprived people may be more likely to have patterns of entry to health service that are somewhat chaotic. There is a tendency for high use of easily permeable services and for 'crisis' presentations in the form of emergency admissions, possibly reflecting poorer overall health but also probably reflecting poorer health maintenance. Lower use of preventive services (for example asthma reviews) and non-attendance at out-patients appointments may reflect a lack of cultural alignment between the needs and priorities of people in socio-economically disadvantaged circumstances and the ways in which health services are organised.

3.2.5 Theme 5: Presentation, adjudication and offers

We have earlier argued that most of the evidence supporting the hypothesis that more deprived people have poorer access to health care comes from a body of work on utilisation, which we have suggested is potentially misleading. Measures of receipt of services do not acknowledge how people present to services, how their candidacy is judged by professionals, what offers are made to people, or whether people choose to accept these offers. We generated the following themes around which to organise our synthesis of the evidence on these issues:

- Presentations.
- Categorisation and disposal: Adjudication.
- Adjudications: Judgements of technical candidacy.
- Adjudications: Moral and social deservingness.

- Referring and adjudication.
- Operating conditions and the local production of candidacy.

Presentations

We earlier distinguished between *putting in appearances* at health services (where people initiate a contact with services following their own identification of candidacy) and *responding to invitations* (where services ask people to attend in response to specified features of candidacy). *Appearing* at health services involves people in asserting a claim to candidacy for medical attention or intervention. The nature of this claim may be highly variable. For example, people may have only a poorly formulated, diffuse, and ill-defined issue for which they are seeking help, or they may have a long-standing problem and need help simply to execute a course of action on which they have already determined, and so on (Thorsen *et al.*, 2001). Whatever the nature of the claim, making it clearly involves work that requires a set of competencies, including the ability to formulate and articulate the issue for which help is being sought, and the ability to present credibly.

More deprived people are at risk in these situations: they may be less used to or less able to provide coherent abstracted explanations, and may feel intimidated by their social distance from health professionals. May *et al.*'s (2004) analysis shows that patients' subjective interpretation of experiences of themselves and their symptoms form the basis for engaging with the doctor. Sword (1999) points out that low income people may feel alienated by the power relations that often characterises encounters with professionals. Dixon *et al.* (2003) suggest that middle class people may be more adept at using their 'voice' to demand better and extensive services: they are more articulate, more confident, and more persistent. Cooper and Roter (2003) summarise the evidence in this area, suggesting that research has indicated that people from lower class backgrounds were less verbally active overall during medical visits, and that this was especially evident in patients' presentations of their symptoms, question-asking, and social talk. They further suggest that people from these backgrounds may appear diffident in asking questions, not because they do not wish to know about medical matters, but because the social distance between themselves and doctors discourages verbal assertiveness.

Gardner and Chapple's (1999) study, based on semi-structured interviews with 15 patients with angina and their four GPs in a deprived area of Liverpool, provides a good illustration of these issues. They found that people had difficulty in describing their problems and offered vague accounts of their problems, and that doctors did not always pick up on the extent of patients' suffering. Somerset *et al.* (1999) reported that in making referral decisions, patients' social status and their ability to articulate verbally were put forward as tacit

influences that affected the likelihood of referral. Hart and Lockey's (2002) study identified that midwives' attempts to address inequalities were strongly influenced by midwives' perceptions of women's expectations. This could mean that women perceived to be 'savvy' (likely to be middle class and seen as 'demanding') got more time and resources.

Presentations – the making of a claim to medical attention or intervention - are also likely to be affected by the time available in consultations. There is some evidence that people from more deprived areas tend to have shorter consultations (Stirling *et al.*, 2001; Wyke *et al.*, 1992). Stirling *et al.* 2001, for example, suggest that mean consultation length falls as the prevalence of positive General Health Questionnaire rises across the deprivation categories, indicating that GPs in deprived areas have shorter consultations and see more patients with psychological morbidity.

A 1991 questionnaire study reported that GPs considered that they explained and listened less to more deprived social groups, and that they were less likely to examine and give advice to people in social classes IV and V, though these were not robust conclusions and small figures were involved (Martin *et al.*, 1991). The reasons for this are unclear, but may be linked to a combination of under-supply of GPs in deprived areas and higher consultation rates among people in deprived areas (described earlier). This combination of supply and demand may leave GPs working in deprived areas more pressed for time and less able to be attentive, but clearly further research would be needed to investigate this hypothesis. What is clear, however, is what we have earlier referred to as *conversion* – the ability of people in more socio-economically disadvantaged circumstances to convert a given unit of health care (such as a GP consultation) may not be as great as that for more privileged people. This in turn may influence processes of categorisation and disposal.

Categorisation and disposal: Adjudication

We introduced, in the general synthesis, evidence that the ways in which people are categorised within health care organisations shape their careers as patients. Once a patient has asserted their candidacy by presenting to health services, the professional judgements that are made about that candidacy strongly influence subsequent access to attention and interventions: the candidacy becomes something to be defined by health services, though individuals may continue to negotiate over this definition and its consequences. We use the term 'adjudication' to refer to the judgements and decisions about disposal made by professionals which allow or inhibit continued progression of candidacy. We also recognise, as we later make clear, that adjudications can be challenged by people: they may find another way to gain access to a service they want, or they may choose to reject a service they are offered.

In this section, we suggest that the candidacy of socially disadvantaged people is at risk of being judged to be less eligible, at least for some types of interventions, but that the evidence that this does happen is not particularly strong. In presenting this analysis, we invoke May *et al.*'s (2004) recent argument that doctors' interactional behaviours and communication skills are exercised through their own contextual experiences of *types* of patients, *types* of problems, and *types* of disposal options – a repertoire of routine judgements about the possibilities presented by individual patients and the routinely available means of solving these. These typifications are, we suggest, strongly influenced by local conditions, including the operating conditions in which practitioners work. Importantly, we also recognise the ways in which patients themselves influence these typifications.

Adjudications: Judgements of technical candidacy

Our analysis suggests that it is likely that professionals' perceptions of patients who are likely to 'do well' as a result of interventions, possibly influenced by evidence-based guidance, may disadvantage people in more deprived circumstances. As Hughes and Griffiths (1997) identify, a problem with resource allocation by clinicians is that their decisions may rest on often implicit social criteria about which patients 'ought' to receive care. People in disadvantaged groups are more likely to smoke, to be overweight and to have co-morbidities, for example, putting them at higher risk for surgery and making them poorer candidates for many other interventions. In this way professional perceptions of the cultural and health capital required to *convert* a unit of health provision into a given unit of health gain may function as barriers to health care.

Hughes and Griffiths (1997) is one of the few studies to explore how doctors decide how to allocate resources to individual patients, but our analysis suggests that this is a key paper. The authors use a case study approach to investigate the selection of patients for cardiac surgery and admission to a specialist neurological rehabilitation centre. They found that the key question in cardiac catheterisation conferences, in which cardiologists present candidates for cardiac surgery for consideration by the cardiac surgeon, is the technical feasibility of surgery, and discourse in these conferences centres on the technical difficulties presented by cases and assessment of surgical risks.

Judgements of technical eligibility rely, clearly, on doctors' knowledge and skills. Fuat *et al.* (2003), in a qualitative study of GPs' beliefs, practices and decision-making in the diagnosis and management of suspected heart failure, found that GPs expressed considerable uncertainty about good practice, and that some had difficulties in interpreting echocardiography reports, that they had concerns about the appropriate indications and management of particular forms of

treatment, and that they did not feel aware of relevant research evidence.

Heath (undated) argues that healthcare that is increasingly driven by protocols derived from studies of single disease conditions seems likely to disadvantage those with multiple morbidity, which is more common in low income groups. Watt (2002) makes a similar argument, suggesting that most evidence-based guidelines, health technology assessments, national service frameworks and health policies are based on the assumption that individuals have single conditions, but deprived people suffer from considerable co-morbidity. He distinguishes the morbidity of socio-economic deprivation from multiple pathology, arguing that co-morbidity in deprived populations refers to the number, severity, and complexity of health and social problems that exist in families.

Although there is some evidence of increased risks associated with operating on socio-economically deprived people (Taylor *et al.*, 2003), it is likely that much of this can be explained by confounding of smoking status with social class, and that judgements of technical candidacy are in fact socially constructed. Reid *et al.* (2002) found that statins were less likely to be prescribed to smokers (OR 0.55, CI 0.32 to 0.96) although sub-group analyses have shown that statins are equally effective in smokers and non-smokers. This study also found evidence for the importance of co-morbidities in influencing judgements of technical eligibility: statins were also prescribed less often to people with angina, although the authors similarly point out that there seems to be no reason to withhold statins from patients with angina only.

Other evidence that points to the socially constructed nature of technical eligibility includes work which demonstrates the importance of professionals' consideration of how technically interesting a case is (Pope, 1991; Dodier and Camus, 1998). Dodier and Camus (1998) describe 'intellectually interesting' cases as cases that are difficult to solve or unusual, but where there is hope of clarification, and where there is pedagogical interest. They give the example of a woman with an erythema nodosum who excites intellectual interest. However, poorly differentiated problems that are social in origin may be much less intellectually interesting, and vulnerable to being judged to have poorer mobilising worth.

Adjudications: Moral and social deservingness

Hughes and Griffiths (1997) suggest that in addition to issues relating to the technical feasibility of procedures, social and moral dimensions of cases could also be taken into account in some decisions. Goddard and Smith (1998), for example, summarise evidence suggesting that independent of the severity of the disease, some GPs are more likely to refer the economically active and those with dependants, and being economically active has been associated with shorter waiting times for

between angiography and angioplasty. In Hughes and Griffiths' (1997) study, technical issues were important in neuro-rehabilitation admissions conferences, in which a multidisciplinary team assess the suitability of head injury and stroke patients for neurological rehabilitation. Issues such as how overweight someone was could influence decisions to admit, but so too could judgements about social support available on discharge, family circumstances, physical suitability of the home, and prospects for an eventual return to work. Clearly, there is potential for socially disadvantaged people to be disfavoured in such decisions. For example, cardiac surgeons in their study expressed doubt about the acceptability of cases where there was evidence of high risk, such as overweight and smoking, and where patients had not modified their behaviour:

Surgeon: '[...] Any patient of 20 stones plus is high risk for any chest surgery.'

Senior registrar: 'Perhaps the best thing would be to bring him in for three weeks for monitoring and try to get his weight down [...].'

Surgeon: 'Donald, you've had four years to educate this guy [...]. There is no point in operating on this guy if he is going to carry on working in a smoky atmosphere, if he won't modify his lifestyle.'

In some cases that Hughes and Griffiths studied, professionals used narratives designed to influence hearers by setting in play cultural norms for tactical ends, for example drawing on notions of family and 'social deservingness' to justify treating particular individuals. This moral framing can lead to patients being ruled out – denied candidacy – or ruled in – offered candidacy. Interestingly, one case they describe involved a well-off patient being denied candidacy (because it was perceived he was trying to 'buy' candidacy).

A further illustration of how professionals' judgements of candidacy may invoke social and moral judgements is found in Dodier and Camus' (1998) analysis of what they call 'social demands' in a French emergency service. They describe how the category of patient who consults emergency services because of their inability to gain what they need elsewhere or difficulties in accessing medical care arouses complex reactions. These patients are vulnerable to being seen as having low mobilising worth – staff may be reluctant to mobilise resources around them, though differences and conflicts may arise between personnel about the right attitude to adopt. These can include recriminations with delayed or limited mobilisation during treatment. For example, homeless people are often pushed further down the list: the medical decision is at the same time a decision concerning allocation of rights.

There is, however, also evidence that in some areas of health care, there are few social class differences in the ways in which people are categorised. Richards *et al.* (2000) could find no link between the proportion of people with symptoms who received a provisional diagnosis of CHD and deprivation.

Referring and adjudication

The question of whether socially disadvantaged people are less likely to be referred for specialist care was raised earlier in this section. In our analysis, referral is an outcome of processes of adjudication. Clearly, lower rates of referral could explain why in some specialist areas deprived people appear less likely to have some types of interventions, and clearly, it would be important to understand what influences referral behaviours among GPs. O'Donnell (2000) provides a comprehensive review of the literature on GP referral rates. She concludes that the role of social class in the variation of referral rates is not clear-cut. It depends not only on the measure used to quantify deprivation, but also on whether the measure is based on the patients who actually consult a GP or on the practice population as a whole. For example, using the practice based Jarman UPA (8) score as a measure of deprivation, a study in Nottinghamshire found more deprived practices to have high total referral rates and medical referral rates, but increasing deprivation was less associated with decreasing surgical referral rates (Hippisley-Cox and Pringle, 2000; Hippisley-Cox *et al.*, 1997). However, since the Jarman score measures GP workload, it could be expected to be associated with higher rates of referral.

Macleod *et al.* (2000), in a retrospective review of primary and secondary care management of women with early breast cancer from affluent and deprived areas using hospital and general practice records, found that time between the date of the general practice consultation and the date on the referral letter did not vary between women in affluent and deprived areas suggesting that there were no differences in referral behaviour between GPs in deprived and affluent areas.

Offers and resistance

In much of the work on utilisation of health care, there is an assumption that non-utilisation is a direct reflection of non-offer, and the implication is that adjudications must be flawed, or socially biased in some way. However, this type of normative analysis denies people agency, by failing to acknowledge that people may choose to refuse offers. There is a range of strategies that people can use to resist offers (perhaps because they do not agree with the judgement of candidacy made by professionals and the consequences of that judgement, or because the costs of accepting that offer would be too high, for example), and it is possible that patterns of resistance are socially patterned. A small body of work points to issues of *acceptance* and *rejection* of health care, as does the evidence on non-attendance mentioned earlier, but little is known about rates of acceptance and rejection and their influence on uptake of services.

Referral implies that a GP has identified particular features of candidacy and is seeking to match those to a service that deals with that form of candidacy. There is interesting work to show how patients

can choose to assert control over this attempt by GPs to define and act on candidacy. One strategy is to allow themselves to be referred but, as described earlier, not to attend. Another strategy is to resist being referred. Gardner and Chapple's (1999) study, based on semi-structured interviews with 15 patients with angina and their four GPs in a deprived area of Liverpool, found that some patients concealed or downplayed aspects of their illness, and were resistant to being cast as candidates for referral to a cardiologist for assessment. GPs in a qualitative study of behaviour and decision-making in relation to heart failure identify that there is a group of patients who do not want to be hospitalised or referred (Fuat *et al.*, 2003). Similarly, Britten *et al.* (2004) report that 'offers' of medicines prescribed by general practitioners are frequently refused, and moreover, that people do not express their aversion to medicines during consultations. For example, people accept prescriptions from doctors, but then do not 'cash' them (Schafheutle *et al.*, 2002).

Operating conditions and the local production of candidacy

A small body of recent research has identified what might be called local influences on the production of candidacy, and in our analysis these are hugely important. These are the contingent and locally specific influences on interactions between practitioners and patients, which may be emergent over time through repeated encounters. Britten *et al.* (2000), among others, has shown that some decisions made by doctors are made not on the basis of rational clinical evidence but in order to preserve their relationships with their patients. In a recent analysis of data collected in six qualitative studies of GPs' constructs of chronic illness and their responses to them, May *et al.* (2004) highlighted the importance of the patient's motives for presentation and the legitimacy attributed to them, because it was the initial frame in which GPs could determine the congruence between their own model of symptoms and that of the patient.

Doctors' perceptions of people's previous consulting behaviour on their judgements of candidacy were also evident in Granier *et al.*'s (1998) study of recognising meningococcal disease in primary care. People who were judged to have been 'sensible', rational and responsible users of services were more likely to be taken seriously when they presented with something they were very concerned about. Though there is no direct evidence, there is a possibility that high consultation rates among more deprived people, described earlier, might cause a 'crying wolf too often' effect, where GPs are more sceptical about the potential severity or urgency of symptoms reported by frequent consulters.

Also crucial to the local production of candidacy is the perceived or actual availability and suitability of resources to address that candidacy. May *et al.* (2004) found that the ways in which GPs 'disposed' of patients' problems were affected by the resources

available to them. Onward referral for depression, for example, was inhibited by lack of resources, meaning that only the most serious cases were likely to be acceptable referrals, and forcing GPs to attempt to manage most cases within their own resources. Fuat *et al.*'s work (2003) identified some of the operating conditions that prevail in attempts by GPs to manage people with heart failure. Perceived handicaps included variability of open access echocardiography, again affecting the ways in which people were disposed

We have suggested that the ways in which people are categorised and disposed by health professionals leaves socially disadvantaged people at risk. We suggest in particular that perceptions of people's ability to *convert* health care into benefits has a key influence. The need to link provision or supply of resources with the ability to derive benefit from those resources is clearly a key concern of vertical equity. Watt (2002) argues that, with the same resources, primary health care teams in deprived areas who initiate programmes to prevent disease complications and reverse risk, achieve less. This may be because more deprived people may lack what might be called the 'health capital' required to convert receipt of health care into the same degree of benefit. McCarthy (<http://www.ukhen.org/ipeh.htm/h>]. undated) comments that treatments for major diseases (cancer, kidney disease) may be on average less effective for lower socio-economic groups because they more frequently have other conditions (such as obesity, smoking) that contribute to poorer outcomes. Perceptions of this health capital are powerfully linked to candidacy, and in particular to processes of *adjudication*.

The evidence that socially disadvantaged people are in fact disfavoured in adjudications is not, however, easy to interpret or very strong, because much of the research has not distinguished the factors that contribute to people's receipt of interventions. In the evidence on cardiac and oncology services presented earlier in this section, it is clear from some studies that more deprived people are more at risk of not receiving some interventions, but it is not clear why this is.

Summary: Presentations, adjudications and offers

By putting in an appearance at health services, people are making a claim to candidacy for medical attention or intervention. However, their ability to make presentations that allow their candidacy to be judged appropriately is variable, and there is concern that people who are socio-economically disadvantaged may lack skills in demonstrating candidacy or convincing health professionals of the authenticity and legitimacy of their claim, or in showing that they can convert health care into health benefits. There is also concern that the ways in which adjudications are made by health professionals, based on routine typifications of types of problems, types of people, and types of options for dealing with health needs, may disadvantage more deprived people. More deprived people may be judged to be poorer candidates on grounds of technical eligibility, perhaps because of co-morbidities or health behaviours such as smoking, and there is fragmentary and not very strong evidence that aspects of their social and moral candidacy may also be seen as less deserving. People continue to be able to negotiate and control the definition of their candidacy and its consequences, and may therefore choose to decline offers made by health services, but this important aspect of access has been relatively little studied.

3.2.6 Theme 6: Tractability: Policies, service developments and interventions to address inequity in access to health care

Our analysis above suggests that the dynamic and contingent concept of candidacy provides a means of understanding issues of 'access' to health care, as well as a means of understanding the crucially important local influences on the production of candidacy. We described in the previous section a range of policies, service developments, and interventions to improve access to health care. Our sampling of the literature suggests that, in contrast with the work on reducing health inequalities, relatively few of these are dedicated specifically to reducing socio-economic inequities in access, and that most have focused on issues of supply and provision rather than other aspects of the ways in which candidacy is managed by health services. We have organised our synthesis around the following themes generated by our analysis:

- Steering resources towards need.
- Specialised services for particular groups.
- Personal Medical Services.
- Alternative Provider Medical Services and Primary Care Trust Medical Services.

Steering resources towards need

The most prominent attempts to address possible inequities in access have taken the form of efforts to steer resources towards need, primarily through controlling allocation of resources and through incentives.

Controlling the allocation of resources

A number of policy efforts to smooth out historical geographic inequities in the allocation of resources is summarised by Pereira *et al.* (2000). The Resource Allocation Working Party (RAWP) formula introduced in 1976 specifically considered equal access for equal need, taking into consideration regional differences including population size, age and gender, local delivery costs, and health needs relative to the national average. A weighted population approach was used to establish regional financial targets. The method was criticised because the needs factor did not take account of the socio-economic determinants of health, the adjustments made for age were biased, population projections for the over 85s were uncertain, and there were limitations of the statistical methods. A risk-adjusted need index was used from 1997 onwards. This method used more sophisticated multi-level modelling to control for the links between supply and utilisation, as well as taking greater care in adjusting for errors in the data. However, Pereira *et al.* (2000) point out that this method has a number of weaknesses, particularly in assuming a correlation between need and utilisation.

A key issue in the allocation of resources at this level is that it is up to local commissioners in the form of Primary Care Trusts (PCTs), to convert those resources into targeted provision of services, and from there it is health professionals, in their micro-level interactions with patients, to then allocate resources on an individual basis. As we have already described, the processes by which this happens are only poorly understood at present.

Control of allocation of GPs

The allocation of GPs has traditionally been controlled through the Medical Practices Committee (MPC), which limited the supply of GPs to 'over-doctored' areas. The MPC had power to refuse an application to practice in areas where it considered that the number of doctors relative to the number of patients there was adequate. Following the abolition of the MPC, this responsibility has now passed to the PCTs, and it is too early to say what the effects of this change have been.

Policies to increase the attractiveness of 'under-doctored' areas have included deprivation payments, under which a doctor providing general medical services to a patient in a deprived area is eligible for a deprivation payment for that patient. Deprived areas are identified based on the Jarman Index – a combination of population census

variables based on patient characteristics that affect GP workload. However, the extent to which such incentives work to improve access or reduce inequities is uncertain. Gravelle and Sutton's (2001) analysis suggests that there is little evidence that these policies led to a reduction in inequality over the period of their study (1974 - 95).

Incentives

There is some fragmentary evidence that some forms of incentives to providers may increase rather than decrease inequities in the provision of care. Langham *et al.* (1995) found that, following the introduction of payments for health promotion activity in the 1990 GP contract, practices located in areas with high relative need were the greatest financial losers compared with practices in electoral wards with lower relative needs. Leese and Bosanquet (1995) also found that practices located in deprived areas had the most difficulty in responding to the new requirements of the 1990 contract. Lynch (1995), using data on primary immunisation uptake rates in 208 practices in the Greater Glasgow Health Board, similarly found that a disproportionate number of practices achieving the high target were in the most affluent areas.

What is important is that recent efforts to standardise provision and quality of services through policies such as the National Service Frameworks may be much more demanding of organisations that serve deprived communities. Heath (undated <http://www.ukhen.org/ipeh.htm>) identifies double jeopardy – where the greater the need for support, the less likely its community is to be able to offer it – as a problem in access to health care. The effort required to uncover previously unrecognised pathology and implement effective interventions should not be under-estimated.

Transport arrangements

We have identified, earlier in this section, issues concerning transport as a key barrier to access to health care, particularly for some potentially vulnerable groups. A report from the Social Exclusion Unit (2003) reported that free non-emergency patient transport services (PTS) are available for people with medical need. This is an example of a policy intervention to improve access. However, PTS are not available at primary care level, despite the move towards a primary care-led NHS, and the criteria for PTS eligibility vary widely throughout the country.

'Decisions on who gets access to PTS seem arbitrary. Sometimes it's a case of who shouts the loudest, although I can understand that GPs do not want the hassle. I know of cases where the Practice Manager makes the decision not the GP.' Accessible transport officer, quoted in *Making Connections*.

The Social Exclusion Unit (2003) report identifies that many PCTs have not yet developed the capacity and expertise to commission the

provision of transport arrangements, and this will need to be tackled at a policy level.

Financial support for people on low incomes to get to hospital is provided through the Hospital Travel Costs Scheme policy, but again the Social Exclusion Unit found that the scheme is poorly publicised, with many patients and health care professionals either unaware of their existence or confused about whether a patient is eligible for help.

Specialised services for particular groups

Considerable debate has surrounded questions of whether specialist services for particular groups – often distinctive groups of extremely deprived people such as the homeless and travellers – should be provided. On the one hand it is argued that creating specialist services operates to reinforce social exclusion and marginalisation from mainstream society; on the other, it is argued that specialist services reflect the expressed preferences of these very groups. For example, Hewett (1999) reported that 84 per cent of homeless respondents to his survey would prefer a dedicated drop-in centre for homeless people over facilitated access to mainstream services.

Recent policy initiatives that reflect this latter position include National Enhanced Services (NES), which are designed to provide more specialist services to meet the needs of homeless people. The NES for enhanced care of homeless people is aimed at practices that have a critical mass of patients, and covers a range of measures to improve services, including the development and production of an up-to-date register of patients who are homeless; liaison with local statutory services and development of joint protocols, for example with the local authority's Homeless Persons Unit; flexible registration procedures allowing for permanent registration; the provision of training to practice staff ensuring an understanding of and sensitivity towards the particular problems faced by homeless people, both health and non-health related; provision for appropriate and regular screening assessments based on current research in relation to the health needs and problems of homeless people; appropriate referral to counselling and CPN services; and specialist assessment of the physical and mental health of homeless people when registering. Again, no evidence on the effectiveness or outcomes of this initiative is currently available.

Personal Medical Services

Personal Medical Services (PMS) schemes are designed to allow a flexible approach to address the health needs of particular priority groups, such as homeless people. PMS enables health care professionals to develop different organisational models to address gaps in delivery or inadequacies in or inaccessibility of existing services. There is a wide variety of PMS models ranging from surgery-based services (which can be GP or nurse-led) to outreach care

provided in hostels, shelters or day centres. PMS schemes are negotiated locally with PCTs as alternatives to bring about improvements in health and well-being for people experiencing difficulties accessing General Medical Services. There are currently over 100 PMS schemes in England providing medical services for homeless people. The Office of the Deputy Prime Minister (OPDM) (2004) has produced a homelessness and health information sheet on the role of PMS in helping homeless people access health care.

Alternative Provider Medical Services and Primary Care Trust Medical Services

PCTs can now commission services from alternative providers (including commercial providers, voluntary bodies, not-for-profit organisations, and other NHS bodies) through the Alternative Provider Medical Services (APMS) contracting route. For example, a PCT could work with voluntary organisations working with homeless people in order to provide services in an accessible setting. PCTs will also be able to provide services themselves by directly employing staff, under the Primary Care Trust Medical Services (PCTMS) route. The aim of this is to enable PCTs to provide services tailored to the needs of the local population, and to find innovative ways of meeting need in previously difficult to reach areas and populations, but evaluations are currently awaited.

3.3 Conclusions

In this section we have presented an interpretive synthesis of the literature on access to health care by socio-economically disadvantaged groups. We have demonstrated not only that this literature is large and covers a diverse array of issues of access throughout the healthcare pathway, but that the evidence in many areas is inconsistent and contradictory. It proved surprisingly difficult to consistently demonstrate inequities in access to health care for socio-economically disadvantaged groups. Through our synthesis of the evidence we have highlighted both the convergent and divergent themes in the literature and we have offered an understanding of how inconsistencies in evidence may arise through the variation in the interpretation and operationalisation of concepts related to health care such as utilisation, supply, demand, and need, and also related to socio-economic disadvantage. A key conclusion of our analysis above is the need to dissolve the strict distinctions between supply side issues (provision by health services) and demand side issues (use of health services), and to instead see the continually negotiated, iterated, and contingent management of candidacy as the key to understanding barriers to access by deprived people. Rather than seeing poor access as a universal property of socio-economically disadvantaged people, we instead stress the various aspects of

candidacy where they are particularly vulnerable to being denied the opportunity to avail of services.

We have proposed candidacy as the key concept in understanding the barriers of access to health care for people from socio-economically disadvantaged circumstances. Our synthesis offers a novel and informative approach to interpreting the literature in this area. Candidacy enables us to conceptualise access to healthcare in terms of both people recognising their eligibility as candidates for healthcare and also the health service identifying characteristics of candidacy that they can then seek to apply to individuals. This is a more meaningful way of understanding people's interaction with healthcare services, rather than the more traditional concepts of consumers and providers of healthcare. It emphasises that people have to undertake important work in order to recognise their eligibility as candidates and to present themselves at health services, rather than perceiving that healthcare is accessible and ready and waiting to be consumed.

We have explored the impact of the disregard of the concept of candidacy in our discussion of the extent to which the problem of access to socio-economically disadvantaged groups is constructed. We have indicated that by focusing on utilisation of health services, there has been a failure to differentiate between various aspects of candidacy. We discussed how reports of differential rates of utilisation represent reports of differential rates of receipt and that receipt reflects the outcomes of processes of negotiation, presentation, adjudication and acceptance, which are dynamically jointly accomplished by people and health services. Much of the evidence on inequities derives from a body of research on utilisation, but our analysis indicates that utilisation is a highly problematic measure of equity. Even taken at face value, the evidence for widespread inequities in utilisation is not particularly convincing. There is high use of what we called 'porous' services, including primary care and accident and emergency departments, by more deprived socio-economic groups, and inequities in utilisation of specialist care services are again not consistently shown. However, there do seem to be indications that extremely disadvantaged groups, such as the homeless, do experience particular problems.

We argue that the research focus needs to move from utilisation towards research that sees these processes of negotiation, presentation, adjudication and acceptance as distinct, though related, entities so that an attempt can be made to disentangle the complex effects and interactions between people and the health service.

We found a seeming paradox in the apparent readiness of people in deprived circumstances to consult and evidence also of high levels of non-attendance. Scaife *et al.* (2000) suggest that people in socially deprived circumstances may be more ready to consult because of their wider experiences of adverse circumstances. Our analysis suggests that this may be true, but we have also proposed that a key way of

understanding the differential presentation patterns for people from more socio-economically disadvantaged groups is the concept of candidacy as a response to a series of crises rather than treating health as requiring maintenance and prevention. Sociological work has suggested that people in disadvantaged conditions may lack a positive concept of health and be less likely to participate in health maintaining behaviours. This is reflected in the higher rates of appearances by socio-economically disadvantaged people at A&E and out-of-hours care and corresponding lower rates of appearances at screening, immunisations and other preventive services. If healthcare is conceptualised in this way then we can understand that when in crisis mode, care needs to be more easily accessible, and the work required for someone to present themselves for healthcare needs to be minimal. We highlight that services such as A&E and primary care provide this opportunity and consequently lead to increased presentations at these services.

We suggest that non-attendance is a demonstration of aspects of candidacy. Services that use appointments systems, particularly in secondary care, impose conditions of candidacy on people. Attending an appointment requires that an individual shares a view of the legitimacy of this designation of candidacy and is sufficiently able to fit with the cultural values of organisations that insist on attendance at particular times, but do not guarantee being seen at that time. Attending an appointment also requires the mobilisation of a large set of practical and emotional resources that may pose particular difficulties for disadvantaged people.

Although evidence on utilisation of health services fails to identify the various factors influencing access to care, it is possible that the quality of services available in areas of socio-economic disadvantage may be poorer. We suggest that it is important to understand the effects of high levels of demand from people in adverse circumstances with potentially high levels of co-morbidity on the conditions in which primary care has to operate. GPs may find that they have less time available for each patient, and this may, by introducing important stressors, have a range of impacts on practices and behaviours.

If we are to improve the accessibility of less permeable services such as preventive services and out-patient appointments, then healthcare organisation must incorporate this chaotic model of candidacy as a series of crises. It must be recognised that services that use appointments systems, particularly in secondary care, impose conditions of candidacy on people. More empirical research is required to explore how systems can be organised to reduce the work that patients need to do to initiate an appearance or undertake to accept an invitation. The large array of practical and emotional resources that are needed to attend these services also pose particular difficulties for disadvantaged people and need to be taken into account.

In the following sections, we will explore how the barriers to access for socio-economically disadvantaged groups compares and contrasts with the barriers to healthcare for other vulnerable groups, investigating the syntheses for gender, older people, children and ethnicity.

Section 4 Ethnicity and access to health care

4.1 Introduction

It is useful to begin by outlining some of the issues that underlie the study of race and ethnicity in relation to health. Perhaps the most important of these concerns the conceptualisation and operationalisation of 'race' and 'ethnicity'. A critique has emerged of the ways in which medical and epidemiological researchers have traditionally used race and ethnicity to refer to biological or genetic 'realities'. Instead, it is argued, 'race' is a social construct, but much of the epidemiological evidence is dominated by crude categories including asian, black, and white. As Douglas (1998) argues, such classifications are problematic, obscuring important issues of identity and how it is judged, homogenising groups of people who are in fact diverse, and ignoring the increasing numbers of people of mixed parentage. The problems of classification of individuals into minority categories are compounded by other difficulties in studying genuine differences of biology and genetics between different racialised groups, dynamic cultural processes, and variations in social class, religion, and migration. For the most part, in our presentation of the literature below, we have used the terms used by the authors in the original studies, but wish to be explicit about the limitations and inappropriateness of many of these.

Our searching identified an extremely large literature in the area of ethnicity and health. Our sampling of the literature in this area suggested that there was a dearth of high quality research. We found a tendency in the literature (particularly the grey literature, most of which we excluded) towards descriptions of interventions and policy interventions without rigorous evaluation, and in particular without attention to the possible unwanted consequences of interventions. Other reviewers have had similar experiences: a recent systematic review of ethnic variations in pathways to and use of specialist mental health services in the UK, identified only five studies that were deemed to be high quality (Bhui *et al.*, 2003).

Research in the area of ethnicity and health has been inhibited because, until recently, routine information about either the size of ethnic minority populations or their utilisation of health care services was not available in the UK: it has been mandatory only since 1995 for health care providers to collect and record data on the ethnic background of hospital inpatients. Much of the research on minority health from other countries cannot be generalised, because, among other things, of the extreme financial barriers to access faced by people in countries such as the USA. There is considerable evidence that particular minority groups are especially disadvantaged by

insurance-based systems such as those that operate in the US. (Smedley *et al.*, 2003)

In interpreting the evidence, it is also important to note diversity within groups as well as between groups. There may be strong effects of age and gender: younger generations may be literate, able to speak English, and competent in negotiating bureaucracies, while older generations and women in particular may lack these advantages. Some effects of ethnicity may be ameliorated over time – for example as people create social networks and become more familiar with systems and how to negotiate them.

Issues that affect 'visible' minorities (such as people of colour) may be very different from those that affect 'invisible' minorities (such as travellers, Irish people, and people from Eastern Europe). For black people from the Caribbean, issues of language may be much less important than issues of cultural stereotypes. Our analysis suggests that the variable influences of these issues on candidacy have not been sufficiently distinguished in much of the literature on access to health care by minority ethnic groups.

Our searching also suggests that some ethnic minority groups and some diseases associated with these groups have been investigated much more frequently than others. For example people of Jewish and Eastern European origin have been much less studied than people of South Asian origin, and issues relating to coronary heart disease and mental health have received more attention than other illnesses. Apparent under-diagnosis and under-referral of some conditions (such as coronary heart disease) are sometimes cited as evidence of poor access, while apparent over-diagnosis of some stigmatising conditions (such as mental health problems) are cited as evidence of discrimination.

Taken together, these issues make the interpretation of evidence in this area very complex.

4.2 Lines-of-argument synthesis

Our lines-of-argument synthesis of the evidence on access to health care by people of minority ethnicity is organised around a set of central concepts, and in particular the core synthetic category of 'candidacy'. A list of included studies is provided at Appendix 4A.

CANDIDACY describes the ways in which people's eligibility for medical attention and intervention is jointly negotiated between individuals and health services. Candidacy is a dynamic and contingent process, constantly being defined and redefined through interactions between individuals and professionals, and managed in the context of operating conditions, including the availability of resources, local pressures, and policy imperatives.

Key points in candidacy related to minority ethnicity generated by our analysis:

- In most cases of help-seeking (though there are important exceptions) people come to identify and seek to present themselves as having needs (though these may not be well formulated) to which health services can respond: people thus recognise that they are candidates for health care and initiate action. It is also possible for health services to identify features of candidacy and seek to apply these to individuals – for example in the case of screening, when the normal help-seeking processes are reversed.
- **Navigation** refers to routes individuals take from identifying their candidacy to gaining a point of entry to health services. Accomplishing the work of navigation relies on a set of competencies and resources that may not be equally distributed among the population.
- The ways in which people of minority ethnicity come to the attention of health services can be distinguished into three forms:
 - Appearances*, in which people themselves appear before health services through a series of actions initiated, however remotely, by themselves.
 - Invitations*, in which people respond to an invitation about candidacy from health services (through screening or immunisation programmes).
 - Grabs*, in which people lose control over the definition of their candidacy, and are compulsorily submitted to medical treatment.
- People can penetrate, or gain a point of entry, to health services in a number of ways. We will suggest that services can be conceptualised as being surrounded by membranes that are more or less porous. More porous membranes allow people to pass through easily; services that are less permeable require much more work in order to gain a point of entry and sustain engagement with the service.
 - More porous membranes**– Services that have more easily permeable membranes, are culturally sensitive, are more easily negotiated.
 - Less porous membranes** are more resistant and present more barriers, are difficult to negotiate, and require a high level of alignment, including cultural alignment, with the organisational values of the services on offer.

Once an individual has **presented** to health services, they have asserted their candidacy as deserving of medical attention and / or intervention. They may vary in their recognition and aspirations as to the nature of that candidacy. **Presentations** involve people in doing

work, which again requires particular sets of competencies, skills and resources which may be variably distributed in the population.

- **Adjudication** refers to professional judgements about the candidacy of an individual for intervention or service. Such adjudications will determine the subsequent progression of the individual through health services.
- **Conditionality.** Adjudication is contingent on the operating conditions of services. Each stage of candidacy is likely to be influenced by the perceived or actual availability of health service resources, including issues of geographical proximity. Operating conditions may operate at the level of individual interactions – a professional may make an offer that is not warranted on the basis of 'clinical' candidacy in order to preserve the relationship with a patient, or conversely withhold treatment or services because they judge someone's candidacy to be 'undeserving'. They may also operate at the level of the organisation which may withhold or delay offers that could be justified on the grounds of clinical candidacy because of limited resources.
- **Offers** – refers to the offer, or non-offer, of intervention or service.
- **Acceptance and receipt, resistance and rejection** – refers to the uptake of offers by individuals, or attempts to resist and reject offers. People's responses to offers represent their re-assertion of their own definitions of candidacy.

Our synthesis is organised around the following themes, which we generated through our analysis of the evidence:

- 4.2.1 Theme 14.2.1 Theme 1: Construction of the problem of access to health care by minority ethnic groups.
- 4.2.2 Theme 24.2.2 Theme 2: Identification of candidacy.
- 4.2.3 Theme 34.2.3 Theme 3: Navigation: Mobilising resources.
- 4.2.4 Theme 44.2.4 Theme 4: Organisational issues in navigation.
- 4.2.5 Theme 54.2.5 Theme 5: Presentation, adjudication and offers.
- 4.2.6 Theme 64.2.6 Theme 6: Tractability: Policy, service developments and interventions to improve access for people of minority ethnicity.

A table of included studies can be found at Appendix 4A.

4.2.1 Theme 1: Construction of the problem of access to health care by minority ethnic groups

Our analysis suggests a meta-narrative of the inverse care law operates in relation to ethnicity and access to health care as for socio-

economic disadvantage. For example Bhopal (1998), in an 'Education and Debate' review article in the British Medical Journal (BMJ), argued that health services may offer a worse service to minority groups, an assumption also made by the NHS Plan. As with the literature on disadvantage, however, many of the assumptions rest on a relatively small body of empirical evidence, not all of it very rigorous. Much of the empirical literature reported in journals and books, though it continues to be widely cited, is quite dated, and does not reflect the changes that have occurred in recent years, particularly since key policy changes relating to discrimination and organisation of health services have been implemented. This literature also fails to make the kinds of distinctions about issues of candidacy that we identified as important in our analysis of the literature on socio-economic disadvantage and access to health care. We have organised our synthesis around the following themes generated by our analysis of the evidence:

- General practice.
- Specialist care.
- Mental health.
- Preventive services.

General practice

Like research in the area of socio-economic disadvantage, most studies of ethnic minority access to health care have focused on utilisation of health care. The picture that emerges is complex, equivocal, and beset by methodological problems.

Earlier in this report, we discussed evidence about variable supply of GPs in different parts of the country, and suggested that the significance of this would lie in evidence that people had greater difficulties in registering with a GP, or in gaining timely access to good quality primary care. We did not identify evidence that suggests that people of minority ethnicity, other than those very recently migrated perhaps as asylum-seekers, have difficulties in registering with a GP. As summarised by Goddard and Smith (1998), a high proportion of people from most ethnic minority groups appear to be registered with a GP, with most surveys reporting registration rates of 99-100 per cent. Indeed work cited by Chan (2000) suggests that rate of registration with a GP is higher among minority ethnic groups than among the general population, and Ahmad and Walker (1997) found that 72 per cent of people of South Asian ethnicity reported ease of contact with a GP to be 'no problem'. Goddard and Smith's (1998) summary suggests that a high proportion of people from many ethnic groups are registered with a GP from the same group, though this is less common among some groups, including the Chinese. Uddin *et al.*'s (1998) review notes that over four out of five South Asians attend a surgery with an Asian doctor. The evidence summarised by Goddard

and Smith (1998) also suggests that people of minority ethnicity are less likely to have appointments in primary care, instead using open access surgeries, and that they wait longer in the surgery, but the currency of these findings in the light of recent policy developments is unclear.

Our analysis of the evidence suggests that there are generally high rates of GP consultation rates among people of minority ethnicity, but the impact of ethnicity on health service use varies across ethnic groups. Again, as with the literature on socio-economically disadvantaged people, the debate has been about the extent to which higher use reflects higher need or some other variables. Evidence dating back to the early 1980s has repeatedly found higher rates of GP utilisation by South Asian groups, but these studies did not adjust for need (Balarajan *et al.*, 1992; Balarajan *et al.*, 1989). When attempts are made to adjust for need, rates of utilisation of GP services remain higher among South Asians generally, compared with all other ethnic groups (Gillam *et al.*, 1989; Smaje and Le Grand, 1997). Sutton *et al.*'s analysis (2002) suggested that after controlling for socio-economic status and morbidity, individuals classified as Indian, Pakistani and Bangladeshi are more likely to consult, and to consult more often. Smaje and Le Grand's (1997) analysis, adjusted for socio-economic status, found that for people aged under 45 years, people of Pakistani and Caribbean origin were higher users of GP services compared with the white European population, but this was not consistent across gender. Caribbean women were found to consult more frequently, and Pakistani women less frequently, than their white counterparts. The effect of higher GP use is not consistent across all minority groups – Chinese people are likely to be lower users of services. Livingston *et al.* (2002), reporting a study of use of health and social services by immigrant elders in Islington, found that immigrants used primary and secondary care at least at the same level as older UK-born people, but that Africans and Caribbeans appear to have poorer physical health, and this excess morbidity may account for their greater contact with health and social services.

Specialist care

The evidence as regards utilisation of specialist services in secondary and tertiary care is even more equivocal, with apparent variations across ethnic groups, across different medical specialties, between men and women, and between younger and older people within minority groups. The finding that utilisation of GP services by minority groups tends to be higher, and of specialist outpatient and inpatient services tends to be lower, has now been repeated across several studies (Saxena *et al.*, 2002) but is not entirely consistent either across groups or medical specialties. Again, the problem in interpreting the evidence here relates to candidacy: it is not clear whether different utilisation reflects differing patterns of recognition of

candidacy, different presentations, differing patterns of adjudication, or different patterns of acceptance and rejection.

Smaje and Le Grand (1997) found that outpatient consultations were lower across the range of minority groups, a finding also confirmed in Smaje's (1998) analysis of the same data, in which he showed that there are equivalent or higher rates of GP consultation for people from most ethnic minority groups relative to whites (the Chinese population being the exception) and lower levels of outpatient utilisation. Sutton *et al.* (2002) reported that people of Indian, Pakistani and Bangladeshi origin have lower than expected outpatient and day case treatment, and Bangladeshi individuals have less inpatient treatment. Cooper *et al.* (1998) reported that South Asian children use GPs more than any other ethnic group, with the lowest rate of GP consultation among African Caribbean children, but all children and young people from minority groups were less likely to use hospital outpatients or to be hospital inpatients. White children in this study were around twice as likely to use hospital outpatients (11.3 per cent of white children compared with 6.1 per cent of Indian, five per cent of Pakistani or Bangladeshi, and seven per cent of African Caribbean children).

For asthma there is also some evidence that utilisation of secondary care is higher, bucking the overall trend for lower use of secondary care among people of minority ethnicity. Gilthorpe *et al.* (1999) found that age-standardised admission rates for asthma were higher in all minority ethnic groups than in the white group, irrespective of gender, and these differences could not be explained by differences in prevalence of asthma (though again might possibly be explained by poorer control of asthma). Gilthorpe's analysis also found that although deprivation was observed to have a significant effect on asthma admissions, ethnic differences still exist, and that it is difficult to disentangle the effects of deprivation and ethnicity as minority groups are often deprived.

There has been considerable debate about whether there are differences between South Asian and white people in the invasive management of coronary disease. Taken together, the evidence is not consistent. Gatrell *et al.* (2002) provided some ecological evidence that access to tertiary services may be lower from some minority groups, finding that rates of cardiac investigation (angiography) and treatment (revascularisation) are lower in wards with higher proportion of South Asians (classified by using census data). By contrast, a study in Leicester of people admitted to hospital with heart failure showed that South Asian patients had significantly higher age adjusted admission rates (rate ratio 3.8 for men and 5.2 for women) for heart failure compared with white patients. In the five years before admission with heart failure, 3.3 per cent (n=11 of 336 in the study) of South Asians in this study had undergone a revascularisation procedure compared with 2.1 per cent (n=105 of 5057) of white patients (Chi squared = 1.6; p <0.2). For the follow-up period, values

were 6.5 per cent for South Asians and three per cent for whites (Chi squared = 10.4; $p=0.001$) (Blackledge *et al.*, 2003).

Much of the evidence in relation to cardiovascular services has been summarised by Feder *et al.* (2002) and by Carter *et al.* (2001). Feder *et al.* (2002) argue that most studies in the area have been affected by small sample sizes, omission of details on severity of illness, appropriateness of procedure, and other confounding factors. Carter *et al.* (2001), reporting a systematic review, found that there is evidence for some variation by ethnic group in the management of coronary heart disease, with evidence for lower receipt of angiography and revascularisation for South Asians and lower recognition and treatment of raised blood pressure in white and possibly South Asian groups. However, they comment that the studies they reviewed had small sample sizes, and did not adjust the analysis for possible differences in appropriateness of interventions between different groups. Most studies of secondary care did not adjust for demographic factors, and this could mean that variations between ethnic groups is not a function of ethnicity but of other factors such as socio-economic status. Several studies that Carter *et al.* review suggest that sources of variation in coronary investigation and treatment probably arise in secondary or tertiary care.

Complex debates surround issues of provision for diseases with especially high prevalence in ethnic minority populations. On the one hand, there is a reluctance to label people of minority ethnicity as having exotic or stigmatising diseases, particularly those that pose threats to public health (such as HIV and tuberculosis). On the other hand, it is argued that the distinctive health needs of different minority populations need to be recognised and served. Lack of provision of ante-natal screening for sickle cell and haemoglobinopathies had been criticised as an example of under-provision: sickle cell anaemia has an incidence of one in 400 births among African Caribbeans (Chevannes, 1991) and about 170 babies are born annually with sickle cell disease (Anie *et al.*, 2002). This is likely to have been ameliorated with the recent establishment of the NHS Sickle Cell and Thalassaemia Screening Programme, although such a programme will raise complex questions of ethnicity, racism, citizenship, and consumerism as well as the historical legacies of eugenics (Atkin and Ahmad, 1998).

Mental health

The picture for mental health is very distinctive, and here there is a substantial body of research summarised by Atkinson *et al.* (2001) showing that members of the Black population are more likely to be admitted to psychiatric units, more likely to be held in locked wards, and more likely to be sectioned under the Mental Health Act, while at the same time some types of mental health conditions, including depression and dementia, may be under-diagnosed. There is some

evidence that minority groups tend to have higher GP consultation rates for physical problems but lower rates of consultation for mental health problems. In Bebbington *et al.*'s (2000) analysis of the National Survey on Psychiatric Morbidity, an odds ratio of 0.95 for black people and an odds ratio of 0.37 for South Asian people of GP consultation for a mental health problem compared with white people was reported, but there is considerable evidence pointing to much higher hospital admissions (including compulsory admissions) for black people (Bhui *et al.*, 2003).

Bhui *et al.*'s (2003) recent systematic review found evidence of ethnic variations in use of specialist mental health services in the UK. The evidence most consistently suggests an excess use of inpatient facilities by Black patients (though two studies pointed to an excess of White admissions). Of 23 papers measuring compulsory admissions, 18 showed a higher rate for Black compared with White patients. A meta-analysis of these studies gave a pooled odds ratio (Blacks compared with Whites) for compulsory admission to in-patient facilities of 4.31 (95 per cent CI 3.33-5.58).

In the previous section, we distinguished people's attendances at health services as *appearances* or *responses to invitations*; we further distinguish compulsory admissions as '*grabs*'. We suggest that compulsory admissions represent the forceful seizing of control over candidacy by health services. 'Grabs' represent one of the few occasions when the definition and negotiation of candidacy slips wholly from the control of people and into the control of health services. 'Grabs' are an important example of a negative case in our emergent analysis, which has emphasised the jointly constructed nature of candidacy. It is possible to explain this negative case by referring to the very special properties of 'grabs', which rely on invoking statutory powers, such as those required for compulsory admission. Other examples of 'grabs' of control over candidacy – such as surgery in emergency situations - require similar powers.

Preventive services

Use of preventive services also presents an inconsistent picture. A systematic review of ethnicity and health care access in London (Atkinson *et al.*, 2001), found that uptake of some preventive services (such as childhood immunisation) is high among ethnic minority groups, while uptake of other preventive services (such as breast and cervical screening) is relatively lower. Majeed *et al.* (1995) found that screening rates for breast cancer were negatively correlated with variables that measured the ethnic make-up of practice populations, and also with variables associated with social deprivations. Majeed *et al.* (1994) reported similar findings for uptake of cervical smears. It has also been noted that ethnic minority women have been found to be up to five times more likely to initiate antenatal care 'late' (after 18

weeks) than women of white British origin (Kupek *et al.*, 2002; Petrou *et al.*, 2001).

Summary: Construction of the problem of access to health care by minority ethnic groups

Taken together, the evidence suggests there are important variations within and between ethnic minority groups in their utilisation of health care. Utilisation of primary care is generally high among most ethnic minority population groups, though there are important exceptions. The studies reviewed above do not explain why: possible explanations include higher morbidity, different help-seeking behaviours and cultural orientations towards medicine, different demographics, or poorer quality consultations that lead to repeat use. The evidence on uptake of preventive services is variable. The finding that there is lower utilisation of secondary and tertiary care by people from ethnic minorities is important and interesting and it does not appear to be explained by a reluctance to seek an initial consultation with a GP. There are too few well-conducted studies to be certain of inequities or the nature of these inequities. There is a distinctive picture in relation to utilisation of mental health care.

4.2.2 Theme 2: Identification of candidacy

As we suggest in our analysis of the literature on socio-economic disadvantage, accomplishing access to health care requires considerable work on the part of individuals, and that the amount, complexity, and difficulty of that work may operate as barriers. For people in minority ethnic groups, there may be particular difficulties in aligning their perceptions of health and illness to those of health services, though we do not wish to overstate the distinctiveness of knowledge and beliefs among minority populations. Our synthesis is organised around the following themes, generated by our analysis of the literature:

- Recognition of health needs: People's identification of candidacy.
- Delays and blockages in recognising or acting on candidacy.
- Identity.
- Health maintaining behaviours.

Recognition of health needs: People's identification of candidacy

We analysed articles that examined the extent to which decisions to seek help and strategies used to cope with ill health were influenced by information, knowledge and beliefs in minority ethnic communities. However, there is a need for caution in interpreting some of this evidence. As we showed in the general meta-ethnography, lay beliefs and knowledge take on distinctive forms that are socially and culturally patterned: we do not wish to imply that only minority ethnic

groups have beliefs and knowledge systems that are different from those of medicine. Many of the issues that affect minority groups in relation to beliefs and knowledge are very similar to those that affect people of all ethnicities.

Variations in cultural beliefs about the aetiology, symptomatology, and treatment of health problems are likely to explain some aspects of help-seeking behaviour. The social construction of symptoms and the significance of symptoms varies between ethnic groups. For some cultures, alternative or complementary therapies may be used in preference or instead of contact with formal health services (Chan, 2000). Goddard and Smith (1998) report evidence that the Chinese belief in health as a property of humans requiring continuing intervention may make them less likely to view illness as episodes requiring clinical intervention. Chaturvedi *et al.* and Ben-Shlomo (1997) conducted a questionnaire study based on a vignette to investigate how South Asians and white Europeans would respond to anginal pain. They found that more Hindus and Sikhs than white Europeans reported that they would be concerned if they were to experience the chest pain in the case scenario, and they were twice as likely to say they would definitely seek immediate medical care. However, paradoxically, the readiness to consult a lay network and call a GP may be counterproductive, because these actions increase the delay in administration of thrombolytic therapy. Adamson *et al.* (2003) similarly found that African Caribbean people were more likely to report that they would access care immediately in response to the clinical scenarios presented in chest pain and lump scenarios, but did not report on the type of care that would be sought.

There is some evidence that medical knowledge of some diseases and conditions may be poor among some minority groups, and that this affects help-seeking. Atkinson *et al.*'s (2001) systematic review identified that low levels of cancer knowledge among ethnic minority populations are an important barrier to access. Problems also arise in some minority groups because Western biomedical concepts may not have their equivalents in other cultures. Davies and Webb (2000) explain that Somali culture has a concept of mental illness only in its most severe and florid form, and no concept of emotionally or psychologically based childhood disorders in particular. Talking therapies are unknown in Somali culture. These issues can inhibit use of child psychiatry services. Green *et al.* (2002) suggest that symptoms seen by Western professionals as indicative of psychiatric disease (sleeping problems, lack of energy) are less likely to be medicalised by members of the Chinese community. The tendency of Western medicine to treat the component parts of the body rather than the whole was distrusted by women in their study, and most did not accept diagnoses of mental health problems.

As for all cultures, conditions that are perceived as a source of stigma may cause delays in help-seeking. Chapple (2001), in her qualitative

study of vaginal thrush in women of South Asian descent, also analysed lay beliefs in a minority community, though she did not compare these beliefs with those of other ethnicities. She found that vaginal thrush could be attributed in this culture to lapses of personal hygiene, to witchcraft, to a serious systemic disease, to 'hot' food, and to sexually transmitted disease. Stigma and embarrassment, and beliefs about appropriate treatment, tended to delay or inhibit presentation to a GP.

Our analysis suggests that help-seeking behaviour in minority ethnic communities is, as for all groups, influenced by the level of confidence they have in their beliefs about health and illness, and their understandings of the aetiology of symptoms. The papers we analysed indicated a strong relationship between help-seeking attitudes and behaviour and confidence in self-diagnosis, ability and inability to manage their care (Adamson *et al.*, 2003; Katbamna *et al.*, 2002; Chan, 2000; Li *et al.*, 1999; Nguyen-Van *et al.*, 1995-1996; Free *et al.*, 1999; Allison *et al.*, 2000; Griffiths *et al.*, 2001). Griffiths *et al.* (2001), in a qualitative study of influences on hospital admission for asthma in South Asian and white people, found that South Asian people, who are more likely to be admitted to hospital with asthma, tended to talk in passive terms about controlling asthma and dealing with attacks. This suggests that they lacked confidence in managing the condition themselves. On the other hand, confidence in self-diagnosis and self-management may be high for some conditions in some groups, leading people to believe that no formal health care is required. In the study of antenatal care for Chinese mothers in Britain, Chan *et al.* (2000) reported that the Chinese women did not seek help to confirm their pregnancy because they did not perceive their pregnancy as a health problem and obtaining a confirmation was accorded a low priority.

Delays and blockages in recognising or acting on candidacy

There has been some concern that people from minority ethnic populations may present late or not at all with some health needs. We analysed papers that include evidence on this issue, but did not find a clear or consistent picture: whether there are delays, and the extent of them, appear to vary between diseases and between ethnic groups. Ramirez *et al.* (1999), in a systematic review of factors predicting delay in presentation of symptomatic breast cancer, identified 15 studies that explored the issue of non-white ethnic origin, of which three met their inclusion criteria. The evidence in favour of non-white ethnicity being associated with delay was moderate, but difficult to interpret as some studies were conducted in non-UK contexts where issues of health insurance may be important confounders.

Two studies that we analysed appeared to provide evidence of delays in relation to specific conditions, but it would be inappropriate to generalise from these. Lear *et al.* (1994), in a survey of people

admitted to a coronary care unit in Leicester found that more Asian than white people were admitted with a myocardial infarction, but more white people received thrombolysis. This was attributed to later presentation (thrombolysis is only effective if administered within a short time of the infarction). A systematic review of pathways to mental health services found that Black people were reported in two studies to present in crisis, often seeing the duty psychiatrist in an accident and emergency department as the first point of contact with services (Bhui *et al.*, 2003)

Kai and Hedges (1999) appear to provide an explanation for the often-observed finding that depressive illness appears to be under-diagnosed or under-treated in people of South Asian origin. Their community participation study found that a majority of participants considered that health professionals were unsuitable for dealing with worry or stress; 74 of 104 interviewed did not believe their GP was an appropriate person to approach about personal or emotional distress, instead perceiving health services as providers of care for physical health needs. It is perhaps important, however, not to over-interpret health beliefs among people of minority ethnicity as the primary determinants of their candidacy. Although Chiu *et al.* (1999) describe lack of understanding of the purpose of cervical smear tests among South Asian women, they urge caution in accepting that the apparently distinctive beliefs of minority groups are the primary determinant of help-seeking, pointing instead to the relevance of people's experiences of and satisfaction with services.

Identity

In our general meta-ethnography, we showed how people's need to avoid identity threats can profoundly affect the ways in which they seek help. We found some evidence, albeit fairly fragmentary, in studies on the particular issues that arise in relation to ethnic identity that affect help-seeking.

Saxena *et al.* (2002) cite two studies (Ahmed *et al.*, 1991; Balarajan *et al.*, 1989) – although both quite dated – that suggest that doctors may perceive that certain ethnic subgroups, for example patients of Asian origin – add to their workload and use health services inappropriately. Hawthorne (1994) also cites a now very dated study (Wright, 1983) reporting a survey of GPs working in an Asian community, in which GPs felt that Asian patients consulted more and took up more time. Sensitivity to these kinds of issues on the part of people of minority ethnicity could clearly affect people's willingness to act on candidacy, though we did not identify a body of evidence that has shown this.

There is, however, some evidence to suggest that people are sensitised to how some aspects of their ethnicity may be judged, and that this may influence their willingness to initiate and remain engaged with health services. In Chew-Graham *et al.*'s (2002)

qualitative study of psychological distress and self-harm in South Asian women, women reported that they feared a lack of understanding on the part of white health service staff. They felt they might be judged as an 'Asian woman' and be met by fixed views about the Asian community and 'how extreme Muslims are'. There is other evidence that minority groups may experience a need to protect the identity of their community. Webb *et al.* (2002) argue that children and link workers may experience conflict between ensuring their own safety and protecting their community's image, though the evidence for this is not strong. Katbamna *et al.* (2002) reported that some South Asian carers perceived that their GPs were critical of cultural practices, and that they limited the use of GPs in order to protect their community's identity. A Pakistani muslim woman caring for her disabled daughter reported that:

'The first thing he asks is 'Is it a first cousin marriage? You've had one disabled child, then another.' He's a good doctor but, because of his attitude, I only go when I really have to. I feel embarrassed or ashamed almost. I feel that they must wonder what kind of system Pakistani people have, or that we don't have any sense'

Health maintaining behaviours

The evidence on health maintaining behaviours among people of minority ethnicity is also complex and difficult to interpret. In the previous section we distinguished preventive care arising from *invitations*, *appearances* and *adherence*. There is some evidence that attendances in response to *invitations* for adult health checks, including blood pressure checks and cervical smears, are less likely among minority ethnic groups (Uddin *et al.*, 1998). Hoare (1998), however, points to the contradictory evidence on uptake of breast screening by women of minority ethnicity. Typically, uptake of around 50 per cent is reported for Asian women compared with around 73 per cent for non-Asians. However, she argues, the interpretation of these differences is possibly confounded by the variation in the distribution of factors such as social class. In one study, uptake by black women was higher than that for white women in the same area of inner London, and it would appear that uptake of screening by Asian women may be low, but not necessarily lower than among women of similar socio-economic groups. Goddard and Smith (1998) similarly suggest that it is difficult to disaggregate the effects of deprivation from ethnicity in interpreting studies on uptake of invitation-based preventive care.

We found some evidence that *adherence* may be lower among some communities for some diseases. Goddard and Smith (1998) report evidence suggesting that adherence to anti-hypertensive medication is lower among African Caribbeans. However, there are clearly interactions between the quality of care that affect issues such as *appearances* and *adherence*. This area requires detailed review beyond the scope of this report.

Summary: Identification of candidacy

Initiating the negotiation of a point of entry to health services relies on people recognising themselves as having some claim to medical attention or intervention: they must recognise candidacy. Our analysis suggests that issues relating to recognition and action in relation to health care candidacy by people of minority ethnicity are highly complex and do not lend themselves to firm conclusions. While we recognise that lay beliefs and knowledge may well show distinctive patterns among minority groups, we are reluctant to emphasise these are minority-specific influences on recognition and action. Lay beliefs exist in all communities and are highly variable, dynamic and complex.

We do suggest, however, that there is some evidence that issues of identity, and efforts to protect individual and cultural identity, may influence people's willingness to act on what they recognise to be candidacy for health care. We will suggest in the analysis that follows that this is important in explaining people's use of services that are *culturally permeable*.

4.2.3 Theme 3: Navigation: Mobilising resources

Our analysis suggests that navigation of services by people of minority ethnicity requires access to and deployment of a range of resources, including those of language and forms of support. Our synthesis is organised around the following themes generated by our analysis:

- Knowing where to go and what's available.
- Social support as a resource.
- Practical resources.
- Language resources.
- Newness.

Knowing where to go and what's available

As noted earlier in this report, negotiation of a route to find a point of entry to health services requires some knowledge of the services available. Our analysis suggests that lack of information can be a major problem for many people in minority ethnic communities and affect every stage of interactions with health services. Knowing how to use a service was identified in these papers as a first hurdle that many people in minority communities encountered, which in turn determined their decision to seek help (Rashid and Jagger, 1992; Gammell *et al.*, 1993; Sharma *et al.*, 1994; Bulman and McCourt, 1997; Naish *et al.*, 1994; Chiu *et al.*, 1999). Lindsay *et al.* (1997) found that even among longer established Gujarati elders living in Leicester, a much higher proportion had never heard of services that were inquired about compared with a similar white population. These services included district nurses (64 per cent of Gujaratis had not heard of them, compared with 18 per cent of whites); chiropody (78 per cent

versus 20 per cent) and community psychiatric nurse (90 per cent versus 80 per cent).

Lack of basic information about the services available can compound problems for people whose first language is not English and for those not literate in their mother-tongue. We found evidence that lack of printed literature in minority languages, or in suitable formats for those who are illiterate, discourages people from seeking help and prevents them taking up appropriate services. Ahmad and Walker (1997) reported that 50 of the 84 people in their study supported the statement that language problems stop people knowing about, looking for and / or receiving services. Sharma *et al.* (1994), report that a lack of advice and information in minority languages deters non-English speaking women from seeking advice about infant care. These problems applied to seeking help in emergency situations, as well as seeking help for routine health issues (Nguyen-Van *et al.*, 1995 - 96; Sharma *et al.*, 1994; Naish *et al.*, 1994; Lindsay *et al.*, 1997; Chan, 2000). For example, in an investigation of access to and use of out-of-hours services by Vietnamese respondents, Free *et al.* (1999), found that lack of awareness and lack of information prevented people from seeking help in an emergency. Lack of information and knowledge about the existence of services among people in some minority ethnic groups may be more widespread than is generally recognised (Nguyen-Van *et al.*, 1995 - 96; Karim, 1996; Li *et al.*, 1999; Chan, 2000).

Social support as a resource

Social support refers to the perceived level of support that is available from others and the extent to which the availability of this resource affects their ability to seek help and / or their decision about seeking help. We analysed articles looking at the role of social support in help-seeking behaviour in minority ethnic communities.

Our analysis suggests that members of family, friends and community centres can offer a range of forms of support, including interpreting, advocacy, and help with transport, to enable people of minority ethnicity to seek, negotiate and sustain access to medical care. People may rely heavily on informal social networks comprising friends and family (Littlewood and Elias, 2000; Nguyen-Van *et al.*, 1995 - 96; Bulman and McCourt, 1997; Allison *et al.*, 2000) Some rely on the support of voluntary and statutory sectors such as community centres, social services and GPs (Gammell *et al.*, 1993; Bhui *et al.*, 2001; Katbamna *et al.*, 2002), and others use a combination of informal and formal support to enable them to seek help (Bhui *et al.*, 2001; Katbamna *et al.*, 2002; Li *et al.*, 1999; Chaturvedi and Ben-Shlomo, 1997). However, analysis of two papers suggests that people most adversely affected by the lack of social support are often those in the most vulnerable situations. Cole *et al.* (1995) and Gammell *et al.* (1993) found that ethnic minority patients with mental health

problems were unable to seek help from informal and formal support networks because they were living alone.

For some minority groups, social support may have particularly important roles to play in negotiating language barriers in access to health care. Although informal networks can be an important source of support for people experiencing difficulties in seeking access to health care, evidence suggests that it is not always reliable, particularly for those needing support outside normal office hours (Free *et al.*, 1999). Studies suggest that relatives, including children, are often the only source of help available to overcome language and communication barriers (Gerrish *et al.*, 2004). However, the assistance of a family member or child may be sought only as a last resort, because help from this quarter is not always seen as reliable and acceptable. Using children as interpreters during examination or when sensitive issues were being discussed is a particular problem, and it is not unusual for those unwilling to use their children in this way to miss their appointments with health care professionals or to omit important information (Cohen *et al.*, 1999; Rhodes *et al.*, 2003).

Among many minority ethnic groups, the legitimisation of lay beliefs about ill health and the management of conditions with the help of family, and friends and religious organisations may influence help-seeking behaviour (Littlewood and Elias, 2000; Allison *et al.*, 2000). It was evident in our analysis that the level of trust and faith invested in informal networks and lay advice influenced the decision to seek the help of health care professionals as lay advice was often used extensively before consulting a doctor (Allison *et al.*, 2000). This was demonstrated by Littlewood and Elias's (2000) study of the narratives of African and African Caribbean women on delay in seeking help for breast cancer. This study found that African Caribbean women with breast cancer were more likely to seek and accept treatment for breast cancer if they felt that their behaviour would be approved by the church. It is also evident in some research that some forms of social networks can act as deterrents to help-seeking. Participants in Chew-Graham's (2002) study of help-seeking among South Asian women in relation to psychological distress and self-harm found that a very efficient community grapevine could lead to gossip and speculation about help-seeking that discouraged women from using services.

Practical resources

As we identified in our general meta-ethnography, the availability of practical resources operates to constrain people's access to health care. We analysed papers that reported on specific practical problems affecting minority families (Arai and Farrow, 1995; Pahl and Vaile, 1988; Sharma *et al.*, 1994; Burnett *et al.*, 1999; Littlewood and Elias, 2000; Hawthorne, 1994; Carter and Bannon, 1997; Bannon 1992). A review paper by Hawthorne (1994) identifies a wide range of practical

resources that affect the ability of people from South Asian populations in seeking help. Many of these are related to issues of socio-economic deprivation, which may be particularly severe in some minority groups. Hawthorne suggests that people in minority groups may have limited access to cars and telephones, making it difficult to keep or rearrange appointments. Many South Asian people are self-employed and work long hours, making it difficult to fit around fixed appointment times during standard working hours. Some minority groups may go back to relatives – for example in the Indian subcontinent – for months at a time and be lost to follow-up or be unavailable when called for screening or other preventive services (Hoare *et al.*, 1992).

Other practical resources or issues that affect help-seeking include access to private health insurance, housing or living arrangements; information in minority languages and socio-economic position, particularly lack of employment (Arai and Farrow, 1995; Pahl and Vaile, 1988; Sharma *et al.*, 1994; Burnett *et al.*, 1999). Pahl and colleagues (1988), in a study of travellers, found that nomadic communities are particularly vulnerable to poor access. Carter and Bannon (1997), in a study of health services for pre-school children, reported that mothers whose first language was not English found journeys to clinics more difficult, perceived waiting times to be longer, and had larger families that made attendance more difficult. In some cases, the experiences of service users in minority ethnic communities suggest that the process of help seeking is complex and requires a variety of practical resources. Burnett *et al.* (1999) for instance, found that psychiatric patients who were unemployed were more likely to be referred directly to psychiatric care by police, whereas patients who had the support of their families were more likely to seek referral via their GP.

Language resources

Our analysis identified competence in English language as one of the most important facilitators to help-seeking. We analysed papers that examined the relationship between proficiency in English language and help-seeking behaviour in minority ethnic communities (Arai and Farrow, 1995; Gammell *et al.*, 1993; Nguyen-Van *et al.*, 1995 - 96; Sharma *et al.*, 1994; Karim *et al.*, 2000; Bulman and McCourt, 1997; Bowler, 1993; Naish *et al.*, 1994; Lindsay *et al.*, 1997; Li *et al.*, 1999; Katbamna *et al.*, 2002; Rashid and Jagger, 1992; Cooke *et al.*, 2000; Chan, 2000; Chiu *et al.*, 1999; Atkin *et al.*, 1998; Tang and Cuninghame, 1994)

In almost all studies we analysed, an ability to speak English is seen as a vital resource for negotiating access to health care. Those who do not possess the necessary skills in English face numerous challenges seeking health care (Sharma *et al.*, 1994; Bulman and McCourt, 1997). Some of the main problems identified for those who are

illiterate in English included difficulties accessing information about health and health care services, and in ability to communicate with health professionals and engage in the decision-making (Katbamna *et al.*, 2002; Li *et al.*, 1999; Bowler, 1993). Most had little choice but to rely on official or unofficial interpreters, but these were often not easily accessible, appropriate or reliable (Chiu *et al.*, 1999; Tang and Cuninghame, 1994; Bowler, 1993; Bulman and McCourt, 1997). An analysis cited by Hawthorne (1994) found that 16 - 39 per cent of the most simple questions were mistranslated; for example, terms were changed (madness for epilepsy; obesity for swelling) and some gynaecological words were not translated at all. Non-professional interpreters tended to speak for the patient instead of allowing them to find their own answers.

Anxiety about having to cope with language and communication difficulties operates as a powerful deterrent to seeking help. There is strong evidence to suggest that adequate provision of, and ease of access to, interpreting services is a key factor which influences help-seeking behaviour of people in minority ethnic communities (Bulman and McCourt, 1997; Naish *et al.*, 1994; Sharma *et al.*, 1994). Even after contact with health care services has been established, many minority ethnic people face barriers in negotiating access to health care (Chan, 2000; Bulman and McCourt, 1997).

Lack of appropriate and adequate interpreting services has a disproportionate impact on the decisions of older people and women of child-bearing age to seek help (Bulman and McCourt, 1997; Naish *et al.*, 1994; Sharma *et al.*, 1994; Lindsay *et al.*, 1997). Bulman and McCourt (1997) reported that there was a close relationship between Somali women's negative encounters with maternity services and their access to interpreters. Women who did not have access to interpreters were particularly anxious about seeking help because they were unable to ask questions or describe their health problems. They also found it hard to get explanations, information and the advice they needed to explain their medical history.

Studies exploring the needs of Chinese and South Asian communities found that inability to speak English placed many service users in these communities at a particular disadvantage because they encounter hurdles at every stage of negotiating access to health care, from making appointments and attending alone, to explaining their symptoms and understanding the medical terminology and advice offered by health professionals (Chan, 2000; Rashid and Jagger, 1992). Chan (2000) found that one of the main reasons given by Chinese women for their decision to delay attending their first antenatal appointment was the language barrier.

Newness

Our analysis suggests that recency of migration, or 'newness' should be distinguished from other aspects of ethnicity and may represent a

particularly powerful form of deterrent to help-seeking. The problems that affect those newly arrived in the UK – especially those seeking asylum from conflict – are likely to be very distinct from those that affect longer-established minority populations. Asylum seekers and refugees may be especially at risk of poverty, social disintegration, and poor access to health care (Lynch and Cuninghame, 2000). Lynch and Cuninghame (2000) explain that refugees and asylum seekers, and those awaiting the outcome of an appeal, have free access to NHS services. However, asylum seekers are not automatically eligible for free NHS prescriptions, dental or optical care. Unless permanently registered with a GP, routine appointments for preventive services, including routine child health surveillance and immunisation, will not be sent. In Gammell *et al.*'s (1993) study of refugees and political asylum seekers, 93 per cent of respondents had not been given information about how to register with a GP, and 97 per cent lacked information about how to use hospital services:

'I am not registered with a GP since I came to the UK because I don't know how to register. I could not find any information.'

The amelioration of some barriers to health care over time is evident in Rashid and Jagger's (1992) finding that only six per cent of their sample of Asian people (classified as people whose family originated in India, Pakistan, Bangladesh, or of Indian or Pakistani descent from East Africa) in Leicester reported difficulties in explaining symptoms in English. Although this was significantly higher than the percentage of non-Asian people (0.9 per cent) reporting this difficulty, it represented a significant reduction over the 1983 figure, when 27 per cent of Leicester Asians could speak little or no English.

Summary: Navigation: Mobilising resources

For people of minority ethnicity, negotiating a point of entry to health services and sustaining engagement over time requires considerable work and mobilisation of a daunting array of resources. Minority groups may lack knowledge of the existence of services and how to use them, sometimes because information about services may not be available in a format they can understand (because of language or literacy problems). Knowledge of specific conditions may be poor, and recognition of symptoms and help-seeking may therefore be adversely affected. As for people of all ethnicities, lay beliefs and membership of particular social networks can influence help-seeking behaviour, and there may be delays in help-seeking for conditions perceived as stigmatising. Access to social support, as for all ethnicities, is important in help-seeking, and is particularly important to members of minority populations for help with interpreting. However, reluctance to use family members and children as interpreters can deter help-seeking. Some forms of social networks may also deter help-seeking for sensitive problems by creating grapevines of gossip. Recently migrated people may face particular difficulties.

4.2.4 Theme 4: Organisational issues in navigation

In the previous section we showed that organisational issues in negotiating health services create particular vulnerabilities for socio-economically disadvantaged people. Our analysis suggests that similar, and additional, risks exist for people of minority ethnicity. Our synthesis is organised around the following themes generated by our analysis of the evidence:

- Permeability of services.
- The ideal user and cultural dissonance.
- Provision of language and interpreting services.
- Turbulent and fragmented organisational contexts.

Permeability of services

Our earlier analysis suggests that the most striking feature of access to health care by people of minority ethnicity is the apparently relatively high use of general practice and relatively low use of specialist services. We suggest that one explanation is that services that are permeable to people of minority ethnicity because of their particular organisational features are likely to have higher use.

In our analysis of permeability of services for socio-economically disadvantaged people, we highlighted non-attendance as a highly significant issue, suggesting that non-attendance points to low permeability. Low permeability is a feature of services that require high degrees of agreement on candidacy between users and providers, that impose qualifications on candidacy, and that require mobilisation of many resources. There is some evidence that attendance at specialist services varies by ethnicity. George and Rubin (2003), in their systematic review of non-attendance in general practice, report that race is a predictor of non-attendance in some studies but not others. There does appear to be some very limited evidence of higher rates of non-attendance at specialist appointments among people of minority ethnicity. Gatrad (2000) reported that Asian patients did not attend for 50 per cent of new appointments and 50 per cent of follow-up visits compared with 32 per cent and 33 per cent for European patients, respectively, at paediatric outpatient clinics.

Permeability is a function, among other things, of people's willingness to use services. As for all users and potential users, perceptions of quality of care and quality of interactions can have a major impact on minority people's ability and willingness to seek further advice and information, and engage in the treatment process. Several studies that we analysed indicated that perceptions of quality, including failings of communication by health services, hindered or delayed use of services among ethnic minority groups (Naish *et al.*, 1994; Allison *et al.*, 2000; Katbamna *et al.*, 2002; Chiu *et al.*, 1999). Naish *et al.* (1994) and Chui *et al.* (1999) reported that a lack of explanation

about cervical screening caused a great deal of anxiety and confusion, and this adversely affected uptake.

Misalignments between services and potential users are reflected in papers indicating people's lack of confidence in their ability to gain access, and indicate low permeability (Free *et al.*, 1999; Katbamna *et al.*, 2002; Chew-Graham *et al.*, 2002). In Chew-Graham's (2002) study of psychological distress and self-harm in South Asian women, there was profound lack of trust in mainstream services. A study of musculo-skeletal pain in ethnic minority communities suggested that cultural differences in attitudes towards health care and lack of confidence in health care meant that ethnic minority respondents, particularly those with high-level disability who were living alone and working at home, were more likely to seek lay advice and resort to traditional remedies to manage their health problems themselves (Allison *et al.*, 2000):

'They are only going to say that I can't do anything for you really. It would feel like I'm wasting his time really, complaining about the back it is not really anything you can see.'

Nguyen-Van *et al.* (1995 - 96) found that a majority of Vietnamese respondents were registered with a GP, but poor access to interpreting services and unsatisfactory interactions with the GP meant that the use of Chinese herbal medicine was generally widespread; 16 of 128 respondents (12.5 per cent) took traditional compounds by mouth and 30 (23.4 per cent) applied topical substances such as ointments, cream, and oils.

The ideal user and cultural dissonance

Our general synthesis identified complexity in health care service provision for both providers and users. Some aspects of this complexity may be intensified in relation to ethnicity. Our analysis of the literature suggests that many service developments have traditionally implicitly rested on assumptions about the 'ideal user'. The ideal user of health services, our analysis suggests, is one whose candidacy is legitimised by health services, who has the precise set of competences and resources to negotiate the service successfully, and who match their use of service to the intended uses of the service.

'The ideal user' clearly has a number of competencies and resources, and also has values and norms that are congruent with those of the services on offer. There is some evidence that minority groups do not fit the profile of the ideal user, and consequently are disadvantaged in their access to services. Griffiths *et al.* (2001), in a study of people with asthma, reports difficulties experienced by South Asian people in negotiating access through receptionists, for example. Katbamna *et al.* (2002) similarly describe the difficulties experienced by South Asian carers in negotiating receptionists at GP surgeries, which may arise because of limitations in access to practical resources, such as

telephones, or in the confidence and ability to insist on the authenticity and legitimacy of their candidacy:

'My little girl had a heart operation last year. It was very difficult, because I had no phone, and she fell ill. It was snowing... I had to walk all the way, carrying my daughter to the surgery. When I got there, the secretary sent me back home, saying "Make an appointment over the phone, and then come back".'

Several studies have identified dissonance between the norms of health care organisations and cultural norms in minority groups. There is a large body of work on mental health in particular. Bhugra (2002) cites evidence from the USA suggesting that African Americans may mistrust white therapists and feel more comfortable with African American clinicians. McLean *et al.* (2003) argue that it is in the micro-level interactions between community members and health services that exclusion or inclusion in services is experienced. However, there is a lack of research that has directly observed interactions between health service staff and members of minority groups. The research that does exist, including McLean *et al.*'s work, has relied on reports of interactions from staff and patients.

Our analysis demonstrated that perceptions of the extent to which services are perceived to be culturally sensitive operate as important influences in negotiating a point of entry and sustaining engagement in health services. We analysed 14 studies (Gammell *et al.*, 1993; Nguyen-Van *et al.*, 1995 - 96; Sharma *et al.*, 1994; Webb and Sergison, 2003; Bulman and McCourt, 1997; Bowler, 1993; Naish *et al.*, 1994; Liplely and Parish, 1999; Lindsay *et al.*, 1997; Li *et al.*, 1999; McLean *et al.*, 2003; Chan, 2000; Chiu *et al.*, 1999; Atkin *et al.*, 1998) suggesting that perceptions of the availability of culturally sensitive support affected help-seeking. Several studies report that perceptions of professionals' lack of awareness about values and beliefs, and especially lack of awareness about the needs for language support for people who did not speak English, were barriers to help-seeking (Gammell *et al.*, 1993; Nguyen-Van *et al.*, 1995 - 96; Sharma *et al.*, 1994; Li *et al.*, 1999; Chan, 2000; Atkin *et al.*, 1998). Free *et al.* (1999) reported that doctors rarely took of notice of the fact that their Vietnamese patients were, because they did not speak English, unable to follow their advice or instructions. Similar concerns are highlighted in other studies which suggest that interpreters may not be available at all times (Nguyen-Van *et al.*, 1995 - 96; Sharma *et al.*, 1994; Chan, 2000; Atkin *et al.*, 1998).

Our analysis suggests that perceptions of negative stereotypes, and lack of sensitivity shown by health professionals to ethnic minority patients, also adversely affect people's inclination to assert their candidacy (Bulman and McCourt, 1997; Bowler, 1993; Lindsay *et al.*, 1997; Li *et al.*, 1999; McLean *et al.*, 2003; Chiu *et al.*, 1999; Karim *et al.*, 2000; Katbamna *et al.*, 2002; Chan, 2000). Atkin *et al.* (1998) describe how services for haemoglobinopathy disorders are perceived

by parents, professionals and managers to be insensitive to the needs of the children. Some of the issues raised, for example monthly blood transfusions for children with thalassaemia, are immutable on clinical grounds, but others, provision of pain relief for children with sickle cell anaemia crises, are related to organisational issues such as diagnostic triaging and the administration of medication. Such problems can lead to *rejections of offers*.

There is some evidence to suggest that health care staff may be poorly informed about the practices and beliefs of minority groups. Menon *et al.* (2001) report a questionnaire survey of community and hospital paediatricians and general practitioners in Manchester. This suggested a lack of knowledge about a number of important issues. For example, 44 (41 per cent) respondents did not know whether Sikhs eat beef, and 36 per cent did not know whether people with diabetes are permitted not to fast at Ramadhan. There is also some fragmentary evidence, cited by Manthorpe and Hettiaratchy (1993) that some minority groups – for example Eastern European people – may not be recognised by service providers as ethnic minorities with distinctive needs. Thus a cycle develops in which inappropriate services are developed, disenfranchising particular groups who do not attempt to challenge for changes in the services (Atkin *et al.*, 1998). More recent evidence does, however, suggest that health professionals are increasingly aware that a lack of knowledge and understanding about cultural backgrounds of ethnic minorities are serious obstacles to help-seeking (Gammell *et al.*, 1993; Webb and Sergison, 2003; Liplely and Parish, 1999).

Provision of language and interpreting services

The 'ideal user' is able to identify a claim to candidacy that can be endorsed by health service providers as authentic and legitimate, and can negotiate a point of entry to health services and to sustain engagement with a minimum of communication difficulties. Evidence that we have analysed suggests that people who do not speak English encounter particular difficulties when seeking the help of health professionals because access to an interpreting service is not always guaranteed, particularly for those needing help out-of-hours (Bulman and McCourt, 1997; Chan, 2000). Green *et al.*'s (2002) study found that Chinese women reported significant language problems in interactions with doctors. Women in their study felt unable to express themselves fully in English and could not understand what the doctor said to them. Karim *et al.* (2000) and Atkin *et al.* (1998) found that some professionals were aware that the difficulties they encountered in communicating with their patients reduced opportunities to engage patients in the decision-making process, but many were divided about the extent to which they believe communication barriers affect their work. Chui and colleagues' (1999) work found that GPs claimed to have fewer problems communicating with their Chinese patients, whereas health visitors said that they encountered great deal of

problems. GPs seemed to be satisfied to 'make do' with non-verbal communication involving gestures or signs.

Turbulent and fragmented organisational contexts

We identified earlier in this report that as organisations try to adapt to multiple agendas, requirements, and population groups, they create complex organisational forms with constantly changing boundaries. As for other groups, organisational turbulence and fragmentation can threaten the negotiation of a route to health care by people of minority ethnicity. Katbamna *et al.* (2002) describes how South Asian carers depend on health professionals to access services, but this often appeared to be a random and variable process, made more complex whenever organisational change takes place. The reliance on health professionals to understand health care provision means that potential users are not empowered to critically appraise the range of services that might be appropriate for them, and they report a lack of confidence in the appropriateness of provision of health care services. Atkin *et al.* (1998) describe how the aspiration of inter-agency collaboration for children with haemoglobinopathy conditions became too much even for the paediatricians, who found social services departments too complex to deal with. Similarly, social services staff found haemoglobinopathies, which were regarded as medical rather than social conditions, too complex to understand. The service was described as fragmented, incommunicative and unco-ordinated.

Li *et al.* (1999) and Bulman *et al.* (1997) found people felt that services, including psychiatry for the Chinese community and maternity services for Somali women respectively, that provided continuity of care by a single health professional met their needs better. They also reported the obverse, in that where services did not enable continuity of care by a single health professional, even the provision of a formal interpreting service did not fully compensate for the lack of personal interaction with the health professionals. In such circumstances, the health professionals often became task-oriented without encouraging communication.

There is some fragmentary evidence that administration systems may not meet the needs of some minority groups. In two studies Hoare *et al.* (1992) and Bradley and Fredman (1993) noted deficiencies in record-keeping were found to have significantly affected up-take rates for preventive services, as appointments were sent to the wrong address in a high proportion of cases. Feder *et al.* (2002), in their study of apparent differential provision of re-vascularisation to South Asians, speculate that the administrative system through which re-vascularisation is provided involves written communication in English, long waiting lists, and repeated outpatient assessments, which may cause barriers for people of South Asian ethnicity.

Summary: Organisational issues in negotiation

There are risks that organisational features of health services impair the access to ethnic minority populations. Cultural dissonance – discord between the cultural norms of health care organisations and their imagined ideal user – creates, we suggest, low permeability. People of minority ethnicity may become alienated from organisations that appear to stereotype them or treat them with lack of sensitivity, though the direct evidence of interactions between minority users and providers appears to be lacking. Provision of language and interpreting services is variable and patchy, and causes extreme difficulty for people who cannot speak English. Having to co-ordinate aspects of candidacy through organisational turbulence and fragmented boundaries poses considerable challenges and drains resources, particularly for those with problems of newness.

4.2.5 Theme 5: Presentation, adjudication and offers

It is possible that micro-level interactions between members of ethnic minority populations and health care staff may involve processes of overt or indirect discrimination that cause and perpetuate inequities. Professional beliefs about the distribution of illnesses, the incidence of conditions in particular groups, the appropriate classification and treatment of symptoms, and the need for specialist care, may all interfere with access for those from ethnic minority populations. The status of various actors within the healthcare system and the ethnicity of professional groupings may involve power relationships that particularly disadvantage people from minority groups. We organised our synthesis around the following themes generated by our analysis:

- Presentations.
- Categorisation and adjudication.
- The specific case of mental health.
- Adjudication and referring.

Presentations

Putting in an appearance implies that people have found a point of entry to health services, and in doing so have asserted a claim to candidacy for medical attention or intervention. As we identified in the general synthesis and in the section on access by socio-economically disadvantaged people, the ways in which people are classified (categorised) and subsequently investigated, referred or treated (disposed) are hugely important in the progression of candidacy, and are likely to be influenced by people's *presentations* at health services. Making such claims, and demonstrating the authenticity and legitimacy of those claims, requires a set of competencies and resources on the part of individuals and, we suggest, a degree of cultural alignment between the participants in the consultation.

Clearly, as we have already described, issues of language interfere with people's ability to assert and describe their candidacy. However, while Cooper and Roter (2003) have identified the phenomenon of race-discordant relationships in the United States, there has been surprisingly little research in the UK on the distinctive issues related to ethnicity that may arise in encounters between health professionals and patients. What research does exist has tended not to compare between groups, and has tended to focus on reports of behaviours rather than on observation. Some of the research is now very dated or of questionable methodological rigour. There is a strong tendency in this work to locate difficulties in communication or interaction in the moral failings of health service staff. It is likely that the forms of 'racism' reported in this work are more specific forms of the more generalised tendency of staff in health care systems to use heuristics, typifications and stereotypes to categorise patients, as well as more generalised forms of discriminatory attitudes at work in society as a whole.

Categorisation and adjudication

Cooper and Roter (2003) suggest that ethnic origin and cultural background contribute not only to the definition of what symptoms are noteworthy, but also to how the symptoms are presented to health professionals. They summarise research (though very dated) in the USA that indicates that doctors deliver less information, less supportive talk, and less competent clinical performance to people of minority ethnicity, which the authors propose may stem from cultural stereotypes about the capacities, expectations, and desires of such patients, or because patients of minority ethnicity do not insist on better performance because of cultural norms and impaired confidence. There is some UK evidence pointing to the experiences of people of minority ethnicity of being negatively stereotyped (Chiu *et al.*, 1999; Bowler, 1993; McLean *et al.*, 2003; Maxwell *et al.*, 1999). Coyle (1999) reported that seven out of nine participants in her qualitative study felt they had been stereotyped. They described encounters where they felt their intelligence had been undermined, and commented on not being provided with information about their own conditions or those of the people they cared for because staff had made assumptions about their ability to assimilate and understand the information. Chiu *et al.* (1999) report that smear-takers in their study told stories that were generally stereotypical, relating to what were viewed as specific cultural mores and behaviours among Muslim women. Smear-takers expressed the view that South Asian women lack independence because of a male dominated culture, and explained non-attendance as the result of particular behaviours and negatively interpreted social and cultural attributes.

Rashid and Jagger (1992) reported that nearly half of South Asian patients in Leicester did not appreciate the gatekeeper role of general practitioners with respect to specialists, the mainstay of the National

Health Service in the UK. The result of such differences in expectations of what a service should be delivering is that patients from some ethnic minority groups are perceived as demanding and unrealistic by the staff (Hawthorne, 1994).

There is only a small body of fairly dated evidence that has directly observed professional practices in relation to minority groups, and it is difficult to generalise from this. Bowler's (1993) ethnographic study in a maternity department of a teaching hospital in southern England in 1988 reports on observations of midwives' interactions with midwives and interviews with midwives. She reported that communication difficulties resulted in Asian women being characterised as unresponsive, rude and unintelligent. Women were perceived by midwives to be 'over-users' or 'abusers' of the maternity service. Midwives assumed that Asian women had no interest in family planning. It was also perceived that Asian women were 'attention-seeking' and had low pain thresholds and easier deliveries, with possible implications for provision of pain relief. This work, though widely cited, is based on observations made 16 years ago, and it is unclear whether, even if the ethical difficulties could be overcome, similar results would be found today.

The studies we have analysed suggest there is a risk that the ways in which health professionals make judgements about the candidacy of people of minority ethnicity, based on aspects of presentation as well as more generalised typifications, may influence processes of categorisation and disposal. Our sampling of the evidence did not identify studies that would allow us to identify the extent to which judgements of technical eligibility and social and moral candidacy influence adjudication decisions, though Bhui and Bhugra (1998) appear to suggest that models of evidence-based practice may fail to recognise different value systems that may be important to minority groups.

We did analyse some evidence indicating that outcomes of adjudication vary by ethnic group. Smaje's (1998) analysis appeared to confirm earlier suggestions that all minority ethnic groups are more likely to receive a prescription during a GP consultation. Smaje speculates that people from some minority groups may have different expectations about prescriptions, or that difficulties of language and communication encourage the use of prescriptions. It may, he suggests, be the case that language difficulties result in the sort of unsatisfactory consultation in which a prescription is offered as a non-verbal way of terminating the interaction. However, in the absence of qualitative studies observing interactions, it is difficult to know how well grounded any of these possible explanations might be.

Adjudications have also been studied in some detail in relation to families caring for ill, elderly or disabled members and have been identified in a number of studies. Manthorpe and Hettiaratchy (1993) summarise these studies, suggesting that there is a pervasive

assumption that ethnic minority elders live in close-knit kinship groups, but family structures in minority groups are much more variable than this assumption suggests. Katbamna *et al.* (2002), in a study of South Asian carers, report that older GPs, whose training had greater emphasis on medical rather than social aspects of care, tended to make unwarranted assumptions about carers, while younger GPs appeared to be sensitive to carers' needs.

Offers

There is only limited evidence on 'offers' to people of minority ethnicity, but clearly this is a very important area for future investigation. A very dated Birmingham study (Lowry *et al.*, 1984, reviewed by Carter *et al.*, 2001) reported lower proportions of South Asian people receiving coronary artery bypass grafting. They also recorded the *offering* of bypass grafting to their cohort and found no difference between ethnic groups.

The specific case of mental health

Perhaps the area of greatest research activity in relation to issues of categorisation and disposal has been mental health, because of its relevance for stigma, discrimination, and forms of social control. Much effort has gone into explaining the higher rates of compulsory admissions to hospital for mental health problems among some minority groups, particularly African Caribbeans. The social control argument suggests that the 'medicalisation of racism' is responsible for disempowering and controlled disadvantaged groups, including those from minority ethnic groups (Goddard and Smith, 1998). A recent systematic review found evidence of ethnic variations in use of specialist mental health services in the UK (Bhui *et al.*, 2003). Black people had more complex pathways to specialist services, and were less likely to be referred by their GP to specialist services. Some studies have attributed this finding to a lower likelihood of GPs recognising a psychiatric problem in Black people, though the direct evidence for this appears thin.

An extensive literature on mental health inequalities faced by African-Caribbean communities is usefully summarised by McLean *et al.* (2003). Epidemiological research has consistently found disproportionate representation of African Caribbean people among people diagnosed with schizophrenia and detained under the Mental Health Act. McLean *et al.* (2003) note that members of the African Caribbean population are three to 12 times more likely to be diagnosed with schizophrenia than their white counterparts. The literature has identified cultural stereotypes that mean that African Caribbean patients are more likely to be viewed as dangerous, threatening and irrational. McLean *et al.* point out that the applicability of Western psychiatry to people of non-Western cultural origin has been the subject of extensive debate. People's desire to avoid the

experience of ethnocentric stereotyping and culturally inappropriate communication may result in refusal to access health services, so that African Caribbean people may come to the attention of mental health services late, when problems have far advanced, or at times of crisis. Reporting their own empirical research, Mclean *et al.* (2003) describe how African-Caribbean mental health patients felt that they were categorised according to their racial and cultural characteristics. For example, participants perceived a lack of understanding of African Caribbean culture on the part of staff, and felt that customs and modes of self-expression particular to African Caribbean community members were misinterpreted as signs of pathology, so that 'loud' modes of interactions were seen as threatening and that 'people are shrinking away from them'. Participants in this study felt that they were offered limited options, pharmacological treatments rather than non-pharmacological interventions (McLean *et al.*, 2003). This meant that potential users, of African Caribbean descent, were reluctant to present themselves to mental health services.

'Because you know it's not for you, just by the atmosphere you know it's not for you.'

Bhui, *et al.* (2001) compared help-seeking and general practitioners' assessments of common mental disorders among Punjabi and English people. Comparing assessments of mental health using questionnaires and general practitioners' assessments of mental health, they found that prevalence of common mental disorders assessed by mental health questionnaires was similar between the two groups. Punjabis were more likely to have depressive ideas, yet GPs were less likely to detect disorder among Punjabis with these symptoms. This study appeared to confirm previous work (Wilson and MacCarthy, 1994) suggesting that even when psychological complaints are expressed by members of the South Asian population, GPs are still more likely to make a diagnosis of a physical disorder. The authors speculate that that there may be aspects of presentation among Punjabis that deters psychological enquiry while reinforcing physical explanations. GPs may appraise distress among Punjabis to be culturally congruent and not to reach the intensity characteristic of a mental disorder.

Issues of adjudication have also repeatedly arisen in relation to evidence of rates of admission to mental hospitals. Burr's (2002) qualitative work using focus groups and interviews with health professionals concludes that mental health professionals see cultural difference in terms of fixed, immutable categories that cast 'non-Western' understandings as inferior and have the potential to misdirect diagnosis. Such adjudications may result in higher rates of compulsory admissions, or '*grabs*' as we earlier described them, where people lose the ability to control their candidacy.

Adjudication and referring

As we have identified earlier, most ethnic minority groups appear to have higher rates of GP consultation but mostly lower rates of specialist consultation. It is possible that variations in patterns of referral to specialists by GPs are likely to make an important contribution to this phenomenon, but as yet there has been little investigation of ethnicity issues in referral and this area is poorly understood. There has been persistent concern that people of minority ethnicity are less likely to be referred to specialist services. However, without evidence on patterns of *presentation, offers* as a result of *adjudications* and how these relate to technical candidacy (i.e. clinically defined 'need'), the epidemiology of referral, and uptake of referrals (*acceptances and rejections*), it is extremely difficult to interpret the scant evidence in this area.

Smaje (1998) did not find an ethnic pattern to GP referral rates, though he acknowledges that one possibility is that the dataset used in the analysis contained insufficient cases to detect underlying patterns of referral that could account for the ethnic disparities between GP and outpatient use. In a prospective study, Feder *et al.* (2002) found that South Asian patients had more visits to their GP in the year before angiography but did not spend longer on the waiting list for angiography. There was no difference between South Asian and white patients in the proportions deemed by a panel to be appropriate for revascularisation, but South Asian patients were less likely to receive it than white patients. However, this was not a statistically significant finding (age adjusted hazard ratio 0.69, 95 CI 0.47-1.00, $p=1.00$), and it is not clear whether it reflects differences in *offers* or *acceptances*. Among patients in this study deemed appropriate for coronary artery bypass grafting, South Asian patients were less likely to receive it than white patients (age adjusted hazard ratio 0.74; 0.58-0.91). However, the difference between South Asian and white patients in rates of coronary artery bypass grafts was attenuated by adjustment for education (0.80: 0.59-1.08), income (0.88: 0.65-1.20) and education and income combined (0.81: 0.60-1.16). It is important to note these differences arose after patients had been put on the waiting list: there was no difference between South Asian and white patients in the proportions for whom cardiologists' intended management after angiography was re-vascularisation, and doctor bias in recommending patients for re-vascularisation therefore did not seem to explain the differences in rates of provision. The authors of this study speculate that patients' understandings and preferences, and ability to negotiate the system, may influence uptake of re-vascularisation. In our model, this would correspond to differential *acceptance of offers*.

It is likely, however, that issues of referral are highly condition-specific, and it would be inappropriate to generalise from one clinical area to another. Karim *et al.* (2000), in a qualitative study of GPs and

hospital consultants, found that doctors overwhelmingly believed that minority families prefer to provide palliative care by themselves. Doctors in this study believed that, in these cultures, sending a family member away to be cared for by strangers would be seen as shameful. These doctors reported that they tended to delay referrals to hospice care, partly because of perceptions that palliative care might not be suited to the needs of minority populations. For example they were concerned that staff from black and Asian communities, fluent in languages spoken in these communities, would not be available. They also suggested that families sometimes withhold the diagnosis of a terminal disease from the patient, and that this limits doctors' options. Health professionals from ethnic minority groups may not themselves be necessarily aware of the range of services available to their patients. For example, older and non-UK trained general practitioners are reported to be the least likely to refer patients from ethnic minority groups to services such as palliative care services (Gaffin *et al.*, 1996). This may reflect their training and beliefs about the role of health services for diagnostic, treatment and curative purposes.

Summary: Presentations, adjudications and offers

Presentations at health services require considerable work in order to demonstrate a claim to candidacy for medical attention and intervention, and to secure the endorsement and authentication of the claim and subsequent progression through the system. Issues of language and culture may interfere with people's ability to make competent presentations, but these issues have been poorly studied.

The ways in which people are categorised by health service staff, and how adjudications are made, are of considerable interest in understanding people's access to health care. There is evidence that some people of minority ethnicity feel stereotyped and negatively judged because of their ethnicity in their interactions with health services, but there is a lack of recent, good quality research based on direct observations that would allow insight into issues of power and control in medical encounters that are specific to ethnicity.

The studies we have analysed suggest that there are risks that adjudications about the candidacy of people of minority ethnicity could be disadvantageous, but little research has directly investigated this. Mental health represents a specific case where issues of categorisation and disposal have been better studied, and most of the research here suggests that medical judgements about candidacy for mental illness may be influenced by perceptions of ethnicity.

'Offers' of medical attention or intervention to people of minority ethnicity have been little studied. The evidence about referral behaviour is difficult to interpret, but there are suggestions that the extent to which individuals endorse the judgements about candidacy made by professionals may be important: people of minority ethnicity may choose to reject some offers, for example.

4.2.6 Theme 6: Tractability: Policy, service developments and interventions to improve access for people of minority ethnicity

As Atkinson *et al.* (2001) conclude, there are few evaluative studies focused on how to improve access for ethnic minority groups, and where such studies do exist they are reported mainly in the grey literature and demonstrate significant weaknesses. These include lack of appropriate study designs, lack of appropriate analysis, and absence of economic evaluation. Case study approaches, such as the work reported by Ghebrehewet *et al.* (2002) on the lessons to be learned from experiences with Kosovan refugees, do not rely on any recognised evaluative methodology and instead assert rather than demonstrate the appropriateness and effectiveness of particular forms of organisation for the needs of minority ethnic groups.

We have distinguished a number of ways in which attempts have been made to address the needs of people of minority ethnicity, based on our analysis of the evidence:

- Improved health needs assessment.
- Altering mainstream provision.
- Cultural brokerage: Language services.
- Cultural brokerage: Linkworkers and advocates.
- The debate about 'special' services.
- Educational interventions and reminder systems.

Improved health needs assessment

The need for health needs assessment that is sensitive to the needs of minority populations was evident in papers that we analysed. Memon *et al.* (2001) report a review of public health reports of 13 Health Authorities (HAs) and 22 Primary Care Groups (PCGs) from areas which had been identified as having a high proportion of minority populations. One of the 13 HA reports made no mention of minority populations. The most frequently identified concern was the high prevalence of diabetes in black and ethnic minority populations, but only four HA reports indicated projects to address these issues. Ten of the 22 PCG reports reviewed identified health care issues affecting black and ethnic minority populations, and eight set out action to address these.

MacKintosh *et al.* (1999) provide an overview of how health needs assessment for ethnic minority groups might be achieved. They describe the problems associated with using misleading categories (such as 'South Asian') in conducting epidemiological research, showing how, for example, 'lumping together' many diverse populations can obscure important sub-group issues, such as the

extremely high prevalence of smoking among Bangladeshi men. They suggest that much of the research and commentary has a focus on a specific disease where minority groups have an excess, and that there is uncritical use of 'white populations' as a standard to which minority populations should aspire. They describe a range of methods, from 'hard' information about the epidemiology of disease to 'soft' data derived from 'local voices' initiatives.

Crowley *et al.* (2002) describe a project involving a local community in the development of a community action plan culminating in a community conference. They report an evaluation of the project in which 77 per cent of health, local authority and voluntary staff felt that the project was worthwhile and beneficial for their work with service users as well as identifying the needs of the community. Generally, however, efforts at this type of action research have been poorly evaluated, though some recent studies demonstrate how such research is improving.

Chew-Graham *et al.*'s (2002) study provides a good example of how qualitative research can feed into health needs assessment and planning, providing practical recommendations for PCTs based on research grounded in the priorities of the participants in their study. Chiu *et al.* (1999) urge the use of participatory action research as a means of problem identification, solution generation, and solution provision. The premise of participatory action research is change, and it often involves a planned intervention into a practical problem that is collaboratively solved by participants and researchers. Such an approach might involve the use of cultural insiders as co-researchers. Similarly, consultation with members of ethnic minority communities about their needs and priorities in using services has been mooted as one means of organising services. Kai and Hedges (1999) also show how a community participation approach to needs assessment and service development can help to identify culturally sensitive ways in which services can respond to psychological distress in Pakistani and Bangladeshi communities.

Altering mainstream provision

A clear emphasis in much of the work on improving access of people of minority ethnicity to health care has been attempts to make mainstream services more capable of responding to and serving diverse communities. This has taken the form of attempts to improve the cultural sensitivity of services, through initiatives such as staff training in cultural competence and altering provision of food in hospitals. It has also involved attempts at cultural brokerage: provision of services intended to mediate between mainstream services and ethnic minority users. Few of these initiatives have seen rigorous evaluation of the extent to which they genuinely improve access because, we argue, of confusion about which aspects of candidacy they are intended to influence. It is not clear, for example,

whether providing training in cultural sensitivity is intended to influence issues of *negotiation* (by making services more permeable); issues of *presentation* (by making it easier for people to demonstrate the nature of their claim to candidacy); issues of adjudication (by making staff more sensitive to the possible effects of their typifications on decisions and judgements); or issues of *acceptance and rejection*.

Improving cultural sensitivity

We earlier identified that it may be at the micro level of interactions between professionals and patients that aspects of discrimination and exclusion may be played out. It has been consistently proposed that culturally sensitive practices could be encouraged by having training programmes for staff about the language, culture and religious aspects of potential users of health services (Chevannes, 1991; Hawthorne, 1994; Ahmad, 1995). Forbes (2000) argues that cultural dissonance arises when the view of the world held by the health professional is culturally different from that of the patient. Such differences can alienate patients from the mainstream and from the power necessary to operate effectively in any social system in which another perspective is dominant. Recent years have seen a move towards improving sensitivity to cultural issues in the provision of health care, and there is some evidence of demand for training by health service staff (Chiu *et al.*, 1999). Other attempts at cultural sensitivity have included the provision of food in hospitals and other health care settings that meets the religious and cultural requirements of users.

However, early efforts at 'anti-racism training' were subject to a sustained critique because of their tendency to a 'cookbook' approach to listing cultural norms, and their tendency to perpetuate, rather than challenge, cultural stereotypes (Webb and Sergison, 2003). More recent efforts have been more sophisticated in form but poorly evaluated. Bhui and Bhugra (1998) suggest that the core features of a programme to help develop better services for ethnic minorities must include basic information such as:

- Sociodemographic information on minority ethnic groups in the UK.
- Definition and impact of racism and anti-racism.
- Differences and similarities in cultures both at macro and micro levels.
- Use and practice of alternative healing.
- Idioms of distress used by specific cultural groups.

Examples of attempts to address such objectives include Webb and Sergison (2003), who describe the development and evaluation of a training course – Equal Rights Equal Access – in which the main objective was the promotion of cultural competence, defined as an evolving process that depends on self-reflection, self-awareness and

acceptance of differences, and is based on understanding rather than knowledge. Their evaluation of this intervention was limited, in that it relied on professionals' self-reports of changes in their attitudes and behaviour, rather than observations of actual practice. However, they do conclude that training in cultural competence has the potential to change behaviours and practice, including promoting good practice in communication across linguistic and cultural differences.

The evidence about whether users of services have experienced health care as more culturally sensitive and 'accessible' as a result of staff training is fragmentary, though Mclean *et al.* (2003) reported that participants in their study felt that there had been a reduction in institutional racism, and welcomed recent improvements that protected against overt or explicit racism. These improvements were often located within a context of wider social change including government policy and the McPherson inquiry (<http://www.archive.official-documents.co.uk/document/cm42/4262/4262.htm>).

It is, however, important to recognise the unwanted or unanticipated effects of attempts to be culturally sensitive. Webb *et al.* (2002) suggest that in cases of suspected child abuse, professionals attempting to be culturally sensitive may collude with abusers and prioritise, for example, family's requests for privacy over the welfare of a child. Webb (2000) argues that professionals providing services to people from cultures other than their own have a delicate path to tread in attempting to be culturally sensitive between cultural blindness – failing to recognise the different needs of different groups – and cultural deficit – accepting or applying different standards to different groups. Fear of being perceived to be racist may cause staff to behave differently towards people from minority groups.

It is also important to distinguish which needs are required specifically to be culturally sensitive and which needs are those that all potential service users, regardless of their ethnic status, would identify as important. For example, the importance of being able to see a female doctor to women from some minority groups is often cited (Hawthorne, 1994; Chiu *et al.*, 1999). However, Rashid and Jagger (1992) found that a higher percentage of non-Asian people (11.9 per cent) compared with Asian people (10.4 per cent) reported lack of access to a doctor of a particular sex as a factor that made it difficult for patients to explain their symptoms to a doctor or nurse. The question then arises as to whether women from specific minority groups should be prioritised in terms of their access through provision of female professionals.

Finally, one suggestion that appears to have been little studied is that made by Forbes (2000), who proposes that one way forward is to promote a 'citizenship' model. This would aim, she suggests, to provide disadvantaged groups with the strategies necessary to participate in health care on a more equal footing in accessing and

using social institutions by emphasising their rights and responsibilities.

Cultural brokerage: Language services

Perhaps the most widely used strategy to adapt a standard service model for ethnic minority people is to provide language and interpreting services. At face value, the provision of interpreting services enables those encountering language barriers to access services on their own terms, albeit with a third party assisting them, and converts a standard service model to a user-focused service with respect to language. However, research on the outcomes of provision of interpretation, translation and language services generally has been lacking. Atkinson *et al.* (2001) concluded that more evidence is needed of improvements in outcomes following provision of language services, that research on staff usage of interpreters and their effects on the consultation was required, and there was a need for investigation of the value and impact of telephone-based interpretation and information giving.

Our analysis of the evidence suggests that provision of interpreters is not a complete solution to language problems in health care. Green *et al.* (2002) describe the problems of Chinese women in relying on interpreters. Professional interpreters did not always arrive when promised, and women were fearful about confidentiality. Women suggested that 'if you talk to the doctor you can express yourself 100 per cent, but through a translator it is 75 per cent'. In Chew-Graham *et al.*'s (2002) study of psychological distress and self-harm in South Asian women, women in focus groups argued that even their basic health needs were not fully met through interpreters, and that they were loath to speak of sexual health or family planning in front of them. Participants indicated that would not be able to talk about family problems or feeling very upset with an interpreter there unless they were very desperate. There were also concerns about the risk of gossip associated with using an interpreter.

Chiu *et al.* (1999) suggest that use of interpreters can help to reproduce an asymmetrical power relationship between users and providers of services. Bulman *et al.* (1997) describe how access to interpreting services was controlled by the health professionals, in this case midwives for Somali women. While the women described how they would value the opportunity to have interpreting services, many were unaware of their availability and were dependent on the midwifery staff to access the services on their behalf. Thus the staff had to prioritise their available resources, time and forward planning, according to their perception of the needs of their patients, such as the degree of language barriers, availability of informal interpreters, likely need for confidentiality and sensitivity. Far from enabling people from ethnic minority groups, interpreting services became another service provision that depended on staff deciding on behalf of their

patients whether such a service was appropriate. Rather than risk having no interpreter, most of the Somali women described how they would bring informal interpreters from among their family and friends. Such interpreters were often inappropriate and ill-equipped.

It is also clear that some aspects of language may not be recognised as language problems. For example, in McLean *et al.*'s (2003) study of African Caribbean interactions with mental health services in the UK, African Caribbean vernacular is not perceived to require special interpretation by health service providers, yet it is distinctive in form and may mask cultural differences.

Cultural brokerage: Linkworkers and advocates

As Gillam and Levenson (1999) explain, there is growing interest in linkworkers as a means of providing cultural bridges between health professionals and ethnic minority populations. However, the diversity of labels and understandings given to the role of linkworkers is a source of confusion. Some appear to see linkworkers solely as interpreters, while others see them as having a wider role, including advocacy, ensuring cultural sensitivity, coordinating across the boundaries of statutory organisations, and challenging individual and institutional racism. In this latter definition, linkworkers act as brokers between health services and members of specific minority groups.

A report for the Joseph Rowntree Trust (2002) summarises the debate, suggesting that some black service users and black projects, especially those providing services for South Asian communities, believe that interpretation is a necessary component of advocacy. Other advocates agreed that interpretation and advocacy share the aim of improving communication, but saw them as distinct services. There is also some debate about the role of advocates. It was found that low expectations among excluded and disempowered communities created a climate where advocacy is not considered as useful or realistic.

There have been few rigorous evaluations of linkworkers and it is difficult to determine their effectiveness in improving 'access', again in part because of difficulties in distinguishing which aspects of candidacy they are intended to address. Khanchandani and Gillam (1999) report a process-focused, uncontrolled and limited evaluation of linkworkers in a single general practice, and suggest that they were not aware of other published evaluations of the linkworking role in UK general practice. We were unable to identify any formal evaluations since then, although Jack *et al.* (2001) describe how regular monitoring and evaluation from users and providers are used to maintain and develop an Ethnic Minority Liaison Officer role for a palliative care service in Bradford. The Ethnic Minority Liaison Officer is not intended to supplant the role and responsibilities of the health professionals with respect to their patients or clients, but to improve communication,

facilitate access to the palliative care services and to raise awareness of them among the local South Asian community.

There is some fragmentary evidence suggesting that linkworkers in cases of suspected child abuse who are also members of ethnic minority communities may experience conflict of loyalties between their perceived duty to their community and their professional obligations (Webb *et al.* 2002). Bhui and Bhugra (1998) also caution that an individual in the 'culture broker' model may be seen as having 'sold out' to statutory services. Unless linkworkers are careful, they may be seen to be allied with the services rather than truly impartial.

The debate about 'special' services

It is important to distinguish between services designed to meet the distinctive needs of specific minorities – such as for sickle cell disease – and the creation of special services within mainstream provision – such as the creation of mental health services focused on specific ethnic groups. Hawthorne (1994) and Bhui and Sashidharan (2003) describe a debate about whether 'special' clinics should be offered to specific minority groups separately from other ethnic groups – for example specialist diabetes clinics or mental health services. To date, separate services for minority groups have mainly existed in the voluntary sector (Bhui and Sashidharan, 2003). It is argued that on the one hand, specialist services are argued to be a cost-effective use of specialised staff that meet patients' needs for cultural sensitivity. It is argued that existing mainstream services do not offer a system of care in which minority groups can expect to receive the least coercive treatment, and they do not guarantee that cherished cultural, spiritual and religious beliefs are even known about by professionals, let alone accommodated into care plans.

McLean *et al.* (2003) suggest that institutions are ill-equipped to cope with the unique characteristics presented by minorities, and that the mainstream frameworks and assumptions that are at work in the design of services may result in services unsuitable for or inaccessible to minority ethnic users. They argue that large institutions can have difficulty in making radical change or accommodating minority demands, and tend to assume that minor alterations to mainstream services will be sufficient to make them appropriate and accessible to minority ethnic users. Virtually all participants in their study pointed to the one dedicated African Caribbean mental health service in the area as a model of good practice. Four characteristics of the service were identified as being particularly important. First, it was felt that the service recognised people as individuals, in contrast with a perceived depersonalisation of users by mainstream mental health institutions. Second, the service included discussion of issues of exclusion and cultural identity that were important to African Caribbean clients and located their experience in a wider society context. Third, the service

was committed to providing information about mental health issues. Fourth, it was seen as a service that truly reflected the needs of its community by having organic roots in the local African Caribbean community. Mental health workers' familiarity with a local frame of reference was seen as highly important to the service's success. However, while this service appeared to be widely praised by users, no wider evaluation – of outcomes or cost-effectiveness – was reported.

Opponents of separate special services argue that it is wrong to segregate people by their ethnic group or to provide services for one group and not another. Sasidharan (in Bhui and Sashidharan, 2003) argues that the idea of separate mental health services for different ethnic groups is based on the premise that the needs of minority ethnic groups are different from those of others, a premise he rejects. He suggests that the more likely explanation for cultural inequities in mental health services is that they are a product of institutional factors embedded in professional practice and influenced by the culture and history of Western psychiatry. Solutions must therefore involve the mainstream of psychiatric practice rather than marginal initiatives that emphasise the further segregation of minority needs, he argues. He further adds that setting up services that emphasise the significance of culture only in relation to ethnic minorities can result in a pathologising and stigmatisation of specific cultures, and will allow those working in the mainstream to continue turning a blind eye to the needs of a multicultural society.

It could be argued that research into people who register with general practitioners of the same ethnicity might provide useful insights into the extent to which 'ethnic matching' reduces problems of access. Such work might also allow assessment of the unwanted or anticipated effects of 'ethnic matching'. For example, women in Chapple's (2001) study of the illness behaviour of South Asian women in relation to thrush reported that they particularly disliked consulting male Asian GPs, either because they were family friends or because they perceived male Asian GPs (particularly older ones) treated them in a patronising way:

'But male Asian GPs, they've got this status problem. They think we don't have a voice, we shouldn't voice our opinions at all. If we voice our opinions at all... They are like demi-Gods and we have to accept it.'

Some women in this study said they preferred to consult white doctors, in part because of issues of confidentiality. Similarly, in Chew-Graham *et al.*'s (2002) qualitative study of psychological distress and self-harm in South Asian women, the perception that breaches of confidence might occur in using 'Asian' services acted as a powerful deterrent to help-seeking.

'You can't just turn up at the doctor's. They know you and the family.'

There are indeed very few studies of the outcomes of matching ethnicity of service to ethnicity of user. Bhugra (2002) cites a study by

Sterling *et al.* (2001) of ethnic matching of African American cocaine dependent cases with therapists, and found that matching of race did not make any difference to the number of early drop outs or influence the number of those who completed treatment. However, Bhugra points out that this study included no evaluation of beliefs about illness or any contribution of the individual's perceptions of the therapist's ethnicity.

Educational interventions and reminder systems

We discussed in the general meta-ethnography the use of educational interventions including leaflets and reminder systems for improving access to health care. There are two distinct concerns in relation to such interventions in relation to people of minority ethnicity. First, there is concern that educational interventions tend to be based on a 'deficit' model that locates reasons for poor access in the 'ignorance' of minority groups rather than in issues of quality and cultural competence of services (Chiu *et al.*, 1999). Second, there is a concern that some minority groups are much less well provided for in terms of leaflets and other information resources (Mackintosh *et al.*, 1999).

The argument that educational interventions tend to be based on 'deficit' models was also proposed in our general synthesis as applying to educational interventions more generally. Chiu *et al.* (1999) cites two examples in which the deficit model forms the basis for educational interventions to increase uptake of screening in ethnic minority women. Some studies have tried to use more participatory approaches to avoid these kinds of criticisms, but with inconclusive results. Hoare *et al.* (1994) found that home visiting of Bangladeshi and Pakistani women by culturally matched linkworkers did not increase uptake of breast screening. Naish *et al.* (1994) used focus groups to explore factors that deter non-English speaking women from attending for cervical screening. This consultation identified that women were very positive about screening once they understood the purpose and procedures, but that there were problems with call and recall letters, letters being issued in English, inappropriate translation (for example 'smear' translated as 'fat' in one language) and concerns about standards of hygiene in general practice surgeries. Chinese, Bengali and Punjabi groups would prefer a woman doctor and to be accompanied by a familiar health advocate.

The impact of such interventions is likely to be very variable across minority communities, and to be strongly influenced by resources such as language competence and literacy. Hawthorne (1990) reports a study of diabetic clinics in Nottingham that showed that 45 per cent of the predominantly Mirpuri Muslim patients could not read appointments sent to them by post. In Chew-Graham *et al.*'s (2002) study, South Asian women suggested that leaflets in their own language would be most helpful. Gatrad (2000) reported an audit suggesting that a range of interventions, including better

communication, appointment bookings systems that avoided periods of religious observance, improved tracking of addresses, and education of staff and people about appointments, improved attendance at paediatric outpatients clinics.

A strong recent theme in some work has been an emphasis on using community resources to disseminate knowledge about services. In Mclean *et al.*'s (2003) study, there was a view among members of the African Caribbean community that informal support networks including church groups and African Caribbean radio stations could be used to disseminate information relating to mental health provision and provide informal referral services. Interviewees in this study emphasised the importance of recognising locally specific and African Caribbean specific community strengths as a means of improving mental health service outreach. Participants in Chew-Graham's (2002) study similarly identified the potential for using Asian Sound radio to disseminate information about mental health.

Summary: Tractability: Policy, service developments and interventions to improve access for people of minority ethnicity

Efforts to address the distinctive needs of minority users in accessing health care have included improved health needs assessment that attempts to be sensitive to all aspects of ethnicity. There has been particular interest in participatory forms of needs assessment, where communities help to define their own needs, but generally evaluation of this form of action research has been poorly evaluated.

Altering mainstream services to make them more sensitive to the needs of diverse communities has been perhaps the key strategy in improving access to health care by people of minority ethnicity. Improving cultural sensitivity has taken the form of training of staff, though early efforts at anti-racism training were criticised for their tendency to perpetuate rather than challenge cultural stereotypes. The evidence about whether training of staff improves the experiences of minority users seems to be largely lacking, and there are potential unwanted consequences of these kinds of efforts at cultural sensitivity. Forms of cultural brokerage, in which attempts are made to mediate via brokers between minority communities and health services, have included the provision of language services. However, language and interpreting services are prone to a range of problems, and may help to reproduce an asymmetrical power relationship between users and providers of services. Cultural brokerage has also taken the form of linkworkers and advocates, but these have been poorly evaluated.

A debate about special services has focused on whether distinct, separate services should be provided for people of minority ethnicity. Such services are argued on the one hand to be maximally culturally sensitive, but on the other to promote exclusion and segregation. There are some hints in the literature that 'ethnic matching' would need careful evaluation, because of possible unwanted consequences.

Finally, a debate about educational interventions and reminder systems has focused on the one hand on the lack of provision for people of minority ethnicity, and on the other on the tendency for such interventions to be based on deficit models. Increasingly, there is interest in using community resources, including radio, to disseminate information.

4.3 Conclusions

There are multiple complexities in obtaining reliable measures of need and provision that can allow insights into inequities in access. The evidence with regard to minority ethnic groups is especially complex because of problems in the classification of minority groups and because of the confounding of issues of ethnicity with issues of more general socio-economic disadvantage. Most minority communities are at risk of poverty, with some, particularly the Bangladeshi and Pakistani populations, at more at risk than others. There is often a failure in the literature to distinguish between issues that affect all socio-economically disadvantaged groups in society and those that are specific to particular groups. For example, it is probable that the issues that affect utilisation of health care by highly successful professional people who are second or third generation migrants from the Indian subcontinent may be very different from the issues that affect recent migrants from war-torn regions of Africa. As noted by Goddard and Smith (1998) and Carter *et al.* (2001), many studies have not controlled for social-economic variables, and it is possible that 'ethnicity' variables are therefore capturing the effects of socio-economic differences. It has therefore again proved surprisingly difficult to show conclusively, inequities in access by ethnicity. However, our analysis does confirm that people of minority ethnicity are at risk of poor access, and has identified their vulnerabilities through the synthesising construct of candidacy.

We argue that, as with the literature on socio-economic disadvantage, aspects and stages of candidacy have been poorly differentiated in the literature, and evidence of variable levels of utilisation have been widely interpreted as variations in 'access'. However, as we suggested in our analysis of these issues in relation to socio-economic disadvantage, reports of different rates of utilisation are in fact reports of different rates of receipt. Receipt clearly reflects aspects and stages of candidacy including negotiation, presentation, adjudication and acceptance or rejection, jointly, dynamically and iteratively accomplished by people and health services. 'Grabs' of control by health services – such as those that occur in relation to compulsory admissions for mental health – provide an important example of where people cease to have any control over their own candidacy. Many of these different aspects and stages of candidacy have been poorly studied in the empirical literature.

Our analysis shows that people of minority ethnicity, particularly those who do not speak English well, are at risk in their attempts to use services because of the nature of the resources required to gain a point of entry and make presentations to services. There is evidence of cultural dissonance in the organisation and delivery of health services, and people of minority ethnicity may feel alienated, uncomfortable, or otherwise lacking in the characteristics of the ideal user of services. There may be a tendency to default to services that are most porous and comfortable, likely to be primary care services. They may find it difficult to match their wants from services with the intended uses of services. Relying on informal interpreters is problematic, but formal interpreters also are not a complete solution. Though widespread concern has been expressed about cultural stereotyping and racism in health services, good, recent empirical evidence is difficult to identify, though it is clear that the typifications that health service staff use have the potential to disadvantage people of minority ethnicity as they do for other users of services.

Two primary models of attempting to improve the accessibility of services to people of minority ethnicity have been proposed: one which attempts to make mainstream services more acceptable and fitting for minority groups, and the other which provides specialist services to address particular defined minority groups. As for the provision of specialist services for the homeless described in the previous section, there are contentious debates over the merits and disadvantages of these models and a need to evaluate the possibly unwanted effects of specific models, including that of 'ethnic matching'. Although there has been considerable interest in using community participation models to identify needs and design services, it is only recently that good quality research is beginning to appear. Caution is required in providing educational interventions for people of minority ethnicity, because of the potential for invoking a deficit model of understanding, but it is equally clear that good access to knowledge and information is required to facilitate recognition of candidacy and negotiation of services.

Section 5 Childhood and access to health care

5.1 Introduction

Although the definition of a child is legally straightforward (the Children Act defines a child as someone aged under 18 years), children and young people form an extremely diverse group. Recent work in the sociology of childhood has attempted to 'denaturalise' childhood, pointing to the socially constructed nature of childhood, the historically recent emergence of adolescence as a social and biological category, and the ways in which the definition of childhood has varied across cultures and over time. In this section, in keeping with the National Service Framework for Children (Department of Health, 2003) we will use the term 'child' to refer to babies and children, and 'young person' to cover older children and young adults. However, 'child' will also be used as a shorthand to refer to all under 18s. We use the term 'parents' and 'families' to include mothers, fathers, carers, and other adults with responsibility for caring for a child or young person.

Again, as in the previous sections, our review of this area was conducted in a context of rapidly changing policy and social change, making it difficult to interpret the continuing relevance and validity of some of the published literature. The Bristol (2001) (http://www.bristol-inquiry.org.uk/final_report/), Alder Hey (2001) (<http://www.rlcinqury.org.uk/>) and Victoria Climbié Inquiries (2003) (<http://www.victoria-climbié-inquiry.org.uk/finreport/finreport.htm>), and the emerging National Service Framework for Children, make this a period of very intense focus on the distinctive needs and concerns of children in health care and beyond. The National Service Framework (Department of Health, 2003) argues that distinct and tailored services are needed for children because of their different physiology, the range of disease and disorders (including rare and often complex congenital and inherited disorders), their mental capacity and level of understanding, their legal status, their greater vulnerability, and the status of the parents or guardians caring for them. However, as the Bristol Inquiry found, there was evidence that services treated children as if they were mini-adults, requiring only smaller beds and smaller portions of food.

It is also important to acknowledge the extreme diversity of health care use among children and young people, ranging from neo-natal intensive care for very ill newborns, to contraception for young people, and from children with long-term life-threatening illness, to children with acute minor illness. The role of parents as gatekeepers, advocates and facilitators for, as well as barriers to children and young people accessing healthcare will vary across different situations and different ages. Although we recognise that parents have distinctive needs of their own which health services should seek to address, we

have not addressed these as part of this review (Young *et al.*, 2003; Sloper, 1999).

The literature we sampled was striking in the absence of research with children, rather than 'on' children or their parents. It is only recently that a literature that has attempted to access the voices of the children themselves has emerged, but this has primarily looked at children's experiences of health care without a specific focus on access (Young *et al.*, 2003; Dixon-Woods *et al.*, 2002; Sartain *et al.*, 2000). A recent report to the Commission for Health Improvement described an attempt to scope investigations of gaining feedback from children on health services (Boylan, 2004). It identified 59 reports of feedback, mostly very recently published as grey literature, and mostly with only a limited focus on issues of access.

5.2 Lines-of-Argument synthesis

Our lines-of-argument synthesis of the evidence on access to health care by people of minority ethnicity is organised around a set of central concepts, and in particular the core synthetic category of 'candidacy'. A table of included studies can be found at Appendix 5A.

CANDIDACY describes the ways in which children's eligibility for medical attention and intervention is jointly negotiated between families and health services. Candidacy is a dynamic and contingent process, constantly being defined and redefined through interactions between parents, children and professionals, and managed in the context of operating conditions, including the availability of resources, local pressures, and policy imperatives.

Key points in candidacy related to childhood generated by our analysis:

- Identification of candidacy involves parents and young people in determining that there is a need for medical intervention or attention. This may occur spontaneously, or in response issued by health services (for example an invitation for immunisation). Importantly, for children, identification of candidacy is strongly mediated by parents' social roles as the guardians of their child's well-being, and, for some adolescents, by a search for independence which may seek to deny this role.
- Navigation refers to routes individuals take from identifying their candidacy to gaining a point of entry to health services.

Children and young people can penetrate, or gain a point of entry, to health services in a number of ways. We will suggest that services can be conceptualised as being surrounded by membranes that are more or less porous. More porous membranes allow children and young people to pass through easily; services that are less permeable require much more work in order to gain a point of entry and sustain engagement with the service.

- Once children have **presented** to health services, they have asserted their candidacy as deserving of medical attention and / or intervention. They may vary in their recognition and aspirations as to the nature of that candidacy. **Presentations** involve people, particularly parents, in doing work, which again requires particular sets of competencies, skills and resources which may be variably distributed in the population.
- **Adjudication** refers to professional judgements about the candidacy of an individual for intervention or service. Such adjudications will determine the subsequent progression of the individual through health services, but will often be **conditional** on the operating conditions of services.
- **Offers and uptake** – refers to the offer and acceptance of intervention or service.

Our synthesis is organised around the following themes generated by our analysis of the evidence:

- 5.2.1 5.2.1 Theme 1: Construction of the problem of access to health care by children.
- 5.2.2 5.2.2 Theme 2: Recognition and response to health needs, identification of candidacy in childhood.
- 5.2.3 5.2.3 Theme 3: Navigation.
- 5.2.4 5.2.4 Theme 4: Organisational issues in navigation.
- 5.2.5 5.2.5 Theme 5: Presentations, adjudications and offers.

5.2.1 Theme 1: Construction of the problem of access to health care by children

In the groups we have looked at so far in this review – people who are socio-economically disadvantaged and people of minority ethnicity – the ‘problem’ of access has been assessed primarily by examining the extent to which utilisation of services compares with apparently privileged ‘standard’ reference groups, such as middle-class white people. For children, there is no obvious standard comparison group. The problem of access by children has been largely rendered through a focus on supply, and particularly a supply of services that are especially designed for children. The issues of ‘need’ are therefore much more prominent in this literature.

‘Need’ has often focused on the need for separate, specialised provision of services for children, and, more recently, for adolescents. We analysed papers that addressed issues of availability, sometimes in terms of closely related issues such as flexibility in the way services are offered and the appropriateness of particular forms of care. Our synthesis is organised around the following themes generated by our analysis of the evidence:

- Primary Care.
- Specialist Care.
- Use of A&E, out-of-hours services and emergency admissions.
- Preventive services.
- Young people.

Primary Care

The evidence on the availability of GPs has been summarised earlier in this report. A recent theme in the discussion of primary care services has been the re-emergence of an argument in favour of specialist GP paediatricians, but this has yet to achieve widespread uptake (Peile, 2004). While generally registration of children with a GP is very high, some groups, such as refugees and asylum seekers, may have more difficulties. A study by Anderson *et al.* (1997) reported that over half of the travellers studied did not have a GP they could name and many were registered with GPs significant distances from where they were currently living. Similarly, Feder *et al.* (1993) found that only 17 per cent (four out of 24) of traveller gypsy children could name their GP compared to 90 per cent (35 out of 39) among a group of control children.

Studies have consistently found high rates of GP consultation among younger children. Rogers *et al.* (1999b) report that the highest consultation rates are found among children aged up to four years (and among people aged over 75 years). Saxena *et al.* (2002) found that the proportion of children and young adults aged up to 20 years consulting their General Practitioner in the preceding fortnight was 8.7 per cent (equivalent to 2.3 consultations per person, per year). After adjusting for age, social class, and chronic health status, Indian and Pakistani children were more likely to have seen their general practitioner in the preceding fortnight (though less likely to have attended outpatient departments in the preceding three months). Self-reported health status, rather than socio-economic status or ethnicity, was the best predictor of use of primary and secondary care services: children who had long standing illnesses were more likely to have seen their general practitioner, and more than twice as likely to have attended hospital as an outpatient or inpatient in the preceding year. Goddard and Smith's (1998) review noted that most studies have found that children living with single mothers are more likely to consult GPs, though one study (Carr-Hill *et al.*, 1986) reported having a sole parent was found to be significant for girls only, the direction being towards less frequent attendance at the surgery.

Specialist Care

The debate in specialist care has, in the last 20 years, focused on the need for a distinct paediatric service, including children within adult

services, is increasingly seen as unacceptable. Whether there is sufficient capacity in specialised services to match children and young people's 'needs', and whether they are appropriately configured, particularly geographically, is not easy to determine, in part because of the methodological and theoretical issues discussed in the preceding sections. Variations in the availability of specialist care for children are frequently asserted in policy documents and statements by child health organisations. Most of the evidence centres on a small selection of clinical specialities, much of it from a series of reports during the 1990s by the, now disbanded, Clinical Standards Advisory Group (CSAG). The reports from the CSAG did point to substantial variations in the availability and quality of specialist care for children in the selection of conditions on which they conducted reviews, though it is difficult to assess the currency of the data, and difficult to interpret the extent to which findings in these specific areas can be generalised to other areas of child health. For example, a 1994 CSAG report on provision of services for cleft lip and palate identified serious problems of fragmented services with low volume operators, but was followed by the drawing up of national guidelines and co-ordinated improvements in services (Williams *et al.*, 1995).

For epilepsy, the CSAG (1999b) reported that there were too few neurological staff to meet the demand on hospital services. Most children were seen in general paediatric clinics, but most of these lacked staff with specialist interests and qualifications in epilepsy, and there was general agreement that clinics specialising in epilepsy could provide better care. Access to and facilities for children in paediatric clinics were considered to be better than adult neurology clinics. This report also identified the limitations of a 'hub and spoke' model of neurology services, arguing that the centripetal momentum inhibits the development of local services that are more geographically accessible.

A report on cystic fibrosis revisiting the early 1990s CSAG investigation (www.cfstudy.com/sara/csag2.pdf) identified continuing regional variations in access to specialist clinics [CSAG investigation (www.cfstudy.com/sara/csag2.pdf)]. Access for children remained good in three areas, and improved in three other areas, but in the South Western region it was poor and had shown no improvement. Access to specialist care remained lower for adults than for children, and was very low in some regions. Most cystic fibrosis units had experienced increases in staffing, but this was insufficient to cope with increasing workload, resulting in a real deterioration in staffing levels.

The Clinical Standards Advisory Group on Outpatients (1999a) reported a steady increase over time in the number of hospital consultants in paediatrics, from 630 in 1987 to 1,190 in 1997. This represented an average annual change in the number of consultants of over eight per cent: higher than for any of the adult specialities. Over the period 1992 - 97, there was an average annual increase in

outpatient attendances of two per cent. Dodd and Newton (2001) similarly report increases in paediatric outpatient activity from 232,000 to 355,000 new attendances and from 941,000 to 1,030,000 subsequent attendances during the period 1992 - 98. Referral rates were reported to be higher to surgical specialities than to paediatric medicine (86.5 per 1000 versus 61.3 per 1,000). However, concern has persistently been expressed about long waiting times for some paediatric appointments. Stern and Brown (1994) reported under-capacity and lengthy waiting lists for a child and family clinic.

More recently, Jefferson *et al.* (2003) reported that no national register of children with diabetes existed and there was no list of paediatricians with special responsibility for children with diabetes. The findings of their survey were focused on aspects of provision, including quality of provision. They found improvement in a number of aspects of paediatric diabetes care: fewer consultants look after an appropriately small number of children, and substantially more run designated diabetes clinics. The provision of paediatric diabetes specialist nurses and paediatric dieticians had increased since the previous survey. However, 26 per cent of consultants had clinic populations of fewer than 40 children, and where there was not a paediatrician with a specialist interest in diabetes, 26 per cent did not measure glycosolated haemoglobin (the only evidence-based measurement related to long term microvascular complications). Routine annual complication screening has also not been universally adopted. Many of the diabetes nurses had to cover other sub-specialties, or were part of adult diabetes services, and almost half had not been trained as children's nurses. Finally, 35 per cent of clinics did not have a paediatric dietician and 78 per cent did not have access to psychological counselling services.

The availability of specialists was identified as important by parents in many of the studies that we analysed. Gibb *et al.*, (1997) in their study of the role of family clinics in the provision of care to children infected with HIV, found that the acceptability of the service for parents was couched in terms of the availability of paediatric nurses, paediatricians specialising in infectious diseases, and so on. Similarly, Haylock *et al.* (1993), in their study of community care for children with motor disabilities, found that parents would have liked more access to physiotherapy, speech therapy and occupational therapy services. The importance of access to specialists is also acknowledged by health professionals themselves; Bryce and Gordon (2000) surveyed GPs in Scotland and found that although 57.5 per cent of GPs said that they felt that child and adolescent mental health service (CAMHS) were in accessible locations (referring to geography), only 31.3 per cent of GPs felt that they were actually easy to access because of other problems. 81.8 per cent said that waiting times influenced their decision-making. The importance of this combination of the availability of specialists in an accessible location was also reported by Robinshaw and Evans (2001), who found that parents felt

that the quality of service provision available to them and their children improved when professionals from different disciplines and agencies worked from the same location. This may be particularly important for children and young people with complex and chronic conditions, where effective management depends on the involvement of a number of specialists.

The special issues in providing services for rare or complex conditions in childhood raise the familiar tensions between centralisation / quality of services and local accessibility (Arul and Spicer, 1998). The benefits of centralisation include concentration of expertise, more appropriate consultant on-call commitment, development of support services, and junior doctor training. The disadvantages include children and their families having to travel long distances for care, and loss of expertise at local level.

Whatever the shortcomings in capacity in various areas, there appears to be little doubt that children are heavy users of hospitals for paediatric and surgical inpatient care, with up to half of infants aged under 12 months and one quarter of older children attending an A&E department in any given year, one in 11 children referred to hospital outpatients clinic, and one in ten to 15 admitted to hospital (Department of Health, 2003). However, the inclusion of healthy newborns staying in hospital after birth distorts the official figures to some extent, and there are variations between health authorities (MacFaul and Wernecke, 2001). More than twice as many children are now admitted to hospital compared with 30 years ago, but they stay one quarter as long as they used to (Royal College of Paediatrics and Child Health, 2002). MacFaul and Wernecke (2001) report that the majority (85 per cent) of admissions to hospital involve an average length of stay of 2.6 days, equating to about four to five per cent of children age 0 - 14 years being admitted for care by a paediatrician in any given year. The majority of children stay only one night in hospital (Department of Health, 2003). MacFaul and Wernecke (2001) report that over half of all admissions for children are for surgery and, of these, half are emergencies. There is some evidence of social class effects: MacFaul and Wernecke (2001) and Hull *et al.* (2000) summarise evidence suggesting that 7.2 per cent of the most deprived children were admitted to hospital each year compared with 5.5 per cent of the most advantaged, and admission rates for children aged up to four years ranged from 33.4 per 1000 for the most affluent to 67 per 1000 for the most deprived, with similar patterns affecting respiratory admissions. Other factors influencing hospital utilisation by children include proximity to hospital, degree of urbanisation, and different clinical practices resulting in different pathways to hospital. Saxena *et al.* (2002), however, found that associations between social class and use of health services were non-significant and also found that girls were less likely to have attended outpatient clinics than boys (odds ratio 0.78; CI 0.66 to 0.93).

Use of A&E, out-of-hours services and emergency admissions

There is good evidence that paediatric attendances at A&E, and paediatric emergency admissions to hospital, are rising (Armon *et al.*, 2001; MacFaul and Wernecke, 2001; Stewart *et al.*, 1998). Stewart *et al.* (1998) conducted a questionnaire-based study of 887 consecutive emergency general paediatric admissions to five Yorkshire hospitals during two separate three week periods in summer and winter. Most children admitted to hospital during the study were very young; most were less than two years of age. Over half (53 per cent) were admitted in the evening and at night, and most (61 per cent) stayed one night or less. Most had minor illness, but serious illness was found in 13 per cent and could not be predicted from the presenting problem. Self-referral to A&E departments was common, and resulted in admission in one third of cases. These admissions were more often seen in children over 12 months of age for illnesses of short duration and for fits. Stewart *et al.* (1998) suggest that one possible explanation for the rise in emergency paediatric admissions is the gradual change in the function of hospitals from places solely of diagnosis and treatment to places where observation and monitoring may be provided. In their study, young children made up half the admissions and were often admitted for observation only. Stewart *et al.* (1998) also note that the spectrum of illness, age distribution, and the time of presentation were similar in children with different deprivation scores, but children with a high deprivation score were more likely to use A&E departments as a source of health care. As we suggested in our analysis of the effects of disadvantage on access to health care, this may reflect a tendency to manage health as a series of crises and to default to the most porous service among more socio-economically deprived people.

Three studies in our sample appear to provide further evidence for this effect for children (Shipman *et al.*, 1997; Bowling *et al.*, 1987; Hull *et al.*, 2000). Shipman *et al.* (1997) studied the relationship between the use of out-of hours GP services and accident and emergency services and found that people using the latter had tried to access GP services, but had found them either unavailable or inappropriate in some way (such as the unavailability of diagnostic equipment and the delay involved). Similarly, Bowling and colleagues (1987) listed a number of reasons cited for using A&E services, including the GP surgery being closed and the appointment system in primary care involving unacceptable delay. Conversely, Hull and colleagues (2000), in their study of the impact of practice-based preventive child health services on hospital use, found inverse associations between the amount of health visiting support available to practices, and patterns of emergency admissions and outpatients referrals.

Preventive services

Peile (2004) suggests that there are significantly higher consultation rates in children from socially disadvantaged families for minor to serious illnesses, but these families also have lower rates of child health and preventive consultations (Saxena *et al.*, 2002). Preventive services for children include immunisation and screening programmes. Goddard and Smith (1998) summarised evidence suggesting lower rates of immunisation in areas of high levels of socio-economic deprivation. Children living with a lone parent were less likely to be vaccinated; high mobility, and families of larger size were also associated with non-uptake of immunisation. Reading *et al.* (1993) found that the percentage of children not screened at six weeks was significantly higher among the most deprived decile (6.8 per cent) compared with the most affluent (five per cent) and at 18 months, 21 per cent of the most deprived had not been screened compared with 13.6 per cent of the most affluent (Reading *et al.*, 1993). Research from the early 1990s seemed to suggest lower uptake of immunisation among more deprived groups (Reading *et al.*, 1993), but some have speculated that the MMR vaccine may have depressed middle class uptake of immunisation. Nonetheless, Middleton and Baker (2003) found that mean coverage levels were two percentage points higher in the affluent areas compared with the deprived areas.

As we mentioned in previous sections, there is some evidence that uptake of preventive services for children varies by ethnicity and deprivation. Streetly *et al.* (1994) found that coverage of the neonatal (Guthrie) screening programme was incomplete in children of African ethnic groups. These infants were more than twice as likely as the African Caribbean infants not to have a result.

Young people

Young people (broadly defined as those aged 12-18) form a distinctive group in terms of health service use. Patterns of use of GP services appear to change over the course of childhood and adolescence, and to differ between sexes. Over half of young people attend GPs on their own by the age of 15, and this appears to coincide with a drop in use of services. Sweeting's (1995) analysis suggests that the average number of consultations per person per year falls from seven in the up to four years age group to three per year in the five - 15 age group. The ratio of male to female GP consultation was somewhat greater for males in the up to four years age group, but this was reversed in the five - 15 age group. Among 16-44 year olds, the proportion of females consulting their GPs was double that of males. Some evidence points to poorer health-maintaining behaviours among young people, signalled by lower levels of attendance at review appointments for long-term illnesses. McCarlie *et al.* (2002), using data from a diabetes register, identify young people as a group at high risk of missing fundoscopy and glycosolated haemoglobin measurements. Stephen *et*

al. (2003) similarly show that adolescents with epilepsy are at risk of non-attendance at specialist clinics and non-adherence with treatment regimens, leading to poorer clinical outcomes.

Sweeting (1995) proposes that one explanation of the apparently lower use of health care by male adolescents lies in the onset of 'independent' use of services. She suggests that the male excess in medical consultations in early childhood may be a reflection of bias – parents may be more likely to take male children to see the doctor, though we did not find any direct evidence of this, and it may well be the case that males have an excess of injuries that would explain their higher attendance.

Much of the evidence about young people and access to health care has focused on access to reproductive health services, where there is a large literature, much of it summarised by Jolley (2001), and Walker and Townsend (1999). This points to inadequacies in contraceptive and sexually transmitted infections services for young people. More generally, as Walker and Townsend (1999) summarise, there has been a tendency in the literature to pathologise aspects of adolescent behaviour, including smoking, diet, sexual behaviour, and exercise, and to see health services as having a correctional role. This may account for findings of much higher levels of dissatisfaction with primary care services among young people (Jacobson *et al.*, 1998).

For young people diagnosed with serious illness there has been persistent concern about the quality and suitability of hospital services, which tend to be oriented around the needs either of adults or of young children. Tilstone (2004) reports a conference which suggested that there is late diagnosis of young people with cancer, lack of a clear referral route for young people diagnosed with cancer, and arbitrary allocation to paediatric or adult protocols.

Summary: Construction of the problem of access to health care by children

Children show a pattern of high use of services, particularly in primary care, though this varies along the course of childhood, with much lower rates of consultation during adolescence, and there is some evidence of variation with deprivation. There is very high use of 'crisis' based services, including use of out-of-hours services, accident and emergency departments, and emergency admissions to hospital. The debate has centred on whether current utilisation, though high, is not high enough to reflect 'need' (though the issue of how to define and measure need has been little addressed in this literature).

There has been long-standing concern about sufficiency of capacity of paediatric services, but the evidence on this is difficult to interpret in a period of rapid policy change and investment in the NHS. The evidence on uptake of preventive services is also difficult to interpret, though provision would appear to be equal across districts. Young people appear to make much less use of health services as they enter and progress through adolescence, and this may mark a period of vulnerability.

5.2.2 Theme 2: Recognition and response to health needs, identification of candidacy in childhood

Identification of candidacy in childhood arises spontaneously when parents or children identify a health need as potentially qualifying for medical attention or intervention, or in response to invitations which impose qualifications for candidacy (screening and immunisation), which parents or their children may choose to accept or reject. We have organised our synthesis of the evidence on identification of candidacy around the following themes generated by our analysis of the evidence:

- Readiness to consult: Uncertainty and moral agency.
- Identity.

Readiness to consult: Uncertainty and moral agency

Our analysis points to the particular roles parents take on, both in their moral responsibilities towards their children and in their exercise of agency on the behalf of their children. A large proportion (n=27) of the papers we analysed dealt in some way with the role of parents as advocates (Gibb *et al.*, 1997; Hopton *et al.*, 1996; Jacobson *et al.*, 2001; Klasen and Goodman, 2000; Morrison *et al.*, 1991; Robinshaw and Evans, 2001; Sayal *et al.*, 2002; Shipman *et al.*, 1997; Shipman *et al.*, 2001; Thomas, 2000; Webb *et al.*, 2001; Whitehead and Gosling, 2003; Burack, 2000; Carter *et al.*, 2002; Carter and Bannon, 1997; Cunningham-Burley and Maclean, 1987; Li and Taylor, 1993; Dixon-Woods *et al.*, 2001; Donovan *et al.*, 1997; Anderson *et al.*, 1997; Edwards and Pill, 1996; Feder *et al.*, 1993; Kai, 1996b; Kai, 1996a; Cornford *et al.*, 1993; Drummond *et al.*, 2000; Anie *et al.*, 2002).

Parents clearly distinguish between the ways in which they judge candidacy for themselves and the ways in which they judge candidacy for their children. Children are seen as being much more legitimate candidates, and moreover are seen to being much more vulnerable to being suddenly overwhelmed by serious health threats such as meningitis. In Rogers *et al.*'s (1999a) qualitative study, mothers gave accounts of using services in which their own needs were relegated in importance compared with those of their children. Our analysis

suggests that it is important that candidacy for children be understood as *family* candidacy, and that some elements of what prompts recognition of candidacy will be related to parents' needs or their perceptions of the needs of the family. Rawlinson and Williams (2000) argue that parents' recognition of their children's psychological problems, and the decision to seek help, is not wholly dependent on the needs of the child, but is also substantially influenced by the needs of the parent. Hopton *et al.* (1996) found that help-seeking on behalf of a child was sometimes motivated by a desire not to allow a child to pass on their illness to other children, again demonstrating the family-based nature of help-seeking.

Our analysis indicates that the work of parenting involves key responsibilities for safeguarding children's health. We distinguished several types of behaviour. Many studies that we analysed found that parents were highly sensitised to this responsibility and were often nervous about its execution. Sometimes parents are seeking a *professional opinion* to confirm that a particular set of symptoms is not serious, and allowing the parent to discharge her / his role as a proper guardian of the child's health. Parents were often involved in dilemmas in distinguishing between symptoms which might well be those of minor illness, but might also be those of a serious pathology. Kai (1996a) found that parents felt confident in their ability to decide that something was wrong with their child but less so in determining what the problem was and whether it was serious. Hopton *et al.* (1996) found that a previous 'fright' with child illness had left some parents lacking in confidence and unable to cope with determining and managing serious and minor illnesses. Similarly, Houston and Pickering (2000) found that some previous experiences, such as the death of a child or serious illness in a child, disempowered them subsequently in the management of minor illnesses.

We analysed papers that discussed issues of confidence and anxiety in diagnosing and managing illness in children and young people. These papers suggested that uncertainty and anxiety about the import and significance of symptoms in children is a key factor in the construction of childhood candidacy, and is strongly linked with the responsibilities that parents feel they must exercise on behalf of their children. In papers by Houston and Pickering (2000) and by Kai (1996a, 1996b), parents located their confidence in dealing with childhood illness within the context of their sense of responsibility as parents. Parents' readiness to consult is a function of the perceived severity of symptoms or illness, of the skills they feel they possess, of their awareness of their responsibilities as advocates for a dependent and vulnerable individual, their consideration of the effects of a health problem on the family as a whole, and, as discussed later, their need to protect their identity as good and responsible parents.

There is some fragmentary evidence of social class or ethnic variations in stage of presentation with some childhood health problems. Smith

et al. (1994) identified a difference of 22 months in the average age at presentation between children with anisometropic amblyopia in the most deprived and least deprived areas of the study. Shah (1997) suggests that impairments in Asian children are under-reported and sometimes undetected by parents, resulting in delays in interventions. There is also some evidence, reported by Shah, that parents with language difficulties may miss out on early intervention support. There is also some evidence that families in more deprived circumstances may recognise candidacy as arising from a financial need: that of receiving a free prescription rather than paying for medicine. Rogers *et al.* (1999) describe parents making visits to their GP specifically in order to obtain prescriptions for their children, although they were aware that they could have treated the symptoms without a medical consultation.

There was more limited evidence in the papers studied about the role of parents in seeking in some way to limit or restrict access to health care. Sayal (2002) and colleagues make reference to the importance of parents as gatekeepers in their study of pathways to care for children with hyperactivity disorder. This might reflect, as discussed earlier, that parental willingness to seek health care might be compromised in those areas where the quality of their parenting, or family functioning more generally, might be called into question. Evans *et al.* (2001) show how parents' beliefs about the dangers of immunisation lead them to restrict access to MMR vaccination. It is very clear in the accounts given in this study that parents understand the medical definition of candidacy, but contrast this with their own role as moral agents on behalf of their children, which requires at times a willingness to defy or challenge such definitions.

'You have this doubt in your mind, however small I may feel it may be...autism... Crohn's disease... why put parents through the anxiety of thinking "well did I do it by giving them the immunisation or would it have occurred naturally?"' (Non-immuniser quoted in Evans et al., 2001)

For young people, distinctive issues relating to recognition of candidacy may arise. Burack (2000) touched on the inhibiting role that parents can play in relation to the provision of sexual health services to young people. Interestingly, 66 per cent of boys and 43 per cent of girls in that study wanted to see their GP on their own, and only 16 per cent of girls and 11 per cent of boys wanted their parent with them during a consultation with their GP. However, most GP consultations involving 13-15 year olds still take place with a parent present. Again, in relation to a more sensitive area of healthcare, parents can be seen to have a slightly ambivalent role as advocates, although more work is needed in this area.

Identity

Our analysis suggests that access to health for children and young people is powerfully mediated by issues of identity, including parents'

and young people's sense of self, the embarrassment that might be caused by encounters with health professionals, and the dilemmas that people face when seeking medical attention and intervention on behalf of their children (Hopton *et al.*, 1996; Houston and Pickering, 2000; Jacobson *et al.*, 2001; Kai, 1996b; Kai, 1996a; Klasen and Goodman, 2000; Robinshaw and Evans, 2001; Shipman *et al.*, 1997; Shipman *et al.*, 2001; Whitehead and Gosling, 2003; Carter *et al.*, 2002; Cornford *et al.*, 1993; Cunningham-Burley and Maclean, 1987; Gibb *et al.*, 1997; Bailey and Pain, 2001; Burack, 2000.) The identity that parents seem to wish to protect in the studies that we analysed is one of vigilance and responsibility in the face of the vulnerability of their children. For young people, different issues of identity arise, and they may need to protect their identities as being healthy and independent.

The importance of behaving in an appropriate manner, and especially in being seen to act in a responsible way, was important for parents in many studies. In the studies we analysed, parents need to protect their identities as responsible, reasonable carers, but also as responsible, reasonable users of services. This frequently manifested itself in dilemmas about whether or not to consult a doctor in relation to child illness. Parents reported anxiety about making the wrong decision as to when to call for professional advice and treatment. Houston and Pickering (2000) found that parents felt more entitled to use out-of-hours GP services when calling on behalf of a child. Similarly, the study by Shipman *et al.* (1997) found that parents of under-fives made the most marked use of health services. They speculate as to whether help-seeking for this group erred on the side of caution, given the moral responsibility felt by parents to seek help, even to allay minor concerns, just to be 'on the safe side'.

The sense of moral responsibility to seek help for a sick child is, as we have seen, very strong. However, parents were also concerned not to bother health professionals unnecessarily. This dilemma was reported in a number of papers. Dixon-Woods *et al.* (2001) reported that parents said they did not want to seem too anxious, overprotective or neurotic by consulting a doctor too early or too often about their child. Similarly, the paper by Kai *et al.* (1996a) found parents expressing similar dilemmas:

'If you bring them in early they say "leave it a few days and see"...if you wait they say "you should have brought them sooner"...you feel stupid,...you can't win.'

The balance between the obligation to seek help on behalf of children, and at the same time to avoid unnecessary consultations, is evident in the strategies parents use before initiating a medical consultation. In Cunningham-Burley *et al.*'s (1987) study, mothers reported that using over-the-counter remedies was a way of showing that they had made every effort to treat the child at home prior to seeking medical help. Rogers *et al.* (1999a) graphically describe how parents limit their own

use of services so as to allow their children to consult more frequently without damaging their identities as reasonable users. This study and others also demonstrate that parents are prepared to accept that they may need to accept some spoiling of their identities in order to promote the needs of their children. One mother in Rogers *et al.*'s study is quoted as saying:

'I don't generally go [to the doctor's] for myself, no. It's mainly my kids or J [husband]. I don't bother with myself. I really don't. I mither the doctor enough over the kids, never mind myself. I feel like I'm mithering enough with my kids and J, to not mither about myself.'

Identity work is also reported as affecting access in studies that suggest that parents may fear their identities will be spoiled by the judgements made by health services. Klasen and Goodman's (2000) study into the experiences of parents of hyperactive children found that professional responses influenced parents' willingness to share information. One mother, who had waited a long time to see a specialist, was thinking of turning down the appointment because she had received a questionnaire that focused on the family and feared that the family would be blamed for the child's behaviour.

As we noted earlier, consultations fall during adolescence. While some of this drop may be explained by lower levels of minor illness, it is also the case that other health needs may arise – for example in relation to reproductive health or dermatology. Our analysis suggests that important aspects of identity work may help to explain lower consultations. As young people move towards independence, they may grow reluctant to share or discuss information about health needs and avoid involving parents in judgements about candidacy. Dixon-Woods *et al.* (2001) describe how some adolescents did not disclose symptoms of cancer to their parents in the early stages. Churchill *et al.* (2000) found that young people frequently cited embarrassment as a barrier to obtaining a consultation in primary care. This was particularly the case for girls seeking advice about contraception or gynaecological issues. Similarly, Donovan *et al.* (1997) found that a third of the young people sampled identified embarrassment as a barrier to seeking advice about contraception; this made it the most common barrier identified. However, this study also found that embarrassment about discussing personal issues reduced the more consultations the young people had.

**Summary: Recognition and response to health needs:
Identification of candidacy**

For younger children, parents are engaged in forms of work in interpreting and judging the candidacy of their children. This work is itself a form of moral agency, in which the moral responsibilities of parents as the guardians of their children's well-being are very prominent, and in which candidacy may be judged in a family context rather than an individual context. Children have enhanced claims to

candidacy by virtue of their intensified vulnerability. Although parents of younger children feel generally that it is more acceptable to seek help for children than for adults, and that children are more indulged by health services as needing to have their candidacy assessed professionally, parents are frequently involved in dilemmas about whether to seek assistance or manage apparent health needs by themselves. They have to conduct identity work, where on the one hand they need to protect their identities as responsible and vigilant parents, and on the other hand avoid acquiring the identity of being neurotic, over-protective, and exploitative of health services. Young people may be a particularly vulnerable group. They may shun parental involvement in the judgements of candidacy and experience difficulties in negotiating their own identities in relation to health services.

5.2.3 Theme 3: Navigation

For parents and young people, as for others, the recognition of candidacy and the decision to act on it is then followed by navigation of a route to enter and progress through health services. Again, negotiation of services requires mobilisation of resources, and depends on particular forms of competencies. We organised our synthesis around the following themes generated by our analysis of the evidence:

- Information resources.
- Practical resources.
- Social and professional support and resources

Information resources

A particularly important issue in helping parents (as well as children and young people themselves) to resolve uncertainties in self-diagnosing and self-managing illness is the availability of information. Fourteen of the papers discussed these issues (Fiorentino *et al.*, 1998; Haylock *et al.*, 1993; Jacobson *et al.*, 2001; Kai, 1996b; Kai, 1996a; Klasen and Goodman, 2000; Pain, 1999; Robinshaw and Evans, 2001; Whitehead and Gosling, 2003; Burack, 2000; Carter *et al.*, 2002; Cunningham-Burley and Maclean, 1987; Anderson *et al.*, 1997). In several studies (Haylock *et al.*, 1993; Kai, 1996b; Robinshaw and Evans, 2001; Whitehead and Gosling, 2003; Davis, 1995), parents reported dissatisfaction with the information they had received about childhood illness, ranging from incomplete information about a diagnosis to a lack of information about sources of further support.

The evidence shows that parents would like information that is accurate, consistent and specific. Kai (1996a) found that parents felt that they were not well enough informed about what was wrong with their child. The label 'virus' was often too vague and ill-explained and reflected uncertainty on the part of the doctor involved. Similarly,

Klasen and Goodman (2000) found that both parents and GPs felt that information about hyperactivity was often ambiguous and / or conflicting.

Jacobson *et al.* (2001) surveyed the views of young people about primary care, and found a large degree of uncertainty regarding the availability of advice and information. Similarly, Burack (2000) found that there were important areas where young people's beliefs about primary care were inaccurate. For instance, 59 per cent of boys and 54 per cent of girls thought that contraception was only available post-16, with 34 per cent of boys and 27 per cent of girls thinking that one had to be over 16 to visit the doctor alone. However, the evidence available was overwhelmingly concerned with parental confidence, and more research may be needed which addresses these issues to children and young people themselves.

Practical resources

We analysed papers relating to the importance of practical resources in mediating access to healthcare for children and young people (Field and Briggs, 2001; Morrison *et al.*, 1991; Robinshaw and Evans, 2001; Shipman *et al.*, 1997; Shipman *et al.*, 2001; Tang and Cuninghame, 1994; Bailey and Pain, 2001; Tickle *et al.*, 2000; Carter and Bannon, 1997; Donovan *et al.*, 1997; Anderson *et al.*, 1997; Feder *et al.*, 1993).

Access to transport and arrangements for looking after other children are important mediators of ability to utilise health care. Field and Biggs (2001) found that both the mode and cost of travel to a primary care centre was a greater hindrance for those living within one to three miles than for those living over five miles away. Morrison *et al.* (1991) found that lone mothers were more likely to call out a doctor after hours, and that reasons for doing so included the absence of another adult who could provide advice and reassurance, and the difficulty of making alternative arrangements for other children in the family. The difficulty of arranging care for other children was also highlighted by Shipman *et al.* (2001). As Goddard and Smith (1998) summarise, low rates of completion of courses of vaccination among children with older siblings and those living with a lone parent may reflect barriers to attending clinics. Parents with large families may find it difficult to arrange attendance.

Social and professional support and resources

We analysed papers that addressed issues relating to social and professional support and resources that are important for the ways in which children and young people access health care (Fiorentino *et al.*, 1998; Gibb *et al.*, 1997; Haylock *et al.*, 1993; Houston and Pickering, 2000; Jacobson *et al.*, 2001; Kai, 1996b; Kai, 1996a; Morrison *et al.*, 1991; Pain, 1999; Robinshaw and Evans, 2001; Whitehead and

Gosling, 2003; Carter *et al.*, 2002; Li and Taylor, 1993; Anderson *et al.*, 1997).

Two sets of issues emerged from analysis of these papers. Firstly, contact with non-professionals is important for many parents dealing with child illness. This is true not only in the case of contact with other parents who have similar experiences, but also of contact with voluntary organisations who are able to offer advice and support. Pain (1999) found that both sources of support were important for parents of disabled children. Similarly, parents of deaf children found the support available through informal contact with other parents of deaf children very important (Robinshaw and Evans, 2001). In particular, they were able to shape and express their own queries, gain advice through informal discussion, and were helped in establishing 'normality':

'This is what the centre has given me, that focus on how to deal with a deaf child, and then the support network for the parents as well, which is just amazing. I actually realised that [...] was not abnormal and that I was not abnormal in not knowing how to deal with it.'

In addition, parents in the study by Robinshaw and Evans (2001) perceived that such informal support was also beneficial for their children because it gave them an opportunity to make friends and develop friendships with other children who were deaf.

Secondly, parents in the papers studied stressed the importance of receiving professional help and advice that was supportive. For some, it was important to share with others (professionals as well as family and friends) responsibility for managing child illness (Kai, 1996a). For others, it was important that professionals had an enabling role, supporting and underpinning parents in a trusting way rather than in a policing or bureaucratic fashion. For instance, in the study of the health needs of traveller families by Anderson *et al.* (1997), the availability of a *trusted* nurse who could visit the travellers, and talk about health issues with them, was of particular importance. Indeed, there was evidence that the uptake of six-week checks had improved following a period when the midwife had visited the site on a daily basis to provide ante-natal care. Parents saw an important role for health professionals in signposting them to broader sources of treatment and support. This was particularly the case for parents with disabled children. In the study by Robinshaw and Evans (2001) parents of deaf children who had made use of private or voluntary sector services expressed frustration at the lack of direction to these services. Parents in these cases perceived a lack of openness, and a 'state vs. independent sector' divide which did not take into account the possible benefits to their children.

Summary: Navigation

Use of health services by children and young people is strongly mediated by the resources, including information resources, practical

resources, and support resources, available to them and their parents. Resources need to be considered broadly in this context, taking account of the socio-economic circumstances in which families live, the personal resources (such as self-confidence) that parents, and children and young people, possess, as well as the way in which health professionals, family and friends, act as resources enabling easier access to health care.

5.2.4 Theme 4: Organisational issues in navigation

There was clear evidence of organisational issues in people's navigation of services for children and young people. We generated the following themes around which our synthesis is organised:

- Permeability.
- Turbulent organisational contexts.
- Perceptions of quality.

Permeability

As discussed in other sections, the assertion of candidacy can be strongly influenced by the permeability, or perceived porosity, of service provision. For instance, evidence suggests that relatively 'porous' services, which do not require appointments or require qualifications of candidacy (NHS Walk-in centres, A&E and so on), may be easier to use than services which impose strict conditions of candidacy and require more personal and practical resources, such as outpatients departments. Such services, which specify a formal time and place, may be more difficult to access for those without cars, with inflexible employment conditions, with sole responsibility for other family members and so on.

Our analysis suggests that more porous forms of service provision are especially suitable for children living in what might broadly be described as socially excluded circumstances. Features that reduce the permeability of primary care services include the need to be registered, the need to make and keep appointments, the gatekeeping role of practice staff, and so on. The practicalities of remaining registered with a GP, of making sure records are transferred, and so on, are likely to present particular difficulties for parents living in such circumstances. Similar considerations emerge from studies of the health needs of traveller communities. However, caution against oversimplifying this evidence is required, for a number of reasons. Firstly, different needs may be associated with different sets of circumstances in which children and young people live. It is possible that the quantity and severity of health need associated with living in marginalised circumstances may make direct access to secondary care a more rational approach for parents to take. For instance, Richman and colleagues (1991) found that children living in temporary accommodation were more likely to present with burns and scalds

than their peers living in the community. This reflects potential hazards that may be exacerbated by cramped and unsafe living conditions. Secondly, parents may have to balance the greater porosity of particular services with other factors inhibiting use; being tied to an appointment to see the GP may present difficulties, but on balance fewer than accompanying a sick child, and siblings, on public transport to attend an alternative service.

There is also some evidence of non-attendance at less permeable services such as outpatients. The Clinical Standards Advisory Group report on outpatient services (1999) found an overall 'did not attend' rate of about 12 per cent at paediatric outpatients. McClure *et al.* (1996) compared attenders and non-attenders at a paediatric outpatients clinic in Leeds, and reported that 50 per cent of appointments were not kept in social class V compared with less than 20 per cent in social class II. Non-attenders had many of the characteristics of deprivation: they were more likely to be in a lower social class, living in poor housing, to have unmarried parents, and to live more distant from the clinic. Parents' perceptions of the severity of the illness did not affect attendance – in fact, in this study, illness was rated as more severe among the non-attenders. Non-attendance rates are thought to be particularly poor in child and adolescent mental health services (Rawlinson and Williams, 2000).

While there appears to be some evidence of lower use of services with low porosity, there is corresponding high use of highly permeable services among more disadvantaged children. Richman *et al.* (1991), studied rates of attendance at outpatient and accident and emergency services among children living in temporary bed and breakfast accommodation compared to the local resident population. They found that children under five years old in temporary accommodation were around twice as likely to have attended hospital than local resident children, although for older children this difference was less marked. These findings are similar to those found in a study of the use of hospital services by homeless families in an inner-London health district carried out by Victor and colleagues (1989). In this study, the control rate of admission to local residents aged under 16 was 2.9 per 1000; the admission rate for homeless children was 6.4 per 1000. Similarly, Brooks and colleagues (1998), in a study of health services provided to children living in domestic violence refuges, found that while primary care use was low for this group, secondary care use was higher than for the general population. This helps to explain significantly lower levels of immunisation among this group of children: for instance, 76 per cent of children living in refuges were immunized against diphtheria, compared to 91 per cent registered with local GPs. The rates for pertussis (68 versus 79 per cent) and MMR (66 versus 77 per cent) immunisations showed similar differences. Morrison (1991) found that lone mothers, those of low educational achievement, those in receipt of benefits, with no access

to a car and who did not own their own home, were more likely to use out-of-hours services.

The ways in which porosity of service provision shape the way in which candidacy is asserted for children and young people is likely to be contingent on other sets of issues. Cooper *et al.* (1998) compared health service use by children from different ethnic and social class backgrounds and found that the use both of inpatient and outpatient services was higher for white children than for each of the other groups observed – South Asian (including Pakistani, Indian and Bangladeshi communities), and black-Caribbean. Conversely, rates of consultation with general practitioners were higher for South Asian children than for white children, with black-Caribbean children consulting GPs even less frequently. However, access to health care for children and young people from minority ethnic backgrounds may also be further mediated by the language skills and confidence of their parents. In these circumstances, the less porous way in which services are organised might be countered by the advantages of seeing health professionals with whom communication is easier (for instance, if the GP can speak languages other than English).

Several studies highlighted what parents and / or young people see as organisational barriers to the service they would like to use. Dixon-Woods *et al.* (2002) found that many young people with asthma make appointments by themselves, and expect to attend on their own. However Jacobson *et al.* (2001) found that young people were apprehensive about interacting with receptionists, with one commenting:

'There's no point in going down there if you are going to get a response like that.'

Indeed, 14 per cent of young people reported being asked by receptionists why they wanted to see the doctor, and the majority saw this as a breach of confidentiality.

The gender of health professionals (and of those seeking health care) was also important in some instances. Burack (2000) studied the provision of sexual health care to young people by GPs, and found that girls were more likely to want to see their GP in the presence of a friend. The paper suggests that the fact that 135 out of the 182 GPs in the study area were male as a possible explanation for this, although the authors express caution by discussing these gender differences in terms of wider gender stereotyping which see boys as able to manage things on their own and girls needing support to do so.

Turbulent organisational contexts

The Bristol Inquiry (2001) (http://www.bristol-inquiry.org.uk/final_report/) identified a need for better co-ordination in the provision of child health services, arguing (recommendation 177) that there must be greater integration of primary, community,

acute and specialist care for children, so that services for children are better integrated and organised around the needs of children and their families. Simpson and Stallard (2004) argue that at present, however, children's services are hosted and managed by different organisations, and comprehensive commissioning and service development can be problematic. The provision of children's services is complex, delivered by a range of professionals and in different locations. Access to these services is often by a number of independent referral routes that may differ in terms of entry, urgency, and eligibility criteria, and work to different geographical boundaries. They also suggest that there is poor communication and co-ordination between services. Referral pathways are a source of particular confusion, especially where there are multiple needs or where the most appropriate service to address a child's needs is not clear. They describe the frustration and demands of navigating such a complex system for referrers, children, and their families.

We found some evidence of the difficulties in sustaining engagement with health services over complex boundaries and turbulent organisational contexts in the papers we analysed. Spencer and Battye (2001) interviewed 40 professionals involved in managing palliative care for children with cancer, and found that there was complexity and inconsistency in the provision of services. Particular problems appear to arise in the transition from paediatrics to adult services (Fiorentino *et al.*, 1998). Fiorentino *et al.* showed that the extent to continuity of provision depended on the type of impairment and the type of school a disabled child attended, and on whether the person was 'statemented' as having special educational needs.

Perceptions of quality

In the papers we analysed, parents' and young people's perceptions of the quality of services appeared to influence their help-seeking behaviour. Whitehead and Gosling (2003) found that parents valued experiences where they had been given honest and accurate advice and, where health professionals had been open, supportive and willing to listen, parents felt more able to contact them again in the future. Paradoxically, however, confidence in the quality of health care and advice available could, in some circumstances, deter parents from seeking medical advice. Whitehead and Gosling (2003) found that not all of the parents of children who had tuberous sclerosis sought medical advice immediately. Some felt that if something had been wrong with their infant, it would have been picked up by a health professional involved with ante-natal care.

Jacobson *et al.* (2001) studied the way in which young people and health professionals viewed each other, and found that young people were apprehensive about making primary care appointments, and also about interacting with receptionists – fewer females than males found the receptionist approachable. General practitioners expressed divided

views about young people – some emphasised their competence and rationality while others viewed them in terms of their indulgent and risky lifestyles, and wanted more of a 'back to basics' approach to teenage health issues such as pregnancy and smoking. Similarly, Churchill *et al.* (2000) also found that young people had negative experiences of attending primary care, sometimes involving the lack of privacy in the waiting areas as well as difficulties in getting the GP to take them seriously, leading to problems in confiding in GPs.

Summary: Organisational issues in negotiation

There is considerable evidence that children and young people in socio-economically disadvantaged circumstances may make low use of services such as outpatients clinics, because of their low permeability. These services have poor permeability because they impose conditions of candidacy and the way they are organised around rigid appointments systems is demanding of personal and practical resources which may not be available in more deprived families. Lower use of services among young people may be linked to feelings of alienation from the ways in which services are organised. Primary care may be less permeable for young people because of their reluctance to negotiate organisational barriers such as receptionists. Perceptions of quality of care in health services may deter parents and young people from help-seeking.

5.2.5 Theme 5: Presentations, adjudications and offers

The ways in which parents, children and young people present to health services is clearly important in gaining professional recognition of candidacy, and subsequent access to services. We organised our analysis around the following themes:

- Presentations.
- Adjudications.
- Technical and social / moral candidacy.
- Offers and uptake.

Presentations

The ability of parents to act as advocates for their child has important implications for treatment, and therefore for equity in the provision of services. Klasen and Goodman (2000) found that referrals to specialists were linked more to parental persistence (as well as a perceived inability to cope) than to a systematic assessment of symptoms; moreover, rapid referral was linked to parental persistence rather than the severity of child hyperactivity. The evidence also suggests that parents can have a particularly important role as advocates in relation to children with conditions which are difficult to

diagnose or which are unpredictable in their symptomatology. Carter and colleagues (2002), in their study of parental assessment of pain in children with profound special needs, found that parents were particularly able to pick up on symptoms, and on their child's pain cues, in a way which health professionals would find very difficult. Whitehead and Gosling (2003) make a similar observation in relation to children with tuberous sclerosis: parents described having to make several visits to their doctor before being referred to a paediatrician. Significant here is the fact that children are more likely to get treatment if they have confident (or perhaps desperate) parents, with worrying implications for those who are less able to act as advocate in this assertive way.

However, our analysis suggested that discordance between professional and parent / child perspectives on candidacy is common (Jacobson *et al.*, 2001; Kai, 1996b; Klasen and Goodman, 2000; Robinshaw and Evans, 2001; Whitehead and Gosling, 2003; Carter *et al.*, 2002; Churchill *et al.*, 2000; Coleman and Finlay, 1997; Cornford *et al.*, 1993; Bryce and Gordon, 2000; Dixon-Woods *et al.*, 2001; Donovan *et al.*, 1997). The issues can be separated into those principally about the different perspectives adopted by health professionals and families about whether a child was an authentic candidate for medical attention and intervention, judged by a clinical canon, and those (less commonly) where a child is judged to be in need of clinical intervention but this is resisted by families.

Studies which looked at discordance between health professional and parental perspectives focused in particular on definitions of illness, and on how seriously professionals took reported symptoms and recognise parents' special expertise. Such studies reveal the differing ways in which parents and professionals may conceptualise candidacy. In some cases, parents may seek to demonstrate that their child has a legitimate and authentic need for health care – a valid claim to candidacy – and may report frustration in getting professionals to recognise this. Their claims of their own special abilities in recognising candidacy are frequently based on the distinctive, intimate, and detailed knowledge of their child, which they see as having a particular status (Dixon-Woods *et al.*, 2001; Arksey and Sloper, 1999; Klasen and Goodman 2000). Klasen and Goodman, in their study of hyperactivity, found that health professionals often did not believe in hyperactivity as a medical problem, seeing it instead as a product of family dysfunction. This influenced their willingness to share information with parents and sometimes had serious implications for treatment decisions. Whitehead and Gosling (2003) found that parents of children with tuberous sclerosis reported having to make several visits to their doctor before getting a referral to a specialist; in many cases, the symptoms were recognised only once a health professional had witnessed them personally. Dixon-Woods *et al.* (2001) found that many parents of children diagnosed with cancer said that they had had to argue with GPs to demand further investigations.

Similar struggles over the labelling of problems occurred in children with acute illness in studies that we analysed. Kai (1996a) found that parents felt excluded from the 'mystique' involved in a doctor reaching a diagnosis. For example, parents would fear a chest infection when their child's chest sounded 'rattly', but the doctor would pronounce the chest clear despite evidence to the contrary. This ran parallel to differences in desired treatment: parental beliefs about the prescribing of antibiotics are more likely to be grounded in notions of severity and impact (for instance, disturbed sleep) than in the actual cause of the illness itself. Similar struggles between parents and doctors over the diagnosis of common illnesses, such as coughs, were reported by Cornford *et al.* (1993).

The importance of acknowledging the expertise that parents have developed was discussed in several papers. For instance, Robinshaw and Evans (2001) found that a large proportion of parents reported suspecting, and following up on, hearing problems in their children, but felt that professionals had not listened adequately to these concerns; indeed, they frequently reported being made to feel stupid for reporting them. Similarly, Pain (1999), in a study of how parents cope with childhood disability, found that parents' skills often were not utilised, and that this led to parents feeling devalued and to emotional damage as they felt less able to protect their child from pain.

In other cases, families may not recognise candidacy as it has been defined for them by professionals. Dodd and Newton (2001) point to evidence that parents do not always agree with staff on the extent to which review visits in outpatients are necessary, possibly explaining high rates of non-attendance.

An important component of struggles between lay and medical perspectives concerned communication barriers. Seven papers address this issue (Jacobson *et al.*, 2001; Tang and Cuninghame, 1994; Whitehead and Gosling, 2003; Carter *et al.*, 2002; Carter and Bannon, 1997; Churchill *et al.*, 2000; Davis, 1995). In some cases, communication difficulties arose from parents not speaking English as a first language (Tang and Cuninghame, 1994; Carter and Bannon, 1997). In others, communication difficulties arose from the different perspectives that health professionals and young people had. For instance, Jacobsen *et al.* (2001) found that young people felt that lack of time hampered their ability to communicate effectively with their GP, with 21 per cent reporting their consultations with GPs as not long enough. This was compounded with a perceived inequality of status and their view that doctors tended to talk 'briskly'.

The evidence we looked at suggests that it is possible to make sense of the different perspectives held by parents, young people and health professionals in terms of power and disempowerment. We have already touched on these issues in relation, for example, to the struggle that parents have to be recognised as having expertise in caring for their children. Ten papers addressed these issues (Hopton *et*

al., 1996; Houston and Pickering, 2000; Jacobson *et al.*, 2001; Kai, 1996b; Kai, 1996a; Robinshaw and Evans, 2001; Whitehead and Gosling, 2003; Carter *et al.*, 2002; Cornford *et al.*, 1993; Donovan *et al.*, 1997). In particular, there is evidence that parents can feel disempowered in their ability to manage minor illnesses in their children by previous experiences such as serious illness or death of a child (Houston and Pickering, 2000). Moreover, this ability can also be compromised by the lack of readily available information, and the lack of understanding of parental concerns and beliefs on the part of health professionals (Kai, 1996a).

Counter-intuitively, however, it is possible for negative experiences to have an empowering effect on the way parents negotiate access to health care with professionals. Hopton *et al.* (1996) found that previous negative experiences of health care had empowered respondents, and made them *more* proactive in seeking out-of-hours help from their GP in the future. For children and young people, disempowerment may result from their status as children and from their lack of experience in negotiating with adults in positions of authority. Jacobson *et al.* (2001) found that young people using primary care services often felt that they were not respected as a patient and were liable to be treated like children. Clearly, an important issue here is the ability of health services and health professionals to differentiate between young and older children in terms of the way in which they are spoken to, the information they are given, and so on.

Adjudications

In previous sections we have suggested the processes of adjudication – how decisions are made about categorisation and disposal – are key to understanding issues of how candidacy is managed. The categorisation of children, for example into diagnostic categories, has a key impact on how they are subsequently managed by health services. The papers we analysed demonstrated a strong relationship between availability of services – or ‘authorisation’ to use services – and diagnostic status. Klasen and Goodman (2000) found that as soon as parents received a diagnosis of hyperactivity, other avenues of support opened up to them, including reading material, self-help groups and expert help. This pattern, of support and services being triggered quite suddenly by the receipt of a firm diagnosis is also found in studies of childhood cancer (Dixon-Woods *et al.*, 2001) and of children with tuberous sclerosis (Whitehead and Gosling, 2003). An accurate diagnosis is frequently delayed; in the study by Klasen and Goodman (2000), the time between parents approaching their GP and confirmation of a diagnosis was between nine months and five years. Frustration was also expressed by parents about inconsistencies in diagnosing and prescribing between different professionals (for instance, in the study by Kai, 1996a).

Klasen and Goodman (2000) found that parents saw medical recognition and 'verification' of the symptoms of hyperactivity observed in their children as extremely important. One parent who 'succeeded' in having their child diagnosed as hyperactive commented:

'I felt very happy that there was a name, that I hadn't been imagining things, that I didn't have a monster, that there was a reason for his behaviour.'

Similar findings emerged in Whitehead and Gosling's (2003) study, where parents felt a sense of 'vindication' that they had not been imagining symptoms or over-reacting, and in a study by Robinshaw and Evans (2001), where parents who had to wait until after their child's first birthday to receive confirmation of deafness or hearing difficulties were particularly relieved.

However, studies of how professionals come to decisions – or make adjudications – about children are surprisingly rare. A series of classic studies has explored issues involving children's consultations (not included in our sample, but including Strong (1979); Silverman (1987), among others), but mainly as exemplars of other theoretical points rather than having a focus on issues of children themselves. This work does offer important insights into adjudications. Dingwall and Murray (1983) demonstrate the special indulgence granted to children who attend accident and emergency departments. Children's attendance, even for clinically non-important problems, was seen as more legitimate and acceptable than for adult attendance for the same types of issues.

Bloor's (1976) classic observational study of decision-making by ear nose and throat surgeons showed how surgeons drew on heuristics, or 'rules of thumb', that broadly reflect issues of technical and social and moral candidacy that we have described in earlier sections. Some surgeons drew largely on clinical signs as the primary indication for surgery, while others drew on evidence about repeated episodes of tonsillitis that were affecting a child's education. However, there have been very few studies of this nature and quality, and it is difficult to interpret the continuing applicability of these findings almost 30 years on, after major changes in policy and the shift in the epistemological basis of medicine from individual authority to evidence-based practice. Moreover, recent years have seen the emergence of the recognition that decision-making in paediatric consultations may involve several parties, and that decisions may be jointly negotiated between children, parents, and professionals, but as yet there are few empirical studies of the outcomes of such consultations (Dixon-Woods *et al.*, 1999; Young *et al.*, 2003).

Technical and social / moral candidacy

Diagnosis depends on professionals detecting or recognising pathology. The extent to which a perceived set of problems or

symptoms were given medical labels and explanations was an important issue in papers that we analysed (Hopton *et al.*, 1996; Kai, 1996a; Klasen and Goodman, 2000; Robinshaw and Evans, 2001; Sayal *et al.*, 2002; Whitehead and Gosling, 2003; Cornford *et al.*, 1993; Dixon-Woods *et al.*, 2001; Edwards and Pill, 1996). Our analysis pointed to difficulties in health professionals determining the technical eligibility of children for some diagnostic labels, intervention, or referral. Klasen and Goodman (2000) report that general practitioners were often unsure about the boundary between normality and abnormality and were struck by the wide social and cultural variation in what was seen as acceptable child behaviour. Rawlinson and Williams (2000) suggest that there is low recognition of psychological disorders by primary care professionals, with substantial under-diagnosis.

Granier *et al.* (1998), in an interesting qualitative study of how general practitioners process clinical and contextual information in recognising meningococcal disease, demonstrated the heuristics used in diagnosing potentially serious illness. While some technical information – such as presence of a haemorrhagic rash - was used in making judgements about candidacy for the diagnostic label of meningitis, intuitive knowledge, including GPs' perceptions of the credibility of parents – was also very important.

As in the previous sections, consideration of the 'social deservingness' of some candidates is evident in some recent work in general practice (ReesJones *et al.*, 2004). In this study, one GP is reported as saying:

'It's all very well for the PCG to tell us that (GPs should cut prescribing costs) but you try telling a mother who has got 3 children on income support: "so I am not going to give you Calpol you can go and buy it from the counter".'

Rawlinson and Williams (2000) cite evidence that social factors such as parental unemployment, financial stress, and lack of support from the extended family may influence referral decisions to child and adolescent mental health services. Advocacy in seeking help with childhood illness has implications for the equitable provision of services, albeit in complex ways. Klasen and Goodman (2000) found that referrals to specialists were more often determined by parental persistence, or an inability to cope, than by a systematic assessment of the child's needs. Similarly, Edwards and Pill (1996) compared patterns of help-seeking in affluent and poorer groups of parents with toddlers. They found that while poorer parents were more likely to seek help for common problems such as infections and colds, more affluent parents were more willing to pursue services in relation to child behavioural problems.

Our analysis also demonstrates the importance of 'operating conditions' in issues of categorisation and disposal for children, including the beliefs and characteristics of professionals in particular setting. We identified the perceived unwillingness of doctors to discuss

alternative therapies and alternative options in the independent sector, reported by Robinshaw and Evans (2001) in their study of services to pre-school deaf children and their families.

Offers and uptake

We found little evidence about offers in our sample of the literature, apart from the evidence on non-attendance already summarised. There is some fragmentary evidence that parents or young people may resist diagnostic labels that would trigger access to forms of attention or intervention. For example Young *et al.* (2002), and Dixon-Woods, *et al.* (2002), found that some parents resist the label of 'asthma' that professionals have sought to apply to their children.

Summary: Presentations, adjudications and offers

Our analysis suggests that the candidacy of children is often contested between parents and professionals. Parents are called upon in consultations to do the work of demonstrating that their child has an authentic and legitimate claim to candidacy, but they may vary in their ability to do this. In making a claim for their children's candidacy, parents draw on their intimate, experiential, intuitive knowledge of their child to judge whether something is wrong, while professionals draw on clinical experience and medical knowledge. There are frequent reports of parents struggling to get diagnoses of serious illness in their children because of the discounting of their private knowledge, and there are also reported disagreements over the diagnosis and management of the candidacy of children with minor illness. Parents and young people may feel disempowered in their interactions with health services, and this may create forms of suffering.

Adjudications of candidacy are important in allowing children to gain access to investigations, treatment, or other forms of health care. There is some evidence that children's attendance may be indulged, in the sense that even when they attend for problems that are not clinically important they are not seen as being illegitimate users. However, the ways in which professional judgements about children's candidacy for diagnostic labels or treatment are made are poorly understood, though there are some indications that issues of technical and social / moral candidacy are likely to be important as they are for other groups. Again, these judgements are made in the context of operating conditions, including scarcity of resources, which may influence the selection of candidates.

5.2.6 Theme 6: Tractability: Policies, service developments and interventions to improve access by children

The Bristol (2001) (http://www.bristol-inquiry.org.uk/final_report/), Alder Hey (2001) (<http://www.rlcinquiry.org.uk/>) and Victoria Climbié Inquiries (2003) (<http://www.victoria-climbié->

inquiry.org.uk/finreport/finreport.htm) have led to a period of focus on the distinctive needs of children in health care, and rapid change is currently underway. Because of the rapidly changing environment, few evaluations have yet appeared, and our account below is therefore mainly descriptive. Our synthesis below is organised around the following themes generated by our analysis:

- Towards focus, standards and integration.
- Provision and capacity of child-centred services.
- New organisational forms.
- Educational interventions.

Towards focus, standards and integration

Until recently there has been no national or governmental body or person specifically charged with responsibility for the well-being of children or with assessing the impact and coordinating policies from individual government departments (Aynsley-Green *et al.*, 2000). The evolving National Service Framework for children aims to address the Bristol Inquiry's recommendation that there be better integration of primary, secondary, community, acute, and specialist services for children (Department of Health, 2003). The NSF will aim to craft services around the 'journeys' that children take as they need health care, and will recognise that at any stage the care pathway may need to link in social care, education, and other services.

Simpson and Stallard (2004), taking up these themes, propose that there should be a comprehensive single point of access for all paediatric referrals, which would assess and administer the referral. A preliminary evaluation of the single point of entry (SPE) model suggested that benefits included simplicity, efficiency, improved co-ordination and communication. Difficulties included wanting more access to secondary services, possible delays, training for referrers, and the need for an electronic version of the SPE form. Further evaluation of this interesting proposal is underway. Managed clinical networks are another important step towards achieving the aim of integration. Aiming to ensure that high quality effective services are equitably provided, they co-ordinate care around the needs of the child rather than being constrained by organisational or professional boundaries (Cropper *et al.*, 2002).

Aynsley Green *et al.* (2000) also complained that, at the time of writing, children's needs were found in only 16 per cent of health improvement plans, and only one in ten health authorities had in place any policies on adolescent physical health. A number of recent initiatives has aimed to increase capacity in children's services. The National Service Framework undertakes to ensure that there are sufficient numbers of appropriately trained staff in the right locations,

to increase the number of staff available, and increase workforce capacity and productivity.

Improvements have been seen in the capacity and quality of paediatric intensive care since the publication of the paediatric intensive care framework report in 1997 (Department of Health, 1997; Doyle and Orr, 2002). Pearson *et al.* (2001) report a doubling in intensive care use by children in Birmingham between 1991 and 1999, coincident with a period of centralisation of paediatric intensive care provision and an increased number of beds in the lead centre. The authors argue that their data point to unmet need in 1991, and that centralisation of paediatric intensive care may have contributed to the fall in child mortality observed over the study period. However, the authors warn that there is continuing evidence of unmet need, albeit at a lower level than in 1991.

Development of child-centred services for specific diseases is also increasingly common. The distinctive needs of children are now being met by distinctive services, staffed by people with specialist qualifications in paediatrics. However, such services pose difficulties in evaluation. Gibb *et al.* (1997) describe a family-centred clinic for HIV services, but offer little in the way of rigorous evaluation. Peckham and Carlson (2003) describe an evaluation, based on questionnaire surveys and participatory group assessment methods, of 'Bodyzone', which provides confidential drop-in clinics for young people in schools, and argue that these services address adolescent health needs that otherwise remain unmet. Their study highlighted the importance of confidentiality in services for young people. The recent introduction of services for young people, for example specialist adolescent units for young people with cancer, also require rigorous evaluation.

New organisational forms

As we have described in earlier sections, the current NHS is characterised by rapidly proliferating diverse organisational forms. Some of these have implications for, or are specifically directed at, children and young people.

Managing emergency admissions

The assumption in much of the literature is that a significant proportion of health service use by children and young people is unnecessary, particularly as it applies to inappropriate hospital admission, and considerable effort has been devoted to finding alternative ways of managing children's health needs. Coleman and Finlay (1997) found that a paediatric emergency clinic appeared to be successful in diverting children away from hospital admission. Similarly, a study by Esmail and colleagues (2000) of paediatric records in thirteen district general hospitals in southern England, found that admissions of children under the age of one were approximately seven times more likely to be 'inappropriate' than

admissions for young people aged 15. Most studies address ways in which inappropriate admission can be reduced although, as Esmail and colleagues (2000) argued, there is no gold standard of appropriate admissions, and it is possible that in units and services with a low rate of inappropriate admission, there may be some patients who need to be admitted but are not. Morrison *et al.* (1991), in a study of out-of-hours service use, found that a small proportion of children account for a very high proportion of service use, again, the assumption is often that such patterns of service use reflect an inappropriate presentation of need and that ways of reducing such use should be found (usually in the form of other diversionary services). We would suggest that assumptions about 'inappropriateness' often fail to recognise the nature of children's candidacy, and in particular the need for parents to accomplish the work of managing that candidacy.

NHS Direct

McLellan (2004) argues that reports about NHS Direct have failed to analyse the adequacy or appropriateness with which children are served, and points out that only one per cent of NHS nursing staff have a background in paediatrics. He argues that specific standards are needed for meeting the needs of children. In effect, McLellan is arguing that the distinctive features of children's candidacy be recognised and incorporated into NHS Direct working practices.

Out-of-hours centres

Under the new GP contract, there is likely to be an expansion of out-of-hours primary care centres, to which people will be expected to travel. The evidence we have analysed suggests that these centres may provide a welcome means for parents to consult a health professional out-of-hours, but may have the effect of making out-of-hours care much less permeable to children. Shipman *et al.* (2001) found that, though they welcomed the chance for their child to be 'seen', parents expressed anxiety about taking an ill child out in the night to visit a primary care centre. Some had problems in arranging transport and in organising babysitting for other children, particularly in the middle of the night. Travelling with sick children often required the support of another adult, and this was not always available, particularly to lone parents. The difficulties of managing crying / vomiting children were described, and could be particularly problematic if other children had to be brought as well. Cragg *et al.* (1994) found that although the attendance rate at out-of-hours centres was highest in children under five, several parents made the point that choice of attending should lie in the control of the patient.

Educational interventions

We identified in our earlier analysis the importance of parents' confidence in their ability to manage their children's symptoms and illness. Most interventions have focused on provision of leaflets and

other information resources to address this need. Kai (1996b) illustrates with reference to the need for information about meningitis to be of good quality if unnecessary anxiety is to be reduced among parents. Similarly, the comments of parents in the study by Robinshaw and Evans (2001) illustrated that they expected better access to more comprehensive information very early in the process of diagnosis. Finally, parents require information that is timely, accessible and available from the appropriate source. While some parents preferred written information (albeit without the use of jargon) in primary care settings (Kai, 1996b), others preferred personal contact with health professionals (Pain, 1999). In the latter study, one parent with a child with learning disabilities said:

'There was no substitute for real people, written information is nice to have as a comfort factor, but you really get your information from people, talking face to face with them.'

The efficacy and appropriateness of educational intervention, or the forms that this type of intervention should have taken, remain largely unproven. Interest is now growing in other ways of improving parents' confidence. These include face-to-face support, and the help and information available from other parents who were in, or had been in, similar circumstances. This emerged in the studies by Robinshaw and Evans (2001), and by Pain (1999). Robinshaw and Evans (2001), in their study of pre-school services to deaf children, found that where services had been received in a family-centred environment, parents demonstrated greater skill-acquisition and appeared to be more confident, independent and creative in the application of these skills.

Summary: Tractability: Policies, service developments and interventions to improve access by children and young people

Policies aimed at improving access to health care by children and young people have primarily focused on the development of capacity and focusing of services specifically on the distinctive needs of these groups. The effects of many of these efforts have not yet been evaluated, but it is evident that there has been an increase in capacity, including increases in the numbers of consultant paediatricians. New organisational forms in the NHS have a number of implications for children. Initiatives aimed at managing emergency admissions have focused on reducing 'inappropriate' admissions, through creating diversionary services, but our analysis suggests that such measures often fail to recognise important issues of candidacy and candidacy work that parents undertake. There has been criticism that NHS Direct has failed to acknowledge the distinctive needs of children, and that out-of-hours primary care centres may cause difficulties in access to health care for children by creating serious practical obstacles which may disproportionately affect the socio-economically disadvantaged. Educational interventions about using services have traditionally relied on deficit models of parent

understanding of child health, and again may fail to address important aspects of candidacy and how parents manage candidacy.

5.3 Conclusions

Our analysis suggests that children have high use of health services, and benefit from the provision of a range of screening and vaccination services aimed at children and young people, an infrastructure of health surveillance aimed at identifying health problems in children (the school nursing service), the absence of prescription charges and free dental care, and the provision of distinct services. Again, however, we argue that measures of utilisation provide a very poor guide to understanding access. Our analysis of how their candidacy is recognised, negotiated, and adjudicated suggests that they are at risk in terms of access.

Some of these risks arise from the vulnerabilities inherent in childhood. Children have fewer rights and lack the resources necessary to secure their own well-being through, for example, economic independence. Our analysis confirms the important role that parents play in advocating on behalf of their children, whether in terms of seeking medical advice, obtaining a diagnosis or securing appropriate treatment and support. This parental role is mediated by other factors, such as socio-economic disadvantage, and changes over the course of childhood, so that parents' involvement may be rejected by older children and young people.

It is clear that there is very high use of what might broadly be termed emergency services among children. Broader social changes (higher rates of lone parenthood, the fragmentation of communities, the dispersal of families) may have left some parents less able to cope with episodes of child illness, and therefore more reliant on health services (primary and secondary). At the same time, expectations of parents to act as guardians of their children's health has never been greater, with the increased emphasis on vigilance about meningitis being a key example. Parents are therefore continually caught in dilemmas where they are expected to be the judges and advocates of their children's candidacy, but must also be prepared to accept that their own identities as rational, responsible, reasonable people may be spoiled as they exercise their responsibilities in these respects. Of course, it is also the case that the accounts of parents who are negligent in caring for their children's health do not appear in the studies that we analysed. It is likely that parents who participate in research projects are those who generally are also highly socially engaged, and that in offering their accounts they are seeking to protect their identities.

The appropriateness, or otherwise, of paediatric service use must be seen therefore in its wider context. To assume that such appropriateness can be judged simply in terms of clinical 'objectivity'

is to make a positivist assumption about the existence of a clear, neatly defined level of need to which health services can respond in a cost-effective way. Further, the embedded nature of 'inappropriate admission' as a key theme facing health services may be experienced as a barrier by parents, particularly if it is expressed in terms of doubts about the existence and / or severity of a child's illness, moral criticism about the over-use of services, and so on.

Our analysis suggests that the nature of children's candidacy is often contested at different levels. Although the attendance of children at highly porous services such as accident and emergency departments, general practice, and out-of-hours services may be indulged because of the claim to candidacy implicit in children's vulnerability, disputes over categorisation and disposal between parents and professionals are relatively common. 'Medicalisation' is a term used in the sociological literature to describe a process whereby health professionals come to exercise control and expertise, often with resistance from 'patients'. In relation to the evidence reviewed here, however, the reverse is the case with regard to access to healthcare by children and young people and / or their parents, at least for some health problems, particularly of a behavioural or mental health nature. Notwithstanding recent pressures for more partnership-based approaches to medical consultations, there is substantial evidence in many of the studies that we analysed that the 'voice of medicine' prevails (Mishler, 1984). Parents frequently report that the voice of medicine is used to appropriate or discount the voice of the 'lifeworld', or what we might call the voice of the 'parentworld', where their intimate knowledge of the child is their most valuable resource. Parents often feel that this resource is ignored in professional decision-making, sometimes, in the case of some serious and difficult-to-diagnose conditions, leading to significant delays.

Young people represent a neglected group in terms of study of access, and demonstrate considerable vulnerabilities. Most research has focused on 'teenage problems', including contraception and drug use, but research on their more general use of services is more lacking. They appear to have low use of general practitioner services, likely to be related to the low permeability of these services during adolescence and young adulthood. Using primary care may involve negotiations about independence from parents and navigation of organisational barriers such as receptionists that may make attendance unattractive. During the period of rejecting parents' involvement in health issues, young people may be highly vulnerable as they lose both an advocate and a vigilant monitor of their own health.

Section 6 Access to health care for older people

6.1 Introduction

In this section we present an interpretive synthesis of the literature on access to health care by older people. Older age does have the advantage, in contrast with some of the groups we have looked at in the previous sections, of being easy to measure. However, simple divisions based on chronological age do not express the great diversity that exists within the broad category of 'older people'. If the conventional lower age limit of sixty-five years is used to classify people as older, then the age group has an age range of some thirty years or more potentially covering a third of the life-span. With increasing age a risk factor for a large number of physical and mental health problems in turn associated with disability, the health needs of those at either end of the age scale are likely to differ markedly, but even within narrow chronological bands there are likely to be widely varying needs. In terms of ethnicity, there is currently less diversity among older people than in younger age groups although this is set to change over the next thirty years. In the 2001 census, 15 per cent of those from non-White minority ethnic groups were aged over 50 years compared with a third of the population as a whole (<http://www.statistics.gov.uk/cci/nugget.asp?id=874>). Social and economic class divisions may be exacerbated in old age, although social class has proven difficult to measure in later life. Income falls sharply in retirement and income is associated with occupational group among men, and household type and marital status for women (Bardasi and Jenkins, 2002).

Older people are not a minority group: those aged 65 or over now outnumber those aged 16 and under. Despite evidence of high use of services by older people, there has been persistent concern that they are disadvantaged in their access to health care. Again, recent rapid policy changes, most notably the publication and implementation of the National Service Framework for Older People (NSF) pose challenges for the interpretation of the literature. Many of the papers in this area, both empirical and theoretical, date back over a number of years and many are from outside the United Kingdom. We have included a small selection of papers from the USA, where evidence from the UK was lacking.

Our core synthetic construct of candidacy is used to explain the jointly produced nature of health problems in older people, including the ways in which health problems are identified and health care is navigated through a process of negotiation and adjudication between users and providers.

6.2 Lines-of-argument synthesis

Our lines-of-argument synthesis of the evidence on access to health care by vulnerable groups is organised around a set of central concepts and in particular the core synthetic category of 'candidacy'. A table of included studies can be found at Appendix 6A.

CANDIDACY describes the ways in which older people's eligibility for medical attention and intervention is jointly negotiated between older people and health services. Candidacy is a dynamic and contingent process, constantly being defined and redefined through interactions between individuals, their carers, and professionals, and managed in the context of operating conditions, including the biography of the relationship between patients and staff, the typifications staff use in categorising people and diseases, availability of resources, local pressures, and policy imperatives.

Key points in candidacy related to older age generated by our analysis:

- **Identification of candidacy:** In most cases of help-seeking (though there are important exceptions) older people or their carers come to identify and seek to present themselves as having needs (though these may not be well formulated) to which health services can respond. It is also possible for health services to identify features of candidacy and seek to apply these to individuals – for example in the case of over-75s' health checks, when the normal help-seeking processes are reversed.
- **Negotiation** refers to routes individuals take from identifying their candidacy to gaining a point of entry to health services. Accomplishing the work of negotiation relies on a set of competencies and resources that may not be equally distributed among the population, and which may be greatly diminished in older age.

Older people can penetrate, or gain a point of entry, to health services in a number of ways. We will suggest that services can be conceptualised as being surrounded by membranes that are more or less porous. More porous membranes allow people to pass through easily; services that are less permeable require much more work in order to gain a point of entry and sustain engagement with the service.

- **More porous membranes**– Services that have more easily permeable membranes (do not require appointments, literacy, knowledge, or social skills) are more easily negotiated and more consistent with an impoverished environment. To a large extent, these services do not rely on judgements by health services about candidacy at an individual level, and include general practice and accident and emergency (A&E) services.

- **Less porous membranes** are more resistant and pose more barriers, are difficult to negotiate, and require a high level of alignment with the organisational values of the services on offer. These services normally require some professional judgement of candidacy of individuals, and include outpatient appointments and procedures undertaken in hospital.

Once an individual has **presented** to health services, they have asserted their candidacy as deserving of medical attention and / or intervention. They may vary in their recognition and aspirations as to the nature of that candidacy. Presentations involve people in doing work, which again requires particular sets of competencies, skills and resources, which may be variably distributed in the population.

- **Adjudication** refers to professional judgements about the candidacy of the individual for intervention or service. These involve two types of judgements, but judgements are highly conditional and contingent:
 - **Judgements about technical candidacy**, in which judgements are made about the technical feasibility of providing interventions or services. People who are older, because of co-morbidities, later presentation, or more serious illness, may be judged to be poorer technical candidates.
 - **Judgements about social and moral candidacy**, in which judgements are made about the likely social benefits of the intervention or the moral worth of the candidate.
- Conditionality refers to adjudication and disposal being conditional on the operating conditions of services. Each stage of candidacy is likely to be influenced by the perceived or actual availability of health service resources, including issues of geographical proximity. Operating conditions may operate at the level of individual interactions where a professional may make an offer that is not warranted on the basis of 'clinical' candidacy in order to preserve the relationship with a patient. They may also operate at the level of the organisation where an organisation may withhold or delay offers that could be justified on the grounds of clinical candidacy because of limited resources.
- **Offers** – refers to the offer, or non-offer, of intervention or service by professionals.
- **Acceptance and receipt, resistance and rejection** – refers to the uptake of offers by individuals, or attempts to resist and reject offers.
- **Conversion** – refers to the conversion of health care into outcomes.

We have organised our synthesis of the evidence on access to health care into the following themes generated by our analysis:

- 6.2.1 Theme 16.2.1 Theme 1: Construction of the problem of access to health care by older people.
- 6.2.2 Theme 26.2.2 Theme 2: Recognition of candidacy by older people.
- 6.2.3 Theme 36.2.3 Theme 3: Navigation of a route to and through health services.
- 6.2.4 Theme 46.2.4 Theme 4: Presentations, categorisations, adjudications and offers.
- 6.2.5 Theme 56.2.5 Theme 5: Improving access to health care for older people.

6.2.1 Theme 1: Construction of the problem of access to health care by older people

We have organised our synthesis of the way in which the 'problem' of access to health care by older people has been constructed in the literature around the following themes:

- General practice.
- Specialist care.
- Vulnerable subgroups.

General practice

Older people are high users of general practice services; the highest consultation rates are found among young children and those aged over 75 (Rogers *et al.*, 1999). McNiece and Majeed (1999), using data from the fourth national survey of morbidity in general practice, reported that older people accounted for 14 per cent of all patients in the morbidity survey, but for 21 per cent of all contacts with a doctor or nurse. Overall, annual contact rates were about 50 per cent higher in older people compared with other age groups, with a rate per person of 4.64 in older people compared with 3.03 in people aged 16-64 years, a rate of 4.32 in people aged 65-74 years increasing to 5.04 in those aged 75-84, and 5.09 in those over 85. McNiece and Majeed also found evidence about social class differences in GP consultation. Contact rates were highest in people from social class IV and V, but the differences in contact rates were highest in the 65-74 age group. In people aged 75-84 there was no association with social class, and contact rates were higher in social class I in the over 85s.

A Department of Health / Office of National Statistics report (2002) on the 2000 Health Survey for England calculated the GP consultation rate as the proportion of people aged 65 and older who had an NHS GP consultation in the previous two weeks. In private households, 20 per cent of men and 21 per cent of women reported contacting their GP in the two weeks prior to interview. Men's consultation rates did

not vary much with age, but the percentage of women aged 80 and over was lower (17 per cent) than those aged 65-79 (23 per cent), possibly because of the mobility problems associated with older age. In care homes, GP consultations were significantly higher than in private homes: 29 per cent of men and 26 per cent of women had contacted their GP in the two weeks prior to interview. Virtually all (99 per cent) of these consultations took place in the care home. Rates of consultation showed a direct relationship with self-assessed health, both for those in private households and those in care homes, suggesting a link between consultation and 'need'. In private households, men from manual social classes had higher GP consultation rates (23 per cent) compared with non-manual classes (18 per cent), but this was not statistically significant after adjustment for age.

Despite high rates of consultation among older people, an important minority of people do not consult general practitioners, or consult infrequently. There has been long-standing concern that people who do not consult may have unreported needs and no identifiable informal carer (Williams, 1984). There is some debate about the extent to which the needs of infrequent consulters are exaggerated. It has been suggested that unidentified needs tend to be 'simple and remedial' rather than 'serious or complex'. A large case control study, comparing older 'non-consulters' (not seen by a GP in past 18 months and aged 65 years or more) with 'consulters', found the former group were in better health with lower levels of disability than the latter (Ebrahim *et al.*, 1984). Nonetheless, concern that there was an 'iceberg' of unmet need among older people, and that those most in need were hidden from view without the resources to recognise, report and receive care for a range of health problems, was the basis for the introduction of the over-75 health checks in general practice.

Recent evidence suggests, however, that there may be continuing unmet need. Shah *et al.* (2001) reported that rates of consultation for psychiatric disorder, including depression, in people aged over 65, were much lower than expected, particularly for men. Nelson *et al.* (2002), in a cross-sectional questionnaire study of 1085 older people interviewed at home in London, reported that dementia is a negative predictor of GP and hospital consultation. Only 44 per cent of those with dementia had consulted their GP in the last three months compared with 61 per cent of people without dementia, suggesting that this vulnerable group may be under-consulting.

It is also reported that some illnesses of older people are under-detected and under-treated. Katona and Livingston (2000) report that the overwhelming majority of older people with depression remain untreated, citing evidence in one study that only ten per cent were treated with anti-depressants. Glaucoma, predominantly a disease of older people, is also substantially under-diagnosed (Green and Siddall, 2002).

Specialist care

Much of the evidence supporting the claim that older people are disadvantaged in their access to health services is based on studies that have examined the relationship between increasing age and utilisation of specialist services in secondary and tertiary care. This evidence base is generally epidemiological or ecological, making firm conclusions difficult to draw, primarily because the level of need tends to be assumed rather than measured, and because, as we have argued in the previous sections, measures of provision and utilisation take no account of 'offers' and 'acceptances'.

The evidence points to high use of specialist care by older people. The Department of Health / Office of National Statistics (2002) report on the Health Survey for England found that those aged over 65 constitute about a sixth of the population but occupy almost two-thirds of acute and general hospital beds. In the survey, 12 per cent of men and eight per cent of women in private homes reported being admitted to hospital for treatment as a day patient in the year prior to interview, while in care homes nine per cent of men and eight per cent of women aged 65-79, and ten per cent of men and seven per cent of women aged over 80 had been admitted. In private households, 43 per cent of older people had attended the outpatient or A&E department of a hospital in the last year. Outpatient attendance was lower among residents of care homes, with only a third having attended an outpatient department. This latter finding is of some concern, given the much higher rates of GP consultation we noted earlier, and the generally higher level of morbidity in the care home population, and here research that investigates patterns of categorisation, adjudication, and acceptance would be very helpful.

The DoH / ONS survey again does give some broad indication of a relationship between 'need' and use of specialist services. In private households, those with fair or bad self-assessed health were approximately 20 per cent more likely to have attended an outpatient department within the last year than those with self-assessed 'good' health. A similar picture was seen in care homes. The association between self-assessed general health and inpatient attendance appeared stronger in private households than in care homes. However, in private households, eight per cent of women and 12 per cent of men reporting good health had been inpatients, compared with 21 per cent and 25 per cent respectively of those with fair or bad health. By contrast, only small differences were seen in care homes, since hospitalisation rates were high even among those reporting good health.

Studies of specific services show a mixed picture, with some evidence, based on data before the introduction of the NSF, pointing to lower receipt of some types of health care by older people. Goddard and Smith (1998) summarise evidence suggesting that older people receive less treatment. For example, the chances of being admitted to

hospital following myocardial infarction (MI) were reported in one study they reviewed to fall with age, and the chances of undergoing further investigation and revascularisation were found to fall sharply after the age of 65, with those in the oldest age group (85+) having a three per cent chance of investigations and a two per cent chance of re-vascularisation compared with the younger group, though it is unclear again whether such differing levels of receipt reflect differing offers or differing acceptances of offers. Goddard and Smith do note that overall, patients undergoing re-vascularisation have been getting older over time, and rates in older groups have increased faster than in younger groups.

Older people may have particular difficulty in accessing specialist services that are either new or in short supply, or where there is a more general service available. Analysis of community specialist palliative care (CSPC) nurse use found younger age a predictor for CSPC use (Addington-Hall and Altmann, 2000). Consultants in old age psychiatry reported being more likely to take a sexual history from younger men than older men, and were more likely to refer younger men with sexual dysfunction to a specialised clinic and older men to a community psychiatric nurse (Bouman and Arcelus, 2001).

Majeed and Cook (1996) found a sharp decline in the proportion of consultant episodes for ischaemic heart disease that led to further investigations after the age of 65. Although the authors fall short of explaining this as ageism, they make the point that age alone should not be a barrier to further treatment. A review of case notes to investigate whether services for ischaemic heart disease are supplied differently depending on the age of the individual found that exercise tolerance tests were less likely to be carried out among those aged over 75 years, and there was evidence suggesting that older people were less likely to receive surgical intervention or thrombolytic drugs (Bond *et al.*, 2003).

We did not find a consistent pattern in our analysis of papers on critical care. In a study designed to examine whether age determines how trauma victims are managed, Grant *et al.* (2000) found that when other factors were controlled for, greater age was associated with the initial management not occurring in a resuscitation room, not being admitted to an intensive care bed and not being transferred to a regional specialist centre, suggesting that older people are less likely to receive critical care. Similarly, in an American study using vignettes to investigate factors informing physicians' decision-making in admitting to the 'last available critical care bed', age was one of a number of clinical and social factors that were considered before a decision was made (Nuckton and List, 1995). However, the Hubbard *et al.* (2003) study found no evidence of age being a barrier to admission to intensive care. This study used an expert panel to blindly review the clinical data (diagnoses, procedures and test results) of 4058 'sick' patients from both wards and intensive care units and consider the

best place of care for each patient. Age was not associated with a greater likelihood of being inappropriately placed. It is possible that barriers to specialist services occur at an earlier stage in the process, so that older people denied particular procedures and tests would be excluded from a study of this kind.

Lung cancer that is potentially operable is at least as common among older people with this disease as among younger age groups (Peake *et al.*, 2003). Peake *et al.*'s (2003) study of 1,648 cases of lung cancer with a median age of 69 years found that of those over 75 years, 54 per cent had tumours that were rated by respiratory physicians as 'potentially operable', compared with 47 per cent in the 65-74 year age group, and 43 per cent in those less than 65 years. Yet this same study found inverse correlations between age and active treatment and survival.

Vulnerable subgroups

As with all ages, within older age groups there are sub-groups of older people who may face particular problems or issues in negotiating their candidacy for health care. We analysed a small sample of literature on two vulnerable subgroups of older people: older people from ethnic minority groups and older people living in nursing and residential homes.

Older people from ethnic minority groups

Alison Norman's seminal work on older immigrants in the UK coined the term 'triple jeopardy' that has been much used, although with some inconsistency, ever since (Norman, 1985). The triple jeopardy that Norman refers to is the risk of the combined effects of old age, cultural and racial discrimination, and lack of access to housing and social services. Norman's work related to a particular cohort of people from ethnic minorities who came to Britain and grew old in their 'second homeland'. Some of her observations relating to the acceptability and understanding of the GP role and the generally less well understood role of other community services, may still be relevant, though, as we show in the section on ethnicity, the data are contradictory and difficult to interpret.

In inner London, Livingston *et al.* (2002) carried out a cross-sectional survey of 1085 elders' need for and utilisation of health and social services. Across the six groups (those born in the UK, Ireland, Africa and the Caribbean, other European, and other) no empirical evidence was found for worse access to services for the non-UK groups. After controlling for confounders, African and Caribbean elders were twice as likely to use social services and Cypriot elders were twice as likely to access GP services. For Asian elders the story may be different. A comparative study of Asian Gujarati and White elders found poorer uptake of services among the former which could not be explained by better health (Lindesay *et al.*, 1997). The Asian group had higher

levels of physical disability, diabetes and visual impairment yet knowledge and understanding of services was poorer. Although fewer Asian Gujarati elders applied for services, for those that did, their likelihood of success was less. In this study there was evidence of greater family support for the Asian Gujarati elders but their dissatisfaction with services that were accessed was greater than among white elders.

Older people in institutional settings

By definition, older people in institutional settings, including residents of nursing or residential homes, represent a highly vulnerable group in terms of their physical dependency and availability of informal social support. Private nursing homes are the main supplier of long-stay care in the UK, but perhaps because they sit outside of the NHS, the evidence base for the effectiveness of health care in this particular environment is notoriously weak (Turrell, 2001).

The focus of the literature in this area has been access to health care services for residents of nursing homes. O'Dea *et al.* (2000) conducted a telephone survey of nursing home managers and compared provision of various community services accessed by residents with a national survey conducted a decade earlier. There was a much lower level of use of NHS physiotherapists and community nurses in the later study.

The ways in which general practitioners are involved in providing medical care for older people in institutional settings is far from straightforward. Kavanagh and Knapp (1998), in a study with some methodological problems, reported that people in residential or nursing homes were more likely to consult their GP and to receive visits from their GP. The numbers of GPs serving an individual home may range from between one and 50 (Glendinning *et al.*, 2002b). Although only a minority (8.5 per cent) of homes paid general practices for GP services, those that did varied greatly in the amount paid. A qualitative follow-up interview study of Glendinning *et al.*'s survey attempted to explore nursing home managers' and GPs' views of the way medical services are provided to nursing home residents (Jacobs, 2003; Glendinning *et al.*, 2002b). Most homes favoured efficiency over resident choice. In other words, if residents retained access to their own GP, then this was seen as having a potentially detrimental effect on communication between care staff and a larger number of GPs ultimately leading to a less effective primary care service for the resident.

Fahey *et al.* (2003) explicitly examined the quality of care services for older people. This case control study compared the quality of care received by nursing-home residents and those living at home. Evidence from this study suggests that older people in residential care are less likely to receive beneficial drugs, less likely to have existing

health problems monitored, and more likely to receive potentially harmful drugs including neuroleptic medication and laxatives.

Given that the number of beds in nursing and residential homes will need to double between 2000 and 2050 (Wittenburg et al., 1998) to meet the needs of an ageing population, concerns have been raised about future shortages of nursing home care. Kerrison and Pollack (2001) point out that while care homes are subject to inspection and regulation by statutory bodies (Commission for Social Care Inspection), the actual quantity of places in care homes is driven by market forces alone. This means that there is no legislation in place that requires that homes are provided; unlike other health services, where primary care trusts are required to provide services to meet the health care care needs of a particular population. What decides whether or not a nursing-home is available is whether or not it is economically viable for the home owner.

Other vulnerable subgroups

Urban-rural variation was the focus of a study looking at service provision for older people through a structured interview survey (Fordyce and Hunter, 1987). Although urban dwelling elders tended to have more contact with services such as district nursing, health visiting, and meals-on-wheels, these differences were largely due to other factors. No evidence was found for an 'urban-rural divide'. However, older rural dwellers may be more disadvantaged when it comes to non-domiciliary services or more centralised services.

Although no other geographical patterns of inequality in access were apparent from the studies we analysed, there was evidence of large variation in the way services are distributed and delivered. One study examined the variation in old age psychiatry services (Challis *et al.*, 2002). They varied in terms of their lower age limit and also in terms of the professional groups and users the service would accept referrals from.

Older people living alone have raised concerns about their potential vulnerability. Illife *et al.* (1992) found that living alone did appear to increase use of GP, community, and social services, but people living alone were not more likely to be in contact with hospital services. Overall there did not appear to be an excess of morbidity, or disproportionately lower use of services among the living alone group. The main point of vulnerability identified for this group was the need for a contact in cases of emergency.

Summary: Construction of the problem of access to health care by older people

Older people are heavy users of health services, although there is some evidence that in certain areas of health care there may be under-utilisation among this age group relative to their need.

Depressive disorders in particular may be under-diagnosed. Although there is some evidence of decreasing receipt of some services and interventions with increasing age, the explanation for this finding is not evident from studies of receipt and utilisation. Some vulnerable sub-groups may be especially unlikely to use or receive services, but the needs of older people from ethnic minority groups is a relatively under-researched area. Far more work has looked at the health care provision for older people in nursing and residential homes, and there are concerns that people living in such residential settings may receive poorer quality of care.

6.2.2 Theme 2: Recognition of candidacy by older people

Our analysis of issues relating to how older people recognise their candidacy for health care was organised around the following themes:

- Identification of candidacy and age attribution.
- Identity.

Identification of candidacy and age attribution

Although a number of studies analysed in our sample started with the premise that older people consider a large number of potentially treatable health problems to be part of the natural process of ageing, a phenomenon described by Walters *et al.* (2001) as 'age-attribution', the evidence for this was mixed (Morgan *et al.*, 1997; Delaney, 1998). There is a suggestion that older people and younger people do view symptoms differently, but the relationship is not straightforward. There was no independent effect of age observed when social class and ethnicity were controlled for in a vignette study of primary care patients' likelihood of consulting primary care or emergency services (Adamson *et al.*, 2003). In an Australian study, symptoms of a more serious nature were considered more urgent by older participants, whereas non-serious symptoms were considered less urgent than among younger participants (Helmes and Duggan, 2001). Older people may be less inclined to seek help for more trivial problems because of the effort they perceive will be involved in reporting their problems. Alternatively, older people may fear the more drastic consequences, or be more informed about the implications of more serious symptoms. However, in an American survey of public knowledge of symptoms of stroke, those in older age groups were less knowledgeable than their middle-aged counterparts about stroke symptoms and the need for contacting emergency services (Greenlund *et al.*, 2003).

Walters *et al.* (2001) in their study of primary care users and their carers, reported that help was sought by older people for less than a quarter of identified needs. This was explained by 'withdrawal' from social contact, resignation to the situation, and low expectations of

any potential benefit of contacting their doctor. Age attribution was found to be less common than might be expected, except in relation to memory problems. Similarly, Morgan *et al.* (1997) studied older people's perceptions of seriousness of a list of symptoms and the action they were likely to take in response. Although most participants indicated that they would consult for serious symptoms, there were a number of symptoms of psychiatric disturbances considered by older people as 'normal' and not warranting medical attention. Examples might include forgetfulness, which might be considered as a normal part of ageing but may be a symptom of dementia; and somatic symptoms such as change in appetite, sleep patterns and general fatigue, which may be symptoms of depression.

Most investigations of help-seeking behaviour and symptom interpretation among older people have been condition specific. In a qualitative interview study of people who had consulted with dyspepsia, delayed consultation was frequently due to individuals putting their symptoms down to 'old age' (Delaney, 1998). The finding by Shaw *et al.* (2001), that older people with urinary symptoms are more accepting of their symptoms and less likely to seek help is difficult to interpret. Acceptance could be a more positive interpretation of what is described elsewhere rather more bleakly as 'resignation', or it could be that older people are more sensitive to the stigma associated with certain symptoms and seek to protect their identities, as we discuss later (Walters *et al.*, 2001). Green and Sidall (2002) found that, at the time of diagnosis of glaucoma, participants in their qualitative study could recall a range of eye problems that were only recognised as symptoms in retrospect. Such symptoms were experienced as part of the range of minor problems that affect most people from time to time, and were easily accommodated as normal signs of ageing, tiredness or expected deterioration of vision over time.

There is some evidence that depression in particular may be seen by older people as an illness not requiring or not deserving of medical attention. In a qualitative vignette study of white British and Black African Caribbean older people, Marwaha and Livingston (2002) found most people, regardless of ethnicity, did not consider a vignette of a man with depression to indicate illness. Both ethnic groups proposed that mental health services were not for treating depression.

Identity

For older people, even those with chronic diseases (such as heart disease or renal failure) there is evidence that for many older people, being healthy, independent and active is central to their sense of identity. There is also strong evidence to suggest that older people are highly sensitive to the perception that they are an unwelcome burden on health services, and that they ration their use of services to protect their identities as responsible and unselfish. Two studies of uptake of

influenza vaccination demonstrated that for some older people, the need to show that they are in control of their health, and not a 'bother' to health services, may discourage them from being immunised (Cornford and Morgan, 1999; Dixon-Woods *et al.*, 2004). However, it was also evident that protecting their identity as responsible, rational individuals encouraged other people to take up offers of immunisation. A recent quantitative study similarly found that perceived good health was an important variable in predicting uptake (Evans and Watson, 2003). The importance of not wishing to seek help unless it was absolutely necessary may also be related to many older people's identity. In Foster's study of out-of-hours care, an uncomplaining attitude towards health was frequently expressed (Foster *et al.*, 2001). Participants in this study also placed great value on receiving care by a trusted general practitioner familiar with their identity in terms of their own history. Having known a time without a national health service, there was evidence in at least one study that older people felt they should only consult a doctor in extreme circumstances, and that this habit was hard to break (Shaw, 2001).

Our analysis suggests that issues of identity are particularly important for carers of older people. Their identity of 'a carer' as based on 'duty and endurance' may inhibit help-seeking (Walters *et al.*, 2001). Further evidence for an identity based on duty was found in a small study looking at barriers to health care access faced by older people in a rural setting (Bentley, 2003). Interviewees reported a far greater concern with their responsibilities as users of health services than with their rights. Notions of identity are also apparent where those seeking help do so by placing their health problems in the context of their family history (Delaney, 1998).

Summary: Identification of candidacy by older people

Identification of candidacy is affected by 'age-attribution' although this may be restricted to particular health problems and symptoms. Symptoms of low mood, memory problems and anxiety may be considered by older people as part of the natural ageing process but the stigma many older people associate with mental health problems may also contribute to discouraging consultation. There was some suggestion in our analysis that this may be that age-attribution is a more comfortable explanation for service providers than disillusionment with services that some older people may feel.

There is evidence that there is a strong need for older people to retain an identity as being fit and healthy almost regardless of their actual health. Our analysis suggests that older people and informal carers place great importance on their own responsibilities and duty in health care interactions, occasionally resulting in declining offers of help or services to avoid being perceived as burdensome.

6.2.3 Theme 3: Navigation of a route to and through health services

We have organised our analysis of the issues in older people navigating a route to find a point of entry to health services, or to sustain engagement in health services in pursuit of a claim to candidacy, around the following themes:

- Practical resources.
- Social support.
- Comfortable services.
- Discontinuities and permeability of services.

Practical resources

As for the other groups we have discussed already in this review, older people's use of services often requires the mobilisation of a daunting array of practical resources. Our analysis demonstrated that mobility is perhaps the most significant problem. Travel was an issue for older people who participated in a focus group study of out-of-hours care, with public transport considered unreliable and unsafe, and taxis too costly or untrustworthy (Foster *et al.*, 2001). In Foster *et al.*'s study (2001) a reluctance to use the telephone, feeling too unwell, and feeling unsafe out of the house at night were other reasons for choosing not to make contact with out-of-hours primary care services. Difficulties in getting to screening appointments because of problems in the availability of private or public transport may disproportionately affect older people. In a follow-up of women invited for breast screening in two rural communities, uptake was significantly higher among younger (less than 60 years) than older (60 to 64 years) with transport difficulties cited as a reason for non-attendance (Stark *et al.*, 1997).

Social support

Although older people draw on many resources that any age-group are likely to draw upon, such as family and friends, they may also favour certain types of resources. A survey of coping and help-seeking behaviour, found younger people coped with health problems by using more informal help, whereas older participants tended to favour more formal sources of help such as doctors and priests (Barker *et al.*, 1990).

Family and friends can provide both a supportive function and one of legitimisation. Lay consultations where an individual involves family and friends before consulting their general practitioner are not uncommon (Delaney, 1998). There is evidence for this among the female participants in a qualitative study of older people living in a rural community (Bentley, 2003). In the same study a suspicion of

medications and a tradition of 'coping in the village' led to a greater reliance on friends and neighbours.

Comfortable services

In previous sections we have emphasised that people tend to use services which are most porous to them. These are likely to be services which are most closely aligned with their own life circumstances, and least dissonant with their cultural and social background, and require least effort to use. Our analysis suggests that similar issues operate in affecting older people's use of services. We suggest that they are most likely to use services which they perceive as most 'comfortable'. These are services, which they perceive to require least effort to use, where their expectations that they will be treated in a sensitive way are greatest, and where they feel most comfortable, both physically and psychologically.

It has, however, proved difficult to study older people's views of services. Owens and Batchelor (1996), among others, have identified the tendency for older people not to express criticism of services. Some patients are reluctant to criticise services because of their dependency on these services or for fear of increasing workload on health service staff. It is also argued that seeking older people's views is not necessarily a benign exercise, and that people may feel 'used' or that the questions are too personal.

Low expectations of the ability of health services to intervene successfully may play a part in people's willingness to act on identified candidacy as well as on their choice of services. Most surveys of patient satisfaction, notwithstanding the methodological difficulties inherent in such studies, have found that greater satisfaction with health services increases with age and that this is consistent over time (Bollam *et al.*, 1988; Calnan, 2003). There are various interpretations of this finding. Older people have greater experience of health care and more direct contact may temper expectations of provision. However, if older people's dependency is re-enforced during contact with health providers then what is reported as satisfaction may be more accurately described as gratitude and passivity. Within older age groups, there is evidence that older people from ethnic minority groups are generally less satisfied with services (Lindesay *et al.*, 1997).

Qualitative work in this area appears to be more sensitive in identifying dissatisfaction of health care. Conway and Hockey (1998) carried out 15 in-depth interviews with older people that suggested that many of their health-beliefs were at odds with conventional medicine and their role in interactions with health services was far from passive and uncritical. When offered theoretical options, older people show great variation in what they consider important. In a study using conjoint analysis, there is evidence that potential service users of cataract surgery make judgements along a number of

dimensions and make trade-offs between complication risk and waiting time (Ross *et al.*, 2003).

The perceived attitudes of health providers may be important in influencing whether older people are faced with psychological barriers to seeking help. This is particularly true of stigmatising conditions. There may be a period of 'tentative testing' by older people of the likely reaction their presentations may inspire. In primary care, who patients get to see may also affect their initial presentation. This may be truer of older patients. In a cross-sectional study of 111 patients, greater age was associated with both preference for and receiving continuity of primary care (Freeman and Richards, 1993). With government directives to improve the speed of access to an appointment with a general practitioner, older people may be disadvantaged if this has the likely effect of reducing choice of doctor.

Discontinuities and permeability of services

Fragmentation, discontinuity and a lack of permeability appear to present older people with difficulties in progressing with their candidacy. One study suggested that older people disliked having to go through their general practitioner for ophthalmic outpatient services (Percival, 2003). Some of the visually impaired interviewees felt that their general practitioner was not receptive to their needs and believed that the outpatient process should be 'faster, clearer and more user-friendly'. The way health services are organised and the impact this has on stroke recovery was the focus of one of the studies analysed by Hart (2001). In her study 13 out of 57 stroke survivors suffered setbacks which were 'system-induced' and a direct result of interactions with health and social services. These setbacks were not as a result necessarily from lack of intervention, but often due to an exhausting range and number of overlapping professionals involved, or in lack of service co-ordination.

In Tod *et al.*'s (2002) study of staff and users of post myocardial infarction cardiac rehabilitation services, the older people in their sample reported faring worse in terms of access because of gaps between services. In this study, an absence of resources meant staff focused on the delivery of the service they were responsible for, but little attention was paid to the way services were connected. Services tended to be centralised and hospital based and this presented older people in particular with problems of access.

Glendinning *et al.* (2002a) have highlighted a number of discontinuities at the boundaries between services that are required to work closely together to help older people maintain good health, or recover from ill health. The 'Berlin Wall' between NHS and social care boundaries has been discussed extensively but within health or social care, a number of organisations have different eligibility criteria and funding arrangements that make care pathways problematic. Glendinning *et al.* suggest that older people who experience relatively

common problems such as hip fracture are faced with a myriad of clinics and professionals to deal with and substantial discontinuities between them.

Summary: Negotiation of a route to and through health care

We identified a number of factors that appeared to discourage older people from pursuing their candidacy for health care. Receiving treatment from a doctor unfamiliar with the older person's medical and social history appears to be a particular problem and the chances of this happening may affect the decision to seek help. Perhaps because older people have invested more in their relationship with their GP over a number of years they are more reluctant to accept help from an alternative source. General practice is a 'comfortable' service for older people who appear to place greater value on continuity of health care.

Health care discontinuities appear to present older people with more problems than younger age groups. It is possible that with a higher level of co-morbidity in late life, more complex service packages are required to meet the health needs of many older people. However, there is evidence that there are a daunting number of gaps and overlaps of service provision within care pathways. There may be fewer resources to negotiate care or their use may be less straightforward.

6.2.4 Theme 4: Presentations, categorisations, adjudications and offers

We organised our analysis of the literature on the ways in which older people present to health services and decision-making about services and interventions for older people around the following themes:

- Presentations.
- Categorisations.
- Adjudications.
- Technical and social candidacy.
- Offers and uptake.

Presentations

As with the groups reviewed in the earlier sections, direct observational studies of doctor-patient interactions for older people are rare, but there are indications in the existing literature that older people are disadvantaged in their interactions with health professionals: they may not 'present' in ways that allow their problems to be readily recognised, may have more difficulties in understanding what is said, may be less willing to make choices, and may be more passive (Cooper and Roter, 2003). There are also important effects of 'companions', who accompany older people to consultations, that have

been little studied. Cooper and Roter (2003) summarise evidence showing that when a companion is present, older patients raised fewer topics, were less responsive to the topics they did raise, and were less assertive and expressive. There was sometimes a tendency for a family member or other companion to take on the information-giving role in the consultation, sometimes contradicting the patient or disclosing information the patient had not wanted revealed.

The way in which health problems manifest themselves in later life, or the greater degree of co-morbidity may affect the ways in which people present their health problems in consultations, and may in turn influence the adjudications made. Late-life depression is an example of this. Older people may be more willing to seek help and report physical symptoms than symptoms of mood or psychological problems (Beekman *et al.*, 1995; Evans and Katona, 1993; Livingston *et al.*, 1990). In the 1990 follow-up to the original Gospel Oak Study, only 38 per cent of those with 'probable pervasive depression' had declared their symptoms to their general practitioner (Blanchard *et al.*, 1994). A large proportion of primary care patients surveyed in the United States (21 per cent) had symptoms of depression but a much lower proportion (1.2 per cent) cited depression as a reason for visiting their GP (Zung *et al.*, 1993). Gender as well as age may also play a part. In a study restricted to older people, women were less likely than men to seek help from their doctor if they were depressed (Bruce *et al.*, 1999).

Categorisations

Throughout this report we have emphasised the importance of the typifications made by professionals about groups of people and about the health problems of those people. Editorial and review work in the area of older people has often argued that 'ageist' behaviour pervades the health service, and that the ways in which older people are categorised amounts to discrimination. However, discrimination has largely been inferred from studies of receipt of services, and the empirical evidence-base is lacking on processes of decision-making, how adjudications about referral, prescribing and offers of interventions are negotiated, and investigation of the contextual influences on these processes.

Most of the literature on how older people are subjected to 'ageist' assumptions has come from North America where, among people aged 60 years and over, the experience of ageist incidents is both widespread and frequent (Palmore, 2001). A meta-analysis of studies that compared attitudes towards older and younger people found that attitudes to older people were generally more negative (Kite and Johnson, 1988). In studies included in Kite and Johnson's review that attempted to measure ageist attitudes, over the age of 65 years, the majority of older people have reported experiencing some form of ageist behaviour although, as with other stereotyping, difference in

attitudes is diminished when individuals are compared rather than groups. There is some evidence that a significant minority of older people perceive that the NHS discriminates on the grounds of older age (Age Concern, 1999). In this poll of 1597 adults over the age of 50 years, one in 20 respondents reported being refused treatment on the basis of age, and one in ten said they felt that they had been treated differently by health care providers.

What is clear is that detection of some types of illnesses in older people may be more difficult. For example, diagnosis of depression in older people is more difficult because it may be more likely to present with somatic and anxiety symptoms rather than overt sadness (Katona and Livingston, 2000). Mental health problems where symptoms may not be physical are particularly hard to detect in older people where physical co-morbidity is prevalent. Estimates of rates of 'missed' depression vary from six to 50 per cent (Jenkins *et al.*, 1994; Illife *et al.*, 1991; Crawford *et al.*, 1998). Patients whose depression was missed by their GP may be more likely to be male, married, have higher levels of physical handicap, suffer from visual impairment and have a lower level of education than older people whose depression was recognized by their GP (Helmes and Duggan, 2001; Crawford *et al.*, 1998)

Age-attribution may be a factor in the way health providers respond to presentations by older patients. A retrospective case note review of 999 calls that did not result in transported cases found falls among older people were the largest single group of cases (Marks *et al.*, 2002). The study authors argued that this was either evidence for the need for alternative responses to 999 calls or that the attitude of the ambulance crew may be affecting the older person's decision to refuse to go to hospital.

Adjudications

For presentations to be converted into interventions to improve outcomes, some form of recognition is required, usually by primary care providers. There is a body of evidence that suggests that older people are disadvantaged by the adjudications made by staff, but because this has failed to distinguish the different dimensions of candidacy, and in particular has focused on utilisation and receipt rather than offers and uptake, it is difficult to draw firm conclusions. The evidence that does exist suggests that older people may be disadvantaged because of judgements about *conversions* – their ability to convert interventions into benefits, and in particular benefits that will persist sufficiently long to justify the investment; judgements about *use of resources* – whether resources used for older people would be 'better' used for younger people, who might have greater ability to make conversions; and judgements about *acceptability* – the extent to which older people want or can cope with interventions.

There is some evidence that those who perceive that they are being treated on the basis of their age rather than their clinical need may have worse outcomes. A US telephone survey of 1812 older women with breast cancer found that those who perceived that they had been subjected to ageism in treatment decisions, had worse health outcomes in terms of bodily pain, mental health and general satisfaction levels (Mandelblatt *et al.*, 2003). Yet there is no suggestion that this amounts to cause and effect. More compelling evidence of the effect of stereotyping on older people's physical functioning was found in a randomised controlled trial by Haurisdorff *et al.* (1999) who compared two groups of older people who had been exposed to positive and negative stereotypes of ageing. Those exposed to the positive stereotypes showed greater walking speed immediately after, with no change in the group exposed to negative stereotypes.

As a speciality, caring for older people has been seen as an unpopular choice for nurses in the health service. Nurses tend to view older people in terms of their physical and mental dependence although health care assistants who work more intimately with older people in hospital settings may view older people in terms of their personality (Cooper and Coleman, 2001).

Technical and social candidacy

We have shown in earlier sections that considerations of 'technical' candidacy – the extent to which individuals fit the profile of eligibility for particular interventions, and their ability to 'convert' interventions into health gains – may strongly influence adjudications and offers. We have emphasised the highly negotiated character of adjudications.

There is a body of evidence that appears to show that issues of technical candidacy are important in explaining lower than 'needed' receipt of some services and interventions among older people. For example, work carried out in the United States assessing the use of adjuvant therapies for post-menopausal women with breast cancer found that older women were more likely to receive hormonal therapy and less likely to receive chemotherapy or both chemotherapy and hormonal therapy (Guadagnoli *et al.*, 1997). The authors argued that this pattern broadly reflects what is known about treatment efficacy. Varekamp *et al.* (1998) similarly show how considerations of the fitness of people influence judgements of the suitability of older people for renal transplantations.

Again, however, there is evidence that judgements about technical candidacy may be flawed, that they may contain elements of social candidacy, or that technical candidacy may be invoked to justify decisions made on other grounds. Goddard and Smith (1998) report that doctors may mistakenly believe that some groups cannot benefit as much as others. Older people may well experience greater levels of co-morbidity which may make them less favourable candidates for

surgical procedures, but age bias has been found in studies of coronary heart disease which control for this factor. One of the studies we analysed found statins were half as likely to be prescribed to 65-74 year olds as to the under 65s (Reid *et al.*, 2002). There is no RCT evidence that statins are less effective among older people, and because they are unlikely to cause an individual a great deal of inconvenience and burden in the way that physical tests, outpatient appointments, and surgical interventions may, the finding by Reid *et al.* is more easily explained by provider rather than user preference.

Similarly, Lamping *et al.* (2000) argue, based on a prospective cohort study of outcomes in 221 people with end-stage renal failure aged over 70 years, that age should not be used as a barrier to dialysis. The one-year survival rates for older people in this study (71 per cent for all patients who started dialysis and 81 per cent for those who survived 90 days) compared highly favourably with the 63 per cent and 85 per cent survival rates reported in a previous UK study of patients of all ages who were 15 years younger on average.

However, a key problem is that the evidence base for the effectiveness of many treatments for conditions / health problems experienced by many older people is weak, and judgements made apparently on 'technical' grounds may in fact be social constructions of technical eligibility. Callahan (1996) points to the research literature that suggests depression in late life is unrecognised and under-treated, and argues this can be explained by the lack of scientific data to guide the treatment of late life depression. A 'catch 22' situation exists in that older people are often excluded from trials that provide the evidence base for effectiveness of treatments. Exclusion of those over upper age limits is common and goes unjustified in approximately half of research protocols reviewed by ethics committees (Bayer and Tadd, 2000) and over a third of reports of clinical research (Bugeja *et al.*, 1997). It is possible that this situation is getting worse. In a review of published RCTs of drugs used to treat the motor symptoms of Parkinson's disease, few studies included those over the age of 75, with more recent studies being the worst offenders (Mitchell *et al.*, 1997). Elsewhere, the lack of evidence for interventions for older people with diabetes has been noted (Croxson, 2002).

The reasons behind the exclusion of older people from clinical trials are often not made clear but may be varied. Trials for new treatments are often carried out on subjects with little or no co-morbidity to avoid unnecessary risk and limit the effect of confounding variables. Obtaining informed consent from older people with cognitive impairment to participate in clinical trials raises ethical issues that can be avoided if cognitive impairment becomes part of the exclusion criteria. There is no evidence that we are aware of that older people are any less likely to want to take part in clinical research than any other age group. The net result is that older people are at risk of

receiving treatments that are tested on younger age groups or denied treatments due to absence of evidence for effect.

In a retrospective study of emergency hospital admissions for those aged 75 years and over there was a five-fold difference between practices on emergency admission rates despite relatively similar demographic profiles (Ambery and Donald, 2000). In this study more than half of the GP's interviewed admitted that they were greatly influenced by patient and family views.

Offers and uptake

We have been concerned throughout this report to show that measures of utilisation and receipt do not allow access to an understanding of offers and uptake. Our analysis suggests that older people may not be made offers that are made to younger people, but there is insufficient evidence to conclude that lower levels of offers are the result of inherent discrimination on the part of health care providers – instead offers may be the outcome of a negotiated process between professionals and patients. Offers to older people may be less likely to be accepted, because of the higher emotional, social, psychological and economic threats involved in accepting offers.

Goddard and Smith (1998) point to evidence showing that GPs report that they are more likely to refer younger patients with coronary heart disease compared with older ones with similar stages of disease, and that they believe age should be taken into account in prioritising people for re-vascularisation. The reasons behind this are not clear and although some doctors seem to believe that older people will get less benefit from the treatment, others have found that referral decisions involving older people are independent of perceptions of the benefits, suggesting a conservative approach. Goddard and Smith comment that some GPs feel that older people would not want lots of investigations, and that older people who live a long way from specialist centres would not want to travel. However, it is not clear whether GPs make offers that are refused, or whether they do not make offers at all.

In a rare example of a study of not only help-seeking but the extent of offers of help made, Walters *et al.* (2001) interviewed 31 older primary care users and 11 carers. Of the 104 needs identified through a formal schedule, help was found to have been offered for less than a fifth of the unmet needs identified. Data on 'offers' generally are lacking, limited primarily to studies where some kind of formal offer is made in the form of letters or other contact by health providers. However, this kind of offer represents the minority of offers made to older people. Most offers occur in private following a process of adjudication and negotiation with health care providers and, other than case-notes – an unsystematic and often unreliable form of data – there is no formal record available to researchers. Obtaining valid data on actual health-seeking behaviour among older people using self-

report measures is problematic. In a study assessing the use of old age psychiatry services, many older respondents denied their use despite being prescribed anti-dementia drugs which were only available following referral to a specialist service (Livingston *et al.*, 2002). We can therefore say little about the offers made as a result of help-seeking behaviour and forms of candidacy that are initiated by older people themselves. The two areas where offers and uptake in relation to older people have been fairly extensively studied are in over-75 health checks in general practice, and influenza vaccination.

Although annual health checks for registered patients aged over 75 years were introduced in 1990, their implementation over subsequent years has been patchy and variable (Brown *et al.*, 1992; Wilkieson *et al.*, 1996; Trelleman, 1992). Over a three-month period, in 40 practices only 12 per cent of registered patients aged 75 years and over were seen in contrast to the 25 per cent expected (Brown *et al.*, 1997). There is a suggestion that those older people who are most in need are least likely to know about the availability of health assessments (Chew *et al.*, 1994). In contrast to this, no evidence of poorer health among those who declined the offer of a health check compared with those who accepted it was found in a data linkage study (Jagger *et al.*, 1996).

A more recent randomised controlled trial comparing methods of over-75 assessment approach (lay interview, nurse interview, postal questionnaire) found the highest uptake for the postal questionnaire (Smeeth *et al.*, 2001). This finding suggested that willingness to travel may affect uptake of assessments held in general practices. Acceptance of offers for health checks by any approach was inversely associated with increasing age. The concern remains that the more vulnerable and older are not availing themselves of the opportunity for assessment, or that they feel their problems are already dealt with.

All those aged 65 years and over are now encouraged to come forward annually for vaccination against influenza, but uptake rates are in the region of 70-75 per cent. Many older people do not consider themselves ill and therefore do not perceive themselves to be at risk of serious consequences of influenza (Cornford and Morgan, 1999). Not coming forward for influenza vaccination has been associated with fear of adverse side effects, and the perception of not being susceptible to influenza (Honkanen *et al.*, 1996; van Essen *et al.*, 1997). However, among those who hold negative beliefs about the effectiveness and adverse consequences of the vaccine, information from a health visitor may encourage older people to receive the influenza vaccine (Honkanen *et al.*, 1996). Nonetheless, as recent evidence shows, some older people who refuse influenza vaccination do so for reasons that are important to them, in terms of protecting their identity and maintaining control over their health; they feel in refusing immunisation they are making an informed choice (Dixon-Woods *et al.*, 2004). It is important that the choices older people

make in declining 'offers' be respected rather than read as straightforward evidence of inequity or poor services.

Summary: Presentations, categorisations, adjudications and offers

Older people may make presentations in ways that tend to disadvantage them. When older people report certain conditions they may do so in an indirect way to test the likely response of their doctor. Service providers may need to heighten their sensitivity to the presence of potentially stigmatising conditions, such as urinary incontinence and mental health problems.

Review evidence, and some empirical work, suggests that care pathways that involve a number of health and social care organisations often involve discontinuities in services that discourage older people from persevering.

There is evidence that older people feel stereotyped by service providers and while most commentators agree this occurs, the evidence base for this is weak and based on vignette studies. We found evidence that where older people do feel stereotyped, this results in a loss of confidence, decisions not to seek help and worse health outcomes. The stereotype of the older, grateful patient is reinforced in data from satisfaction surveys but challenged in the qualitative literature.

Most of the empirical literature providing evidence for worse access to health care by older people looks at service utilisation. For various specialist services, there is evidence that older people are managed in a less aggressive way (with some exceptions), and are more likely to receive generic rather than specialist services. The lack of high-quality evidence available to providers on effectiveness of interventions for older people also inhibits offers being made.

It is unclear whether lower rates of receipt of services among older people are a result of fewer offers being made, or a higher rate of refusal by older people themselves. At present evidence for the relationship between offers and uptake is restricted to preventive services that are initiated by providers.

Older people from ethnic minority groups appear to interact differently with service providers and gatekeepers but the evidence for this is limited and varies between ethnic minority groups. There was a substantial body of literature that argues that being a resident of a nursing or residential home is a barrier to accessing both mainstream and specialist NHS services.

6.2.5 Theme 5: Improving access to health care for older people

Our analysis above highlights the difficulty in pinpointing where, how, and at what point older people might be disadvantaged in accessing health care. The policy response to this has been dominated by The NSF for Older People. This is an attempt to ensure 'fair, high quality

[and] integrated services' for older people by promoting certain values that should cut across services for older people, and prioritising and target setting for specific services. Perhaps because there is uncertainty about the point in the process where interventions should be targeted, there have been few methodologically strong intervention studies designed to improve health care access for older people. We did locate intervention studies targeted at improving uptake of specific services among older people, and studies aimed at improving service providers' knowledge about health problems that often go unrecognised among older people. However, the majority of the papers we analysed within this theme are policy critiques and descriptive evaluation reports of local initiatives.

We organised our analysis around the following themes:

- The New Framework.
- Health Needs Assessment.
- Specific interventions.

The New Framework

The National Service Framework for older people, introduced in 2001, was preceded by a number of policy reports by statutory bodies and pressure groups suggesting that health care services for older people were under-funded and under-performing. Help the Aged's (2000) review of hospital services found a number of examples of poor care standards, in particular, the problems of inadequate nutrition for older people in hospital and a lack of attention to preserving older people's dignity. An Audit Commission (2000) investigation of mental health services highlighted a lack of co-ordination between primary care and specialist services, an eight-fold difference in expenditure on old age psychiatry services between different localities, and a general dearth of information provided to older users and their carers.

Unlike previous NSFs that have focused on specific health problems and clinical services, this was the first NSF that took a much broader approach by defining a group in terms of their age rather than their health status. The eight standards of the NSF, all of which directly or indirectly deal with the issue of access, are:

- Rooting out age discrimination.
- Person-centred care.
- Intermediate care.
- General Hospital care.
- Stroke.
- Falls.
- Mental health in older people.

- Promotion of health and active life in old age.

Commentators are divided on how older people are likely to fare under the new NSF policies and proposed service models. Shortly after the publication of the NSF, Evans and Tallis (2001) argued that there is implicit institutionalised ageism in the need to put a brake on acute hospital admissions by people aged 75 years and over. They suggest that the term 'inappropriate bed use' is too often attached to the patient rather than the treatment. The proposal to use intermediate care as a new organisational form to speed up recovery was criticised by the authors. They suggest that intermediate care has the potential of bypassing sites with high levels of diagnostic expertise and technical resources or could be treated as a way of unblocking hospital beds that older people should have an equal right to accommodate. The authors of a systematic review of the effectiveness of hospital at home make a similar point: there is insufficient evidence to support the widespread adoption of hospital at home services while discontinuing existing hospital based capacity for older medical patients (Shepherd and Iliffe, 1998).

Swift (2002) makes a distinction between two groups of standards in the NSF. The standards that propose service models for the sub-specialties of stroke, falls, and mental health, are largely applauded, underpinned as they are by evidence and 'operational experience'. However, he raises the concern that standards relating to ageism, person-centred care and intermediate care suffer from a lack of conceptual clarity and operational feasibility. His arguments are backed up by a telephone survey of 75 senior managers of health and social care organisations responsible for implementation of the NSF. Three quarters of senior managers believed that age discrimination was present in their service and few were clear on how it could be 'rooted out'.

The NSF appears to fall within the wider policy context of integrating services for older people. Glendinning *et al.* (2002a) argues that funding and contractual relationships between services, introduced in the 1980s and 1990s, may have increased the difficulty of co-ordinating services. They suggest that this problem remains with the introduction of primary care trusts as chief commissioners for acute services and the responsibility for integrating primary care and community services. Although there is a statutory duty to work in 'partnership', this may be difficult to reconcile with the need to meet externally prescribed targets.

It is too early to say whether the ambitions of the NSF will be fully realised. The Health care Commission is currently undertaking reviews of the local and national implementation of the NSF. Some surveys of service providers directly affected by the NSF suggest that there are problems of clarity over what is required and concern over funding to support this. A postal survey of stroke physicians found that few NHS trusts were likely to have all components in place in order to meet the

NSF targets by the set date of 2004. A general lack of training opportunities for junior doctors meant that this situation was unlikely to change in the short-term (Rodgers *et al.*, 2003).

Health Needs Assessment

The key policy initiatives in recent years for identifying and assessing need have been the over-75 health checks, introduced with the 1990 GP contract and the Single Assessment Process (SAP) that forms part of the NSF for older people. As discussed earlier, the over-75 health checks were put in place in response to a concern that a significant proportion of older people's needs were unreported, unrecognised and unmet. The evidence for the effectiveness of such an intervention was contradictory although the most recent meta-analysis that we could identify suggests there are positive outcomes to home-based preventive visits (Elkan *et al.*, 2001). In Elkan *et al.*'s (2001) systematic review, 15 trials were analysed and home visiting to older people was associated with reduced mortality and reduced admission to long term institutionalised care.

The SAP on the other hand is part of the drive for greater co-ordination of services and assessment is in proportion to need. The work by Hart (2001) discussed above provides examples of older people feeling swamped with assessments by professionals from different organisations. The purpose behind the SAP is to share information across a range of service providers to avoid repetition and over-burdening. There will be significant challenges in the information technology infrastructure required and the methods needed to secure consent from users and carers to share information.

Specific interventions

Examples of good practice for each of the NSFs are available to the general public (<http://www.dh.gov.uk/PolicyAndGuidance/HealthAndSocialCareTopics/OlderPeoplesServices/OlderPeoplePromotionProject/fs/en>) but evidence for their success remains anecdotal without formal evaluation. Of the eight standards, only the first, rooting out ageism, has yet to provide an example of good practice, supporting other commentators who have suggested that this is likely to be the most difficult of the eight standards to implement.

We found no good UK intervention studies that tested whether negative attitudes of health care staff toward older people can be improved. Perhaps unsurprisingly, negative attitudes are identified at an early stage in medical careers. In an American study using vignettes to look at the effect of age on medical students' recommendations for treatment of breast cancer, respondents were more likely to recommend breast conserving treatment for younger women and modified radical mastectomy for older women (Madan *et al.*, 2001). It is important that training in age sensitivity does not

result in age stereotyping. Cooper *et al.* (2001) reported health care assistants more likely than registered nurses to view older people in hospital more in terms of their personality rather than their clinical condition, this may suggest that generic training may unintentionally re-enforce negative stereotypes of older people. Educational interventions we suggest need to be highly focussed if they are to have an effect on the way decisions around older people's health care are adjudicated.

Recognition of mental health problems may be improved by education interventions for GPs, but the evidence is weak. A non-randomised intervention study carried out in Australia examined an intervention to improve the detection of depression and dementia (Pond *et al.*, 1994). Six months after a 15 minute education programme there were improvements in the detection of depression but no improvement was seen in the recognition of dementia. There is a lack of evidence that improved detection and recognition improves mental health outcomes.

Other interventions have sought to actively identify older people who are depressed and deliver specialist services. There is evidence that depressed older people may benefit from nurses acting as case managers (Blanchard *et al.*, 1995) or multi-disciplinary psychogeriatric team interventions (Banerjee *et al.*, 1996). However, although Arthur *et al.*'s (2002) randomised controlled trial of a community mental health team intervention for depressed older people was underpowered, there was some suggestion that those randomised to the community mental health team had worse outcomes. The authors suggested that there may be a negative effect of active case-finding for potentially stigmatising conditions and older people may be more comfortable with seeking help from their GP on their own terms.

Education of informal carers may improve both user and carer outcomes. Kalra *et al.* (2004) evaluated the effectiveness of training informal care-givers of stroke patients in basic nursing techniques and found both reduced rehabilitation costs, and improved quality of life in both users and carers. This suggests that empowering the user or carer may be more effective in achieving improved health outcomes than interventions focussed on service providers.

There are no comparative studies that we are aware of that have looked at how and whether the active involvement of older people in the planning and delivery of health care services improves access or health outcomes. In an American paper by Katz *et al.* (2000) the introduction of a 'Council of Elders', in which a group of community elders were invited to work as collaborators alongside medical residents in dealing with problems and dilemmas in providing health care for older people. Although the study is descriptive, the authors argue that the project resulted in more decision-making with, rather than for, the older patient.

The impact of older people's champions, introduced in the NSF, is yet to be known. Older people's champions refer to those with either a managerial, clinical or user representative lead within an organisation to ensure that older people's interests are represented throughout the organisation

(<http://www.publications.doh.gov.uk/nsf/olderpeople/roleofchampions.htm>). Yet it may be that at a more operational level for a specific service, a dedicated worker can have a greater impact. Croxson (2002) has argued for the need for case management workers for older people with diabetes who work to guidelines and prompting care.

Summary: Improving access for older people

Recent policy in health care for older people has been dominated by the National Service Framework (NSF). The NSF was launched in 2001 in response to concerns from service users and providers alike that health services were failing older people in terms of both access and quality. Whereas the new service models for specific areas such as stroke services and falls prevention have been broadly welcomed, the drive for person-centred care and anti-ageism has thus far proven difficult to disseminate and implement. It is too early for evidence to have emerged for the effectiveness of new initiatives like intermediate care.

The need for a more tailored and sensitive method of assessing health and social care needs has long been overdue and the new single assessment process has been put in place to address this. It is hoped that this will deal with some of the problems of discontinuities between providers our earlier analysis identified. There is a notable lack of evaluations that have been aimed at improving older people's access to services. Examples of local initiatives exist, but there is a need for rigorous investigation of the effectiveness of anti-ageist training for health care staff. There is also need for caution and attention to the unwanted consequences of identifying and making offers to older people on the basis of assumptions about 'unmet need'.

6.3 Conclusions

In this section, we have conducted an interpretive synthesis of the literature on access to health care by older people. Older people do not represent a minority group of health care users and their needs are highly diverse. For many services, older people represent the majority of users. The evidence on older people vividly illustrates the need to better understand the ways in which the candidacy of older people is negotiated. While there are accusations of 'ageism' implicit or explicit throughout the literature, it is clear that a more sophisticated understanding is required of how adjudications are made that appear to disadvantage older people. Older people, their carers, and the professionals who look after them must be able to navigate complex organisational structures to secure some forms of medical interventions and attention. It may well be the case that the work involved in doing this is overwhelming, and that older people may

prefer to continue using 'comfortable' services such as their GP, or that their GPs themselves either find it too difficult to co-ordinate these negotiations, or deem that their patients would prefer not to put themselves through the effort and discomfort involved in pursuing a claim of candidacy across a number of boundaries. It is important to recognise that professionals make adjudications in environments where they have little control over the distribution and availability of resources at a macro-level, and are highly sensitised to the need for efficiency in the use of those services.

Much of the debate in the literature has centred on the apparent rationing of expensive services to favour younger people. Using age as a selection criterion for treatment is justified by some theorists but rejected by others. The available literature does not allow us to explain why, for some specialist services, older users are under-represented. There appears to be a tendency for older people to be investigated and treated less intensively for certain conditions such as cancer and coronary heart disease. Whether this is due to ageist assumptions on the part of gatekeepers and service providers, as is often supposed, or whether it is the outcome of an adjudication process where older people are able to make an informed choice, is not possible to say based on current evidence. Our analysis does suggest that the level of co-morbidity among older people may have the effect of obscuring the need for these specialist services or that the preference for a familiar 'comfortable' service discourages older people from accepting some forms of care.

We found evidence that although older people form a large proportion of those who receive treatment in critical care environments, older people appear to receive less aggressive treatment for certain conditions. In the literature we analysed, it was often simplistically assumed that these measures of utilisation reflect decisions about such treatments by health care providers on the basis of ageist assumptions. We believe that, based on utilisation data, there is insufficient evidence to favour this interpretation over the others. It is not clear how often older people are denied the opportunity for specialist services or how often they choose to decline an offer of specialist health care. It is also possible that older people are disadvantaged in terms of the barriers they face in accepting an offer such as lack of social support, difficulties in accessing information, and access to transport. We need to be able to pinpoint the points in care pathways at which some older people are deciding to discontinue or are facing barriers.

We found some evidence that, where there are care options, older people may be less likely than younger people to receive the more specialised health worker, health environment, or intervention. Where these are new service developments, older people may either prefer to trust more familiar generic services, or their co-morbidity may be a barrier to the availability of specialist care. Beds in nursing and

residential homes are funded publicly and provided by the private sector. This places a group who are often physically and / or mentally frail in a position where they are often overlooked or denied certain NHS services that would be available to older people living in their own homes.

There is some evidence to suggest that older people may dismiss symptoms of potentially treatable health problems as due to a natural process of ageing. This has been described in the literature as 'age-attribution'. Our analysis has found that 'age-attribution' may be more common for certain stigmatising diseases such as incontinence and mental health problems. Many older people have a low expectation of services to successfully intervene and this is likely to result in a decision not to assert their candidacy. This finding indicates that providers may be in a stronger position than they realise to influence the early stages of candidacy for older people. For some older people, it is important to protect their identity as fit, healthy and unburdensome to health providers. A concern over responsibilities rather than rights was evident from our work. Continuity of service provision seems to be more important for older rather than younger adults yet the complex service pathways that many have to negotiate are often fragmented and discontinuous.

There is very little reporting of interventions that are aimed at improving older people's access to health care and those studies that exist are often descriptive rather than evaluative. Most of the intervention literature looks at preventive services and ways of improving uptake. Although there are a number of claims about institutionalised ageism in the health service, and some attempts at measuring ageist attitudes, we found no empirically-tested educational interventions in the form of anti-ageist training. The NSF for older people was introduced in 2001 and set out to address many of the concerns about age discrimination in health and social care. It is too early to tell how the implementation of the targets and service models within the NSF will successfully address these issues. More tangible initiatives like intermediate care can, and should, be subjected to rigorous evaluation studies to assess their worth and ensure that older people are not being 'displaced' from hospital to inferior forms of care. How older people's health needs are being assessed is currently undergoing change. The focus for health needs assessment for older people during the 1990s was the universal model of the over-75 health checks in primary care although the implementation of this was patchy and variable. The single assessment process is currently being developed in an attempt to ensure that assessment is in proportion to needs and information is shared across multiple agencies.

Section 7 Gender and access to health care

7.1 Introduction

In this section we present an interpretive synthesis of the evidence on access to health care by gender. While it was sensible to start with the hypothesis that some of the groups already considered in this report (such as people who are socio-economically deprived, or people of minority ethnicity) might be at risk of poor access, when it comes to gender, it is difficult to frame even a working hypothesis of who is 'more disadvantaged'. Gender has been a relatively neglected dimension in research on access to health services. The term 'gender' has typically been used as a synonym for women; research on men's service use is very recent and under-developed; and consequently gender-comparative research is rare. As a result, the body of evidence drawn from articles summarised in this section is rather fragmentary and tends to raise far more questions than it answers.

Further issues are posed with respect to treating gender within the framework of 'vulnerable groups' since it is clearly not the case that either men or women are *prima facie* more vulnerable as a group. Rather, the vulnerability of men and women is likely to vary in respect of particular health conditions and the use of particular services. In this respect, as Doyal *et al.* (2003) make clear, neither men nor women can be conceptualised as 'minorities' in need of special treatment: 'All patients in the NHS are male or female and if services are to be effective, efficient and evidence-based, the recognition of this reality needs to be at the heart of planning and policy' (Doyal *et al.*, 2003: 41). Gender equity in access to health care ultimately depends on gender sensitivity; that is, an awareness that men and women may have different biological and social needs associated, for example, with reproductive health, coupled with the recognition that a person's gender does not determine either their health behaviour or their specific service needs.

A tradition of feminist research, stemming back to at least the 1970s, points quite clearly to the problems than women experience in accessing care, but it has been difficult to properly identify the extent to which these problems are a product of gender-related experiences and attitudes in the absence of comparative research on men. This problem is beginning to be rectified with the emergence and increased visibility of men's health research. Interest in men's health within the UK can be dated to the early 1990s. Building on the framework that had been developed by feminist and other research on women's experiences of health and healthcare, policy makers, social scientists, men's groups, and healthcare professionals have begun to challenge a number of gender-based assumptions about men and their health, pointing out that that men have a 'hidden disadvantage', where their

distinctive needs are obscured by their apparent privilege. These concerns are underpinned by the quite recent recognition that gender is not just about women; men have gender too. The social and economic privileges that men have traditionally enjoyed once made gender relatively unproblematic. As these privileges are increasingly challenged by labour market insecurity and changes in gender-related attitudes, attention has increasingly been drawn to masculinity's 'downside'.

In principle, recognition that men 'have gender', and that this is likely to impact on their health, is a positive move towards creating a more gender-inclusive research agenda. However, this has not yet developed. The main reason for this is political. While there are sympathies between those interested in women's health (mostly women) and those interested in men's health (mostly men), there is also an element of competition; a fear that one 'side' will gain the ear of policy makers and resources at the expense of the other. Research on gender and health therefore risks lapsing into a zero-sum game as researchers and commentators compete to present either men or women as the 'most disadvantaged' (Coote and Kendall, 2000; Riska, 2003).

The development of a robust comparative evidence-base is also inhibited by the wider failure to incorporate gender into clinical and health services research. The fact that routine UK health statistics are typically presented separately for gender makes gender analysis possible. However, research on specific health conditions and their treatment is often blind to gender. It is not unusual to find that even where men and women have been included in research samples, results are not presented separately and, therefore, any similarities or differences by gender are concealed. This problem of course is not confined to the UK. Given that, historically, research has taken male health and the male body as the 'gold standard', this has mainly posed a problem for research on women's health and use of health care (Kaufert, 1999). Bird and Rieker (1999) point out that biomedical research tends to focus on men's experience of life-threatening chronic illnesses (which are common to both men and women), while when women are the focus, research is typically limited to sex-specific disease.

7.2 Lines-of-argument synthesis

Our lines-of-argument synthesis of the evidence on access to health care by men and women is organised around a set of central concepts, and in particular the core synthetic category of 'candidacy'. A table of included studies is provided at Appendix 7A.

CANDIDACY describes the ways in which people's eligibility for medical attention and intervention is jointly negotiated between individuals and health services. Candidacy is a dynamic and contingent process, constantly being defined and redefined through interactions between individuals and professionals, and managed in the context of operating conditions, including the biography of the relationship between patients and staff, the typifications staff use in categorising people and diseases, availability of resources, local pressures, and policy imperatives.

Key points in candidacy related to gender generated by our analysis:

- **Gender-health interaction.** The relationship between gender and health is interactive. It is generally recognised that gender influences health through normative expectations and the differential social locations of men and women. But it is also important to appreciate that health and health behaviours are, in their turn, ways of demonstrating gender. Gender and health are therefore integral to the construction of **personal identity**.
- **Gendered candidacy.** Identification as a candidate for healthcare is often highly gendered and associated with normative expectations on the part of patients, potential patients, and health professionals. Women and men locate themselves as candidates, and are located by others as candidates, in gendered terms. This often involves a complex process of **negotiation** as individuals move from identifying their candidacy, to gaining a point of entry to health services, to actually using services.

People can gain a point of entry to health services in a number of ways. We will suggest that services can be conceptualised as being surrounded by membranes that are more or less porous. Generally more porous membranes allow people to pass through easily; services that are less permeable require much more work in order to gain a point of entry and sustain engagement with the service.

- **More porous membranes.** Services that have more easily permeable membranes are more easily negotiated. Membranes are more porous when the patient or potential patient 'fits' the expected gender-profile of the service.
- **Less porous membranes** are more resistant and pose more barriers, are difficult to negotiate, and require a high level of alignment with the organisational values of the services on offer. Membranes are less porous when the patient or potential patient does 'not fit' the expected gender-profile of the service.

In both of these scenarios, services normally require a level of patient self-judgement and professional judgement of individual candidacy. 'Porous' and 'less porous' membranes each permit and admit 'appropriate' and 'inappropriate candidacy'.

- **Presentations** in medical consultations may be highly gendered, with strong interactions with the gender of the practitioner.
- **Adjudication** refers to professional judgements about the candidacy of the individual for intervention or service. Gendered candidacy involves two types of judgements, but both judgements are highly conditional and contingent:
 - **Judgements about technical candidacy**, in which judgements are made about the technical feasibility of providing interventions or services. Men or women may be judged to be better or poorer technical candidates due to differences in underlying patho-physiology such as later age at onset of disease and associated co-morbidities.
 - **Judgements about social and moral candidacy**, in which judgements are made about the likely social benefits of an intervention (or non-intervention) or moral worth of male and female candidates. It is these types of judgements which can lead to inappropriate 'facilitation' and 'blocking'.
- **Appropriate and Inappropriate candidacy.** Patient access can be appropriately and inappropriately facilitated. It can also be appropriately and inappropriately blocked. Inappropriate 'facilitation' and inappropriate 'blocking' are highly associated with gender attributions, particularly gender-stereotyping.
 - **Inappropriate facilitation** occurs when patients' route into healthcare is on an inappropriately gendered basis. Examples of this include the 'medicalisation' of social problems and 'natural' social events (such as childbirth), 'over-treatment' and 'inappropriate treatment'
 - **Inappropriate blocking occurs** when patients are kept out of care or denied treatment inappropriately due to their gender. This may occur due to self-assumptions on the part of patients, erroneously judging symptoms in gendered terms, and because of inappropriate adjudications by health professionals, that one gender will benefit, or is more deserving, than the other.
- **Conditionality.** Adjudication and disposal is conditional on the operating conditions of services. Each stage of candidacy is likely to be influenced by the perceived or actual availability of health service resources, including issues of geographical proximity. Operating conditions may operate at the level of individual interactions – a professional may make an offer that is not warranted on the basis of 'clinical' candidacy in order to preserve the relationship with a patient. They may also operate at the level of the organisation – an organisation may withhold or delay offers that could be justified on the grounds of clinical candidacy because of limited resources.
- **Offers** – refers to the offer, or non-offer, or an intervention or services by health professionals.

- **Acceptance** and receipt, resistance and rejection – refers to uptake of offers by patients or attempts to resist and reject offers. This highlights that men and women have a degree of agency in their response to offers made. They may contest ‘inappropriate facilitation’. Women’s resistance to the medicalisation of childbirth is an illustration of this.
- **Conversion** – refers to the conversion of health care into outcomes.

Research on gender and access to healthcare suggests that both men and women can become vulnerable at various stages of candidacy. We suggest that the differences in the ways in which these vulnerabilities are manifest may result in problems of access. Given the limited evidence-base on the relationship between gender and access to health care in the UK, we draw upon material from other developed countries. We also make use of review papers and other commentary. Before we consider the key themes that emerged from the literature search in terms the lines-of-argument synthesis, it is important to draw attention to the meaning of vulnerability in relation to gender and to indicate the ways in which the politics of gender and health research have impacted on the evidence-base.

We have organised our synthesis around the following themes generated by our analysis of the evidence:

- 7.2.1 Theme 17.2.1 Theme 1: Gender differences in use and receipt of .
- 7.2.2 Theme 27.2.2 Theme 2: The identification of candidacy.
- 7.2.3 Theme 37.2.3 Theme 3: Navigation.
- 7.2.4 Theme 47.2.4 Theme 4: Presentations, adjudications and offers.
- 7.2.5 Theme 57.2.5 Theme 5: Tractability: gender sensitive care.

7.2.1 Theme 1: Gender differences in use and receipt of health care

There has been long-standing interest in the gender patterning of use and receipt of health care. We organised our synthesis around the following themes generated by our analysis:

- General practice.
- Specialist care.

General practice

Goddard and Smith (1998) summarise evidence suggesting that women consult more in general practice than men, and the difference is most marked among those aged 16-44. The difference is greatest

for genitor-urinary disease (disorders of the genitor-urinary tract), mental health disorders, diseases of the blood and blood forming organs, and ill-defined conditions, and smallest for serious conditions. Higher rates for GP consultations have been reported for women after consultations for reproductive issues have been excluded. Doyal *et al.* (2003) summarise evidence suggesting that women aged 16-44 make an average of five GP visits a year compared with three for men of the same age, while overall, women make an average of five visits per year compared with an average of four for men. However, Doyal *et al.* caution that these figures need to be seen in the wider context of social class and ethnic variations in consultation rates.

Recent work has focused on attempts to explain male and female differences in consulting in terms of varying symptomatology or response to symptomatology. Bebbington *et al.* (2000) report that severity scores relating to psychiatric symptoms were significantly related to whether people attended their GP with a mental complaint in the year prior to interview, showing severity of the disorder to have a strong influence on contacting a GP. Female contact with a GP was generally higher than male contact overall. Additionally, women were 70 per cent more likely than men to contact their GP with mental health problems even after the severity of the illness had been controlled.

Wyke *et al.* (1998) found that women were significantly more likely to have consulted a GP for at least one of the 33 symptoms specified of minor illness in the months previous to the study. Women were significantly more likely to have consulted for five individual symptoms in the younger cohort and for three symptoms in the older cohort, while men were significantly more likely to have consulted for only one symptom in the younger cohort. However, when only those who had reported a symptom in the last month were included, there were no gender differences in consulting for any of the 33 symptoms in the older cohort and for just three symptoms in the younger cohort. These data do not, therefore, support the most widely suggested explanation for gender differences in consulting: that, once symptoms are perceived, women have a higher propensity to consult a GP than men.

Corney (1990) found that high attenders at general practice (six or more visits in the last year) reported much more physical illness than low attenders (one or no visits in the last year). In low attenders, women were significantly more likely to have symptomatic or chronic conditions than men ($p < 0.05$), which suggests that low attending men were in better physical health than women. Higher attenders had more psychiatric morbidity than low attenders, especially comparing high and low attending women. Predictors of GP attendance were physical symptoms, age and 'caseness' on general health questionnaire (GHQ): high attenders were younger women and those with more physical symptoms or symptoms of minor psychiatric disorder. For men, the best predictors of attendance were more physical symptoms and / or

contact with another agency (social or medical) in the last year. The multivariate analysis shows a close relationship between the presence of psychological problems and consulting among women, whereas men tend to confine their help-seeking to physical problems (Corney, 1990). More specifically, in relation to chest pain, Richards *et al.* (2000) found that men with chest pain are more likely to consult their GPs than women with chest pain. They attribute this tendency to the fact that the dominant public health messages and media images of heart disease target men as 'at risk', causing women to down-play chest pain and their susceptibility to heart disease. This area of the literature, therefore, contains rather 'mixed-messages' concerning whether men and women are equally likely to consult their GPs in response to given symptoms. It does seem clear, however, that men are less likely to consult than women in the case of psychiatric / psychological problems.

It is clear that there are gendered patterns of attendance at general practice, but it is very difficult to interpret the significance of these. Lower attendance might suggest under-utilisation but, equally, higher attendance is no guarantee that needs are being met.

Specialist care

Women are slightly more likely to be admitted to hospital as in-patients (Doyal *et al.*, 2003). Goddard and Smith (1998) summarise evidence suggesting that higher rates of hospital utilisation have been found among young women (probably reflecting childbirth), while middle-aged men appear to have lower rates. The fourth Morbidity Survey from General Practice showed that referrals were higher to outpatients for women between the ages of 16-64 years, but thereafter this was reversed. Referral rates to in-patient beds were higher for women than men until the age of 64-75 years and again thereafter, this was reversed. For mental health, there is a distinctive picture. There are higher admission rates for hospital treatment for mental health problems among men in early life and again in old age, while female rates are higher in middle age (Doyal *et al.*, 2003). This marks a recent change where, until the 1980s, women were more likely than men to be admitted to psychiatric hospitals, and since that time there has been a marked change, highlighting the dangers of relying on older data. Research concerned specifically with young men's use specifically suggests that they are very reluctant users of services, including mental health services in particular, and that agencies have very little understanding of how to target this group to attend (Men's Health Forum, 2002).

Patterns of hospital outpatient attendance also vary between men and women. Office of National Statistics data suggest that women had higher rates overall of GP referrals to outpatients, but the sex ratio varied between different specialties (Doyal *et al.*, 2003).

A body of work has focused on gender differences in receipt of treatment for cardio-vascular disease. Much of this work suggests that women appear to be less likely to be admitted to hospital and may be less likely to receive re-vascularisation, having adjusted for need. For example, adjusted analysis of data in East Lancashire suggests that women were as likely to be admitted to hospital as men, but had lower rates of angiography and coronary artery bypass grafting than men (Majeed and Cook, 1996). Similarly, Petticrew et al (1993) found that men were significantly more likely than women to undergo re-vascularisation (by either angioplasty or coronary artery bypass graft (CABG) surgery) in both South West and North West Thames, after diagnosis of either angina or chronic ischaemia. In North West Thames men were also significantly more likely to undergo re-vascularisation after MI or chest pain (numbers were too small for analysis in South West Thames). Similarly, a nationwide survey reported that men are more likely than women to be waiting to take-up cardiac surgery (19.1 per cent men, 6.8 per cent women $p < 0.001$) (Dong *et al.*, 1996). Richards *et al.* (2001) look at care pathways for coronary care. They indicate that being a woman is associated with low rates of coronary angiography and coronary artery bypass grafting compared to men. Similarly, in research involving 1,064 patients admitted to a random sample of 94 UK hospitals, Raine *et al.* (2003) found that hypertensive men are nearly twice as likely to undergo cardiac rehabilitation after an acute coronary artery disease episode than women. Moreover, Raine (2000), in a critique of studies of gender bias in utilisation of coronary heart disease, points out a number of methodological limitations in this work. Of the 13 studies in this review comparing receipt of coronary artery bypass surgery in men and women, none defined other risk factors (for example co-morbidities), seven did not use any form of adjustment for need or risk, and four studied small samples. However, these studies were conducted before the introduction of the National Service Framework (NSF) on coronary heart disease, and it is difficult to interpret their continuing relevance.

As we have suggested previously, the usefulness of data on differential rates of use and receipt of secondary care services is very questionable without information on people's recognition of candidacy, the ways in which they navigate services, the nature of the presentations they make, the adjudications made about their candidacy, and the extent to which they accept or reject offers.

Summary: Gender differences in use and receipt of health care

Gender differences do exist for men and women in their use and receipt of health care, but the evidence is difficult to interpret and suggests specific effects for different types of health problems. We argue that data showing differences in receipt and utilisation are not in fact very useful, as they provide little insight into the important issues of candidacy that create vulnerabilities for people.

7.2.2 Theme 2: The identification of candidacy

Gender is intimately bound up with the negotiation of candidacy. The gendering of identity is a central dimension of this process. It has been suggested that the historically strong bond between gender and identity is weakening as statuses, social roles and attitudes that were once more or less the prerogative of either men or women become open to both. Changes such as rising trends of female labour-force participation, economic change, and the rise of consumerism are impacting on male and female experience across the board and gender identities are becoming increasingly uncertain. Since the body is often the domain on which new identities are crafted, gender-related changes implicate health insofar as ideas about what activities are appropriate to men and to women in, for example, health-related behaviours such as exercise, diet, alcohol and tobacco consumption are marked on the body. These changes are highly age-defined and to date have mainly impacted on younger men and women. However, it would appear that these trends have yet to have much, if any, impact on attitudes on the perceptions of symptoms of illness and help-seeking which, on the basis of the evidence of our sample of papers, remain resolutely gender-bound. We have organised our synthesis of the evidence on candidacy around the following themes generated by our analysis:

- The female benchmark.
- Accommodating to the 'gender normal'?
- Gender and identity.
- The case of heart disease.

The female benchmark

It is apparent that both practitioners and researchers draw associations between male and female identities and help-seeking. In particular, it has been suggested that gender identities can be problematic, especially for men, since they may inhibit appropriate help-seeking. There is less indication of an association between femininity and female help-seeking. One reason for this may be the long-standing recognition, as we summarised earlier, that women are more likely to seek help than men anyway (Wyke *et al.*, 1998). Indeed, it sometimes appears that women's higher use functions as an un-articulated benchmark or gold-standard against which to evaluate whether men need to seek more care. The evidence about higher use may also mean that women's help-seeking may be seen as less evidently problematic, when this may not be the case.

Here the long-standing issue of whether women 'over consult' (and the less often considered possibility of whether men 'under consult') is relevant. Certainly the conventional wisdom that women are more sensitive to symptoms, and men more stoic and reluctant to seek

help, suggests the possibility that use of care may not be commensurate with need for either gender. This is a difficult issue to research, given the difficulty of establishing any reliable or objective measure of health (Blaxter, 2004).

Macintyre *et al.* (1999) point out that women's over-reporting of illness is frequently attributed to the greater social acceptability of admitting illness, discussing symptoms and seeking help (compared with men) among women, as well as women's greater attention to bodily cues and changes due to menstruation, pregnancy and menopause. By contrast, men's relative privilege may carry not only life-advantages but also heavy burdens of stress and responsibility that are detrimental to health. Norms of masculinity, such as being strong and in control, make it difficult for men to admit to themselves, let alone to others, that they are unwell and in need of help, since illness is traditionally associated with weakness, and attention to health is a typically feminine activity (Luck *et al.*, 2000; Sabo, 2000; White, 2002).

There is, however, little direct evidence to support these propositions. MacIntyre *et al.* (1999) describe the methodological difficulties in establishing an objective standard concerning the level and nature of symptoms between men and women. Their research found no male / female difference in reporting any condition, no male / female difference in reporting 'serious' conditions and no gender differences in proportions reporting 'intermediate' and 'trivial' conditions among the late fifties cohorts, but women in their late thirties were more likely to report 'trivial' illnesses (24 per cent women as compared to 14 per cent men) and men more likely to report 'intermediate' conditions (50 per cent men, 41 per cent women). Counter-intuitively, men reported more conditions in response to the initial global question concerning their health status than did women (50 per cent men, 41 per cent women in late thirties; 56 per cent men, 52 per cent women in late fifties). From a methodological point of view, Macintyre *et al.* (1999) conclude that global questions fail to elicit information which a more detailed approach can invoke, and that greater gender differences are invoked by more detailed than global questioning. The authors argue that their findings contradict the common assumption that it is men who are stoical about illness, since it is women who need to be probed in interview to reveal the extent of their illness. Moreover, Popay's (1992) qualitative research study on 18 households in London reveals that there are a number of constraints on women's help-seeking that themselves emanate from gendered circumstances. Thus, regardless of the age of their children, the type of household they lived in, and whether they had a paid job, women in her study emphasised that when they felt ill, they would 'pretend it wasn't there' or 'just carry on'. For most, there simply was not time to be ill and, much in the manner of men (although for different reasons), they were reluctant to adopt the sick role (Popay, 1992). It is also important to note that any relationship between gender and consulting is likely to vary by the

health condition concerned. In her multivariate analysis, Corney (1990) found a close relationship between the presence of psychological symptoms and consulting in women, whereas men tended to confine their consulting to physical problems.

Accommodating to the 'gender normal'?

Although associations between gender and the identification and interpretation of symptoms are often assumed, direct evidence of their existence is limited. Research is focused on specific health conditions or health issues. This indicates that, to date, it has taken gender and help-seeking to mean conditions that are either specific to men or to women, or conditions that have been identified as a particular problem for one gender or the other (because of much higher prevalence). There are very few articles that we analysed that directly compare men's and women's responses to *common* symptoms or health-related concerns, heart disease being a notable exception. The result is that research may be drawing attention to 'gendered experiences' to the neglect of health-seeking experiences that men and women hold in common.

Lack of gender comparative research means that it is difficult to assess how far self-diagnosis and the management of illnesses are *directly* influenced by gender roles, gender norms and expectations. However, gender norms clearly play some part in the interpretation of symptoms. In their research on male help-seeking for psychological health problems, Good *et al.* (1989) found that men who were worried about expressing affection towards other men and about expressing emotion, held more negative attitudes towards seeking help in the future and reported fewer instances of actual help-seeking in the past. Conversely, those with more favourable attitudes on both of these dimensions were more predisposed to help-seeking.

Bendelow (1993) found that both men and women hold gendered assumptions about pain. In her qualitative research, which involved interviews with 107 men and women drawn from a North London health centre, she found that both expressed the opinion that men take longer to admit and express pain and to seek treatment. This reluctance was in part attributed to pain being 'more abnormal' for men, and by contrast 'more normal' and expected for women. The latter was attributed to the woman's reproductive system and reproductive role which, respondents felt, also meant that women could endure more pain than men. Differences were also seen to result from it being more acceptable for women to express pain, whereas men are supposed to suppress their emotions. One respondent said,

'Men are not allowed socially to express pain as much they're supposed to be stronger, we're allowed to cry and they're not... although women have more breakdowns than men, men don't allow it to come out, they hide it until its unbearable whereas a woman will usually say "I can't cope" long before.' (female, student, aged 18, mixed race)

Cunningham-Burley *et al.*'s (1996) research on men's interpretations of urinary symptoms shows that ageing men accommodate to symptoms such as urgency and nocturia which have an insidious onset and are seen as part of normal male ageing. It is probable that this process of accommodation also applies to women in the onset of incontinence. Shaw *et al.* (2001) suggest that men are more likely to see urinary symptoms as indicative of serious disease because of the link to prostate cancer, whereas women are less likely to see their symptoms as serious and are often unaware of available interventions.

Women may face particular problems when interpreting symptoms associated with reproductive or gynaecological health. In their study of vaginal complaints, Karasz and Anderson (2003) make clear that women judge the meaning of symptoms, which for many cause significant distress, in terms of assumptions of 'normality'. Although 'normality' meant different things to women in the sample, the researchers found that their assumptions were suffused with meanings closely associated with gender roles, and morality. The interpretation of symptoms is therefore bound up with wider assumptions about gender, gender roles and male-female relationships. In similar terms, Free *et al.* (2002) highlight the ways in which young women (aged 16-25, from a socio-economically deprived area) use emergency contraception. The study shows that women's use and non-use of emergency contraception is related to their assessments of the risks conferred by different contraceptive behaviours; their evaluations of themselves as needing contraception; and personal difficulties of asking for emergency contraception. This study highlights the complex nature of personal health management. Although the young women's experience is not specifically interpreted in gendered terms by the authors, it is apparent that they felt anxious, guilty and concerned about how others may think of them as users of emergency contraception.

Gender and identity

It has long been recognised that ill health can be a significant threat to self-identity. This has been most clearly demonstrated in research on accommodation to chronic illness where sociologists have drawn attention to the 'biographical disruption' that often accompanies the onset of illness and the repair work that is necessary to re-establish a sense of self (Bury, 1991; Frank, 1993). When gender is added into this process, it is important to recognise that it is not only individual identities that are gendered as male and female, but also health and illness. In particular, illness has a long-standing historical association with women and femininity (Shildrick, 1997). In contrast, health is typically associated with men and masculinity (Annandale and Clark, 1996). Thus gendered identities are inextricably bound up with perceptions of self, health and illness. As Saltonstall (1993) explains, lived experience of the body entails simultaneous processes of interpretation and communication. In this way, the body is implicated

in communication of one's self and one's health as a member of a social group. Courtenay (2000) argues that poor health beliefs and behaviours are actively used by men to demonstrate gender, the denial of mental illness being an illustration of this.

Although in her qualitative interviews (with middle class men and women in the USA) Saltonstall (1993) found that men and women had similar ideas about health at the abstract level, gender differences emerge in what she calls 'health doings', or specific ideas about what healthy male and female bodies do. She reports that decisions about what health actions to take are heavily coloured by ideas of what is appropriate masculine and feminine behaviour. Both men and women feel that good health is something that needs to be achieved, and that the body is like a machine that needs to be maintained. In this sense they adopt equally a sense of individual responsibility for health. However, men and women have different views on how this can be achieved. Men stress sports and outdoor activities, and eating is important, although mainly as a corollary to effective performance. Women emphasise exercise rather than sport and, when food is mentioned, this is often by using the verb 'to diet' (whereas men are more likely to refer to 'eating well'). Women are also far more likely to stress appearance-related aspects of health such as caring for the skin (using sun block). Saltonstall summarises these, and other, differences in terms of a male emphasis on the body as a medium of action and a female emphasis on function (caring for others) and keeping the body in a presentable condition. This makes clear that it is not simply the case that gender influences health and health behaviour, but also that health practices are constitutive of gender. As Saltonstall puts it 'doing health is doing gender'. Extending Saltonstall's line of argument, we can infer that 'doing health wrong' can also mean getting gender wrong, which could constitute a major threat to identity.

Seeking-help, or the manner in which help is sought, is not just about promoting health or dealing with illness, it is also an affirmation or a challenge to one's identity as male or female. There are certain conditions – notably those associated with reproduction and sexual functioning – arguably the heart of gendered identity – which are particularly difficult to manage since they pose a threat to the gendered self. Moral attributions of appropriate gender identity seem to be very important in this regard. For example, Free *et al.* (2002) found that some young women saw the use of emergency contraception as a 'failure' which generated embarrassment, a fear of what others might think, and a reluctance to seek help (Free *et al.*, 2002).

Free *et al.*'s (2002) work and that of Karasz and Anderson (2003) indicate that women's self-confidence in self-diagnosis, and related service use, is influenced by generally negative moral and

presumptively gendered attributions. There is considerable support for this in the wider literature. Manderson (1999) makes clear that:

'The sexual meanings ascribed to women's bodies influence popular interpretations of the signs and symptoms of health and illness and affect help-seeking behaviour and access to health services and treatment, especially for ailments which might be considered as sexual.'

The Men's Health Forum's (2002) summary of young men's mental healthcare needs shows that emotional weakness is not a component of masculinity. Young men who were interviewed talked about being strong and 'being a man' and emphasised that showing emotions was inappropriate since it was associated with vulnerability and lack of control (identified as female). The majority of men referred to the importance of developing an 'inner strength' to protect themselves from their emotions. Consequently, they invested in strategies that would distance themselves from their emotions and their impact.

The association between male gender and illness management is addressed by Cameron and Bernardes (1998) and The Men's Health Forum (2002). Here it is highlighted that masculinity can confer both advantages and disadvantages. The Men's Health Forum makes clear that men suffering from mental ill-health cope in a variety of ways. This includes activities that 'make them forget' or 'keep on top of the situation' such as sleep, using alcohol, or pills. Strategies to release emotions include praying, listening to music, and sport. Some men talked of 'taking it out on others', through violence, while others kept things to themselves out of a wish not to burden others. Martin *et al.* (1991) report that men were significantly less likely than women to perceive themselves as 'not ill at all' and that they were more likely to consult the doctor only when they perceived that their symptoms indicated a serious medical condition, such that they either felt they needed urgent treatment or significant reassurance from their physician.

Charmaz's (1995) research makes clear that chronic illness in particular puts men in unacceptable relationships of dependency. Cameron and Bernardes (1998) survey of men who had contacted the British Prostate Help Association indicates that prostate problems are 'hidden' problems. Because they are associated with sexual functioning, prostate problems pose a particular threat to men's gendered selves (in this study seven out of ten men reported that their symptoms had changed their sex lives). Along with others, Cameron and Bernardes draw attention to the positive effects of a felt need to 'take charge' once diagnosed with an illness. Men in Chapple *et al.*'s (2002) research saw having a prostate specific antigen test (PSA) as an example of responsible health behaviour; that is, as good preventative health care, which might be seen as a pre-emptive attempt to 'take charge'. Some saw it as a way of 'avoiding later regrets' that might arise had they not taken action.

Our analysis suggests that the ways in which candidacy is externally constructed through the imposition of qualifications for candidacy (for particular types of health interventions) may embody latent gender assumptions. O'Brien and White (2003) report that strategies for screening for Chlamydia Trachomatis in Britain disregard the ways in which gender differences affect patterns of risk and instead focus on practical implementation. Thus even though screening is recommended for men and for women, the focus is on women. This is in part based on the knowledge that the clinical consequences of infection are more serious for women, but also reflects the belief that women are more likely to attend for screening i.e. that targeting women is more cost-effective. Fenton (2000) suggests that screening for men has been less readily pursued on gender-based assumptions that it will be less attractive to them, and calls for a reconsideration.

The case of heart disease

The coupling of heart disease and men has cast a long shadow over research on gender identity and what Emslie *et al.* (2001) conceptualise as 'coronary candidacy'. Mechanical metaphors which are strongly associated with masculinity, coupled with the perceptions that heart disease is associated with stereotypically masculine 'type A' behaviour, has inhibited research on women and comparisons between men and women (Emslie *et al.*, 2001; O'Donnell *et al.*, 2004; Schoenberg *et al.*, 2003). Emslie *et al.*'s (2003) qualitative research in the West of Scotland shows that masculine-styled images of coronary candidacy live on in the popular imagination. Only one of 61 respondents gave examples of coronary candidates who were women. When discussing family, women were conceptualised by respondents not as candidates for 'heart attacks', but of chronic coronary morbidity that disrupted daily activities. Male-gendered perceptions of heart disease are particularly significant given that coronary heart disease (CHD) is the leading cause of death in the UK.

These perceptions of coronary candidacy have important implications for women's perceptions of symptoms. Schoenberg *et al.*'s (2003) narrative interviews with 40 women in Kentucky who either had CHD or chronic conditions considered a risk for CHD, reveal that the 'male candidacy model' of illness and symptoms generate considerable uncertainty for women. For example, when they did not experience the 'standard' stabbing in the chest, they relied on lay rather than formal medical care. In the UK context, Lockyer and Bury (2002) highlight that women's failure to interpret symptoms as cardiac in origin leads to delay in seeking urgent medical attention. This is significant given that around 60 per cent of people who die from a myocardial infarction do so within the first hour after onset of symptoms. Schoenberg *et al.* (2003) make clear that delay is not solely due to inappropriate perception of symptoms. Women in their sample avoided doctors who had previously discounted their symptoms, defined them as 'a worrier' or even worse, a hypochondriac or just plain ignorant. Thus gendered

cultural perceptions *combine* with perceptions of doctors who discount women's own interpretation of their bodily symptoms to disadvantage women in the receipt of care.

Summary: Identification of candidacy

Our analysis has identified the salience of gender in men's and women's constructions of *themselves* as candidates for care. We have seen that this process is highly responsive to cultural expectations of what is gender appropriate. Overall, articles which address confidence in self-diagnosis and illness management suggest a pattern of responses which appears to be either gender-specific or gender-defined. These responses result from the investment of male or female gender-identities in particular health conditions. These gendered investments have a powerful impact on perceptions of candidacy. Viewed in these terms, candidacy is to some extent 'unthinking'; men and women may simply not be aware that they are acting in gendered ways, since health and gender are bound together in common-sense or taken-for-granted ways: they result from gender-health interaction. However, men and women also reflect, to some extent critically, on their gender-related circumstances. In interviews at least, they show an awareness of the way in which gender-expectations affect - and in particular how they limit - their experiences. This has been most apparent of late in research on men's experience of illness. There is some indication that illness and being in need of help operate as a threat to valued male characteristics of strength and invulnerability. In this sense, male masculinity can inhibit effective help-seeking. While recognising this, it is important not to assume that since they are deemed to be more open and expressive about illness, women will seek help when it is needed.

7.2.3 Theme 3: Navigation

We have identified in previous sections the ways in which candidacy becomes vulnerable to the problems of navigating a point of entry to health services, or sustaining engagement 'within system'. Our analysis suggests some gender effects in navigation, which we have organised around the following themes:

- Navigating a route to health services.
- Practitioner gender.
- The social context of help-seeking and use of support.
- Mobilising practical resources.

Navigating a route to health services

Much of our analysis suggests that local GPs are preferred as a source of help for general health concerns but for specific conditions related to some aspects of gender, other more specialised services preferred. Campbell and MacDonald (1996) found that women prefer well-women clinics, self-help groups, counsellors, and social work departments for some types of health problems

Dixon-Woods *et al.* (2001) found that many women preferred to bypass general practice entirely when seeking provision concerning their sexual health. They preferred to access sexual health services directly, preferring the anonymity and confidentiality of such services, and the more relaxed environment. It emerges as significant that women value their feelings of embarrassment and stigma, concerning sensitive or intimate issues, emotional response being taken into account and wish to feel some sense of 'control' when obtaining test results (Dixon-Woods *et al.*, 2001). Echoing a concern with 'confidentiality', Bacchus *et al.*'s (2003) work points out that the lack of privacy in A&E departments causes problems for women seeking help for injuries caused by domestic violence. Women reported being asked about the cause of their injuries in front of partners or others who had accompanied them to the hospital. Health visitors were also a group that were valued by women who had experience of domestic violence (Bacchus *et al.*, 2003). This was associated with the fact that they administered to women under relatively informal conditions and were trusted by such women to act in their best interest. Thus, women who had experienced domestic violence preferred seeking help from health visitors rather than approaching women's groups.

It is also the case, of course, that services for some types of need may not exist or have very limited capacity, and clearly this will inhibit the ability to find an appropriate point of entry to services or to gain help in the way that is required. The literature relating to gender in this area revealed the following examples of suppressed or concealed demand. Karasz and Anderson (2003) in their investigation of the treatment by GPs of vaginal complaints, argue that there is a concealed need for an approach to the treatment of such areas that takes into account the experience and meaning of such conditions for women, rather than responding to them narrowly in terms of a disease model of care; at present they found that the wider, social care, approach is generally not available to women. Hart and Lockety (2002) outline repressed demand in terms of short-falls in the maternity services which, they argue, fail to explicitly and coherently meet the needs of 'disadvantaged' women; in particular the needs of younger mothers from non-English speaking ethnic minority groups. Lastly, Cameron and Bernardes (1998) highlight the under-consultation that exists for men concerning mental health issues and prostate cancer screening. These examples demonstrate low porosity in the membranes surrounding such services for potential candidates attempting to access them.

There is some suggestion that men and women may prefer different therapies and some therapists have begun to adapt their clinical practice to the needs of men (Men's Health Forum, 2002). Such therapists argue that men are more open to problem-solving approaches than to the psycho-dynamic or inter-personal treatments that often require substantial introspection. This research suggests that one of the things that young men fear most is the negative

reaction of other men. Therefore, it may not be the case, as some research has suggested, that men prefer male workers delivering a service to them, rather they may prefer a worker of either sex, as long as that person makes them feel comfortable and valued and treats them positively (Men's Health Forum, 2002).

People's perceptions of symptomatology, here viewed in terms of self-advocacy for care, can also influence use of services. The Men's Health Forum (2002) found that young men preferred agencies which had made access easier by providing anonymous telephone lines or a drop-in centre where no prior appointment was necessary, where they felt welcomed and supported, and where there was minimal risk of stigma. Campbell and Macdonald (1996) report on the development of a local community drop-in centre for women. The centre was set up to provide holistic, patient-centred care. Take up, which was much lower than expected, which may, ironically, be linked to its local nature. Women surveyed reported that they feared local gossip and consequently lack of confidentiality. The informal nature of advertising the centre by word of mouth and through local services may have exacerbated this problem.

In previous sections we have discussed the permeability of services. Our analysis here suggests that for some health problems where there are specific gender-related issues, people may prefer to use services that promote maximum comfort. Features of the ways in which services are organised and delivered may also strongly influence the ease with which people can engage with services. Our analysis of the evidence on uptake of screening provides a good illustration of this. In 1988 a centrally organised cervical cytology screening service was introduced for women aged 20-64 (GPs received incentive targets based on 80 per cent compliance). Achieving such targets is associated with GP and practice characteristics, such as presence of a female partner, more practice nurses and larger practice size (Baker and Middleton, 2003). The general conclusion of these authors is that a primary health care intervention, such as an organised programme (such as that described here) can contribute to reducing inequality in population health. Bentham *et al.* (1995) also found that attendance under the new population-based system of cervical cytology testing was significantly higher than under the old opportunistic system; as with the old system, however, the presence of a female GP in a practice was found to positively correlate with a higher level of such screening being carried out (Bentham *et al.*, 1995). In addition, those practices with higher attendance rates under the old opportunistic system, continued their advantage under the new scheme. Chapple *et al.* (2002) suggest (derived from interview data with male respondents) that because men are reluctant users of health services, the establishment of a national screening programme for prostate cancer may encourage men to be tested for this condition without embarrassment. This indicates that this structural change in service provision led to the creation of a more porous, permeable membrane,

allowing women to negotiate access to the service more easily. This is important because, in the case of some cancers, delays in identification and referral may prove critical in terms of the eventual outcome.

Practitioner gender

Our analysis suggests that the gender of practitioners can affect people's willingness to use services. Focusing on cervical screening, Majeed *et al.* (1994) found that uptake was 12.4 per cent higher in practices with a female partner when all other factors were taken into account. Bentham *et al.* (1995) found a wide range of non-response across practices when cervical screening was opportunistic (before the introduction of the recall system in Britain in 1987). However, patient response was higher in practices with a woman GP, in smaller practices, and where the catchment area had a younger age structure. Like Majeed *et al.* (1994), they conclude that the presence of a female GP encourages uptake. Barker *et al.*'s (1990) research shows that reaching targets for cervical screening (introduced in 1990 with incentive payments for reaching 80 per cent of targets) is linked, among other things (such as more practice nurses, larger practice size) to having a female GP.

Research and critical commentary has also called for 'women-centred care' as stressed by midwives working with women from diverse socio-economic backgrounds in Hart and Lockey's (2002) research. Similarly, women from some minority backgrounds may not use a service with male providers or patients may prefer a local service with lower quality of provision to travelling long distances. More generally, a note of caution is necessary, since there is a strong tendency in much of the literature relating service use to service quality to identify statistical associations, which can then be inferred to suggest policy recommendations to change particular provision (for example that female doctors are necessary to achieve high uptake of cervical screening). Such findings should be viewed with some circumspection, since they distil complex social relationships into simple variables associated with individuals. Where there appears to be an association between screening and gender, a simple interpretation leads to the neglect of questions such as *why* do women prefer a female provider? Without answering this question, we fail to address others, such as could male providers adapt, or not, to meet the needs of women? Such shortcomings in research design limit the value of such research when applied to service interventions. Notwithstanding such potential shortcomings, there is less clear-cut evidence of the influence of sex of practitioner on men's use of services. Cameron and Bernardes (1998) indicate that some men feel that a same-sex practitioner is important, especially when undergoing intimate or invasive procedures for prostate problems.

The social context of help-seeking and use of support

The discussion so far in this section has focused mainly on associations between candidacy and gendered health identities. The sense that individual identities are formed in interaction with others, be this 'general others' such as the media or wider cultural ascriptions, or 'specific others' such as doctors has been apparent. However, the very particular impact that 'significant others', such those within the individual's immediate social network, can have upon help-seeking is deserving of separate attention. Social networks play an important role in the gendering of help-seeking. The research that we considered suggests that they act in gender differentiated ways and help to 'shore-up' gender identities. The long-standing recognition that women talk to and seek advice from other women has recently been supplemented – and our review would suggest, to some extent supplanted in research terms – by an interest in how men engage or fail to engage others in health-related decision-making.

The extent to which gender differences in help-seeking from both lay and professional sources reflect the differential *availability* of various kinds of support to men and women and the extent to which they reflect a differential willingness to *access* support is not clear from the articles reviewed. However, there is some evidence that men and women tend to draw upon different sources of support in the process of interpreting symptoms and taking decisions about whether or not to seek professional health of various kinds. The kinds of support used include discussing health problems with family, partners, close friends, and neighbours (Barker *et al.*, 1990; Chaturvedi *et al.*, 1997; Cunningham-Burley *et al.*, 1996; Tudiver and Talbot, 1999). The overall conclusion is that women are more likely to seek help from these sources than are men. This is supported by research on pathways to care by Rogers *et al.* (1999: 121) which found that 'women are more likely to facilitate access to professional care and exercise greater control over [the health of others] than men, have larger more multi-faceted networks and report more supportive relationships' (Rogers *et al.*, 1999). To the extent that men seek help, this is likely to be from female partners who play a key role in urging them to seek help (Barker *et al.*, 1990; Cunningham-Burley *et al.*, 1996).

Hurdle *et al.* (2001) relate that social support is important to women in both the maintenance of health and the prevention of disease. As Baider and Bengel (2001) explain, traditional gender socialisation can encourage women not only to attend to their own health, but also to the needs of others. Consequently it is relevant to note that marriage has historically been found to benefit the health of men more than women. Rogers *et al.* (1999) also indicate that women are likely to act as proxies for men who are reluctant to articulate their health needs and initiate contact with health services.

The overall implication, therefore, is that men use few lay sources of support, other than wives or female partners, when responding to symptoms and deciding what action, if any, to take about them. We have already seen that it is widely assumed that male reluctance results from an unwillingness to admit to illness because of the weakness and vulnerability that it popularly signifies (Moller-Leimkuhler, 2002). The fact that use of lay support varies by type of health condition lends support to this point. Research by Corney (1990) on the use of general practitioner services for 'minor symptoms' by middle class men and women shows a close association between the presence of psychological problems and consulting among women, but not men (and notes that women are much more likely to have close confidants than men), whereas men confine their help-seeking largely to physical problems. Similarly, a review of suicide and young men's use of services indicates that men are reluctant to highlight personal mental health problems for fear of appearing weak, although they would sometimes talk to 'diamond friends' (Men's Health Forum, 2002). In contrast, sports-related injuries are considered 'safe' to talk about generally (Tudiver and Talbot, 1999).

There is no indication in the articles reviewed that the propensity of women to seek lay help is differentiated by symptom or condition experienced. It is not clear whether this is because women are in fact more likely to seek help whatever the condition, or an underlying unresearched assumption that women 'naturally' seek support from others. In research on women's use of services for Chlamydia Trachomatis, Dixon-Woods *et al.* (2001) found that embarrassment and potential stigma were important factors in mediating use of lay referral systems. This suggests that women's use of lay support is not indiscriminate and may be calculated in much the same manner as men's, particularly when the symptoms concerned are closely associated with gender identity (for example STIs).

Mobilising practical resources

Our discussion of candidacy so far has focused mainly upon the cultural context of gender. However this neglects more practical concerns. Being male or female is associated with differential access to material resources such as the finance, transport, and time. Most studies that we have sampled have focused primarily on the disadvantages women experience in their, often poorer, access to material and practical resources in their use of health care.

In her study of the use of general practitioners by middle-class men and women, Corney (1990) casts doubt on the commonly-held view that family and employment responsibilities affect women's decision to seek help. Thus women with children were not more likely to visit the doctor than those without. Corney's hypothesis that women have more 'time flexibility' than men which makes it more difficult for them to seek care when ill, was not born out by the analysis given that a more

or less equal number of 'high' and 'low' attending women were full time housewives or not working. However, Popay (1992) makes clear that flexibility was 'typically missing from the daily experience of life as mother, housewife or paid employee' in her qualitative case-studies of 18 households in London.

As a result of geographical differences in the supply of services, inequalities of access to health care may be created (Kupek *et al.*, 2002; Bentham *et al.*, 1995; Stark *et al.*, 1997). Kupek *et al.* (2002) found that difficulties in geographical distance adversely affected attendance at antenatal care appointments. Bentham *et al.* (1995) reported the same finding for attendance in relation to cervical cytology (citing rural remoteness as a key reason for not attending for screening) focusing on the relative geographical coverage of cervical cancer screening provision. Baker *et al.* (2003) found that cervical cancer screening coverage was consistently higher in affluent areas from 1991-99 but that ratio rates of inequality between affluent and deprived health authorities narrowed over time. Stark *et al.* (1997) explain that basic practical barriers such as travel costs and bus timetables have a major impact upon uptake of breast screening. This study focused on the effect of access factors on attenders and non-attenders of the National Breast Screening Programme in a rural area. Attendance was lower in the afternoons when travel by bus was more difficult.

Summary: Navigation

There is some evidence of the effects of gender on navigation of routes to and through health care. For some types of problems, men and women may be more likely to access particular types of services, perhaps particularly those where the likelihood of discomfort related to some aspect of their gender is minimised. For example, women may choose to use services for sexual health that are least likely to engender stigma around their identities as women, while young men may prefer services that do not spoil their identities as strong and in control. There are gender effects in the availability and use of forms of support, including lay support, in help-seeking, and while these have been relatively poorly supported in men, the evidence seems to suggest that women's lay networks are more likely to endorse and resource help-seeking. There are likely to be gender specific effects in the ability to mobilise the practical resources required to use health care, but gender-comparative research is rare in this area.

7.2.4 Theme 4: Presentations, adjudications and offers

We have in previous sections pointed to the importance of the ways in which people present their claims to candidacy (consciously or not) in interactions with health professionals, and to the ways in which claims to candidacy are categorised and subsequently disposed by health care providers. Our analysis suggests that these processes may be

subject to strong gender influences. We have organised our synthesis around the following themes:

- Presentations.
- Categorisation and adjudications: A scene of gender struggle?

Presentations

Our analysis suggests that patterns of presentations in medical consultations may be highly gendered, with strong interactions with the gender of the practitioner. Tudiver and Talbot (1999) suggest that physicians perceive that men are more likely to share their health concerns in an indirect, rather than direct way. Men are reported to present with no specific complaint or very general complaints and expect the doctor to ask pointed questions to find out 'why they are really there' (sports related injuries are an exception). Cunningham-Burley *et al.* (1996) suggest that doctors need to initiate discussion with men about urinary symptoms (especially, as discussed earlier, these symptoms tend to be normalised).

As we noted earlier, many of the articles on gender and help-seeking address health problems that are either specific to men or to women. One consequence of this is that much of the research focuses on reproductive health. Given that reproductive health problems are bound up with issues of the gendered body, sexuality, and male-female relationships, it is not surprising that both doctors and patients find them difficult to talk about. Communication barriers appear to arise from the very nature of the symptoms concerned. Hidden symptoms (those that cannot easily be revealed) tend to lead to opaque communication between patient and health provider, which often seems to be underlain with latent gender concerns (Cameron and Bernardes, 1998; Cunningham-Burley *et al.*, 1996). The authors suggest that this may lead to less than optimum health outcomes, notably the failure to appreciate the chronicity of symptoms and therefore the need for longer term follow-up. Bacchus *et al.*'s (2003) study makes clear that women are reluctant to impart information about domestic violence, since they feel embarrassed or afraid to do so. But, interestingly, most women indicated that they would have preferred their doctors to directly ask them about it.

Categorisation and adjudications: A scene of gender struggle?

Some of the research evidence we have analysed points to gender as a site of struggle in health care, dating from the work of feminist social scientists in the 1960s and 1970s. Since that time they have continued to draw attention to the association between patriarchal values and 'offers' of care, highlighting women's negative experiences of health care and problematic health outcomes (Lorber, 1997). Elderkin-Thompson and Waitzkin's (1999) US research found that doctors – who were primarily male – misperceived the seriousness and

nature of women's symptoms, misattributing them to emotional issues or stress. A total of 17 per cent of female patient-respondents in their study, compared to just seven per cent of males, reported that a physician had recently told them that their problems were 'all in their heads'. In the UK, Bendelow's (1992) research on a London pain clinic revealed that health professionals unanimously believed that women were more likely to suffer from pain with psychogenic origins. These gendered perceptions are likely to result in problems of diagnosis and treatment (Elderkin-Thompson and Waitzkin, 1999).

Early research mainly concerned access to reproductive health (Roberts, 1981), but subsequently spread to encompass wider dimensions of health experience. Research documented male power in the medical encounter (women's inability to ask questions, their lack of input into decision-making); doctors' failure to take women's 'lay accounts' of their illness into consideration in consultations; and the imposition of particular medically-defined ways of thinking about what women often took to be 'natural' functions such as pregnancy and childbirth (Karasz and Anderson, 2003). These processes are often conceptualised as the 'medicalisation' of women's bodies and their health. Such categorisations may lead to potentially inappropriate impositions of candidacy on people, which they may find difficult to escape. For example, women may have hospital births, treatment for menopause, screening for breast cancer, and so on, all of which might in some cases constitute inappropriate facilitation – access to health care that is not wanted or needed, where the parties involved do not agree on candidacy.

Gender-related expectations and gender-related patterns of behaviour are often made transparent in the medical consultation. To borrow and extend Karasz and Anderson's (2003) metaphor, 'the gendered body can become the symbolic battleground upon which gendered conflicts are fought'. Viewed in combination, the research articles we have analysed make it clear that doctors tend to de-contextualise patient experience of illness. In failing to take sufficient account of the place of symptoms and the management of illness in everyday life, they may simultaneously invest their patients with their own gendered assumptions and experiences. Articles by Karasz and Anderson (2003), McQueen and Henwood (2002) Bacchus *et al.* (2003) and Cameron and Bernardes (1998) indicate that doctors can fail to pay attention to the patient's own representations of their health problems because of this. Karasz and Anderson's (2003) research shows that doctors and patients (in this case, all attending a family health clinic in New York) had significantly different understandings of vaginal symptoms. In the medical model, vaginitis is viewed as a non-debilitating, self-limiting condition, which is treated effectively with antibiotics. In contrast, the narratives of women patients reveal significant distress, which arises in good part from the significance that vaginitis has within their lives. Thus women feared that infection might spread to infect other reproductive organs, leading to sterility,

even death. This points to a clash of perspectives and potential for struggle around the meaning of symptoms, whereby doctors fail to appreciate the significance of illness within the patient's life world.

It is also the case that men may be disadvantaged by gendered typifications by professionals. Watson (2000) makes clear that stereotypical notions of masculinity have become an orthodoxy among health care practitioners. Practitioners assume, he writes, that 'men's susceptibility to ill health and disease is caused by the adoption and maintenance of lifestyles that are profoundly destructive of body and self'. Similarly, Hayes and Prior (2003) remark that, both public and professional opinion on mental disorder is changing, such that 'stereotypical notions of male behaviour, such as their perceived potential for violence towards self and society, are becoming very influential in discourses surrounding mental disorder'. Watson (2000) reports that, 'changing such behaviours has become a preoccupation for health professionals'. Tudiver and Talbot's (1999) study found that the Canadian family physicians felt that the traditional male role imbues a sense of immunity and immortality, difficulty in relinquishing control, a belief that seeking help is not appropriate for men, and a lack of interest in prevention.

It is also clear that deficiencies in knowledge and awareness can lead to problems in providing appropriate support for gender-specific needs. Thus Bacchus *et al.* (2003) make clear the lack of awareness that domestic violence can contribute to postnatal depression limits the effectiveness of care provided to women. Similarly, Ubido *et al.*'s (2002) research shows that medical staff's lack of awareness of how to relate to deaf women can cause serious barriers to communication. For example, many medical staff looked down rather at the patient they were talking to and used jargon that was difficult to understand. Only seven per cent of respondents said that they 'fully' understood the doctor when they were on their own; 38 per cent said that they 'mostly' did; 44 per cent that they 'sometimes' did, and 11 per cent said that they 'did not understand at all'. The negative consequences are revealed in the case where one woman thought that she was having an antenatal check up when she was in fact being induced. It should be noted that although this paper focuses on women, the issues raised apply equally to men. This area of the literature indicates the need for customised training and substantive improvements in areas such as those of domestic violence and maternity provision (for specific groups, such as disabled people).

Moynihan (2002) explains, in her work on oncology care, that there are dangers that health care providers may bestow certain gender roles on their clients. For example, the stereotypical ideal of the male 'stiff upper lip' can be mistaken as the reality of all men's experiences. Equally she notes that breast cancer, where women are encouraged to embrace expressiveness and emotionality (which is seen as 'women's gift' and linked to reducing cancer distress), has now inappropriately

become the exemplar of all cancer journeys, suggesting that typifications may be imposed in people not as individuals, but as carriers of a gender. Moller-Leimkuhler's (2002) research similarly shows that gender bias in perceptions of mental illness can lead health practitioners to systematically ignore depression in men since it is seen as a 'female condition'.

These differing typifications of men and women may well result in differences in diagnosis of disease, referral patterns, and adjudications, though we found frustratingly little research that could help us tease out these distinct aspects of candidacy. Much of the research that is reported relates to CHD, and here it seems that judgements of technical candidacy by professionals may result in a disfavoursing of women in terms of 'offers'. Richards *et al.* (2000) point out that the probability of a GP provisional diagnosis of CHD is positively associated with being male. Though CHD is more common among men, the authors also feel it may be related to a belief among GPs that men are more likely to benefit from invasive surgery and treatment than women and, therefore, it is more appropriate to make a diagnosis of CHD in men. Controlling for chest pain type, they found that the probability of a GP provisional diagnosis of CHD is positively associated with being male (odds ratio 1.53). Similarly, Petticrew *et al.* (1993) indicate that the reason why men receive more vascularisation procedures than women may be because doctors discriminate on clinical grounds or because they place less benefit on the value that would be gained by women, or what we have called 'conversions' in earlier sections. The authors go on to suggest that doctors may be influenced in this regard by the fact that most studies of prevention and treatment of CHD have been carried out on men. There is also some evidence that women may be more likely to adjust their lifestyle to avoid surgery, less likely to return to work post-surgery and less likely to enter rehabilitation programmes and also to leave them prematurely.

As in previous sections then, adjudications may be powerfully influenced by judgements (that may be flawed) of people's technical eligibility for interventions or attention, and may also be influenced by perceptions of moral / social candidacy, resulting in differential rates of 'offers'. Bowling and Bond (2001) suggest that clinical scoring systems which reflect clinical severity may help to counteract diagnostic biases in treatment and management of cardiac disease. The authors are of the opinion that they are more equitable than an individual clinician's thresholds and value judgements, but clearly caution would be required – clinical scoring systems might embed gendered assumptions, and give the appearance of rationality to a process which is nonetheless inherently intuitive.

It is also important that the ability to resist or reject offers may be gendered, since the strategies available to people in accomplishing the work of accepting and resisting offers are gendered. The large

literature on medicalisation of childbirth is replete with examples of how decisions about labour can be imposed on women in ways which become very difficult to resist. Other offers – services for mental health for men – may be prone to rejection because of the potential threat to identity or lack of agreement about candidacy.

Summary: Presentations, adjudications and offers

The way in which people make presentations about their candidacy in medical consultations is gendered. There is some evidence that men may require more active interrogation by health professionals in order to reveal candidacy, and there is a danger that some needs, especially relating to mental health, may go unrecognised. Issues relating to the gendered body, including sexuality and reproductive health, may be especially prone to opacity. There is also some evidence that the judgements made by professionals about candidacy may reflect judgements about gender. Women may be judged to be less deserving candidates for medical intervention and attention, sometimes because their needs are judged to be lacking in authenticity or inherent value (such as claims about pain), or sometimes because they are seen as being less eligible on technical grounds (though such judgements may not be valid). The candidacy of men for some conditions might also be judged to be absent or unsuitable for treatment. However, there is also evidence of imposition of forms of potentially unwanted forms of candidacy – in relation to the management of childbirth. Thus, while there may be ‘inappropriate’ blocking of candidacy, there may also be inappropriate facilitation of candidacy. Candidacy thus becomes negotiated in gendered terms: the presentations made, the ways in which these are adjudicated, the offers made and accepted, may all be conditioned by gender.

7.2.5 Theme 5: Tractability: gender sensitive care

In this section we conclude by summarising efforts to deal with issues of gender in access to health care. We have organised our synthesis around the following themes:

- Gender analysis and gender sensitivity.
- Gender equity.
- Matching services with need.

Gender analysis and gender sensitivity

Vlassoff and Garcia Moreno's (2002) recent paper, *Placing gender at the centre of health programming: challenges and limitations*, develops a summary of why a gender analysis needs to be central to service policy and development internationally. They point to the many barriers to gender appropriate health care that remain. Five areas in particular are highlighted:

- 1: A gender analysis improves detection and treatment of health problems in underreported groups.
- 2: It improves understanding of the epidemiology of health problems.
- 3: It elucidates psycho-social dimensions of disease for men and women.

4: It improves the relevance of public services.

5: It increases the potential for public participation in health.

However, despite the many reasons for incorporating gender issues into healthcare, many obstacles remain. These include creating awareness and understanding about gender disparities (by linking gender to training and performance of health professionals) and creating equal opportunities for female health care providers at all levels of the system. In essence, Vlassoff and Garcia Moreno (2002) argue that gender needs to be mainstreamed throughout health organisations.

'Gender-sensitivity' has emerged as a major platform for the understanding of health and healthcare delivery internationally. This reflects a growing awareness of the need for mainstreaming – that gender cannot just be 'added-in', but rather needs to be brought to the centre of health policy (Doyal *et al.*, 2003; Khoury and Weisman, 2002). While the British government has endorsed a policy of gender mainstreaming as part of the wider Modernisation Agenda, this has singularly failed to find a place in health policy (Squires and Wickham-Jones, 2002). This is in marked contrast to other nations, such as Canada (Health Canada, 2003a; Health Canada, 2003b), where health policy requires that gender be integrated into day-to-day planning and operations. The majority of UK government modernisation and equalities agendas for health (*The NHS Plan*, DoH, 2000; *Saving Lives: Our Healthier Nation*, DoH, 1999) have failed to acknowledge the impact of gender differences on health outcomes and on the delivery of care. Rather, most health policy is written in gender-neutral language which sets targets for the whole population (O'Brien and White, 2003). The same is true of the Commission for Health Improvement (CHI) and the National Institute for Clinical Excellence (NICE), which are central to clinical governance in the UK. Recent NSFs (on coronary heart disease, and diabetes) make note of male / female variations in the prevalence of disease, but fail to discuss how this influences service delivery. The Government health inequalities agenda is also largely gender blind (DoH, 2001).

Gender equity

Doyal (2000) endorses the point that gender equity is increasingly cited as a goal of health policy nationally within the UK and internationally. However there is considerable confusion about what this could mean in theory and in practice. Three approaches to gender can be identified. First 'traditionalists', who see the concept of 'gender' itself as unhelpful as it over-politicises what are seen as natural differences between men and women. Second, 'feminist radicals' who welcome gender equity, but do not feel that it can be achieved through gender mainstreaming used as a technological fix – the fear is that once a gender policy has been introduced, it can too easily be claimed by those in power that they have now 'done gender'. Third,

'gender radicals' who hold that despite the difficulties, pursuit of gender equity of health is still a worthwhile goal, and argue that emphasis on gender relations has considerable potential for understanding inequalities between men and women. At policy level 'gender radicals' argue that gender equity approach facilitates collaboration between different groups.

Khoury and Weisman (2002) endorse a gender sensitive approach to healthcare, arguing that it allows health policy and the direct provision of care to take account of both gender specific (male / female differences) needs and to draw away from the idea that men's and women's health are in conflict. This is broadly in line with the 'gender radical' approach. This suggests that there is a need to at once be alert to the possible impact of gender difference in help-seeking and healthcare provision, while also being cognisant that men and women do not always and in every instance have different needs.

While health care providers need to be 'gender aware', it is also important that they are not 'gender stereotypic' in their interactions with patients. This point is endorsed by Miers (2002) who argues that gender sensitive care considers individuals and the particular context within which care takes place, including the interpersonal context of male and female provider and patient relationships. Miers stresses that it is important for nurses (the focus of her discussion) to explore their own concepts of gender and gender identity in order to heighten their recognition of clients' perceptions of power and control.

Research suggests that when they are in receipt of care, both men and women prefer practitioners who are sensitive to the often personal nature of their health concerns. This is shown by research by Free *et al.* (2002), Dixon-Woods *et al.* (2001) and the Men's Health Forum (2002). Although these articles do not frame patients' concerns in explicitly gendered terms, they nonetheless convey the sense that patients' concerns are bound up with health care providers' normative perceptions of gender. Moreover, they suggest that providers' inability to respond to their health problems in a sensitive manner can affect service use. Thus, Dixon-Woods *et al.* (2001) found that women using sexual health services gave staff ability to manage embarrassment and stigma as a priority for care. Free *et al.*'s (2002) research on emergency contraception found that women preferred GPs and pharmacists who were understanding and friendly the easiest to deal with. When practitioners focused mainly on the risks that women had taken, they felt rebuked and reluctant to return. The Men's Health Forum suggests that the stigma of mental illness means that young men prefer anonymous counselling to avoid stigmatisation. Bacchus *et al.* (2003) found that lack of privacy in A&E departments causes problems for women seeking help for injuries caused by domestic violence.

It is for these reasons that McQueen and Henwood (2002) call for practitioners to adopt a 'language sensitive' therapeutic approach

when dealing with teenage boys' distress . Based on in-depth analysis of accounts drawn from open-ended interviews with two young men in receipt of psychiatric services, the authors suggest that practitioners need to attend to how young men describe their experience. This would involve getting beneath overt language to appreciate the struggle to adopt an acceptable masculine subject position. For example, being alert to how the lived experience of emotional distress (often coded as female) may be downplayed by men.

Matching services with need

The above summary suggests that there is no simple way in which services can be matched to one or other gender; rather, as already stated, there is a need to be sensitive to when male or female gender may matter for care and when it may not; that is, a 'critical gender awareness' is more crucial. This point can of course be made with respect to all aspects of care, it is not limited to gender as such. Gender sensitivity is then in good part a matter of being sensitive to the needs of individuals, a point that is made by Hart and Lockey (2002) in their discussion of midwifery care. Similarly, Bunce (2000) shows that homeless men have difficulty gaining access to GP services and are perceived as 'problem patients' by staff. They give examples of a number of community projects that have been sensitive to these men's particular circumstances by providing greater use of community psychiatric nurses and volunteers. Respect of the patient's dignity is also cited a crucial to attracting roofless people into care.

Although not referring exclusively to gender, Sword (1999) argues for a 'socio-ecological model' of healthcare and healthcare utilisation which calls for practitioners to acknowledge the social context that influences patient utilisation and also the socio-economic context of care. There it might be argued by implication that we need to be alert to the way that gender perceptions may mesh with the realities of scarce resources to produce the kinds of biases (such as implicit rationing) that have already been discussed, notably in the case of heart disease. On the other hand, Majeed *et al.* (1994) found that many GP practices in deprived areas achieve high cervical smear uptake rates (their particular focus), demonstrating that effective practices are able to perform well even in difficult environments. This appears to indicate that the effective delivery of services is primarily related to the more general level of performance and effectiveness displayed by individual GP Practices.

While these articles indicate the need to be 'open to gender' influences, others make equally clear that it can also be important to be alert to the influence of gender. Thus the Men's Health Forum (2002) relates that many commentators suggest that men and women may prefer different therapies. For example, men may be more open to problem-solving approaches than to psycho-dynamic or interpersonal treatments that often require substantial introspection.

This may reflect men's 'fix it' approach to life. But male masculinity is not a megalith, it is often more appropriate to refer to masculinities in the plural than masculinity in the singular (Connell, 1995; Watson, 2000). Thus Good *et al.* (1989) suggest that there may be specific interventions that are best suited to 'traditional males' that would encourage service use and reduce drop-out from therapy such as psycho-education on the liabilities of the traditional male role such as the restrictive image of the 'strong and silent type'.

Finally, there is a need for gender-sensitive care to be evident at a systems level in health care, not just at the level of micro-level interactions. Sustaining a claim to candidacy across a range of organisational boundaries requires, as we have seen in previous sections, much work on the part of both services and individuals. An example where multi-agency working has been demonstrated to be especially effective is that of domestic violence. Domestic violence often co-exists with other social problems which health professionals may not be qualified to deal with (Bacchus *et al.*, 2003). Multi-agency arrangements may, therefore, facilitate an offer of an effective service or intervention to the patient by the service providers. Multi-agency working also moves health professionals away from working within the limited medical model that women are reported in the literature to feel is unhelpful and which may be associated with undesired judgements about technical candidacy, conscripting some women into inappropriate candidacy.

Summary: Tractability: Gender sensitive care

The need to analyse the barriers to gender appropriate care is increasingly advocated. It is argued that gender sensitivity is needed to improve health care delivery. Gender sensitivity involves recognising that gender cannot be 'added in', but needs to be brought to the centre of health policy. However, there is little evidence of gender sensitivity in current government health policies: instead, the tendency is to be gender blind. There are varying views on how gender equity might be achieved, but perhaps most persuasive is the argument that pursuit of gender equity is a worthwhile goal (though prone to problems), and that a focus on recognising and serving different needs related to gender is required, but also an understanding that different genders do not always have different needs. In pursuing gender equity, there will sometimes be a need for different services, but more often there will be a need to be 'gender aware' in the planning and delivery of mainstream services. However, it is important that gender awareness does not descend into gender stereotyping. 'Critical gender awareness' is the aim: there is no simple way in which services can be matched to one or other gender, rather, there is a need to be sensitive to when gender matters, and to plan, organise, and deliver accordingly.

7.3 Conclusions

This section has presented an interpretive synthesis of the literature on access to health care by gender. A full and comprehensive answer

to the question of whether access to healthcare is characterised by gendered patterns of advantage and disadvantage is not possible given the current research base. We pointed out at the outset, and wish to reiterate, that gender represents a neglected area of research on access to health care and, where it has been deployed, it has been used largely to focus on women. A focus on men's service use is, therefore, a more recent development; rarer still is gender-comparative material. Historically 'gender and health' has been equated with 'women's health'. In these terms, the women's health movement has drawn significant attention to the problems that women face in accessing care at all levels. However, the identification of problems cannot be equated in any straightforward way with disadvantage *vis-a-vis* men. In the absence of gender-comparative research, we do not know whether men experience equivalent problems because of their gender, whether they are equally advantaged or disadvantaged (although in different ways). Certain differences, such as women's greater use of services, have been long-recognised and were evident in the evidence reviewed in our synthesis. Again, and this is a point we have made throughout this report, different use does not necessarily equate with advantage or disadvantage given that use, or non-use, is not in itself a reflection of need. While it is highly likely that men and women have different, and complex, gender-related vulnerabilities, notions of advantage and disadvantage only become meaningful when these vulnerabilities are either unrecognised, or are recognised but inappropriately dealt with. There is, therefore, a need for the development of a robust comparative evidence base in this area and to devise research which is sensitive to manifestations of gender disadvantage in particular contexts and aspects of service provision.

We have made the point that the way men and women may be unfairly disadvantaged is likely to relate to particular health conditions and the use of particular services; we have seen that women may experience less ready 'access' to cardiac care services, which they may need, and that mental health services appear not to be reaching men who may require and benefit from their expertise. We have identified the saliency of gender in men and women's constructions of *themselves* as candidates for care and also how gender stereotypes, in some instances, inform the professional judgements of health care professionals. Gender-related expectations and circumstances frame and limit the experience of illness and disease of those who are subject to them and gender-related expectations on the part of health care professionals may influence the care and treatment they offer.

Our analysis showed the gendered ways in which claims to candidacy are demonstrated and judged in health care consultations. Historically, the clash between medical and lay perspectives has been strongly equated with the struggle between female patients (or potential patients) and male healthcare providers and highly focused on female-specific health problems and health concerns such as reproductive

health. Although this focus is still apparent in contemporary research papers, the recent growth of interest in men's health has meant that men's health has been construed in similar terms. Frequently now, when men's health is considered, the concerns raised are similar to those that have exercised research on women's health. In other words, issues such as lack of medical attention to lay understandings and the place of health in the wider context of individuals' lives are relevant to both men and women. The important point of course is that the particular nature of the gendered meanings that suffuse lay understandings and gendered attributions of illness often vary considerably depending on whether the patient, or potential patient, is female or male.

It is clearly important to make the conditions under which care is given, both attitudinal and structural, as permeable and negotiable as is feasible, in order to allow easy potential access for those who wish to pursue a claim to candidacy. However it is crucial also to avoid the unnecessary medicalisation of areas of social life – many of which are gender specific, for example childbirth and the menopause. Thus 'access' to interventions is not self-evidently a good thing. What we conceptualise as 'inappropriate facilitation' and 'inappropriate blocking' can occur. Most attention has been given to 'inappropriate blocking' on gendered grounds. This reflects the often unconscious assumption that access is in, and of, itself a good thing, although it should be noted that the recent move to evidence-based practice seeks, among other things, to question this. In the context of gender in particular, it is important to recognise that mis-treatment and over-treatment are the result of 'inappropriate facilitation'. This has been most clearly highlighted by use of the concept of 'medicalisation'. With respect to women, examples of this are legion and include inappropriate entry into mental health care and the medicalisation of reproduction and childbirth. Foster (1995) makes this very evident where she argues that 'women's consumption of healthcare has been far less beneficial than to them than is generally believed' (Miles 1991). However, two cautions are important. First, medicalisation is not simply the product of the way in which healthcare is organised. As Reissman (1992) makes clear, in some contexts medicalisation is women's preference. Second, it is evident that men's health is also subject to medicalisation. An illustration of this is what Riska (2003) terms the 'Viagratisation' of men's sexuality.

Gender-sensitive healthcare has emerged as a major concern for the understanding and improvement of health and health care delivery internationally. Many commentators in the field, cited in this section, argue for an awareness of gender to be brought centre-stage in understanding health and health care provision; both from the point of view of the service user but also from the perspective of the health care professional (as employees and care-givers). Commentators argue that gender awareness should be explicitly recognised at each stage of the healthcare labour process: policy formulation, policy

implementation and service delivery. It should, therefore, also be reflected in the training that health care professionals receive and health promotion education that is communicated to the population. Although there is no simple way in which services can be matched to one or other gender; rather, as already stated, there is a need to be sensitive to when male or female gender may matter for the delivery of care and treatment and when it may not; that is, 'critical gender awareness' is the crucial factor.

Section 8 Conclusions

8.1 Introduction

In this report we have presented an interpretive synthesis of a large and diverse body of evidence on access to health care by vulnerable groups. We have emphasised in all sections that it is inappropriate to conceptualise 'access' as involving separate issues of demand and issues of supply. In particular, we point to the misleading and unhelpful nature of evidence that relies solely on measures of utilisation and receipt, even where these data are adjusted for 'need'. Moreover, the focus on macro social forms such as social class, age, gender and ethnicity in much of the writing on access has tended to produce an overly determinist account that fails to recognise important influences of individuals, setting and environment, situated activity, including the dynamics of face-to-face activity, and aspects of self.

Instead, we emphasise the highly dynamic, multi-dimensional and contingent character of access. In our analysis, health services are seen as continually constituting and seeking to define the appropriate objects of medical attention and intervention, while at the same time people are engaged in constituting and defining what they believe to be the appropriate objects of medical attention and intervention. 'Access' represents a dynamic interplay between these simultaneous, iterative and mutually reinforcing processes, but the institutional authority of health services and its status as a monopoly provider confers significant power advantages.

We emphasise 'candidacy' as the core synthetic and synthesising construct. Candidacy describes how people's eligibility for health care is determined between themselves and health services. Candidacy is a continually negotiated property of individuals, subject to multiple influences arising both from people and their social contexts and from macro-level influences on allocation of resources and configuration of services. All people have vulnerabilities in relation to candidacy; our analysis shows that aspects of these vulnerabilities can be amplified by social, ethnic, age, or gender characteristics. By attending to how vulnerabilities arise in relation to candidacy, the phenomenon of access can be much better understood, and more appropriate recommendations made for policy, practice and future research. Though we have not, for the most part, considered the international literature on access to health care, we believe that the model of candidacy that we have developed has implications for understanding access for all health care systems.

In this concluding section we begin by offering a reflection on the methodology used to conduct our review. We then offer a summary

and reflection on the findings of our synthesis and a discussion of the implications of findings for policy, practice, and future research.

We identify 'candidacy' as the core synthesising construct in understanding access to health care. Candidacy describes the ways in which people's eligibility for medical attention and intervention are jointly negotiated between individuals and health services. Particular groups may experience amplified vulnerabilities in relation to some aspects of candidacy, and these require investigation and attention. In this section we summarise and reflect on our findings and on the methodological issues in conducting our review.

8.2 Using critical interpretive synthesis

Clearly, what we have presented in this report is not a systematic review, nor did we ever aim to report a systematic review. We argued in Section 1 that traditional systematic review methodology is extremely good at achieving aggregative syntheses, where what is required is a summary of the findings of the literature under a set of categories which are largely pre-specified, secure, and well-defined. Papers are included in such a review if they satisfy criteria on study design and the methodological expectations associated with the execution of that study design. Critique of papers tends to be limited to appraisal of the methodological specificities of the individual papers; there is rarely an attempt at any stage to re-conceptualise the phenomenon, to provide a more sweeping critique of the ways in which the literature in the area have chosen to represent the world, or to question the epistemological and ontological assumptions of the literature. We wished, by contrast, to conduct an interpretive synthesis, which would defer definition of the phenomenon and the appropriate ways of conceptualising and analysing it until our analysis was complete.

We explained in Section 1 that we had chosen to base our analysis on methods of meta-ethnography for purposes of achieving an interpretive synthesis. Previous uses of meta-analysis had used only small samples of papers, and had synthesised only qualitative papers. Considerable adaptation and development of the methodology was necessary to render it suitable for our purposes, where we wished to synthesise a very large and amorphous literature comprising many different forms of evidence, both empirical and theoretical. In the event, our modifications to the original form of meta-ethnography were so radical that we considered it no longer appropriate to retain the term, and felt it would be more accurate to describe what we did as a new methodology with its origins in meta-ethnography. We have termed our new methodology 'critical interpretive synthesis'.

Main features of critical interpretive review

The aim of a critical interpretive review is, first, to produce a critical overview of a body of evidence in a particular area; and second, to

develop theory; an insightful and useful way of understanding a phenomenon, that can be used to inform policy, practice, and future research.

The question of the review

Conventional systematic reviews start with well-specified, clearly focused and well-defined questions. Critical interpretive synthesis (CIS) reviews may start with a tentative and fuzzy question, which will be subjected to continual review and refinement.

Searching

As for conventional systematic reviews, searching should be comprehensive and rigorous, but CIS emphasises that techniques for literature retrieval should be 'fit for purpose' rather than pursuing exhaustive searches regardless of circumstance. It is not necessary to specify study designs to be included in the review in advance. Abstract screening should be undertaken to form a sampling frame of 'probably relevant' articles.

Sampling

Purposive sampling may be used to select papers for inclusion in a review. As theory begins to develop, it should inform sampling, and 'negative case' sampling should be used, where findings that are likely to challenge the emerging theory are sought.

Appraisal

Appraisal of papers to be included in the review should be aimed at determining whether papers are fatally flawed. This appraisal will focus primarily on aspects of research practice. Further and more wide-ranging critique of papers will occur during the synthesis itself.

Synthesis

The aim of the synthesis is to produce a *synthesising argument*. The synthesising argument integrates evidence from across the studies in the review into a coherent theoretical framework comprising a network of constructs and the relationships between them. Its function is to provide more insightful, formalised, and generalisable ways of understanding a phenomenon.

The generation of the synthesising argument may require the generation of synthetic constructs. These are concepts that are produced through analysis of the evidence: the products are the result of a transformation of the underlying evidence into a new conceptual form.

The synthesising argument may also incorporate constructs already available in the literature.

Data extraction forms may be used to assist in summarising papers. Synthesis should begin with a detailed inspection of the papers, treating them as analogous to transcripts in primary qualitative research. Tentative theoretical constructs, or categories, that help to explain the phenomena being described in the literature should be developed. The theoretical structures that begin to emerge should be constantly compared against the evidence in the papers, and the credibility of the evidence and its underlying assumptions should be critically assessed. The categories and the relationships between them should gradually become better specified into the integrated set of constructs that forms the synthesising argument.

There are several possible criticisms of what we have done, and we will deal with the major ones here.

Is it reproducible?

Systematic review methodology sets great store by the reproducibility of its protocols and findings. We make no such claim, but wish to address some possible concerns. First, it could be argued that a different team using the same set of papers would have arrived at a different set of conclusions – a different lines-of-argument synthesis might have been produced from the same evidence. We accept this, as would qualitative researchers working with primary qualitative data accept that many possible interpretations might be given to, say, the same set of transcripts. Clearly, lines-of-argument synthesis, as an interpretive process, produces one privileged reading of the evidence, and, as the product of an authorial voice, it cannot be defended as an inherently reproducible process or product. We would suggest that our analysis can be defended on the grounds that it is demonstrably grounded in the evidence; that it is plausible; that it offers insights that are consistent with the available evidence; and that it can generate testable hypotheses and empirically valuable questions for future research.

It would certainly have been possible to produce an account of the evidence that was more reproducible. We could have used the evidence to produce a thematic summary that stuck largely to the terms and concepts used in the evidence itself. However, we felt it important that we produced an interpretation of the evidence that could produce new insights and fresh ways of understanding the phenomenon of access. It was important that the 'critical voice' of our interpretation was maintained throughout the analysis. Simply to have produced a thematic summary of what the literature was saying would have run the risk of accepting that the accounts offered in the evidence-base were the only valid way of understanding the phenomenon of access to health care by vulnerable groups.

Second, subjecting a question to continual review and refinement, as we did, may make it much more difficult for those conducting critical interpretive reviews to demonstrate, as required by conventional

systematic review methodology, the transparency, comprehensiveness, and reproducibility of search strategies. This dilemma between the 'answerable' question and the 'meaningful' question has received little attention, but it underpins key tensions between the two ends of the academic / pragmatic systematic review spectrum. On balance, faced with a large and amorphous body of evidence in an area such as access to health care, and given the aims of an interpretive synthesis, we feel that our decision not to limit the focus of the review at the outset was well justified.

Third, it could be argued that we have synthesised too small a sample of the available papers, or that the processes used to select the papers are not transparent. We recognise that we have analysed and synthesised only a fraction of all relevant papers in the area of access to health care by vulnerable groups. However, a traditional systematic review, by limiting the study types to be included, would have synthesised a much smaller fraction.

Clearly, some form of limiting the number of papers to be synthesised was required. The size of the relevant literature in this poorly defined area – which covered almost every aspect of health care from the macro to the micro – was overwhelmingly enormous. We estimated at one stage that there were up to 100,000 potentially relevant references, and not all of them made their way into our sampling frame. We limited the number of papers that we included in the study by using various forms of purposive sampling in the early stages of the review, and using theoretical sampling in the later stages.

While we have described our methods for sampling as purposive, it is possible that another team using the same approach could have come up with a different sample because, particularly in the later stages of our review, our sampling was highly intuitive and guided by the emerging theory. Again, the question arises as to whether we would have come up with a different theory if we had used a different sample. We think this is unlikely, and that our sample is largely comprehensive and generally representative of the empirical literature. It is encouraging that the review paper by Dixon *et al.* (2003), published late in the course of our project, identified and reviewed a very similar set of papers relating to equity of access.

The final version of the theory we eventually developed did not emerge until quite late in the review process, and much of the later sampling was directed at testing and challenging the theory as we began to develop it. Once we had identified the importance of the literature on categorisation and disposal generally, we developed a focus on the ways in which health professionals judge issues of moral and technical candidacy (initially from the paper by Hughes and Griffiths, 1997), and began a search for other similar types of studies. Again, such forms of searching and sampling do not lend themselves easily to reproducibility, and again the authorial privilege is invoked to defend them.

However, the application of this form of sampling for purposes of synthesis has been rarely tested empirically and Jensen and Allen (1996), and Sherwood (1999) express anxiety that selective sampling may result in the omission of relevant data, thus limiting the understanding of the phenomenon and the context in which it occurs. It is certainly likely that we have omitted relevant papers and, because of the limitations of time, we were unable to sample quite as many papers as we would have preferred (though we think we sampled 'enough'). The key question is whether our conclusions would have changed if we had included them. In primary research 'negative' cases that challenge the emerging analysis in some way are purposively sought out. Given the time available for our review, it was not possible to conduct empirical testing of this, though as far as possible we did attempt to seek out and incorporate diverse types of findings. Testing of whether the interpretations change in response to different findings will be an important focus for future research, which will also need to evaluate the extent to which apparently disconfirming evidence is the result of methodological flaws rather than posing a genuine challenge.

Was it legitimate to synthesise different study types?

Estabrooks *et al.* (1994) argue that studies for synthesis should share a similar research approach, suggesting that even when similar themes can be identified across all studies, the mixing of methods leads to difficulties in developing theory because of the major differences in the epistemological foundations of the methods. Jensen and Allen (1996) concur with this view, arguing that if studies from different methods are mixed, it is unclear what has been obtained and how it has been verified. Sherwood (1999) similarly argues that studies with different methods should be grouped together to allow for comparable analysis. Barbour (1998) offers a vivid discussion of the distinctions, tensions, and conflicts between the different approaches to qualitative inquiry. Some of the most intense debates in the area of qualitative synthesis have focused on the extent to which it is acceptable to synthesise qualitative studies derived from different traditions. Jensen and Allen (1996), among others, argue that meta-ethnography should only be used to synthesise studies within a single paradigm. However, there is no consensus on the epistemological and ontological debates underpinning Jensen and Allen's arguments, and pragmatically, as demonstrated by Campbell *et al.*'s (2003) work, many reviews will seek to integrate studies across different qualitative traditions. Paterson *et al.* (2001) deal with the problem of different approaches in part through their techniques of meta-method and meta-theory. We believe that there is no 'in principle' reason why research produced within diverse methodologies cannot contribute to theory building, and would suggest that our analysis provides an empirical demonstration of this.

Other observations on critical interpretive synthesis

As we explained in the introductory section, some of our methodological decisions were driven by pragmatic considerations – with 18 months to conduct syntheses for five groups (as well as a general synthesis) – there was a limit to what we could achieve. One of our key decisions was to abandon reciprocal translational analysis as a key plank of analysis, having attempted to conduct it on over 300 papers. It simply did not work at a practical level, and after some time we became convinced that it did not work on analytic level either. Its tendency is essentially conservative: it seeks to translate concepts into the concepts that were already extant in the literature. Increasingly, we felt the aim of our interpretive synthesis was certainly to identify useful concepts from the literature, but mainly so that they could be recruited for use in a new synthesising argument. We therefore prioritised the development of our synthesising argument and the synthesising constructs within it, and we feel that this has considerably more explanatory value than a reciprocal translational analysis account.

It is important to emphasise just how demanding, laborious, and time-consuming the production of an interpretive synthesis of this type is. Serious practical problems arise in trying to ask questions that are less well-defined than the ‘what works’ question. One is the problem of how to characterise what one is looking for. In quantitative systematic reviews the normal procedure is to specify a clear set of criteria focused around a specific question. These criteria will usually define the study designs to be identified (RCTs) as well as characteristics related to the question, including populations of interest and outcomes of interest. If it is decided to include the entire range of study times, this means that that reviewers are obliged, as we were, to search across the entire range of qualitative study designs for any research relevant to the topic. This was a burdensome and resource-hungry enterprise, and the difficulty, time, and effort required should not be underestimated by others attempting similar exercises.

Many of the processes involved in the analysis were similar to those used in primary qualitative research, and the amount of data we had to analyse as exceptionally large if papers are likened to transcripts or other forms of qualitative data. Our analysis was similar to that undertaken in primary qualitative research. We began with detailed inspection of the data in the papers, gradually identifying themes that were recurring within the data. We then generated themes which helped to explain the phenomena being described in the literature, constantly comparing the theoretical structures we were developing against the data in the papers, and attempting to specify the categories of our analysis and the relationships between them. To facilitate the process of identifying patterns, themes, and categories across the large volumes of text-based data in our study, we used QSR N5 software. However, it is important to note that, as with any

qualitative analysis, full transparency is not possible because of the creative, interpretive processes involved.

Again practical pressures caused us to make some compromises (though we believe these were not serious) in conducting the synthesis. We had intended to upload all of the data extraction to QSR N5 software, but it was not possible to conduct full, formal data extraction on very large reports or on some papers identified in the later stages of synthesis. However, we were careful and systematic in assigning data from these papers to the categories generated by our analysis, and we would stress that such software is intended only to facilitate analysis in any case. It is likely that reviewers using this type of methodology in the future will need to experiment with different methods of summarising and critiquing papers.

Recommendations for using critical interpretive review methodology

- Critical interpretive synthesis (CIS) is a methodology for conducting reviews of large and diverse literatures.
- CIS reviews will not demonstrate the qualities of reproducibility associated with conventional systematic review methodology, but are nonetheless systematic in the same sense as primary qualitative research is systematic: they involve a systematic and detailed interrogation of the evidence.
- A CIS review is particularly suitable when a fresh way of assembling and understanding the evidence is required, rather than when a summary of data is required.
- It is a demanding and laborious methodology and the resources required to execute it should not be underestimated.
- Because of the privileging of the authorial voice and the nature of the critiquing and interpretation required, teams conducting CIS reviews may need to be led by experienced qualitative researchers, though this is likely to depend on the topic area.

8.3 Summary of our findings

8.3.1 Definitions of equitable access are highly problematic

Precise definitions of access to health care and equity of access have remained elusive. It has proved even more difficult to operationalise these constructs for purposes of research. The practical consequence of problems of defining and measuring access is a set of methodological, conceptual, and theoretical problems in investigating access, and in investigating the extent to which access is equitable in particular.

Many analyses of equity in health care rely on measures of utilisation or receipt of services, but utilisation studies are very difficult to interpret. Older people, children and some ethnic minority groups are very high users of some types of health services, but this does not mean that these groups 'over-use' health care: their needs may be greater than those of lower users. However, trying to adjust for 'need' in analyses of utilisation is highly complex and relies on precarious methodologies.

The failure to theorise access appropriately has had wide-ranging consequences. Our analysis of articles concerned with policies and interventions to improve access found that much of the published research appears to operate with poorly defined and operationalised theories of access; that many interventions and policies are not well matched to what we have identified as the major barriers to access; and that where policies and interventions have been evaluated, there is often a failure to consider these at a systems level or to consider adequately unwanted outcomes. In particular there is a failure to consider the impact of interventions for other aspects of access. A range of methods, from randomised controlled trials through to qualitative research, has been used to investigate policies and interventions to improve access, but many have failed to capture the patient's perspective, instead relying on metrics such as number of appointments. It is also clear that context is highly important, and that success of an intervention or policy in one setting with a particular group of clients may not translate well into other contexts. There has been a failure to recognise sufficiently the relationships between the various interest groups (different professional groups, managers, policy-makers, and patients) within wider institutional, organisational, and policy contexts, and how these might impact on access.

8.3.2 The critique of utilisation

We have identified, particularly in the editorial and policy commentary in the papers we analysed, that there has been a concern to assert that potentially vulnerable groups have poorer access, almost regardless of the underlying evidence or its quality. As we have shown, however, the evidence for the 'problem' of access in the groups we have reviewed rests to a large extent on research on utilisation or receipt of services, and this is far from conclusive in demonstrating that vulnerable groups have poorer access when measured in this way.

The current evidence suggests that different groups have identifiable patterns of use of services, but the significance of these is often difficult to interpret. Studies of the problem of access to specialist care have focused on particular specialities, making it difficult to draw conclusions. Studies of deprived groups are concentrated in cardiology and cancer; studies of ethnicity have tended to focus on mental health especially in the Black population; those on older people, on critical

care. Uptake of preventive services in vulnerable groups is generally poorer than in the general population: there are persisting inequalities in uptake of cervical screening and of immunisation and of antenatal care in deprived areas. Older people, children and some ethnic minority groups are very high users of health services, and socio-economically deprived people appear to have higher rates of GP use and emergency care. There are also gender differences in attendance at general practices, with men being less likely to consult, especially for psychological problems.

Generally we argue that utilisation is an inappropriate and unhelpful measure of access, because it relies on a largely untested set of normative and somewhat suspect assumptions about the 'correct' level of utilisation, and because it obscures important aspects of candidacy. A recurrent theme throughout this report has been the unsatisfactory nature of utilisation and receipt as measures of 'access' to health care. While there have been repeated attempts to investigations of whether use and receipt correspond with 'need', we suggest that the findings of such studies might be misleading and unhelpful.

First, such studies will inevitably rely on some positivistic, normative and difficult-to-measure estimate of 'need', and are logistically and methodologically difficult to conduct except for specified conditions, and even then will be problematic.

Second, they will often rely on normative assumptions about need relative to some apparently privileged though often ill-defined reference group, and therefore risk failing to identify problems in access for that group. Our general synthesis, reported in Section 2, demonstrated that problems in access are not the exclusive property of apparently 'vulnerable' groups: they are a universal feature of attempting to use health services. The dangers of comparing an apparently disadvantaged group with an apparently privileged reference group were perhaps most graphically illustrated in our section on gender, where we showed that assuming one sex or the other to be privileged risks underestimating the disadvantages. Equally, assuming that all white middle-class people have privileged access obscures the important problems of people and sub-groups within that group; those of long distance commuters, people with young children, and so on, whose problems may also be understudied.

Third, such studies may produce misleadingly reassuring results by indicating that 'need' and use or receipt are proportionate. We reported some evidence in Section 3 that appears to suggest that people who are socio-economically disadvantaged consult GPs largely in proportion with 'need', where need-based analyses have been undertaken – in fact some studies suggest an excess of consulting relative to need. Taking all the evidence together, it was also difficult to show consistently that such people are disadvantaged in their receipt of specialist care interventions. On the basis of such evidence,

it could be concluded that there is no problem in access to health care by socio-economically disadvantaged people. We argue that this is misleading, and that a focus instead on *candidacy* demonstrates the vulnerabilities associated with socio-economic disadvantage, minority ethnicity, old and young age, and gender, through various stages.

We are not, of course, the first to criticise measures of utilisation and receipt as measures of access to health care. An obvious criticism of the research on utilisation of GP and specialist care is that attempts to develop indices of health need have usually involved use of proxy measures, and deprivation is often imputed at a ward level rather than at an individual level. An even more powerful critique is beginning to emerge of this body of research. Sutton (2002) suggests that much of the work to date has primarily measured horizontal equity (the principle of equal treatment for equal need), and has therefore provided only a partial assessment of socio-economic inequity in health care use. Vertical equity (the principle that different groups need to receive appropriately differentiated treatment) has been relatively neglected. It is therefore in practice difficult to distinguish whether studies such as that by Payne and Saul (1997) are measuring horizontal or vertical inequity, or a combination of both. Gibson *et al.* (2002) summarise a number of other methodological and conceptual defects in the research on utilisation. They emphasise the overwhelming influence of demography in the case of illnesses such as cardiovascular disease, arguing that deprived populations in England tend to be demographically skewed towards the young, but the young tend to have the lowest disease burden. The use of proxies to capture additional needs due to deprivation tend, therefore, to result in over-estimation of overall levels of need in deprived populations, and to underestimation of use relative to need.

Gibson *et al.* (2002) argues that evidence of inverse care may therefore be as much a function of the use of inappropriate proxies as of genuine, systematic differences in access to healthcare. Indeed, studies such as that by Black *et al.* (1995), which compare deprivation rates against age-standardised intervention rates, suffer from explicitly designing out demographic differences between populations. Moreover, Gibson *et al.* (2002) argue, such analyses do not distinguish the effects of social deprivation on *use* from the effects of social deprivation on *need*.

Dixon *et al.* (2003) advance a similar though distinct criticism of macro studies, which they define as studies that consider the use of NHS services and compare this with the needs of that group as indicated by broad measures of morbidity or mortality. They suggest that the focus on the aggregate distribution of utilisation may not properly capture the distribution of benefit from that utilisation. If poorer groups tend to present later and to have more emergency admissions, they may be shown in these studies as having higher utilisation, but that utilisation may be less effective in terms of

delivering health benefits than those derived from earlier presentation and elective treatment of better off groups with similar needs – in our terms, they are less able to *convert* health care received into the same level of benefit. Dixon *et al.* (2003) argue that micro studies, which study the utilisation of particular services in relation to need, are more likely to show inequities. As our summary of selected studies for each of the groups we looked at demonstrates, however, such studies do not consistently find inequities.

A major plank of critique is our argument that utilisation, or, more appropriately, *receipt* of health care is the outcome of many different complex processes, which all need to be recognised if access is to be properly understood. First, people must recognise and act on symptoms or risks; they must mobilise the resources necessary to negotiate a route to health care; they must make a presentation about their health to a health care professional; that health care professional must then adjudicate on the management of the health issue and make an offer to the person, who must then decide on whether to accept it and act on that decision. All of these processes occur within organisational and social context. The processes are not necessarily linear, and they may interact in highly complex and unpredictable ways. Moreover, they are heavily influenced by operating conditions of health care, including availability and location of services.

The need to understand access in terms of candidacy. We suggest that studies of use and receipt are not very useful in providing insight into access, and are potentially misleading. A focus on candidacy instead helps to identify where and when people are vulnerable: at the stage of recognising and acting on candidacy, in navigating routes to enter and sustain engagement with services; in the ways they present at services; in the ways in which claims to candidacy are judged and adjudicated; in the offers that are made to them; and in their willingness or ability to accept or reject those offers. It also helps to recognise the influence of 'operating conditions' in the form of wider contexts.

8.3.3 Recognitions of candidacy

Our analysis suggests that resources of information, knowledge and beliefs, confidence in self-diagnosis and self-management, and practical resources, powerfully influence people's ability to manage, make decisions, and execute help-seeking actions in relation to health and illness. Initiation of entry to the health services depends on people recognising themselves as having some claim to medical help. This requires some work on the part of individuals or of someone on their behalf: the recognition of candidacy. The vulnerable groups that we looked at occupy somewhat different positions with respect to identification and recognition of candidacy: the ways in which people recognise themselves to be candidates for medical attention and interventions are patterned by social advantage, age, ethnicity, and gender.

In general, cultural expectations of help-seeking affect people's tendency to seek help. Our analysis has identified the salience of gender in men's and women's constructions of *themselves* as candidates for care. This process is highly responsive to cultural expectations of what is gender appropriate. Expectations of gender-appropriate behaviour may inhibit help-seeking by males, as help-seeking may threaten masculine characteristics of strength and invulnerability. Similarly, expectations of what are 'normal' aspects may condition older people's understanding of some health issues, and some older people appear to have a need to retain an identity as fit and healthy. Young people may also erect barriers to the recognition of their health need, shunning parental involvement while experiencing difficulties in negotiating their own identities as candidates in this context.

People often experience uncertainty about help-seeking and may experience key uncertainties about how to match their perceived health needs with the service best suited to dealing with it. Lack of information thwarts people from using services in the way that would most benefit them at every stage of their interaction with health services. Lack of knowledge of services was found to be a key problem in many studies and may disproportionately affect some groups, while medical knowledge is important in knowing when to initiate help-seeking.

There is persistent concern in many of the papers we analysed that people may fail to recognise their candidacy because of deficits in their knowledge or because their beliefs are mistaken, at least when judged from a medical perspective. Certainly there is a body of evidence for each of the groups that we reviewed that shows that where people do not realise the significance of symptoms, or that there is a service that might be able to help, they may not recognise that they have a claim to candidacy or may not exercise it. Recent work by Prior, Wood *et al.* (2003) suggests that what professionals would regard as symptoms of psychiatric disorder are just as easily classified by lay people as social problems or problems in living, and lay people may hold rational, if mistaken, views about the extent to which their problems can be helped by medical intervention. The view that doctors are not likely to be able to help with problems that arise in the context of everyday life is one held by members of some minority ethnic groups (Kai and Hedges, 1999), and may explain low levels of consultation for depression that we noted in our section on ethnicity.

There is strong evidence in the literature that people's preferences for particular forms of services, and their perceptions of the quality of services, influence their willingness to use services. People are especially unwilling to use services that they perceive to be of poor quality or to be hostile to them, or that are likely to impose judgements about the moral character of their help-seeking. Patients sometimes feel that they are rendered powerless in their ability to

define problems or initiate the actions they feel to be appropriate to address these problems. There is a widely reported feeling that lay knowledge is undervalued.

There is a long history of discordance between medically defined 'appropriate use' and patterns of actual use by people. Research we reviewed shows that people are very often highly sensitive to perceptions of their help-seeking behaviour by professionals, and fear of being seen to be irrational or neurotic, or as imposing a disproportionate burden on the NHS, can cause dilemmas about help-seeking and may act as a deterrent. We noted how evident the moral character of help-seeking is, both in the ways people identify themselves as candidates and in the ways they are judged as candidates. For older people and help-seeking on behalf of children we identified considerable evidence of the moral dilemmas involved in deciding to use health services. People appear to be highly sensitised to the limited resources of health services and the need not to make unreasonable or unwarranted demands. Fear of having one's claim to candidacy judged as inauthentic and illegitimate acts as a powerful deterrent to help-seeking. This may be part of the explanation for why people from socially disadvantaged backgrounds appear more likely to access health care as a series of crises: they may wait for a legitimate 'event' to occur rather than seeking preventive or maintaining consultations. In addition, however, people in deprived communities may also 'normalise' symptoms because of high levels of ill-health in their local communities. The constant publicity and efforts to drive down 'inappropriate' use need to be considered in this context; certainly more attention is required to the unwanted effects of discouraging people from using services.

Invitations – for preventive services such as screening, immunisation, and health checks – are subject to similar processes about recognition of candidacy. Invitations seek to impose qualifications of candidacy on people, but people negotiate and make their own judgements about the extent to which they match those qualifications and their preferences about accepting invitations. Those living in deprived circumstances show more readiness to consult in general but might be more likely to do so only in response to specific events or crises. If crises are required in order to allow people to assert candidacy, this means that invitations to attend for screening or review appointments will not result in high uptake as they are not consistent with the people's view of the appropriate use of health care or the extent to which they feel they can prevent illness. Socio-economic factors confound the evidence on recognition of health needs by members of ethnic minority groups. Some studies have found lower uptake of breast screening among Asian than non-Asian women, but one study found higher uptake by black than white women from the same area of London.

Children are a special case in that they are dependent on their parents' or guardians' identification of candidacy on their behalf. Parents recognise that children have enhanced claims to candidacy, but need not to be identified themselves as neurotic and over-protective. Some parents resolve the resulting dilemma by rationing their own use of services so as to be seen as reasonable users. Parents' recognition and response to the health needs of their children must be viewed in the context of their recognition and response to health needs generally, which are influenced by ethnic, socio-economic and gender identity considerations outlined above.

All communities are influenced by the level of confidence they have in their beliefs about health and illness. This confidence appears to be high among some ethnic minority groups for some conditions and may result in late presentation with some health needs, mimicking the crisis-responding referred to above in relation to socio-economically deprived groups. Although this is explained in terms of delay in recognition of candidacy in both ethnic minority and socio-economically deprived groups, the beliefs and circumstances underlying this delay affect the action taken in complex and interwoven ways. Lay referral systems appear to have important influences on help-seeking, but have been relatively little studied in the UK.

While accepting that there will be social and ethnic patterning of 'lay' beliefs, our general synthesis shows that lay beliefs are a universal feature of all help-seeking. Moreover, while it is tempting to argue that people who apparently over-consult or people who apparently under-consult hold lay beliefs that are 'wrong', it is not clear where this argument leads. Interventions to encourage people to recognise pathologies are of limited value and have many unwanted consequences. We suggest the most appropriate way forward is to ensure that accurate information is easily available in forms that people can find and use – suggestions made in the literature include using local radio and community networks that are routinely accessed by people.

8.3.4 Recognitions of candidacy

Recognition of candidacy is a clear area of risk. Recognitions of candidacy are strongly influenced by lay beliefs, and willingness and ability to act on candidacy are affected by beliefs about the extent to which help is likely to be available, appropriate, and of acceptable quality. People are especially unwilling to use services that they perceive to be of poor quality or to be hostile to them, or that are likely to impose judgements about the moral character of their help-seeking. There is considerable evidence of 'self-rationing' of use of services.

Where interventions have been studied to 'improve' help-seeking behaviour, the objective of much of the work is to reduce 'inappropriate' consultations,

particularly for minor illness and particularly for children. Such work is based on a 'deficit' model of people's beliefs about illness, where the interventions are intended to 'correct' misunderstandings about illness. These do not appear to make consulting behaviour more 'appropriate' and also appear to impose a moral character on help-seeking.

8.3.5 Navigating services

Individuals who are acting on their candidacy must find routes to and through health services. **Navigation** refers to routes individuals take from identifying their candidacy to gaining a point of entry to health services. Services may rely on implicit assumptions about the 'ideal user' - someone who uses services precisely in the way they are intended, for precisely the problems providers have identified the services as serving, and who has the exact set of competencies and resources required to make optimal use of the service.

Accomplishing the work of navigation relies on a set of competencies and resources that may not be equally distributed among the population, and which may disadvantage certain groups. Being able to use health services very often depends on being able to mobilise a large set of resources, including practical resources that may depend on the level of affluence, social support, and a range of competencies. Transport is a particular problem, and people without access to a car seem particularly disadvantaged. The most disadvantaged in this respect appear to be those living at distances of a few miles from services, which are often concentrated in towns and cities.

Very disadvantaged groups including the homeless, travellers and recent migrants, may be unaware of where to get help. There is evidence that young people may also be uncertain of where to get advice and accurate information. Knowing what help is available and how to use the services is compounded where English is not spoken fluently or literacy is a problem. Social support in the form of lay consultation is often used by young and old, especially by older women as well as by members of ethnic minorities. More formal social support in the form of community transport, advocacy and interpreters may facilitate access to the health services, although some work has also found that South Asian women may be discouraged from seeking this sort of help and using services, by the gossip it might stimulate within their social network. In general though, women's lay networks are more likely to encourage help-seeking than men's. Certain conditions may be perceived as stigmatising in any group, which inhibits help-seeking. Studies suggest this varies between groups, for example mental-health problems among men, urinary problems among older people or breast cancer among African and African-Caribbean women.

Our analysis identified the complexity of the health care environment and the amount of work people have to do to navigate routes to and

through health care. We will suggest that services can be conceptualised in terms of how **porous** or **permeable** they are. High permeability services are those that are most comfortable for people to use, that demand the fewest qualifications for candidacy, and that require less work. More porous services allow people to pass through easily; services that are less permeable require much more work in order to gain a point of entry and sustain engagement with the service. To a large extent, more porous services, which include general practice and A&E services, do not rely on judgements by health services about candidacy at an individual level. **Less permeable** services are more resistant and pose more barriers, are difficult to negotiate, and require a high level of alignment with the organisational values of the services on offer. These services normally require some professional judgement of candidacy of individuals, and include outpatient appointments and procedures undertaken in hospital.

Permeability is affected by composites of boundaries – between health and social care, between general practice and outpatients, and so on - create the need for management of these boundaries and increase cross-boundary working by staff. These forms of working raise issues of integration of services and questions about the way in which these services relate to each other. In addition to the transaction costs involved in more complex modes of working and service organisation, complexity has important implications for candidacy. Complexity may create low permeability of services: diverse provision, unless accompanied by good communication, may well create confusion rather than promote patient choice and ease of access.

The opacity of the increasingly complex health environment has been associated generally with a lack of common shared vocabulary. Indeed, there has been a proliferation of terms describing the services available and this appears to have led to problems of intelligibility for patients. There is concern about whether patients realise the range and content of what is on offer. This has implications for putting in place adequate communication systems, patient education and information, in order that the function of the different services become more transparent.

The evidence we have reviewed suggests that potentially vulnerable groups are more likely to default to highly porous services such as general practice and A&E, and appear less likely to use specialist services. Our analysis suggests that less permeable services impose more qualifications for candidacy (requiring referral); may require more work and the mobilisation of more resources to use (transport arrangements); and may appear to be less culturally aligned with the needs of particular groups (an emphasis on prevention and monitoring may not be congruent with how some groups make sense of their ability to control their health).

Willingness to use a service depends not just on ease of use but on people's perceptions of the quality of care delivered by that service. Failure of communication at any stage in the process adversely affects uptake of a service. There may be particular problems of language among ethnic minority groups, but language is not the only factor. Among all groups, forgetting and family and work commitments are common reasons for non-attendance. Appointments systems may make attendance particularly difficult for vulnerable people. They require people to have stable addresses and, very often, telephones. Socially deprived people tend to have more chaotic lives than the more advantaged, making appointment-keeping difficult. This affects children's attendance at outpatient clinics, as well as adults'. Receptionists and the gender of the health professional are seen particularly by young people as organisational barriers to help-seeking.

For children and for older people, the ease of use of different levels of service is an issue. Communication and co-ordination between services seems to be the basis of these problems. Paediatric services vary in the degree of specialisation, complexity and provision of service between regions. Continuity of provision at the transition stage between paediatrics and adult services presents problems. For older people, a particular organisational problem is at the interface between the health and the social services, added to the sheer range of professionals involved in an older person's care. For some groups and some conditions, a single professional may be more suited to needs, for example maternity services for Somali women.

We identify non-attendance as a signal of poor permeability requiring serious attention by policy-makers, health care providers, and researchers. Non-attendance has traditionally been seen as a nuisance that disrupts attempts to run clinics efficiently and interferes with the ability to run waiting lists appropriately. A number of attempts to describe the epidemiology of non-attendance have shown that those with broadly socially excluded characteristics – those who are socio-economically disadvantaged, of minority ethnicity, and so on – are at high risk of defaulting on attendance. However, this significance of this has rarely been recognised. As George and Rubin (2003) argue, attempts to 'solve' the non-attendance problem have located the problem in patients' behaviour, not in organisations themselves, and sometimes use punitive measures to cure people of non-attendance. Instead, we propose, non-attendance should be seen as a problem that prompts reflexivity (critical self-reflection) on the part of health services to identify features of organisations that lead to low attendance.

8.3.6 Navigating services

Navigating services requires considerable work and use of resources on the part of people. Complexity and proliferation of services, and composite boundaries, increase this work.

Permeable services are likely to have less formal requirements for use, to require less work on the part of people to use them, to require the mobilisation of fewer practical resources, and to have more flexibility.

We see non-attendance as a highly significant signal of low permeability and poor access in systems. Non-attendance is particularly a risk for people of disadvantaged social circumstances. Rather than blaming patients for their carelessness and thoughtlessness in non-attendance, attention needs to be given to the features of organisations that result in non-attendance.

Some groups, particularly children, are increasingly seen as requiring dedicated services, but the question of whether there should be dedicated services for other groups and sub-groups remains contested.

8.3.7 Presentations, categorisations and adjudications

We have emphasised, throughout this analysis, that the ways in which people make presentations in health care encounters are patterned by social advantage, ethnicity, age, and gender. People's competence and willingness to describe symptoms, how they make disclosures, how passive they are, and so on, will all affect the ways in which they defend a claim to candidacy. Claims may be recognised and forcefully asserted by people, as we saw in some of the studies of childhood illness, where there was evidence that parents struggled to have their children's problems recognised as legitimate and authentic objects for medical attention and interventions. Other claims may be asserted passively, without the individual necessarily being aware of a problem, through the presentation of symptoms or signs which are only detected through medical tests – for example hypertension, where a claim is asserted through the discovery of elevated blood pressure. There is some evidence that for some groups (older people and men), subtle cues may be used by people in an attempt to detect how particular symptoms may be responded to by practitioners. This may lead to under-detection of some types of problems.

Throughout this analysis we have emphasised the role that health professionals' typifications and interpretations of people and their health problems play in determining the outcomes of a claim to candidacy. We have shown evidence of concern about health care providers making decisions on the basis of a master trait such as ethnicity, sex, age, or social class. Gender appears to have a key impact on pattern of presentation in medical consultations. The medical model has resulted in differing typifications of men and women and a consequent danger of failure to recognise the candidacy

of men or of women for certain conditions. When health needs are gender specific, appropriate support for these is not always provided because of a lack of awareness on the part of the, probably other-gendered, professional involved.

On top of the possibly inappropriate facilitation or blocking of candidacy which arise as a result of gender, members of ethnic minorities may experience the outcomes of professionally applied stereotypes concerning their ethnicity. One consistent finding is that members of ethnic minorities appear to have high rates of GP consultation but low rates of specialist consultation. It is unclear whether this occurs as a consequence of lower numbers of offers made to members of these groups, a result of adjudication, or in acceptance of offers, or processes of navigation and negotiation.

Numbers of offers made to older people are also difficult to collate, as most offers are not made formally. Older people may feel that they are disadvantaged by stereotyping but the evidence that this exists is weak. Preventive services provide some evidence of older people's reasons for refusal or uptake of offers but have been under-studied.

The persistence of parents may be an important factor in adjudications relating to children. Many parents struggle for recognition of their expertise with regard to their children's health and this may result in feelings of disempowerment. Although there is some evidence of indulgence in children's attendance for health care, studies of how professionals make adjudications about children's candidacy are rare.

Over-generalisations, or prejudices, about particular groups of people clearly have serious implications for judgements of candidacy, including how authentic, legitimate, and deserving cases of candidacy are seen to be by those who control allocation of resources through clinical decision-making or other forms of professional behaviour. The perceived ability of the patient to 'convert' health care into health gain is clearly relevant. 'Deservingness' on social and moral grounds may be brought into the decision-making, alongside technical eligibility such as co-morbidities or health behaviours, resulting in exclusion of disadvantaged people. However, though we identified the relevance of judgements of technical, moral and social eligibility for the ways in which candidacy is categorised and disposed by health professionals, there was disappointingly little direct evidence in this area.

Despite the lack of evidence, we found a recurrent tendency in the literature to locate the reasons for lower receipt of some interventions – cardiac treatments for women and those of minority ethnicity - in the moral failings, such as prejudice and discrimination, of clinicians. Work in the USA has also argued that the stereotypes drawn on, often unconsciously, by clinicians operate to create forms of discrimination (Burgess *et al.*, 2004). Burgess *et al.* summarise a body of research that indicates that 'perceivers' often behave in ways that result in support of their preconceived beliefs about a 'target'. This suggests

that if a health care provider believes that black people are less likely to want surgery or transplants, they may unintentionally confirm these beliefs through the questions they ask and do not ask.

At present the evidence inherent bias on the part of health care providers in the UK is very scanty. Our analysis identified the importance of what Dodier and Camus (1998) call the 'mobilising worth' of individuals, and how this may be judged on the basis of some master trait, such as gender, ethnicity, age, or social disadvantage. Those master traits may make individuals less eligible candidates because of judgements of their other vulnerabilities of whether they are able to 'convert' health care into benefits (Dodier and Camus, 1998). It is likely that these issues of technical eligibility, based on clinical epidemiology, may also create stereotypes about particular groups which then inform decision-making if professionals fail to assess people individually and instead rely on probabilities. An important area of future research will concern the extent to which evidence-based guidelines tend to disadvantage particular groups through their highly specified formulation of eligibility criteria. Equally important will be research that shows how people themselves contribute, or try to contribute, to adjudications, in the current push towards partnership-based models of decision-making.

Clearly it is important, in advance of such research, that health professionals are not prejudiced in the typifications they make of people's health needs. However, the extent to which tendencies to stereotype people in unhelpful or inappropriate ways can be remedied by strategies such as anti-discrimination training was not clear from the evidence we analysed. Indeed, it was notable that while there is some evidence about anti-racism training – which has highlighted the dangers that attempts to improve sensitivity to ethnic diversity can reinforce stereotypes unless carefully managed – we found much less evidence about anti-ageism training or anti-sexism training, and no evidence at all about how to avoid stereotyping people who are socio-economically disadvantaged. Burgess *et al.* (2004) offer some useful suggestions based on social cognition research. They propose that interventions should be minimally demanding - because interventions demanding extensive resources have the potential to backfire, among other reasons) - and could include simple reflexive tasks such as imagining a day in the life of a particular type of person (a South Asian woman, an older person, a parent, a socio-economically disadvantaged person, and so on); using mental imagery (a cognitive therapy technique involving visualization of particular states); and making people aware of the influence of stereotypes.

8.3.8 Presentations, categorisations and adjudications

The ways in which people make presentations (how they explain their problem) is likely to be patterned by age, gender, ethnicity, and socio-economic disadvantage. Presentations are likely to affect whether health problems are detected as well as adjudications by professionals on how problems should be managed. There is some evidence that perceptions of how likely people are to convert health care into health benefits may affect clinical decision-making, and this may have implications for equity. However the area is poorly researched in the UK.

Much more research is required to understand how eligibility for health care is interpreted by professionals; how people are assigned to different types of categories; how issues of technical and moral or social candidacy are used and invoked; and how adjudications are influenced by the operating conditions of health services. The interpretive processes involved in adjudications are likely to be highly sensitive to locally produced contexts and contingencies, to interpretation of patient factors, including their credibility and likely authenticity, and to broader organisational and policy constraints.

The extent to which stereotyping can be addressed needs to be more rigorously evaluated.

8.3.9 Operating conditions

Many of the papers we analysed, particularly of an editorial type, were prone to making sweeping generalisations about 'discrimination' of various kinds. We suggest that while the consequences of some decisions and behaviour of some professionals may amount to discrimination, a wholesale attack on the moral character of health professionals generally is not warranted on the basis of the empirical evidence that we analysed, and we call for more research in this area. We wish to emphasise the ways that decisions about allocation of resources, including referrals, offers of interventions, and so on, are played out in micro-level interactions with people and are heavily influenced by the operating conditions in which health professionals work.

We have identified the importance of 'operating conditions', including formal relationships in health service settings, sensitivity to resource constraints and the need for allocation of resources between competing demands, in determining the outcomes of claims to candidacy. Government policy has historically focused on issues of supply as a primary determinant of access to health care (Powell and Exworthy, 2003). Issues of capacity and supply have been discussed throughout the report and we have shown that, at a macro level, they set important constraints on access to health care by limiting the 'amount' of capacity in the system. Variations in the supply of health

services significantly affect people's opportunities to access primary, secondary and tertiary healthcare. Lack of capacity, variations in quality, differences in resource allocation and features of service configuration, including geographical patterning and concentration of services, all serve to create access-disadvantaged groups.

One strategy to improve access has involved increasing capacity, where the 'amount' of health care available is increased. However, the effects of increasing capacity are not well understood, with some evidence that increasing capacity stimulates demand and may have the perverse effect of decreasing access.

Standardisation of provision has also become a favoured response to evidence of variations in the provision of care, but research is only now beginning to appear on the effects of this on access. Much of the evidence thus far has focused on the effects of guidance on referrals rather than on less tangible aspects of provider behaviour. Research on changes to appointments systems appears to be promising. Most of these systems allow a greater match between how patients want to use the system and how booking is allowed. However, the effects of the universal roll-out under current government policies such as access to a GP within 48 hours and more convenient booking of appointments with hospital consultants are difficult to anticipate, as most research thus far has looked at well-defined areas with limited implications for other services.

A recurrent theme in the literature concerns the appropriateness of providing 'dedicated' services for particular groups or sub-groups. Here the debates are interesting: children have been recognised as having special needs for dedicated services, and huge effort and resource have been invested in creating specialist paediatric services, but the situation as regards other potentially distinctive groups is more ambiguous. Apart from dedicated services for the homeless, there is little evidence of special services for socio-economically deprived people. The question of whether there should be dedicated services for particular members of ethnic minorities continues to be highly contested; though popular with users, there is concern that the creation of such services could contribute to stereotyping and ghettoisation. One difficulty with this approach is that it can actually encourage stereotyping and the phenomenon of 'cultural deficit' – applying different standards to different groups. There is also concern that such services could be seen as favouring the needs of particular groups and cause resentment and discrimination. More evaluation of such services, with a focus on wider system issues, is needed.

Prioritisation systems involve the use of strategies such as scoring to formalise the priority to be given to patients based on the urgency or importance of their health problems have been studied, and seem to show that access, measured by who most needs help, can be improved by such systems, but there may be corresponding reductions in access for people deemed to have lesser need. It may be

increasingly difficult to implement scoring systems in the context of new policy imperatives that emphasise chronology of referral rather than urgency.

There has been generally a failure to understand how changes in the organisation and delivery of services affect the micro-level interactions between professionals and patients, where issues of categorisation and disposal are played out. Part of our argument is that problems in capacity and other organisational issues operate as important conditions that force health care providers to select between and prioritise different claims to candidacy.

Operating conditions make adjudications contingent, among other things, on the competing demands on scarce resources, and the consequent need to determine the 'best' candidates (on technical or moral / social grounds) for use of those resources. As Irvine and Donaldson (1995) note, health professionals, and particularly doctors, play the key role in rationing available resources through the decisions they make at the micro-level, and they do this in the context of the broader parameters set about availability of resources at a macro level. What we have called 'adjudications' are likely to be subject to broader constraints about the most efficient allocation of scarce resources, and, as we have argued, this is likely to include considerations of the extent to which people are likely to be able to 'convert' interventions into sustainable health benefits. Recent empirical work (Rees Jones *et al.*, 2004) is beginning to demonstrate some of the role tensions that GPs experience in making these judgements, and the extent to which sensitivity to resource constraints limits patient involvement in decision-making. Work on referral to rehabilitation (Foster and Tilse, 2003) is also emphatic about the highly dynamic nature of referral decisions, demonstrating the interpretative processes engaged in by health professionals and their sensitivity to resource constraints.

Other operating conditions arise locally, and may have important influences on candidacy. Our analysis suggests that GPs in socially disadvantaged areas may experience very high levels of demand, and are also often dealing with more complex health problems. These stressors may well lead to poorer quality of service, manifest in the evidence that consultations in disadvantaged areas tend to be shorter.

Limitations on access to health care are imposed by lack of capacity and uneven distribution of services across the UK. These limitations are played out in the micro-level interactions that people have with practitioners.

Practitioners are engaged in continual processes of interpretation and judgement of individual claims to candidacy. These may include normative assessments of master traits such as gender, age, ethnicity, and social class, adjudications about the appropriate candidates for health care, but judgements are also strongly influenced by what we

have called operating conditions, including the limitations of capacity and resources in health services.

Health professionals have to work within organisational boundaries that mean that often have to select the 'best' candidates for particular interventions, or have to ration their time, attention, and energy among the many competing demands. Rather than locating apparent discrimination in the moral failings of health professionals, more attention is needed to how adjudications are shaped by sensitivity to resources constraints and other operating conditions, and the extent to which these are amenable to intervention.

8.4 Recommendations for future research

- Exploration of whether there are systematic differences in the kinds of work people have to do to use health services and the resources available, including lay referral systems, between different age, gendered, social and cultural groups.
- Evaluation of how systems can be organised to reduce the work that patients need to initiate an appearance at health services or to accept an invitation or offer of care. This will include comparison of services with higher and lower 'did not attend' rates.
- Research into why older people, members of ethnic minorities, people of different genders, and socio-economically disadvantaged people are under-represented as users for some specialist services.
- Research into the patterning, by age, gender, socio-economic disadvantage, and ethnicity, are assigned to different types of categories and how problems are defined, how issues of technical and moral or social candidacy are used and invoked, and how adjudications are influenced by the operating conditions of health services. This will include exploration of practitioners' notions of how well people can 'convert' health care into health gain might influence categorisation and disposal, as well as practitioners' sensitivity to the constraints, financial and organisational, in which they have to make decisions about eligibility for services.
- Exploration of the extent to which evidence-based guidelines tend to disadvantage particular groups through their specification of eligibility criteria.
- Exploration of how people themselves contribute, or try to contribute, to adjudications.
- Exploration of whether 'acceptance' of offers made by practitioners varies between different groups, and why.
- Research into the apparent discrepancy between supply of GPs and demand.

- Research into 'companions' or 'brokers' in consultations (those who accompany older people or those from ethnic minorities). This should include evaluation of cultural brokerage involving the use of linkworkers and other advocates.
- Research on the distinctive issues related to ethnicity, socio-economic disadvantage, gender, and age that may arise in encounters between health professional and patients. This will include investigation of issues of stereotyping and discrimination, but will be highly sensitive and prone to ethical problems (because of the potential for damage to practitioners who participate in the research).
- Evaluation of how issues of language and culture affect people's ability to make presentations to health services.
- Research (with a holistic, systems-wide perspective, and including economic evaluation) on the outcomes of matching ethnicity of service to ethnicity of user.
- Evaluation of action research involving communities defining their own health care needs.
- Research with children and young people rather than on children and young people about their perspectives on services.
- Research into the way medical services are provided to nursing home residents.
- Evaluations of anti-discrimination training.
- Evaluation of intermediate care.
- Inclusion of groups who tend to be excluded from clinical trials: older people, people with co-morbidities.
- Gender-comparative research of lay networks.
- Increased research focus on men's service use.

8.5 Recommendations for policy and practice

Studies of utilisation of health care have been the main source of evidence about inequities in health care, but because of the methodological and conceptual problems with this approach, the extent to which distinctive patterns of receipt of services reflect inequities is inconclusive. What is clear, however, is that different groups of people may experience amplified vulnerabilities in relation to candidacy for health care. Many of the issues arise in the social context in which people live, and research evidence about how poorer people can be encouraged to have a more positive conception of health, or older people can or should be encouraged to accept offers of particular procedures, is currently inconclusive. In that sense, how

people constitute themselves as candidates for health care may not be especially amenable to intervention. Pending further research, we suggest the following:

- Information resources about illness should be available in forms that people can find and use readily, but it should also be accepted that educational interventions are likely to have only limited impact in altering help-seeking behaviour, and only then for specified conditions.
- Simplistic assumptions about 'deficits' in people's knowledge should be avoided; help-seeking is highly complex and influenced by a range of resources, only one of which is biomedically 'correct' information. The potential for interventions aimed at promoting 'appropriate' help-seeking to discourage 'appropriate' help-seeking, by imposing a moral character on using health services, needs to be recognised.
- The proliferation of organisational forms in the NHS needs to be managed carefully to avoid creating risks for candidacy. Composites of boundaries between various services are particularly prone to causing problems.
- High levels of non-attendance at services should be treated as a signal of low permeability i.e. a service that is difficult for people to use. Services should assess the extent to which there is social, ethnic, gender, or age patterning of non-attendance and investigate, probably using qualitative methods, reasons for these.
- Services need to establish how much work people have to do, how many resources they need to mobilise in order to use them, and how comfortable people feel about using services. This may be achieved by audits where users and, ideally, non-attenders are asked about transport, workplace and childcare arrangements and arrangements for accompaniment or language.
- Services, particularly those that offer preventive or health-maintaining care, need to evaluate how they can make themselves most congruent with the ways in which potentially vulnerable groups tend to use health care (there appears to be evidence of managing health as a series of crises, and using maximally permeable services).
- Practitioners need to be reflexive (engage in critical self-reflection) and be explicit about how they respond to presentations and make adjudications about people; they need to identify the heuristics, rules of thumb, they use in assessing people's eligibility for particular services. A range of cognitive techniques may help to facilitate this process.
- It will also be important to recognise the team-based nature of many decision-making processes, and to understand the

contributions that different members of the team make, as well as how the patient's view is incorporated in the negotiations.

- The impact on equity of evidence-based guidelines on managing health conditions should be assessed.
- The debate about whether there should be specialised services for particular groups has not yet been resolved. Any evaluation of specialised services needs to pay careful attention to the unwanted effects of specialised services.

8.6 Conclusions

Access to health care is best understood in terms of candidacy. Our review demonstrates that all potential users and users of health services have vulnerabilities in relation to candidacy, and that aspects of these vulnerabilities may be intensified by effects of socio-economic disadvantage, ethnicity, age, and gender.

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Appendix 1A General access to healthcare search terms

ACCESS	HEALTH CARE	INEQUALITIES	METHODOLOGY	NAMES
Patterns of service use	Out-of-hours service	Equity	Qualitative studies	Tudor Hart
Financial incentives (capitation, per-item fees, target payments, allowances, sessional fees, prospective / retrospective payments)	Help-seeking behaviours	Inequity	Ethnography	Acheson Report
Financial barriers	Primary	Social variation	Ethnographic research	Glaser and Strauss
Availability	Secondary	Geographical variation	Phenomenology	Strauss and Corbin
Affordability	Tertiary	Fairness	IPA	Zola
Timely care	Community	Vulnerable groups	Phenomenological research	
Organisational barriers	Delays in treatment	Marginalised groups	Ethno-nursing research	
Having access	Waiting times	Discrimination	Grounded theory	
Gaining access	Ambiguity of symptoms	Priority consultation	Purposive sampling	
Acceptability	GP registering	Social exclusion	Observational method	
Physical access	Appointments	Social isolation	Content analysis	
Patient perceptions	NHS development	Gaps in health care	Thematic analysis	
GP perceptions	NHS plan	Gaps in health needs	Constant comparative method	
Doctors perceptions	Consultation	Opportunity	Field studies	
Barriers	Mental health services	Poverty	Theoretical sample	
Facilitation	Dental health care	Socio-economic status	Discourse analysis	
Uptake of services	Family practice	Differences	Narrative analysis	
Inappropriate use of services	GPs	Variation in services	Interviews	
	Specialists	Disparity	Focus groups	
	Specialist services	Disadvantage	Case studies	
	Health services	Unbalanced		
		Incongruity of services		

ACCESS	HEALTH CARE	INEQUALITIES	METHODOLOGY	NAMES
Inappropriate demand	Hospital care	Inconsistency of services		
Demand	Palliative care	Experience of health care		
Mobility	GP practice	Equalities		
Funds	Treatment	Stigmas		
Costs	Prevention	Physical		
User charges	Mental	Disabilities		
Needs	Physical	Level of support		
Health needs	Risk	Resources		
Waiting times	Physician	Knowledge		
Capacity of health services	Doctor			
Effectiveness	Emergency care			
Efficiency	Accident and emergency			
Delivery of health care	Resources			
Inverse care law	Medicine			
Knowledge barriers	Perceptions			
Information barriers	Carer			
Utilisation	Community practice			
Involvement	Social well-being			
Participation	Illness			
Socio-emotional barriers	Procedures			
Use of services	Surgery hours			
Admission	Surgery			
Experience of health care	Midwifery			
Advocacy	Nursing			
Social barriers	Health visitors			
Psychological barriers				

ACCESS	HEALTH CARE	INEQUALITIES	METHODOLOGY	NAMES
Prescription charges	NHS Direct			
Practical barriers	Walk -in centres			
Resource allocation	Intermediate care			
Flexibility of services	Benefits			
Pathways to care	Referrals			
Supply of services	Ambulance services			
Distribution of services				
Quality of health care				
Patient satisfaction				
Information services				
Service delivery				
Service provision				
Support				
Empowerment				
Patient choice				
Demographics				
Geographic location				
Location				
Enter				
Reaching				
Delays				
Attitudes				
Experience of health care				
Out of date information				
Difficult to understand				
Lack of clarity				

ACCESS	HEALTH CARE	INEQUALITIES	METHODOLOGY	NAMES
Interpretation of information Complexity of forms Beliefs Motivation Help-seeking Priorities IT access Time restrictions Inter-agency difficulties Front desk problems				

Appendix 1B Examples of free text search terms for topics and vulnerable groups

<i>Help-seeking</i>	<i>Provision and availability</i>	<i>Organisational features</i>	<i>Policy and service developments</i>	<i>Children</i>	<i>Older people</i>	<i>Minority ethnic groups</i>	<i>Gender (men and women)</i>	<i>Disadvantage</i>
Help-seeking behaviour	Supply	Organisation	Improving access	Young	Older people	Ethnicity	Gender	SES
Help-seeking	Availability of services	Service configuration	Evaluation	Child	Elderly	Minority ethnic groups	Men	Socio-economic status
Consultation	Provision of services	Service framework	Randomised controlled trial	Children	NSF for older people	Language	Women	Socio-economic groups
Reasons for consulting	Geographical variation	National framework	Cluster trial	Infant	Geriatric	Non-English speakers	Male	Socio-economic position
Barriers to seeking help	Rural provision	Health care delivery	Barriers to access	Baby	Old age	Interpreters	Female	Socio-economic position
(Health) service use	Remote areas	Service delivery and organisation	Intervention	Toddler	Nursing homes	Racism	Gender-sensitive care	Social disadvantage
Use of health services	Rural areas	Service re-configuration	Enhancing access	Child – Male / female	Palliative care	Discrimination	Sexism	Disadvantaged groups
Consultation experience	Single-handed practices	Service design / re-design	Health services research	Youth	End of life care		Discrimination	Poverty
Patient satisfaction	Gender of health professionals	Organisational features	Randomised study	Parent	Ageism		Gender division	Social inequality
Perceived availability	Financial incentives	Organisational characteristics	Controlled trial	Offspring			Sex	Equity
Perceived need	Physical barriers	Organisational culture	Policy	Mother			Sexual health	Equality
Affordability	Payments to hospitals	Organisational barriers	Service	Father			Gendered provision	Inequality
Acceptability	Resource allocation	Organisational form	Service development	Guardian				Housing
	Target payments	Organisational structures	Organisation of services	Neonate				Overcrowding
	Immunisation provision	Organisational change	Reorganisation	Ante-natal				Environment
		One-stop-shops	Regionalisation	Advocate				Poor
		NHS Direct	Service delivery	Advocacy				
		Ambulatory care unit		Paediatric				
				Breast-feeding				

<i>Help-seeking</i>	<i>Provision and availability</i>	<i>Organisational features</i>	<i>Policy and service developments</i>	<i>Children</i>	<i>Older people</i>	<i>Minority ethnic groups</i>	<i>Gender (men and women)</i>	<i>Disadvantage</i>
	Cervical screening Removal from GP lists Emergency medical services Ambulances to rural areas Location of health services Postcode lottery Inverse care law Physical accessibility	Continuity of care Timeliness Delay Care pathway Seamless service Appointment times Referral activity Working hours		Infantile Newborn Adolescent Child health Developing Development Growing				Affluence Affluent Marginalised Inverse care law Need Owner-occupier Home owner(ship) Rented accommodation Council accommodation Local authority accommodation Local authority wards Deprivation wards Transport Car owner(ship) Social inequality(ies) Social support Social capital Social means Social isolation Social exclusion

<i>Help-seeking</i>	<i>Provision and availability</i>	<i>Organisational features</i>	<i>Policy and service developments</i>	<i>Children</i>	<i>Older people</i>	<i>Minority ethnic groups</i>	<i>Gender (men and women)</i>	<i>Disadvantage</i>
								Social reform Social deprivation

Appendix 1C SDO 'Vulnerable groups access to healthcare' data extraction form

Unique Paper Identifier:

Initials of Data Extractor:

Source of Paper:

(e.g. database, expert suggestion, citation search, etc.)

First Two Authors:

(in following format: Surname Initial, Surname Initial)

Title of Article:

(in following format: title in full)

Date of Publication:

(in following format: dd / mm / yyyy)

Country of Study:

(i.e. country where study was conducted, not country of authors)

Vulnerable Group:

Relevant to Access and Group: YES / NO

If NO please do not proceed further and return the form to Debbie/Shona.

Quality

- Are the aims and objectives clearly stated? YES / NO
- Is the design clearly specified and appropriate? YES / NO
- Do the researchers provide a clear account of the process through which findings were produced? YES / NO
- Do the researchers display enough data to support their interpretations and conclusions? YES / NO
- Is the method of analysis appropriate and adequately explicated? YES / NO

Acceptable quality? Excellent / Acceptable / Unacceptable

(judge overall quality, informed but not guided exclusively by questions above)

If Unacceptable, please state the reasons below.

If NO please do not proceed further and return the form to Debbie/Shona.

Stated Aim of Study:

(i.e. aims and objectives)

Sample / Participants:

(i.e. studied population)

Study Design/Data Type:

(e.g. case-control study, focus group study, etc.)

Analytic Approach:

(e.g. descriptive statistics, grounded theory analysis, etc.)

Themes:

(give each theme a title in BLOCK CAPITALS, e.g. '[STIGMA]', then summarise relevant data in ordinary text, e.g. '69 per cent reported feeling stigmatised').

1 [TITLE]

2 [TITLE]

3 [TITLE]

4 [TITLE]

5 [TITLE]

6 [TITLE]

7 [TITLE]

8 [TITLE]

9 [TITLE]

10 [TITLE]

11 [TITLE]

12 [TITLE]

Relevant to Another Group:

(i.e. children & young people, men & women, older people, ethnic minorities)

Comments:

(i.e. interesting aspects of the methodology and results)

Memos:

(i.e. implications for developing concepts and theories)

Meta-narratives:

(i.e. assumed concepts and theories)

Appendix 2A Studies included in general synthesis

<i>Author, year</i>	<i>Type of paper</i>	<i>Aim of study</i>	<i>Study design</i>	<i>Sample / participants</i>
Adams <i>et al.</i> , 2003	QN	To evaluate the extent to which structural variation between English general practices is accounted for at higher organisational levels in the NHS	11 structural characteristics of general practices in England including GP characteristics and those of patients and services provided	All general practices in England
Agarwal, Pierce <i>et al.</i> , 2002	QN	To describe the problems and barriers perceived by general practitioners whilst providing diabetes care in primary care in England and Wales and to identify those health authorities in which primary care reported the most and least difficulty	Self-administrated questionnaire	1873 randomly sampled GP practices
Ambery and Donald, 2000	QN	To explain variation in admission rates for elderly people	Retrospective review	Patients over 75 from 53 general practices admitted to DGH and CH in West Gloucester during three years

Author, year	Type of paper	Aim of study	Study design	Sample / participants
Anderson <i>et al.</i> , 1997	QN	To identify the health perceptions of young families with different lifestyles and from different environments	Questionnaire	50 traveller families identified via the city and county council traveller liaison service and traveller education centre, 50 families from an affluent rural part of Leicester (44 interviewed) and 50 from a deprived inner city area (44 interviewed)
Anie <i>et al.</i> , 2002	QN	To assess sickle cell pain and coping in children and to examine the relation between these factors and the utilisation of health services	Interviews Questionnaire	Cross sectional study with 67 children with sickle cell disease attending three London hospitals
Aylin <i>et al.</i> , 1996	QN	To use data from the fourth national survey of morbidity in general practice to investigate the association between home visiting rates and patient's characteristics	Survey	502 493 patients visited at home from 60 general practices
Bailey <i>et al.</i> , 1994	QN	To establish the extent and nature of specialist outreach clinics in primary care and to describe specialists' and general practitioners' views on outreach clinics	Telephone interviews Postal survey questionnaire	50 hospital managers, 66 specialists and 46 GPs involved in outreach clinics in general practice and 72 GP fundholders associated with 50 hospitals in England and Wales
Bain <i>et al.</i> , 2002	QL	To explore how patients with colorectal cancer perceive their care	Focus group In-depth interview study	95 patients and relatives of patients with colo-rectal cancer

Author, year	Type of paper	Aim of study	Study design	Sample / participants
Baines <i>et al.</i> , 1998	QN	To identify and describe attitudes towards the BMA agenda by undertaking a survey of the views of GPs in one English health authority	Postal questionnaire	Senior partner of each of 105 general practices in Lincolnshire
Baird <i>et al.</i> , 2000	Letter	N / a	N / a	N / a
Baker and Hann, 2001	QN	To test the persistence of the inverse care law in circumstances in which the coverage of chronic disease management, child health surveillance and minor surgery is known to be widespread. To compare the distribution of services between PCGs and between practices within a PCG	Secondary data analysis using GP census data combined with 1991 national census data	All 481 Primary Care Groups in England
Baker <i>et al.</i> , 1999	QN	To develop a measure of patients' attitudes towards care across the interface between primary and secondary care	Patient career diaries	601 patients referred to hospital services (inpatient / outpatient)
Barker <i>et al.</i> , 1990	QN	To identify the pattern of overall help seeking and coping in the UK and examine whether there are any differences in help-seeking and coping behaviour with respect to demographic variables or level of psychological complaints	Interview Data on current psychological health were obtained	1040 adults with a mean age of 45 (498 men, 542 women) quota sampled from the general population
Baldock <i>et al.</i> , 2001	QN	To study change in outcome for people admitted to an intensive care unit after organisational changes	Database review of prospectively collected data	1134 admissions to an intensive care unit

Author, year	Type of paper	Aim of study	Study design	Sample / participants
Bebbington <i>et al.</i> , 2000	QN	To examine how people with neurotic disorders receive professional evaluation, and how this is affected by clinical and sociodemographic differences	Symptom score (inc ICD-10 diagnosis), ADL deficit score and demographic variables were examined in relation to contact with primary care physicians for psychiatric symptoms	Data taken from the National Survey of Psychiatric Morbidity involving over 10 000 subjects
Beech, 2003	Review	Book	N / a	N / a
Bennett <i>et al.</i> , 2001	QN	To evaluate the effect of a risk factor checklist and training video for general practitioners in reducing inter-practice variation and improving the appropriateness of referrals of patients with suspected otitis media with effusion (OME or 'glue ear') to secondary care	RCT	Fifty general practices (177 GPs) from the NHS Trent region and the West of Scotland were cluster-randomised either to a control group or to one of three intervention groups
Ben-Schlomo and Charturverdi, 1995	QN	To examine whether coronary artery bypass graft operations (CABG) reflect socioeconomic differences in ischemic heart disease (IHD) mortality	Ecological study	35 to 74 year-old population statistics for IHD deaths and CABG's in the North East Thames Region compared with the general population
Benzeval and Judge, 1996	QN	To estimate the relative need for GPs by linking evidence from individual utilisation data to the characteristics of small areas	Secondary data analysis of survey data combined with census data	Household survey data on 12 729 adults (Omnibus survey) combined with census data

Author, year	Type of paper	Aim of study	Study design	Sample / participants
Black <i>et al.</i> , 1997	QN	To describe specialist outreach clinics held in fundholding general practices in two specialities from the perspective of patients, GPs and consultants and to estimate the comparative costs of these outreach clinics and equivalent clinics	Prospective data collection Questionnaire	Patients, GPs and consultants
Black <i>et al.</i> , 1995	QN	To explain the reasons for geographical variation in the use of coronary re-vascularisation in the UK	Cross-sectional ecological study	All residents of SE Thames, East Anglian and North West health regions plus three boards in Scotland who underwent CABG or PTCA in 1992 – 93 in either public or private sector
Blair <i>et al.</i> , 1997	QN	To compare and contrast the referral patterns of general practitioners in Nottingham for paediatric specialist opinion in a hospital and community setting	Case note Case activity review	Case note review and activity data from 100 consecutive referrals made by GPs to a hospital paediatric consultant outpatient clinic and 100 consecutive referrals to a community based clinic.
Blatchford <i>et al.</i> , 1999	QN	To determine the principal diagnoses, demographic and socio-economic factors associated with emergency medical admission	Cohort study	A fully anonymised dataset linkage of 43 247 adult emergency admissions to Glasgow medical beds in 1997 was obtained
Bloor, 1976	QL	To explore the issue of variations in the assessment of children for adeno-tonsillectomy	Ethnographic study	Outpatient clinics of 11 ENT specialists

Author, year	Type of paper	Aim of study	Study design	Sample / participants
Boghossian <i>et al.</i> , 1996	QN	To appraise a rapid access proctology clinic (RAPC) set up in St George's hospital, London	Clinic evaluation	A rapid-access proctology clinic
Bond <i>et al.</i> , 2000	QN	To measure the processes of care, health benefits and costs of outreach clinics held by hospital specialists in primary care settings	Questionnaire	Features of 19 specialist outreach clinics (cases) in general practice were compared with matched outpatient clinics (controls)
Bosanquet, 2003	Review	To review the findings of NICE and sketch out future possibilities based on 62 technical appraisal reports	N / a	N / a
Bower <i>et al.</i> , 2003	QN	To examine patients' views on access and continuity in general practice to derive quality standards	Survey	21 905 general practice patients
Bowling, 1996	QN	To elicit the views of a large, nationally representative sample of adults on priorities for health services	Interview survey	2005 adults randomly sampled from the UK population census and surveys
Bowling and Redfern, 2000	QN	To analyse the patterns and process of care for the referral of outpatients together with the views of patients, their GPs and specialists	Questionnaire survey	Outpatients, their specialists and GPs in randomly sampled authorities in the North Thames region

Author, year	Type of paper	Aim of study	Study design	Sample / participants
Bowling <i>et al.</i> , 1987	QN	To examine the factors influencing patients' attendance and frequency of attendance at the A&E of the Queen Elizabeth hospital for children	Documentary analysis Questionnaire	968 attendances by 938 attendees at A&E between Sept 1984 and Sept 1985 & doctor-completed questionnaire over two week periods during November 1983 and February 1984
Bowman <i>et al.</i> , 2001	QN	To investigate admissions to a district general hospital from nursing home beds over 12 months	Retrospective data collection	898 nursing home bed occupants in the Avon catchment area of the Weston General hospital
Brogan <i>et al.</i> , 1998	QN	To determine the use and costs of the principal out-of-hours health services in Buckinghamshire	Prospective cross-sectional survey	Data from general practices, A&E departments, ambulance services and community nursing services
Burgess <i>et al.</i> , 1998	QL	To examine the extent and determinants of patient and general practitioner delay in the presentation of breast cancer	A case control study Semi-structured interview	185 cancer patients attending a breast unit
Campbell <i>et al.</i> , 2001	QN	To examine variations in markers of the structure, process and outcome of care being provided by practices of various sizes with a view to determining association between these markers and to determine how these markers relate to partnership size	Questionnaire survey Patient survey	A randomised sample of GPs and practices from two inner-London areas, stratified according to practice size and patients attending the practice over a two week period

Author, year	Type of paper	Aim of study	Study design	Sample / participants
Campbell <i>et al.</i> , 2001	QN	To investigate whether outlying patients had more advanced disease at diagnosis	Retrospective case note review	Case notes of 1323 patients in North and Northeast Scotland who were diagnosed with lung or colorectal cancer in 1995 or 1996 were reviewed
Campbell <i>et al.</i> , 1998	Review	To describe integrated care pathways, how to create and use them and review evidence of their effectiveness	N / a	N / a
Campbell <i>et al.</i> , 2003	QL	To assess the quality of care in English general practice in 2001 , compared with 1998, in terms of access, interpersonal care and clinical care	Observational study	23 general practices
Carlisle and Johnstone, 1998	QN	To determine the relationship between general practice surgery consultation rates and census-derived socio-economic variables for patients receiving the same primary and secondary care.	Retrospective data collection	Three practices in Mansfield, North Nottinghamshire with 29 142 patients spread over 15 electoral wards
Carter and Bannon, 1997	QNQL	To ascertain the views of a sample of mothers of children aged three about the child health surveillance programme	Survey questionnaire	Ten per cent random sample of mothers of children aged 3 in two West Midlands health authorities
Carter <i>et al.</i> , 2002	QL	To explore the ways in which parents of children with profound special needs assess and manage their children's pain	Qualitative case study design using guided interviews over a three month period	15 parents / carers of 12 children aged 5 to 16 years with profound special needs

Author, year	Type of paper	Aim of study	Study design	Sample / participants
Chang, 2002	Review	To explore the meaning and implications of 'equity in health' and to propose a conceptual framework to delineate the roles of empirical and normative research in determining when inequalities in health are equitable	N / a	N / a
Chapman <i>et al.</i> , 2002	QN	To assess whether the introduction of NHS Direct had any impact on episodes of influenza-like illness and other cases of respiratory infections seen by general practitioners	Prospective data collection	Data on respiratory infections from three general practices
Chapple <i>et al.</i> , 2001	QNQL	To find out which groups of people would use a NHS Walk-in centre that would offer mainly health care advice, staffed by nurses and to understand circumstances in which people would use a walk-in centre	Semi-structured interviews Focus groups	The study was conducted in Wakefield and includes white and ethnic minority groups
Charles-Jones <i>et al.</i> , 2003	QL	To explore the redistribution of medical work in general practice, how health professionals account for how work is being redefined and redistributed and how current government policies and professional discourses combine to refigure identities of both providers and patients	Semi-structured interviews	26 purposively sampled GPs, nurses and practice managers from nine general practices in the North West of England
Charlton <i>et al.</i> , 1991	QN	To examine the delay in diagnosis, both in terms of time and number of consultations and rates of consultation of respiratory problems before and after diagnosis	Survey	212 children under 16 with asthma from two urban general practices in Southampton and Norfolk

Author, year	Type of paper	Aim of study	Study design	Sample / participants
Chau <i>et al.</i> , 2003	QN	To evaluate a rapid access lymph node diagnostic clinic (LNDC) based on analysis of 550 patients	Prospective data collection	550 patients referred to the LNDC
Churchill <i>et al.</i> , 2000	QN	To determine whether the attitudes of teenagers towards general practice are associated with differences in consultation patterns	Postal questionnaire survey compared with the same patients' consultation data from the previous 12 months	Teenage patients aged between 13 and 15 registered with five practices in the East Midlands
Coleman and Wynn, 2001	QL	To elicit GP and practice nurse accounts of change in their clinical practice	Semi-structured interview	18 GPs and 13 practice nurses
Cooper <i>et al.</i> , 1998	QN	To assess whether equity is achieved in use of general practitioner, outpatient and inpatient services by children and young people according to ethnic group and socio-economic background	Secondary analysis of the British General Household Survey (GHS) 1991-1994	20 473 children and young people aged 0 to 19 years
Cornford, 1998	QL	To describe the illness behaviour of patients with a cough	Interviews	Patients who had consulted a GP because of a cough and a group of subjects who had recently had a cough but had not consulted
Cornford and Cornford, 1999	QN	To describe conversations with others and their influence in the decision to consult	Questionnaire Interviews	101 patients who had consulted a GP with new symptoms
Cornford <i>et al.</i> , 1993	QL	To examine mothers' personal accounts of their concerns about their child's cough, their perceptions of the benefits in consulting and to evaluate how they assess their child's illness	In-depth interviews	30 mothers who consulted a GP for their child's cough

Author, year	Type of paper	Aim of study	Study design	Sample / participants
Cox, 2004	QN	To determine the views of dermatologists, with audit and database information where possible, on the overall impact of the 'two week rule' referral standard for suspected skin cancer	Postal questionnaire	139 dermatologists
Coxon <i>et al.</i> , 2003	QN	To investigate the local workload generated by cancer referrals, and compliance with the 'two-week rule'	Prospective data collection	All referral letters sent to the Urology Department, St Helier Hospital, over an eight-week period during June and July 2001
Coyle, 1999	QL	To explore the meaning of dis-satisfaction with health care through the stories or narratives that people tell about their untoward experiences	In depth interviews	41 individuals from inner-city London and Salisbury. 21 women and 20 men aged 18 to 79 years
Cragg <i>et al.</i> , 1994	QN	To study the number, demography and clinical details of patients who agreed or refused to attend centralised primary care centres for out-of-hours medical care and to study the satisfaction with the service of those who attended	Questionnaire	Five out-of-hours primary care centres in the UK. All patients contacting the deputising service to request medical help out-of-hours who were asked to attend a primary care centre
Craven <i>et al.</i> , 1994	QNQL	To identify characteristics of those who responded positively to the campaign encouraging dental attendance and to identify barriers to responding	Focus groups Survey	Six single-sex focus groups from mixed social class backgrounds but representative of a school population, especially of infrequent dental attenders

Author, year	Type of paper	Aim of study	Study design	Sample / participants
Crawford <i>et al.</i> , 2002	Review	To examine the effects of involving patients in the planning and development of health care	N / a	N / a
Crawford <i>et al.</i> , 2001	QN	To ascertain the views of primary care personnel regarding the placing of Community Mental Health Nurses (CMHNs)	Questionnaire	Two primary care practices in South Staffordshire, UK
Cromerty, 1996	QL	To describe the range and types of thoughts which patients have during their consultations	Semi-structured interviews	18 general practice patients from Aylesbury, aged 17 to 73 (14 female, four male)
Crowley <i>et al.</i> , 2002	QN	To assess the practice and impact of a community development initiative in Newcastle: 'Community Action on Health'	Interviews Questionnaire Direct observation	A community in Newcastle with a six per cent black and ethnic minority component and high levels of social and economic disadvantage
Culyer, 2001	Review	To characterise the essential features of an equitable health care system	N / a	N / a
Culyer and Wagstaff, 1993	Review	To explore different definitions of equity in health care. To propose that 'equality of health' (distributing health care in such a way as to get as close as possible to an equal distribution of health) should be the dominant principle	N / a	N / a
Dale and Dolan, 1996	QN	To examine the extent to which patients make appropriate use of A&E and minor injury units	Prospective data collection	Data on patient referred using A&E and Minor Injury Units (1891 Patients)

Author, year	Type of paper	Aim of study	Study design	Sample / participants
Dale <i>et al.</i> , 1996	QN	To compare outcome and costs of GPs, senior house officers and registrars treating patients who attend A&E departments with problems assessed at triage as being of primary care type	Comparative study	4641 patients presenting to an inner city A&E with primary care problems
De Nooljer <i>et al.</i> , 2001	QL	To increase our understanding of the relationship between knowledge and interpretation of symptoms, fear and trust on the one hand, and the decision to consult a GP for cancer symptoms on the other	Interviews	23 patients and ten GPs were interviewed
Debnath <i>et al.</i> , 2002	QN	To measure the compliance to the guidelines and evaluate the effectiveness of two referrals for colorectal cancer	Audit	All patients who were referred to the rapid access colorectal clinic between August 2000 and July 2001
Dingwall and Murray, 1983	Review / QL	To show how 'taking children seriously' requires us to revise recent analyses of processes for classifying patients for treatment	Observational study Interview	Three / four A&E departments in England
Dixon <i>et al.</i> , 2003	Report: Is the NHS equitable? A review of the evidence	N / a	N / a	N / a
Dixon-Woods, 2001	QL	Analysis of discourses about using patient information leaflets	Discourse analysis	Literature about patient information leaflets

Author, year	Type of paper	Aim of study	Study design	Sample / participants
Dixon-Woods <i>et al.</i> , 2001	QL	To determine how parents felt about the process of obtaining a diagnosis of childhood cancer, how it affected them and the implications of early diagnosis and referral	Semi-structured interviews	20 parents of children (4 to 18 years) with a diagnosis of cancer
Dodds <i>et al.</i> , 2004	QN	To examine general practitioners' views and referral practices under the 2-week wait rule	Postal questionnaire	508 GPs in an inner London area (65 per cent response)
Dodier and Camus, 1998	QL / Review	To examine the consequences of dual orientation (being open to heterogeneous medical demands versus selecting patients) on the concrete organisation of work	Observation Field interviews	Emergency services in a French teaching hospital
Dolan and Cookson, 2000		To elicit the general public's views about the extent to which health gain matters vis-à-vis other considerations	Focus group	60 respondents
Donovan <i>et al.</i> , 1997	QN	To discover the attitudes of 15 to 16 year olds to the GP consultation and contraceptive services	Questionnaire	Data was collected from four successive years of national curriculum year 11 students aged 15 to 16 year olds
Dossetor <i>et al.</i> , 1999	QL	To evaluate the feasibility of a tertiary outreach service in child and adolescent psychiatry to two rural health centres in New South Wales, Australia	Video-conferencing interviews	Children with complex and mental disorder
Drummond <i>et al.</i> , 2000	QN	To identify the reasons for contact with the Glasgow Emergency Medical Services (GEMS) in relation to patient socio-demographic characteristics and the nature of the presenting problem	Questionnaire	All contacts with GEMS over a one week period (n=3193) in October 1996

Author, year	Type of paper	Aim of study	Study design	Sample / participants
Dunn and Pickering, 1998	QN	To determine whether the structure of general practice diabetes care influenced the process or outcome and whether efficiency of process predicted improved outcome	Questionnaire and review of notes	During the period of October 1992 to October 1993 approached 51 practices in East Dorset: 45 agreed to participate. A total of 37 practices agreed to be visited
Edwards and Pili, 1996	QN	To assess patterns in help-seeking behaviours for common childhood symptoms	Prospective data collection	Data from parents of 67 children cared for by 28 different GP's
Esmail <i>et al.</i> , 2000	QN	To assess whether the documented rise in paediatric admissions was due to inappropriate admissions	Paediatric Appropriateness Evaluation Protocol (PAEP) used	3324 paediatric admissions in 13 NHS DGHs in the SE of England between April 1990 and March 1991
Evans, 1996	QL	To explore local perspectives on developments at the interface between primary and secondary care and the barriers and opportunities for future development	Semi-structured interviews	Stakeholders from Southampton and South West Hampshire Health Commission; Southampton Universities Hospital Trust; Southampton Community Health Services Trust and local general practices
Falmer and Coulter, 1990	QN	To determine whether there is a relationship between the structure of care for diabetes in general practice and the corresponding admission rates for diabetic patients to hospital	Questionnaire	350 group or single-handed practices

Author, year	Type of paper	Aim of study	Study design	Sample / participants
Feder <i>et al.</i> , 1993	QN	To assess the immunisation status (as one measure of preventative health care provision) of traveller children presenting to primary care services compared with that of a control group	Survey of hospital records	Traveller gypsy children aged ten months to six years presenting to A&E or 12 GPs working in two practices in Hackney between 1988 and 1990
Field and Briggs, 2001	QN	To discern determinants of accessibility and utilisation and how these factors vary across a population	Postal questionnaire	Random sample of diabetics and asthmatics recruited from 13 selected GP practices in Northampton District Health Authority to reflect broad range of areas.
Fiorentino <i>et al.</i> , 1998	QL	To examine the experiences of the disabled young people and their carers in the transition between paediatric and adult services in Sheffield. They seek to highlight the gaps in provision that exist in Sheffield	Interviews	87 disabled young people or their carers in Sheffield
Fox <i>et al.</i> , 2000	QN	To establish a rapid access heart failure clinic (RAHFC) in a DGH to diagnose and manage new cases of heart failure	Prospective data collection	Patients with suspected onset of heart failure referred by their GP
Freeman, 1999	QL	To look at the ways that the dental health professional can, sometimes unwittingly, discourage the patient from seeking dental treatment	Case studies of four dentists	Four dental patients and their dentists
Freeman and Richards, 1993	QN	To evaluate patients' views on continuity	Semi-structured interviews Psychological questionnaire	111 patients from three group practices in Southampton
Freidson, 1961	Review	Book	N / a	N / a

Author, year	Type of paper	Aim of study	Study design	Sample / participants
Fuat <i>et al.</i> , 2003	QL	To ascertain beliefs, current practices and decision-making of GPs in the diagnosis and management of suspected heart failure in primary care, with a view to identifying barriers to good care	Focus groups	30 GPs from four primary care trusts in NE England
Fulop <i>et al.</i> , 2002	QLQN	To study the process involved in, and impact of mergers between, NHS trusts, including the effect of management costs	Cross sectional study of 9 trusts in London and case study with four trusts	96 trust board members, other senior managers, clinicians, service managers, health authority representatives, regional office, community health councils, local authorities, other trusts and PCGs
Gabhainn <i>et al.</i> , 2001	QN	To describe, using a national census, the characteristics of rural general practices and compare these with city and town general practices	Census data Questionnaire	All general practices and GPs in Ireland
Gardner and Chapple, 1999	QL	To explore barriers to patients being referred for possible re-vascularisation	Semi-structured interviews	16 general practice patients under 75 with stable angina and their doctors
Gillam, 1992	QN	To explore the pattern of provision of health promotion clinics across one family health services authority. Provision was then related to measures of health need of the practice population	Health promotion payments made by the family health services authority to practices in Bedfordshire over the three month period ending December 1990 were analysed	One family health services authority

Author, year	Type of paper	Aim of study	Study design	Sample / participants
Glendinning <i>et al.</i> , 2002	Review	Critical review of recent policy developments in England aimed at improving health and social services for older people	N / a	N / a
Goyder <i>et al.</i> , 1996	QN	To examine whether minority of practices not qualifying for payment for structured diabetes care programmes differ systematically from those that do	Retrospective data collection	Leicestershire general practices data on practice size, population structure, deprivation indices, diabetes-related hospital admissions for the period April 1992 to March 1994 and the number of insulin treated patients on the district diabetes register
Goyder <i>et al.</i> , 1998	QN	To determine whether there had been a change in the proportion of patients with diabetes reviewed in primary and secondary care	Prospective data collection	Diabetic patients at outpatient clinics and five general practices between 1990 and 1995
Grant <i>et al.</i> , 2002	QNQL	To compare the quality of clinical care in walk-in centres with that provided in general practice and by NHS Direct	Observational study	20 walk-in centres, 20 general practices and 11 NHS Direct sites. 297 consultations with standardised patients
Gravelle and Sutton, 2001	QN	To compare geographical inequality in the distribution of GPs, other resources and mortality around 1995 in England and Wales; to measure trends between 1974 and 1995	Measurement of relative and absolute inequalities in the ratio of GPs to needs adjusted population	Data from 1974 to 1995 on whole-time equivalent GPs and census-based population estimates at primary care administrative area level

Author, year	Type of paper	Aim of study	Study design	Sample / participants
Green, 1993	QL	To examine the concerns of single-handed GPs working in an inner-London area and to compare the views of GP in partnerships	Semi-structured interviews	25 randomly selected single handed GPs and 24 purposively sampled partnership GPs to match single-handed group characteristics
Griffiths, 2003	Review	N / a	N / a	N / a
Griffiths, 2001	QL	To identify the discursive construction of cases in community mental health teams	Organisational ethnography based on documentary analysis	Data from meetings where Community Mental Health Teams members process referrals and decide not to allocate patients to a team member
Griffiths <i>et al.</i> , 1997	QN	To determine the relative importance of appropriate prescribing for asthma in explaining high rates of hospital admission for asthma among East London general practices	Retrospective data collection	All 163 practices in East London and the City Health Authority. Complete data available for 124 practices
Gulliford, 2002	QN	To evaluate whether population health was associated with GP supply in England	Secondary data analysis for 99 Health Authorities in England in 1999	Secondary data analysis of mortality rates, hospital admissions and teenage conception rates explained by number of GPs per 10 000 population and adjusted for deprivation, ethnicity and long-term illness

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Gulliford <i>et al.</i> , 2001	Report: Access to healthcare: Report of a scoping exercise for NHS SDO R&D programme	N / a	N / a	N / a
Gulliford <i>et al.</i> , 2003	Book			
Hackett <i>et al.</i> , 1993	QN	To assess the quality of care, waiting times for treatment and comparative costs in the management of joint and soft tissue problems within the three practices	Prospective data collection	401 patients. Practice A employed its own physiotherapist, Practice B had direct hospital access to physiotherapy and Practice C had no direct or open access to physiotherapy, patients had to be referred via the consultants
Hallam <i>et al.</i> , 1994	QN	To determine the use and organisation of out-of-hours services in primary care	Telephone interview survey	Officers responsible for organising out-of-hours care in 97 of the 98 family health services in England and Wales
Hamilton <i>et al.</i> , 1997	QN	To describe the personal, social and medical attitudes of doctors who practice on the islands off the west coast of Scotland	Questionnaire survey	52 GPs practising on the islands of Scotland's west coast (80 per cent response rate amongst the total number of 65 who practice)

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Hardman, 2002	QNQL	To describe a set of local initiatives designed to address heart failure services across the interface (and beyond).	Case study report	N / a
Hardy <i>et al.</i> , 2001	QN	To evaluate the effect of information-giving to patients before appointments and subsequent non-attendance rate	Attendance patterns of outpatients compared with historic referrals	325 new outpatients + control of 1336 historic referrals
Harrison <i>et al.</i> , 1996	QN	To evaluate the potential benefits of joint tele-consulting and to examine to what extent it might effectively be used as an alternative to outpatient referral and to obtain an indication of its feasibility and acceptability to all the parties involved	Tele-consultations Exploratory trial of tele-conferenced outpatient referrals of general practitioners	54 tele-consultations were booked and conducted over a period of five months
Hausman and LeGrand, 1999	Review	A discussion of how institutions should be structured so that GPs are motivated to make decisions that are both socially efficient and equitable	N / a	N / a
Haylock <i>et al.</i> , 1993	QN	To ascertain the views of parents with four year old children with motor disabilities to see to what extent integrated, appropriate and supportive services are being provided	Questionnaire	40 parents of four year-old children with motor disabilities
Haynes <i>et al.</i> , 1999	QN	To improve on previous cross-sectional geographical designs and quantify the effects of distance on hospital use while taking into account the potential for confounding influences of variations in the relative health care needs of populations in small areas and the local supply of inpatient services	Standardised ratios in wards to the distance to hospital and the distance to the nearest GP surgery	Analysis of all hospital inpatient first episodes between 1991 – 93 in 555 wards in East Anglia

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Heaney <i>et al.</i> , 2001	QN	To investigate the effect of patient information booklets on overall use of health services, on particular types of use, and on possible interactions between use, deprivation category of the area in which respondents live, and age	RCT	Random sample of patients from the community health index (n=4878) and of those contacting out-of-hours services (n=4530) in the previous 12 months in each of the study general practices
Hensher and Fulop, 1999	QNQL	To determine how needs assessment has been used in the NHS, to assess the influence it has had on decision-making, and to relate the observed uses of needs assessment to competing theoretical models of health care policy-making	Survey of needs assessment activity Semi-structured interviews	Needs assessment activity data on 14 London health authorities and interviews with public health and commissioning staff in each authority
Hill and Rutter, 2001	Review	To report on a collaboration between general practices and local hospitals to speed up access (North Bradford PCT)	N / a	N / a
Hippisley-Cox and Pringle, 2000	QN	To determine the effect of primary care services on access to coronary angiography and re-vascularisation	Cross-sectional survey	180 Nottinghamshire practices in the Trent region
Hippisley-Cox <i>et al.</i> , 2001	QN	To determine whether there are important differences in performance between group practices and single-handed general practitioners and to assess the extent to which these are explained by practice characteristics	Cross-sectional survey	206 singlehanded practices and 606 partnerships in the Trent Region, UK

Author, year	Type of paper	Aim of study	Study design	Sample / participants
Hirst <i>et al.</i> , 1998	QN	To examine whether variations in the number of whole-time equivalent (wte) practice nurses across family health services authorities (FHSAs) can be explained by population characteristics and the organisation of general practice	Nine health and 16 social indicators for 98 FHSAs identified three factors underlying health care needs	98 FHSAs
Hopton <i>et al.</i> , 1996	QL	To investigate patients' accounts of calling the doctor out-of-hours	Semi-structured interviews	23 people who had called out the doctor on their behalf or on the behalf of another adult and 23 people who had called out the doctor on behalf of a child between 6pm and 8am on a week day
Houston and Pickering, 2000	QL	To explore service users' perceptions of the circumstances in which out-of-hours GP services are used	Semi-structured interviews	Purposeful sample of 30 families, sampled according to frequent users, one-off callers, and non-callers to out-of-hours services
Hsu <i>et al.</i> , 2003	QN	To assess the effect of an NHS walk-in centre on local primary and emergency health care services	Before and after observational study	12 general practices
Hughes, 1989	Review	To examine the exercise of discretion by casualty staff and focus on the problems of accountability that arise when judgements made help shape the process of patient categorisation and clinical diagnosis	N / a	N / a
Hughes, 2003	Review	Book	N / a	N / a

Author, year	Type of paper	Aim of study	Study design	Sample / participants
Hughes and Griffiths, 1997	Review	To examine the rationing process using data from case studies of selection of patients for cardiac surgery and admission to a specialist neurological rehabilitation centre	N / a	N / a
Hughes and Yule, 1992	QN	To examine the impact of financial incentives on GP behaviour with respect to maternity care and cervical cytology between 1966-1989	Retrospective data collection	Data collected on maternity care and cervical cytology
Hughes <i>et al.</i> , 2003	QN	to establish the extent of doctor input to occupational health service provision in the NHS (2001 compared with 1998)	Mailed questionnaire	154 occupational health departments in NHS trusts
Hull <i>et al.</i> , 2002	QN	To determine whether telephone appointments offered by GP receptionists increase the uptake of influenza immunisation among the registered population aged over 65 years in east London practices	RCT	Participants were 1820 low-risk patients aged 65 to 74 years who had not previously been in a recall system for influenza immunisation at their general practice
Hurst <i>et al.</i> , 2000	QN	To examine the effect of waiting times on health status of patients referred for a non-urgent rheumatology opinion	RCT	New patients referred to either of two consultant rheumatologists or to 'any doctor' who had been allocated to a non-urgent appointment

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Jack <i>et al.</i> , 2003	QN	To determine whether the management and survival of patients with lung cancer varied among 26 health authorities in South East England	Retrospective data collection	The Thames Cancer Registry identified patients diagnosed with lung cancer between 1995 and 1999 resident in the 26 health authorities
Jacobson <i>et al.</i> , 2001	QL	To determine how teenagers view primary care, to discover how primary care providers view teenage patients and to note any differences of opinion between the two groups	Questionnaire Focus group Semi-structured interviews	2265 teenage patients 14 to 18 years old, 16 GPs, 12 practice nurses and 12 GP receptionists
Jeffrey, 1979	QL	To describe typifications of 'good' and 'bad' patients made by staff working in three English A&E departments	Fieldwork notes Open-ended interviews	A&E senior house officers
Jenkins and Campbell, 1996	QN	To relate the sizes of general practice catchment areas in one London Borough to list size, deprivation payments, medical staffing and locally and nationally recognised measures of quality	Study of general practice catchment area maps. Practice catchment area size with corrections for numbers of doctors and patients	60 out of 71 general practices in Lambeth, London
Jenkins <i>et al.</i> , 1994	QN	To investigate the problems encountered by GPs in one family health services authority in South East London in arranging acute hospital admission	Questionnaire	111 GPs from SE London family health authorities
Jennings, 1991	QN	To assess the effect of a new appointment system on patient's waiting times	Audit of new appointments system	436 patients under regular review with fixed appointment times during six months, in one general medical outpatient clinic

Author, year	Type of paper	Aim of study	Study design	Sample / participants
Jones and Bentham, 1997	QN	To examine whether after controlling for other factors, asthma mortality in England and Wales is associated with remoteness from health services	Retrospective data collection	Deaths from asthma was collected from published statistics for 401 local authority districts in England and Wales for the period 1988 – 92
Jones and Britten, 1998	QL/QN	Explore reasons why people don't cash prescriptions	Questionnaire / interviews	People who attended general practice
Jones and Bentham, 1999	QN	To examine the relationship between asthma mortality and access to primary and secondary health services within the rural region of East Anglia	Retrospective data collection	A geographically based study within 536 electoral wards in the region of East Anglia
Kai, 1996	QL	To identify and explore difficulties parents experienced with acute illness in young children and the information they seek to help them	Semi-structured interview Group interviews	95 parents of preschool children
Kai, 1996b	QL	To identify and explore parents' concerns when young children become acutely ill	Semi-structured interview Group interviews	95 parents of preschool children
Karim and Bailey, 2000	QL	To examine the attitudes of GPs and hospital consultants regarding the potential benefits and / or burdens of hospice and palliative care services for people of minority ethnicity	Semi-structured interviews	27 doctor's records of 1681 patients referred to the hospice between April 1996 and November 1997
Khunti <i>et al.</i> , 2001	QN	To determine how services for people with diabetes are organised in primary care and whether there are inequalities in systematic care of people with diabetes	Postal questionnaire	Three health authorities (Leicestershire, Durham and Suffolk) were responsible for 327 practices of which 264 responded

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Kinnersley <i>et al.</i> , 2000	QN	To ascertain any differences between care from nurse practitioners and that from general practitioners for patients seeking 'same day' consultations in primary care	RCT	Ten general practices in South Wales and South West England. 1368 patients requesting same day consultations
Klasen and Goodman, 2000	QL	To investigate the views that parents and GP's hold about hyperactivity and to explore how these views, and clashes between these views, influence access to services	Semi-structured interviews	Ten GPs and 29 volunteer parents of hyperactive children purposefully sampled from parents groups, community services and specialist clinics
Kleinman, 1980	Book	N / a	N / a	N / a
Lack <i>et al.</i> , 2000	QN	To explore a waiting list point scheme under development in Salisbury, UK, for the fair management of elective in-patient and day case waiting lists	Evaluation	One orthopaedic consultant's elective inpatient and day case list at Salisbury Health Care NHS Trust in December 1996
Laing, 1988	Book	Review	N / a	N / a
Langham <i>et al.</i> , 1995	QN	To evaluate the effect of the change in June 1993, in financial incentives for health promotion activity in primary care on the distribution of health promotion payments in two family health services authorities	Retrospective data collection	Two family health services authorities
Latimer, 1997	QL	To explore how nurses and doctors constitute classes of patient to help accomplish their ordering work	Ethnography of conduct within an acute medical unit	Focus on nurses in an acute medical unit but includes all other agents

Author, year	Type of paper	Aim of study	Study design	Sample / participants
Lattimer <i>et al.</i> , 1998	QN	To determine the safety and effectiveness of nurse telephone consultation in out-of-hours primary care by investigating adverse events and the management of calls	Block randomised trial	A 55 member GP co-operative (involving 19 practices)
Leung <i>et al.</i> , 1998	QN	To evaluate the use of priority criteria for access to coronary artery bypass graft (CABG) developed in New Zealand	Retrospective data collection from medical records	229 patients in Sunderland who underwent CABG 1995 – 96 financial year
Little <i>et al.</i> , 2001	QN	To assess the effectiveness of providing information by post about managing minor illnesses	Randomised Trial	Random sample of 4002 patients from six general practice registers
Lovell <i>et al.</i> , 2003	QN	To examine the acceptability (number of referrals to the clinic, patient attendance and patient satisfaction) efficiency (therapist input per patient, patient use of other health services) and effectiveness (problem severity at follow-up) of a self-help clinic for mental health in primary care	Questionnaire	10 GPs with a practice population of 16 000. Inclusion criteria were age 16 years or over with a GP diagnosis of depression or anxiety
Lovett <i>et al.</i> , 2002	QN	To develop new methods for measuring access to primary health care services, to compare patterns of access to services by public and private transport and to investigate the socio-economic characteristics of populations with the poorest access to services	Retrospective data collection	481 practices in East Anglia and anonymised data on 2 130 530 patients from FHSA records
Lundberg <i>et al.</i> , 1998	QN	To examine the sensitivity towards increases in user charges for different types of drugs and among different socio-economic groups	Questionnaire	5404 respondents

Author, year	Type of paper	Aim of study	Study design	Sample / participants
Lynch, 1998	QN	To investigate the relationship between financial incentives and the provision of primary health care services in Britain	Econometric model and a linear programming model were used	Information on 208 general practices in Scotland
Majeed <i>et al.</i> , 1995	QN	To investigate the relative importance of patient and general practice characteristics in explaining variations between practices in the uptake of breast cancer screening	Ecological study examining variations in breast cancer screening rates using routine data	Routine data on breast cancer screening rates from 131 general practices
Majeed <i>et al.</i> , 1994	QN	To determine the importance of patient variables and practice factors in explaining the variation in cervical smear uptake rates	Cross-sectional study	128 practices in Merton, Sutton and Wandsworth
Martin <i>et al.</i> , 1991	QN	To study patients' perspectives of why they consulted the doctor before and after the consultation and to compare these perceptions to those of the doctor	GP administered the questionnaires for their patients to complete before and after consultation	1972 patients across all ages and social class from general practices in Bedfordshire (three) and Hertfordshire (one) and the GP's from these practices
McEvoy <i>et al.</i> , 2002	QN	To explore how consultant psychiatrists, senior house officers and community psychiatric nurses prioritised referrals to four sectorised community mental health teams	Retrospective survey	Cohort of referrals (1072 eligible patients) from primary care to community mental health teams (CMHTs) in the Salford area in 1997
McIntosh <i>et al.</i> , 2003	QL	To ascertain patients' and clinicians' experiences and expectations of information in low back pain in order to suggest a suitable 'patient-centred' content for a patient information pack to be used in a primary care setting	Semi-structured interviews for the GPs and focus groups for the patients. All GPs and patients were given a patient information booklet 'The Back Book' before the study	15 GPs and 37 patients with low back pain

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McKee and Waghorn, 2000	QL	To identify the key problems in organising an outpatient department as seen by staff, and to understand their responses to them	Individual and group interviews exploring problems facing the clinic and the staff's responses	57 staff working in or with routine interaction with the outpatients clinic of a district general and teaching hospital in South East England
McKinley <i>et al.</i> , 1997	QN	To compare the outcome of out-of-hours care given by general practitioners from own patients' own practices and by commercial deputising services	Randomised control trial	2152 patients who requested out-of-hours care
McKinley and Roberts, 2001	QN	To describe relationship between patient satisfaction and different types of out-of-hours services	Interviews with questionnaire	1466 patients who requested out-of-hours care
Milewa <i>et al.</i> , 2000	QNQL	To consider the impact of a prominent patient education booklet that makes reference to over 40 common ailments	Questionnaire and semi-structured interviews	A random sample of adults in South England
Miller <i>et al.</i> , 2003	QN	To determine whether patients with acute coronary syndromes requiring coronary angiography and re-vascularisation have inferior access to these services if admitted to DGHs compared to similar patients admitted to tertiary cardiac centre	Retrospective cohort study	184 patients admitted to tertiary centre, of which 95 (52per cent) initially admitted to feeder DGH
Miller <i>et al.</i> , 1999	QN	Routine data is used to examine the scale of the changes that have occurred between care settings	Routine data	Routinely available data; programme budgets; Scottish Health Service Costs and Scottish Office Annual Audited accounts

Author, year	Type of paper	Aim of study	Study design	Sample / participants
Mitchell <i>et al.</i> , 2002	QNQL	To evaluate a rapid assessment service for patients with jaundice	Evaluated by measuring aspects and changes in waiting times for referral; consultation; diagnosis; treatment; length of stay in hospital; GP and patient satisfaction	Service evaluation, documentary analysis, GP / patient survey at the Royal Cornwall hospital
Moore <i>et al.</i> , 2002	QN	To assess the effectiveness of nurse follow-up in the management of patients with lung cancer	A randomised controlled trial	203 patients with lung cancer who had completed their initial treatment and were expected to survive three months
Morgan, 2003	Book			
Morgan and Beech, 1990	Review	To review trends in lengths of stay and day case surgery and examine between-country variations; to examine the causes of these variations and consider implications for more innovative patterns of care; to consider the ways in which changes in clinical practice style may be facilitated to promote greater efficiency.	N / a	N / a
Morris <i>et al.</i> , 2001	QN	To describe GPs' attitudes to minor ailment consultations and their attitudes towards minor ailment management	Questionnaire survey based on 20 qualitative interviews of GPs (mean age 46 years) males over represented and single-handed practices under represented	447 GPs from across the England

Author, year	Type of paper	Aim of study	Study design	Sample / participants
Munro <i>et al.</i> , 2000	QN	To quantify the impact of NHS Direct on the use of accident and emergency, ambulance and GP cooperative services	Measured changes in trends in use of immediate care services in the year following the introduction of NHS Direct.	Users of NHS Direct, A&E, ambulance and GP co-operative services in three areas of England
Murphy, 1998	Review	Review research relating to the definition, incidence and reasons for attendance of 'inappropriate attenders	N / a	N / a
Murphy <i>et al.</i> , 1996	QN	To see whether care provided by GPs to non-emergency patients in an A&E department significantly differs from care by usual A&E staff in terms of process, outcome and comparative cost.	RCT	A&E dept in a busy inner-city hospital that employed Gps
National Treatment Agency for Substance Misuse, 2003	Review	N / a	N / a	N / a
Neal and Linnane, 2002	QN	To consider the awareness of access to and views of patients and professionals about the two existing specialist continence services.	Questionnaire	Over a period of three months (between April and July 2001) primary care staff, particularly GPs, practice nurses and patients, filled in questionnaires.
Nelson <i>et al.</i> , 2000	QN	To survey dieticians involved in diabetes care regarding the provisions for patients with diabetes	Survey of dieticians	391 dieticians engaged in diabetes care

Author, year	Type of paper	Aim of study	Study design	Sample / participants
O'Cathain <i>et al.</i> , 2000	QN	To survey callers to determine how helpful they found the advice offered by NHS Direct	Postal survey questionnaire to determine perceived helpfulness of the service.	719 callers to NHS Direct
O'Reilly and Steele, 1998	QN	To explore the resource implications of the proposed changes to the methods of allocating GP deprivation payments within Northern Ireland	Evaluation of three alternative systems of allocation	566 electoral wards and 3729 enumeration districts
Olsson and Hansagi, 2001	QL	To explore what lies behind repeated emergency department (ED) use from the patient's perspective	In depth qualitative interviews	Stratified purposive sample of ten adults (five female, five male, aged 23 to 82, mean 51years) who had visited the ED of Huddinge University Hospital, Stockholm six to 17 times in the preceding 12 months
O'Reilly <i>et al.</i> , 2001	QN	To examine geographical variation in the rates of out-of-hours calls and to see if there is any systematic variation in how the co-operative that covers the area responds to calls	Secondary data analysis	110 357 calls received by the co-operative during the second year of its operation
Partridge <i>et al.</i> , 1997	QN	To describe the type of people attending UK A&E depts because of asthma, including demographic information, information about prior care, details of perceived severity and reasons for attendance and disposal	Census over one week based on questionnaires completed by triage nurses and A&E staff. 30 forms were distributed per department	111 A&E depts with a full time A&E consultant and having more than 30 000 new attendances per annum

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Paterson and Britten, 2000	QL	To explore the views of people with asthma about the organisation of asthma care in general practice	Semi-structured interviews in one practice with a nurse-run asthma clinic	The study took place in a practice of 6500 patients in Taunton, Somerset in 1998. 20 patients were selected
Pattenden <i>et al.</i> , 2002	QL	To identify the themes that influence decision-making processes used by patients with symptoms of acute myocardial infarction	Semi-structured interviews	22 patients admitted to hospital with confirmed second, third or fourth acute MI (91per cent male with a mean age of 66 years)
Patterson, 1997	Review	To examine provision of information to children	N / a	N / a
Peay and Peay, 1998	QN	To investigate the discrepancy between doctors and patients and their beliefs about the need for treatment	Questionnaires completed by each group rating 35 symptoms on perceived urgency with which they would seek medical advice	176 outpatients, 54 GPs and 335 potential patients
Pereira <i>et al.</i> , 2000	Report: What are the main characteristics and causes of inequality in health care in the UK? What implications do these have for policy?	Online document: http://www.econ.qmw.ac.uk/NHS_reforms.com/downloads/policy_inequality.pdf	N / a	N / a

Author, year	Type of paper	Aim of study	Study design	Sample / participants
Perrett, 1997	QN	To describe the activity of specialist outreach clinics in Sheffield, focussing on comparative waiting times between fundholding and non-fundholding practices	Study of routine outpatient data and list of outreach clinics obtained from fundholding practices	Patient records and data
Pitchforth <i>et al.</i> , 2002	QN	To assess whether the uptake of chemotherapy for colorectal cancer varied by hospital type in Scotland	Retrospective data collection	Colorectal cancer cases were obtained from cancer registrations linked to hospital discharge data for the period January 1992 to December 1996. The final data set used in the multilevel analysis contained 7303 cases
Pope, 1991	Review	To examine the day-to-day organisation and management of surgical waiting lists and provide a critical analysis of the main theoretical perspectives on waiting lists	N / a	N / a
Raine <i>et al.</i> , 2003	QN	To demonstrate the importance of measuring both the horizontal and vertical components of equity in order to examine whether patients are receiving the health care that they need	A theoretical demonstration followed by analysis of a prospectively collected national random sample of acute cardiac admissions to 94 hospitals in the UK	1064 patients under 70 years old
Reading <i>et al.</i> , 1993	QN	To measure social inequalities in a variety of indicators of child health in a rural county in the north of England using 'small area' geographical methods of social classification	Secondary analysis of health data taken from two sources: district computerised child health records and survey data on school children's height	Over 21 000 children resident in Northumberland born between January 1985 and September 1990 and 9930 children aged five to 8.6 years in Northumberland schools

Author, year	Type of paper	Aim of study	Study design	Sample / participants
Reid and Todd, 1989	QN	To investigate the travel arrangements made by all attenders at outpatient clinics in Smalltown hospital over one week	Questionnaire	All attenders at outpatient clinics during one week in 1987 were surveyed. A total of 698 patients cooperated in the study representing a 80 per cent response rate
Reid <i>et al.</i> , 1999	QN	To quantify the extent of the variation in hospital admission rates between general practices, and to investigate whether this variation can be explained by factors relating to the patient, the hospital and the general practice	Characteristics of patients, GP surgeries and hospitals were examined in relation to admission rates for overall, emergency and elective admissions	209 136 hospital admissions in 1995 – 96 in patients registered in 120 practices in Merton, Sutton and Wandsworth Health Authority (inc inner and outer London)
Rice and Smith, 2001	Review	Explores the notion of geographical equity in access to healthcare	N / a	N / a
Richards <i>et al.</i> , 1998	QN	To compare effectiveness and acceptability of early discharge to a hospital-at-home scheme with that of routine discharge from acute hospital	Pragmatic randomised control trial. Patients' received hospital-at-home care or routine hospital care	Acute hospital wards and community in north Bristol
Richardson and Rabiee, 2001	QL	To explore the experiences, feelings, attitudes and beliefs of a sample of young men from Corby about their use of health services	Focus groups	14 Males age 15 to 19, including four attending a school exclusion project
Rogers <i>et al.</i> , 1999	QL	To examine perceptions and experiences of rationing in primary care and the potential impact this has on people's use of services	Qualitative interviews with users of primary care services	53 households from North West England
Rogers <i>et al.</i> , 1999	Review	Exploring ways to improve access	N / a	N / a

Author, year	Type of paper	Aim of study	Study design	Sample / participants
Roland and Bewley, 1992	QN	To evaluate an initiative to improve communication between GP's and orthopaedic specialists	Questionnaires completed by the GP and the specialist. Also, referral patterns to the orthopaedic outpatient clinic were monitored to establish the impact of the service	'Boneline' initiative involving GPs and orthopaedic surgeons at Doncaster Royal Infirmary
Rosen and Mountford, 2002	QL	To describe the emerging roles of walk-in centre nurses, and explore the causes of role stress and review arrangements for training, development and support	Semi-structured interviews	29 managers and nurses from nine walk-in centres in London, ten stakeholders providing other primary care services near to three walk-in centres
Rosen and Pearce, 2000	QL	To investigate the importance of inter-professional collaboration in the introduction and development of NHS Direct	Interviews with 29 people involved in establishing the service to help inform development of the service elsewhere	Health professionals involved in setting up NHS Direct at two London sites.
Rosen <i>et al.</i> , 2001	Report: Access to health care: taking forward the findings of the scoping exercise	N / a	N / a	N / a
Ryan <i>et al.</i> , 2000	QN	To establish whether residents living on the Isle of Wight are prepared to travel to the mainland for elective surgery where waiting times are shorter but travel costs may be greater	DCCA questionnaire	Random sample of 1000 people living on the Isle of Wight

Author, year	Type of paper	Aim of study	Study design	Sample / participants
Salisbury <i>et al.</i> , 2002	QN	To describe the structure and activities of NHS walk-in centres	Collection of 'routine data' from walk-in centres. Comparative data on visits to general practice taken from the Fourth National Morbidity Study	36 walk-in centres (of 40 NHS pilot sites)
Sanderson <i>et al.</i> , 2003	QN	To look at the evaluation of six pilot schemes selected for the Action On ENT programme where they are using specialist GPs to provide ENT services in the community	The experience of these sites was evaluated from late 2001 to the end of September 2002	Ealing, Gloucester, Ipswich, North Staffordshire, Oxford and St George's London
Sayal <i>et al.</i> , 2002	QNQL	To apply pathways of care model to children with pervasive hyperactivity in order to provide quantitative description of the filters in help-seeking pathway through primary care, and investigate the relative contributions of child, parent and GP factors in determining service use	Strengths and difficulties questionnaire (SDQ). Interviews with parents using the hyperactivity section of the Parental Account of Children's Symptoms; semi-structured interviews	Children aged five to 11 identified from a community sample screened for pervasive hyperactivity and children with a clinical diagnosis of adhd
Schafheutle <i>et al.</i> , 2002	QL	To explore how charges for medicines incurred by patients influence their decisions for managing acute or chronic conditions, and whether prescription cost and affordability issues are discussed in the GP – patient encounter	6 focus groups	31 people recruited through community pharmacies in North-West England

Author, year	Type of paper	Aim of study	Study design	Sample / participants
Schneider <i>et al.</i> , 1999	QN	To explore the structure and the operation of mental health services in practice and relate them to measurable data	Questionnaire responses were received from 145 individuals for the implementation and administration of the Care Programme Approach (CPA)	All 183 NHS trusts in England providing mental health services were surveyed in 1997 – 98
Sexton <i>et al.</i> , 2000	QN	To identify the services that hospital pharmacies were providing in 1999 to facilitate seamless care upon discharge	Postal questionnaires containing closed and open questions	163 Chief pharmacists or deputies from UK Hospital trusts
Shaw <i>et al.</i> , 2001	QL	The aim of the study was to explore help-seeking behaviour in people with urinary symptoms such as leakage, frequency, nocturia and urgency in order to identify barriers to service use	Unstructured, taped interviews	Thirty-one people who either had agreed to treatment as part of an intervention study or who were receiving treatment at a hospital outpatient clinic for their urinary problems.
Sheikh and Ogden, 1998	QNQL	To assess the relationship between knowledge about cancer-related symptoms and help-seeking behaviour and to explore the role of patient's beliefs about cancer in explaining the gap between knowledge and behaviour	Quantitative component was a questionnaire and the qualitative component was interviews	The quantitative component consisted of a random sample of 400 patients, and in the qualitative component there were 20 patients consisting of 14 women and six men
Sherwood and Lewis, 2003	QL	To explore notions of self-help and volunteerism in the delivery of services by reference to 'rural wheels', a volunteer medical transport scheme in rural Northamptonshire	Service evaluation	Rural wheels scheme

Author, year	Type of paper	Aim of study	Study design	Sample / participants
Shipman <i>et al.</i> , 2001	QL	This study was designed to understand patients' views, expectations and experiences of attending an out-of-hours primary care centre which was part of an inner-London GP co-operative	Semi-structured telephone interviews	72 primary care centre attendees
Shipman <i>et al.</i> , 2000	QN	To compare patient satisfaction with GP out-of-hours GP services	Questionnaire, satisfaction survey, measuring overall satisfaction and ten subscales	Stratified sample (by organisational contact: co-operative, deputising service, practice-based). Overall 53.2 per cent response rate (n=1,823).
Shum <i>et al.</i> , 2000	QN	To assess the acceptability and safety of a minor illness service led by practice nurses in general practice	Randomised trial	1815 patients in five general practices in SE London
Skeate <i>et al.</i> , 2002	QN	To examine the psychological processes that influence the decision-making process to contact primary care in individuals with emerging psychosis	Examination of patient records looking at coping style, health locus of control and past help-seeking behaviour, duration of untreated psychosis (DUP). Use of Miller Behavioural Style Scale, multi-dimensional health locus of control scale and GP records	42 clients and patient records of individuals screened for schizophrenia and related disorders and in the early stages of treatment
Smaje, 1998	QN	To investigate the nature of the GP consultation as the possible occasion of inequity in health care between ethnic groups and the source of differential ethnic filtering into secondary care	Secondary analysis of GHS survey	GHS respondents from eight years (1984 – 91) were aggregated

Author, year	Type of paper	Aim of study	Study design	Sample / participants
Smaje and Le Grand, 1997	QN	To explore whether the NHS provides equal treatment for equal need to different ethnic groups	Secondary analysis of aggregated data of GHS between 1984 to 1991 / 92	A random sample of data from a GHS survey of minority ethnic and white respondents
Smiley and Cooper, 2002	QN	To provide a national record of specialist ID health services for Scotland	A 15-item postal questionnaire	NHS PCTs, general managers of two health boards and lead clinician / clinical director
Smith <i>et al.</i> , 2001	QN	To test the hierarchical scale designed to measure help-seeking behaviour in chronic pain in postal surveys of the community and to explore factors associated with responses	The Chronic Pain Grade (CPG) and the Glasgow Pain Questionnaire (GPQ) and the Level of Expressed Need (LEN) scale	5036 random participants from 29 general practices in the Grampian region of Scotland, then screened appropriateness and stratified for age and gender. 3065 took part in final study
Social Exclusion Unit, 2003	Report: Making the connections: final report on transport and social exclusion	N / a	N / a	N / a
Somerset <i>et al.</i> , 1999	QL	To explore understandings concerning referral to and re-attendance at outpatients and to elicit detailed descriptions of the complexities of the outpatient experience for both providers and recipients of care at the primary / secondary interface	Semi-structured interviews	Individuals from three groups involved in the provision of care across the primary / secondary interface: nine patients attending outpatients, 1 ten general practitioners and ten consultants

Author, year	Type of paper	Aim of study	Study design	Sample / participants
Sparrow <i>et al.</i> , 2003	QN	To investigate loop diuretic prescribing in general practice, to analyse recorded clinical features, patient investigations and ACE inhibitor use in this population	Secondary analysis of patient records	1301 patients taking loop diuretics
Stallard and Lenton, 1992	QN	To ascertain parents' satisfaction with the services they had received and how these could be improved	Parents of 41 pre-school children with special needs	Consumer survey consisting of a 25-item structured interview/questionnaire
Stern and Brown, 1994	QN	To determine the effect of the introduction of a waiting list on initial appointment attrition rates in a child and family clinic which had not previously operated a waiting list system	Questionnaire	Watford Child and Family clinic provides an outpatient service to the children of its catchment area and their families.
Stevenson <i>et al.</i> , 2003	QL	To examine the range of self-treatments people use and the discussion of these treatment in medical consultations	Data was collected from: audio-taped consultations, semi-structured interviews with patients before and after consultation; interview with GP after consultation and field notes completed after each interview	20 doctors and 62 patients (39 women and 23 men, 60 white, two afro-Caribbean, aged between three months and 84 years)
Stoddart <i>et al.</i> , 2003	QN	To investigate the provision of 'same-day' care and the characteristics, treatment expectations and priorities of patients attending 'routine' and 'same-day' appointments	Questionnaire	362 same-day and 362 routine appointments at 15 general practices in Avon and Gloucestershire
Svensson, 1996	QL	To investigate doctor and nurse accounts of the division of labour	Semi-structured interviews	20 doctors and 39 nurses

Author, year	Type of paper	Aim of study	Study design	Sample / participants
Talley <i>et al.</i> , 1997	QN	To identify whether psychological factors or abuse explain health care seeking for IBS	Questionnaires, plus two validated psychological questionnaires (GHQ and Eysenck Personality Questionnaire) and a set of questions on sexual abuse experience	730 subjects from the general population (although slightly older) of Penrith and surrounding suburbs of Sydney, Australia
Tarrant <i>et al.</i> , 2003	QL	To explore patients' perceptions of the features of personal care and how far these are shared by healthcare providers; whether a continuing relationship between a health professional and a patient is essential for personal care; and the circumstances in which a continuing relationship is important	Semi-structured interviews	Six general practices in Leicestershire, 40 patients, 13 GP's, ten practice and community nurses and six practice administrative staff recruited through participating practices
Teale <i>et al.</i> , 2000	QN	To develop an evidence-based protocol for the follow-up of women with low-grade cervical abnormalities for whom treatment is not immediately warranted	Population study	577 women referred to Birmingham City Hospital colposcopy clinic Oct 1986-Jan 1997; 87 women referred between Jan 1997 and Jan 1998 were used to validate the model
Tod <i>et al.</i> , 2001	QL	To identify factors within the south Yorkshire coalfields that influence use of health services by people with angina	Individual and group interviews	14 patients with stable angina (seven men, seven women aged 52 – 73), nine primary care staff, five community groups and one group of GPs

Author, year	Type of paper	Aim of study	Study design	Sample / participants
Van Doorslaer <i>et al.</i> , 2000	QN	To quantify and test for violations of principles of 'equal treatment for equal need' that are related to socioeconomic status reflected in income	Household surveys based on two-stage sampling design	Survey data from ten European countries and the USA
Venning <i>et al.</i> , 2000	QN	To compare the cost-effectiveness of general practitioners and nurse practitioners as first point of contact in primary care	Multi-centre RCT of patients requesting an appointment on the same day. Outcome measures of consultation process, patient satisfaction, health status, return visits over two weeks and costs	1292 patients from 20 general practices in England and Wales
Walsh M, 1995	QN	To examine reasons why people attend accident and emergency	Questionnaire administered by interview	200 adult patients attending A&E
Werrett <i>et al.</i> , 2001	QN	To identify nurses; perceived deficits in the knowledge and skills required to provide effective seamless care, so that appropriate training can be provided	Questionnaire generated from focus groups	172 nursing staff from participating trusts
Whitehead and Gosling, 2003	QL	To examine the lived experience of parents' perceptions of interactions with health professionals before, during and after diagnosis of Tuberous Sclerosis (TS)	Interviews at home or over the telephone with families in West Yorkshire	109 participants from 40 families with children with a diagnosis of TS
Wilkin <i>et al.</i> , 2003	QN	To examine the relationship between the size and performance of primary care organisations, the effect of and the reasons for mergers	Telephone and mail surveys of primary care groups and trusts measuring 22 performance measures and size	Data on proxy measures of performance and merger intentions for 71 organisations

Author, year	Type of paper	Aim of study	Study design	Sample / participants
Williams and Cheung, 2000	QN	To evaluate whether follow up of patients with inflammatory bowel disease is better through open access than by routine booked appointments	Pragmatic RCT, postal questionnaire, additional data on costs to patients from hospital case notes and GP records; postal questionnaire for GPs and semi-structured interviews with a sub-sample of GPs	180 adults with bowel disease recruited from outpatient clinics during October 1995 to November 1996
Williams <i>et al.</i> , 2002	QN	To describe diabetes service provision in primary care in the UK so that geographical variations in provision could be identified	Questionnaire sent to practices with reminders	Primary Care Organisations (PCOs) in the UK. All 542 in Wales, all 533 in Scotland and a random sample of 600 in each of the NHS regions in England. Total 5854 practices
Wilson <i>et al.</i> , 2002	QL	To consider GP attitudes to the use of advanced nurse practitioners, focusing on barriers to their use and how to overcome them	Focus groups	Four general practices in Yorkshire
Winocour and Ainsworth, 2002	QN	To examine the provision, and variations in secondary care diabetes services in the UK	Postal survey	238 secondary care providers of diabetic services
Wootton <i>et al.</i> , 2000	QN	To evaluate the health outcomes and cost-benefits of tele-dermatology compared with conventional dermatological care from a societal viewpoint	Randomised controlled trial	Two hospital dermatology departments and four health centres in Northern Ireland

<i>Author, year</i>	<i>Type of paper</i>	<i>Aim of study</i>	<i>Study design</i>	<i>Sample / participants</i>
Wright <i>et al.</i> , 2003	Report: On Target? Government by measurement	N / a	N / a	N / a

Appendix 3A Studies included in synthesis of literature on socio-economic disadvantage and access to health care

<i>Author, year</i>	<i>Type of paper</i>	<i>Aim of study</i>	<i>Study design</i>	<i>Sample / participants</i>
Acheson, 1998	Report: Independent inquiry into inequalities in health	N / a	N / a	N / a
Alberts <i>et al.</i> , 1998		To see if higher educated and more proto-professionalised individuals are (i) less likely to seek professional help and more likely to take OCT medication for everyday symptoms (ii) just as likely to seek professional help for chronic health problems but more likely to receive specialist treatment	Questionnaire	Curacao non-institutionalised population of 18 years or older
Allen, 1997	Review	To make a further contribution to Svensson's (1996) debate and also to the sociological understanding of doctor / nurse relationships	N / a	N / a
Anderson <i>et al.</i> , 1997	QN	To identify the health perceptions of young families with different lifestyles and from different environments	Questionnaire	50 traveller families, 50 families from an affluent rural part of Leicester (44 interviewed) and 50 from a deprived inner-city area (44 interviewed)

Author, year	Type of paper	Aim of study	Study design	Sample / participants
Baker and Hann, 2001	QN	To test the persistence of the inverse care law in circumstances in which the coverage of chronic disease management, child health surveillance and minor surgery is known to be widespread and to compare the distribution of services between PCGs and between practices within a PCG	Secondary data analysis using GP census data combined with 1991 national census data	All 481 Primary Care Groups in England
Baker and Middleton, 2003	QN	To examine changing inequality in coverage of cervical screening	Screening coverage data from Health Authorities	Screening coverage in 99 Health Authorities in England
Bardsley <i>et al.</i> , 1997	Review	Web page	N / a	N / a
Barker <i>et al.</i> , 1990	QN	To identify the pattern of overall help-seeking and coping in the UK and to examine whether there are any differences in help-seeking and coping behaviour with respect to demographic variables or level of psychological complaints	Survey interview Data on current psychological health were obtained	1040 adults with a mean age of 45 (498 men, 542 women) quota sampled from the general population
Ben-Schlomo and Charturverdi, 1995	QN	To examine whether coronary artery bypass graft operations (CABG) reflect socio-economic differences in ischemic heart disease (IHD) mortality	Ecological study	35 to 74 year old population statistics for IHD deaths and CABG in the North East Thames Region compared with the general population

Author, year	Type of paper	Aim of study	Study design	Sample / participants
Benzeval and Judge, 1996	QN	To estimate the relative need for GPs by linking evidence from individual utilisation data to the characteristics of small areas	Secondary data analysis of survey data combined with census data	Household survey data on 12 729 adults (Omnibus survey) combined with census data
Black <i>et al.</i> , 1995	QN	To explain the reasons for geographical variation in the use of coronary re-vascularisation in the UK	Cross-sectional ecological study	Residents of SE Thames, East Anglian and North West health regions plus three boards in Scotland who underwent CABG or PTCA in 1992 – 93 in either public or private sector
Blatchford <i>et al.</i> , 1999	QN	To determine the principal diagnoses, demographic and socio-economic factors associated with emergency medical admission	Cohort study	A fully anonymised dataset linkage of 43 247 adult emergency admissions to Glasgow medical beds in 1997 was obtained
Britten <i>et al.</i> , 2000	QL	To identify and describe misunderstandings between patients and doctors associated with prescribing decisions in general practice	Qualitative study	20 general practitioners and 35 consulting patients in the West Midlands and South East England
Burgess <i>et al.</i> , 1998	QL	To examine the extent and determinants of patient and general practitioner delay in the presentation of breast cancer	A case-control study Semi-structured interview	185 cancer patients attending a breast unit

Author, year	Type of paper	Aim of study	Study design	Sample / participants
Calnan, 1987	Review	Book	N / a	N / a
Campbell <i>et al.</i> , 2001	QN	To examine variations in markers of the structure, process and outcome of care being provided by practices of various sizes with a view to determining association between these markers and to determine how these markers relate to partnership size	Questionnaire Patient survey	A randomised sample of general practitioners and practices from two inner-London areas
Campbell <i>et al.</i> , 2001	QN	To assess variations in the quality of care in general practice and identify factors associated with high quality care	Observational study	Stratified random sample of 60 general practices in six areas of England
Campbell, 1999	QN	To describe the variation in patients' perceptions of medical urgency, to investigate the influence of socio-economic deprivation on such perceptions and to investigate the association between patients' perceptions of urgency and their perception of doctor availability	Questionnaire	4999 patients attending their GP over the 17 participating practices
Carlisle and Johnstone, 1998	QN	To determine the relationship between general practice surgery consultation rates and census-derived socio-economic variables for patients receiving the same primary and secondary care	Retrospective data collection	Three general practices in Mansfield, North Nottinghamshire with 29 142 patients spread over 15 electoral wards

Author, year	Type of paper	Aim of study	Study design	Sample / participants
Carlisle <i>et al.</i> , 1998	QN	To investigate the relationship between out-of-hours activity and a&e services with deprivation and distance from a&e	Longitudinal survey	4745 out-of-hours contacts generated by 45 182 patients from 23 electoral wards registered with six practices.
Carr-Hill <i>et al.</i> , 1996	QN	To identify the socio-economic determinants of rates of consultation in general practice	Analysis of data from the fourth national morbidity survey of general practices (MSGP4)	60 volunteer practices between September 1991 and August 1992 on consultations by all patients fully registered for part or the whole of the study period (n=502493)
Chapple, Rogers and Halliwell, 1998	QL	To identify the impact of paid and unpaid labour on access to healthcare	Qualitative interviews with people consulting in primary care	Interviews in North West of England
Charturvedi <i>et al.</i> , 1995	QN	To examine whether coronary artery bypass graft operations (CABG) reflect differences in ischaemic heart disease mortality	Ecological comparison of operation rates was undertaken for CABG for 1991 and IHD mortality for 1981 – 85 by quartiles of Townsend deprivation score	Residents of North Thames Region aged 35 to 74 were the denominator population. Numerators were 26 834 IHD deaths and 1041 CABG operations for the defined time periods

Author, year	Type of paper	Aim of study	Study design	Sample / participants
Coleman <i>et al.</i> , 1999	Report: Cancer survival trends in England and Wales 1971 – 1995; Deprivation and the NHS region	N / a	N / a	N / a
Cook <i>et al.</i> , 1990	QN	To provide data on consultation rates in general practice for middle-aged men over three years according to their age and social class	Prospective study of men over eight years. Data on consultation rates during years six to eight were collected retrospectively from practice records	Over 1000 general practices in Great Britain by year eight. Initially (in 1978 – 80) the men had been selected at random from one practice in each of 24 towns
Cooper and Roter, 2003	Review	To further the understanding of ethnic disparities in health outcomes through investigation of the interpersonal processes related to the provision of health care	N / a	N / a
Cornford and Cornford, 1999	QN	To describe conversations with others and their influence in the decision to consult, compare the relative importance of conversations with partners to conversations with non-partners and investigate whether patients with a worse perceived health status are less likely to use lay referral networks than patients with a better perceived health status	Questionnaire	101 patients who had consulted a GP with new symptoms
Cornwell, 1984	QL	Book	N / a	N / a

Author, year	Type of paper	Aim of study	Study design	Sample / participants
Cragg <i>et al.</i> , 1994	QN	To study the number, demography and clinical details of patients who agreed or refused to attend centralised primary care centres for out-of-hours medical care and to study the satisfaction with the service of those who attended	Prospective data collection Satisfaction questionnaire	Five out-of-hours primary care centres in the UK. All patients contacting the deputising service to request medical help out-of-hours who were asked to attend a primary care centre
Dixon <i>et al.</i> , 2003	Report: Is the NHS equitable? A review of the evidence	N / a	N / a	N / a
Dodier and Camus 1998	QL / Review	To examine the consequences of dual orientation (being open to heterogeneous medical demands versus selecting patients) on the concrete organisation of work	Ethnography involving observation, field notes and interviews	Emergency services in a French teaching hospital
Edwards and Pill 1996	QN	To assess patterns in help-seeking behaviours for common childhood symptoms	Outcome measures of parental reporting of common symptoms, utilisation of professional advice and GP records of consultations were studied for clinic attenders aged nine to 18 months of two child health clinics on Tyneside	Parents of 67 children cared for by 28 different GPs

Author, year	Type of paper	Aim of study	Study design	Sample / participants
Feder <i>et al.</i> , 1993	QN	To assess the immunisation status (as one measure of preventative health care provision) of traveller children presenting to primary care services compared with that of a control group as part of a larger project to assess the health care of traveller gypsies in Hackney, East London	Documentary analysis Survey of hospital records	Traveller gypsy children aged ten months to six years presenting to A&E at the Queen Elizabeth Hospital for children or to any of twelve GPs working in two practices in Hackney between 1988 – 90
Field and Briggs, 2001	QN	To discern determinants of accessibility and utilisation and how these factors vary across a population	Survey two specific groups of primary care service users – diabetes and asthma sufferers Questionnaire	592 questionnaires from patients of 13 general practices
Fuat <i>et al.</i> , 2003	QL	To ascertain the beliefs, current practices, and decision making of general practitioners in the diagnosis and management of suspected heart failure in primary care, with a view to identifying barriers to good care	Focus groups	Stratified and purposive sample of 30 general practitioners from four primary care groups
Gardner and Chapple, 1999	QL	To explore barriers to patients being referred for possible re-vascularisation	Semi-structured qualitative interviews	16 general practice patients under 75 with stable angina and their doctors

Author, year	Type of paper	Aim of study	Study design	Sample / participants
Gattrell <i>et al.</i> ,	QN	To assess the extent to which the need for tertiary cardiac care is being met uniformly within two Health Authorities in North West England.	Analysis of small-area data from 1993 – 96 on standardised rates of investigation (angiography) and surgery (bypass grafts and angioplasty).	Small area analysis
George and Rubin, 2003	Review	To discuss the nature of non-attendance in general practice and review the evidence for strategies to reduce it	N / a	N / a
Gibson <i>et al.</i> , 2002	Review	To present and evaluate an alternative to conventional proxies of need that draws upon epidemiological evidence concerning the age, sex and social class distribution of morbidity in order to estimate the prevalence of specific conditions in designated populations	N / a	N / a
Gillam, 1992	QN	To explore the pattern of provision of health promotion clinics across one family health services authority, provision was then related to measures of health needs of the practice population	Health promotion payments made by the family health services authority to practices in Bedfordshire over the three month period ending December 1990 were analysed	One family health services authority
Goddard and Smith, 1998	Report: Equity of access to healthcare	N / a	N / a	N / a

Author, year	Type of paper	Aim of study	Study design	Sample / participants
Goyder <i>et al.</i> , 1996	QN	To examine whether a minority of practices not qualifying for payment of structured diabetes care programmes differ systematically from those that do	Retrospective data collection	Information on Leicestershire general practices on practice size, population structure, deprivation indices, diabetes related hospital admissions for the period April 1992 to March 1994 and the number of insulin treated patients on the district diabetes register
Granier <i>et al.</i> , 1998	QL	To describe the presentation of meningococcal disease in primary care; to explore how GPs process clinical and contextual information in children with meningococcal disease; and to describe how this information affects management	Qualitative semi-structured interviews	26 general practitioners who between January 1994 and December 1996 admitted 31 children in whom meningococcal disease was diagnosed

Author, year	Type of paper	Aim of study	Study design	Sample / participants
Gravelle <i>et al.</i> , 2001	QN	To compare geographical inequality in the distribution of GPs, other resources and mortality around 1995 in England and Wales; to measure trends between 1974 and 1995 in the inequality of GP distribution, to examine the implications of different need adjustments and inequality measures on the degree of geographic inequality and to analyse impact of policies (increased supply; area inducements and entry regulation) on inequality	Retrospective data analysis	Data from 1974 – 95 on whole time equivalent GPs and census-based population estimates at primary care administrative area level
Gulliford, 2002	QN	To evaluate whether population health is associated with GP supply in the UK	Secondary data analysis for 99 Health Authorities in England in 1999	Secondary data analysis of mortality rates, hospital admissions and teenage conception rates
Hart and Lockey, 2002	QL	The project addresses inequalities in health from the point of view of new directions in midwifery education and practice	Focus group In depth interviews	Midwifery education and practice and service provision in three 'very different' parts of England
Haynes <i>et al.</i> , 1999	QN	To improve on previous cross-sectional geographical designs and quantify the effects of distance on hospital use while taking into account the potential for confounding influences of variations in the relative health care needs of populations in small areas and the local supply of inpatient services	Secondary analysis of patient records	All hospital inpatient first episodes between 1991 – 93 in 555 wards in East Anglia

Author, year	Type of paper	Aim of study	Study design	Sample / participants
Hewett N, 1999	QN	To determine the views of homeless people in provision of services	Questionnaire survey of users of a clinic for the homeless	86 homeless users completed the questionnaire
Hippisley-Cox and Pringle, 2000	QN	To determine the effect of primary care services on access to coronary angiography and re-vascularisation	A cross-sectional survey	180 Nottinghamshire practices in the Trent region
Hippisley-Cox <i>et al.</i> , 1997	QN	To determine the effect of deprivation on variations in general practitioners' referral rates using the Jarman underprivileged area (UPA(8)) score as a proxy measure	Cross sectional survey	All referrals from 183 general practices in Nottingham to 19 hospitals in the Trent region
Hippisley-Cox <i>et al.</i> , 2001	QN	To determine whether there are important differences in performance between group practices and single-handed general practitioners and to assess the extent to which these are explained by practice characteristics	Cross sectional survey	206 single-handed practices and 606 partnerships in the Trent Region, UK
House of Commons Committee, 2003	Report: Inequalities in access to maternity services	N / a	N / a	N / a
Hughes and Griffiths, 1997	Review	To examine the rationing process using data from case studies of selection of patients for cardiac surgery and admission to a specialist neurological rehabilitation centre	N / a	N / a

Author, year	Type of paper	Aim of study	Study design	Sample / participants
Hunt <i>et al.</i> , 2001	QL	To systematically investigate which factors affect whether people regard themselves as having a family history of CHD or not	Semi-structured interviews	61 men and women who were middle class or working class from a large cross-sectional survey
Jack <i>et al.</i> , 2003	QN	To determine whether the management and survival of patients with lung cancer varied among 26 health authorities in South East England	Retrospective data collection	The Thames Cancer Registry identified patients diagnosed with lung cancer between 1995 and 1999 resident in the 26 health authorities. After excluding death certificate only patients, 32 818 patients were analysed
Jenkins and Campbell, 1996	QN	To relate the sizes of general practice catchment areas in one London Borough to list size, deprivation payments, medical staffing and locally and nationally recognised measures of quality	Study of general practice catchment area maps	60 out of 71 general practices in Lambeth, London

Author, year	Type of paper	Aim of study	Study design	Sample / participants
Kee <i>et al.</i> , 1993	QN	To determine the effects of patient's sex and area's material deprivation on utilisation rates of coronary catheterisation and angiography in the investigation of ischemic heart disease	Retrospective data collection	24 179 episodes of patients discharged from hospital with a primary diagnosis of ischaemic heart disease and 1270 episodes relating to patients with an underlying diagnosis of ischaemic heart disease who had either coronary catheterisation or angiography
Khunti <i>et al.</i> , 2001	QN	To determine how services for people with diabetes are organised in primary care and whether there are inequalities in systematic care of people with diabetes	A piloted postal questionnaire	Three health authorities (Leicestershire, Durham and Suffolk) were responsible for 327 practices of which 264 responded. The practices in the three health authorities served a population of over two million. Two practices refused to participate and 61 failed to reply, therefore, the number of practices was 251

Author, year	Type of paper	Aim of study	Study design	Sample / participants
Langham <i>et al.</i> , 1995	QN	To evaluate the effect of the change in June 1993, in financial incentives for health promotion activity in primary care on the distribution of health promotion payments in two family health services authorities	A retrospective study to determine the level of health promotion payments before and after the contractual amendment	Data was analysed from 78 practices in Bedfordshire and 85 practices in Kensington, Chelsea and Westminster
Leese and Bosanquet, 1995	QN	To investigate the changes in the structure and service provision of general practice in areas with different socioeconomic characteristics	Interview survey Postal questionnaire	260 group and 80 single-handed general practices in six family health services authorities in England
Leung <i>et al.</i> , 1999	QN	To investigate access to cardiac services	Audit	Case notes of 229 Sunderland residents who underwent coronary angiography in the 1995 – 96 financial year were reviewed
Lovett <i>et al.</i> , 2002	QN	To develop new methods for measuring access to primary health care services, to compare patterns of access to services by public and private transport and to investigate the socio-economic characteristics of populations with the poorest access to services	Documentary analysis GIS	481 practices in East Anglia and anonymised data on 2,130,530 patients from FHSA records

Author, year	Type of paper	Aim of study	Study design	Sample / participants
Lynch, 1995	QN	This study set out to examine the relationship between the factors which provide a broad profile of practices and general practitioners' performance in terms of primary childhood immunisation targets	Secondary analysis of immunisation data and patient / practice characteristics	208 practices in Greater Glasgow Health Board and selected characteristics of the practices and their patient populations
Macleod <i>et al.</i> , 2000	QN	To investigate whether poorer survival of breast cancer among deprived women compared with affluent women is related to their NHS care	Retrospective review of hospital and general practice case records	Women diagnosed with breast cancer in 1992 – 93 who lived in the most affluent and the most deprived areas of Glasgow
Majeed <i>et al.</i> , 1994	QN	To determine the importance of patient variables and practice factors in explaining the variation in cervical smear uptake rates	Cross-sectional study	128 practices in Merton, Sutton and Wandsworth
Majeed, Cook, Anderson <i>et al.</i> , 1995	QN	To produce practice and patient variables for general practices from census and family health services authority data, and to determine the importance of these variables in explaining variation in cervical smear uptake rates between practices	Population-based study examining variations in cervical smear uptake rates among 126 general practices using routine data	Inner and outer London Health Authority
Majeed, Cook, Given-Wilson <i>et al.</i> , 1995	QN	To investigate the relative importance of patient and general practice characteristics in explaining variations between practices in the uptake of breast cancer screening	Ecological study examining variations in breast cancer screening rates among 131 general practices using routine data	Merton, Sutton, and Wandsworth Family Health Services Authority, which covers parts of inner and outer London

Author, year	Type of paper	Aim of study	Study design	Sample / participants
Martin and Sterne, 2001	QN	To examine the socio-economic differences in consultation rates in 16 to 39 year-old men	Secondary analysis of survey data	Consultation data on 502 493 patients from the Fourth National Survey of Morbidity in General Practice
Martin <i>et al.</i> , 1991	QN	To study patients' perspectives of why they consulted the doctor, how ill they thought they were, and what happened in the consultation. To compare patients' perspectives before and after the consultation and to compare these perceptions to those of the doctor	Questionnaire	1972 patients across all ages and social class from general practices in Bedfordshire (three) and Hertfordshire (one) plus the GPs from these practices
May <i>et al.</i> , 2004	QL	To explore the ways in which the legitimacy and authority of medical knowledge and practice are organised and worked out in relation to three kinds of chronic illness: menorrhagia; depression; and chronic low back pain / medically unexplained symptoms	Re-analysis of qualitative data from previous studies	Series of studies of British family doctors between 1995 and 2001
McClure <i>et al.</i> , 1996		To identify the characteristics of children who do not attend appointments at general outpatient clinics	Questionnaire	Parents of 359 children who had an appointment at a general clinic
Middleton and Baker, 2003	QN	To examine the extent to which the trend for a decline in MMR vaccines reflect different patterns of uptake in affluent and deprived areas and changes in the equitable coverage of immunisation for MMR	Secondary analysis of MMR immunisation coverage	60 health authorities in England

Author, year	Type of paper	Aim of study	Study design	Sample / participants
Murphy, 1998	Review	To review research relating to the definition, incidence and reasons for attendance of 'inappropriate' attenders	N / a	N / a
O'Donnell and Propper, 1991	QN	To examine the extent to which the NHS allocates healthcare according to need	GHS data	Health economics modelling
O'Donnell, 2000	Review	To describe variation in referral rates; to identify likely explanatory variables; and to describe the effect of GP decision making on the referral process	N / a	N / a
Paterson <i>et al.</i> , 2002	QN	To explore the effects of deprivation on the mortality of patients with head and neck cancer	Cancer Registry data analysis	20 686 cases of head and neck cancers from four regional cancer registries
Payne and Saul, 1997	QN	To explore the relation between rates of coronary artery re-vascularisation and prevalence of angina to assess whether use of health services reflects need	Postal questionnaire	16 750 subjects (18 to 94 years) admitted to hospital for coronary heart disease; patients who died; and patients undergoing angiography, angioplasty, or coronary artery bypass graft. Cohort of 491 people with symptoms from survey
Pell <i>et al.</i> , 2000	QN	To determine whether the priority given to patients referred for cardiac surgery is associated with socio-economic status	Cross-sectional survey	Cardiac surgery patients

Author, year	Type of paper	Aim of study	Study design	Sample / participants
Pereira <i>et al.</i> , 2000	Report: What are the main characteristics and causes of inequality in health care in the UK? What implications do these have for policy?	Online document: http://www.econ.qmw.ac.uk/NHS_reforms.com/downloads/policy_inequality.pdf	N / a	N / a
Petrou <i>et al.</i> , 2001	QN	To measure the independent effects of clinical factors and non-clinical factors, such as provider and socio-demographic characteristics, on the number of antenatal visits made by women in England and Wales	Survey of secondary case records	20 771 women with singleton pregnancies
Pitchforth <i>et al.</i> , 2002	QN	To assess whether the uptake of chemotherapy for colorectal cancer varied by hospital type in Scotland. Hospitals were classified according to cancer specialisation: hospitals were classified as 'cancer centres', 'cancer units' and 'non-cancer' hospitals	Retrospective data collection	Colorectal cancer cases were obtained from cancer registrations linked to hospital discharge data for the period January 1992 to December 1996. The final data set used in the multi-level analysis contained 7303 cases

Author, year	Type of paper	Aim of study	Study design	Sample / participants
Pollock and Vickers, 1998	QN	To examine the relation between deprivation and acute emergency admissions for cancers of the colon, rectum, lung and breast in south east England	Ecological analysis with data from hospital episode statistics and 1991 census	146 639 admissions relating to 76 552 patients aged <100 years on admission, resident in the Thames regions, admitted between 1 April 1992 and 31 March 1995
Pope, 1991	QL	To examine the day to day organisation and management of surgical waiting lists and provide a critical analysis of the main theoretical perspectives on waiting lists	N / a	N / a
Ramirez <i>et al.</i> , 1999	Review	To assess the quality and strength of evidence on risk factors for delays by patients and providers	N / a	N / a
Reid and Todd, 1989	QN	To investigate the travel arrangements made by all attenders at outpatient clinics in Smalltown hospital over one week	Questionnaire	All attenders at outpatient clinics during one week in 1987 were surveyed. A total of 698 patients cooperated in the study representing an 80 per cent response rate

Author, year	Type of paper	Aim of study	Study design	Sample / participants
Reid <i>et al.</i> , 1999	QN	To quantify the extent of the variation in hospital admission rates between general practices, and to investigate whether this variation can be explained by factors relating to the patient, the hospital and the general practice	Characteristics of patients, GP surgeries and hospitals were examined in relation to admission rates for overall, emergency and elective admissions	209 136 hospital admissions in 1995 – 96 in patients registered in 120 practices in Merton, Sutton and Wandsworth Health Authority (inc inner and outer London)
Reid <i>et al.</i> , 2002	QN	To investigate possible inequities in the use of statins for people with coronary heart disease according to a wide range of social and clinical factors	Survey	760 adults with coronary heart disease
Reid, 2003	Review	Health Secretary's speech to the NHS Confederation Annual Conference	N / a	N / a
Richards <i>et al.</i> , 2000	QN	To describe the prevalence of angina and chest pain in men and women in socio-economically contrasting areas; proportions of men and women who present with symptoms and who receive preliminary diagnosis of CHD, to assess effects of gender and deprivation	Questionnaire	Random general population samples from contrasting SES areas surveyed using Rose angina Questionnaire. (n=1107 men and women aged 45 to 64)
Richards <i>et al.</i> , 2002	QL	To explore socio-economic variations in perceptions of and behavioural responses to chest pain	Semi-structured interviews	Adults with exertional chest pain
Rogers <i>et al.</i> , 1999	Review	Book	N / a	N / a

Author, year	Type of paper	Aim of study	Study design	Sample / participants
Scaife <i>et al.</i> , 2000	QN	This study was carried out to determine the effect of a range of socio-economic features on frequent attendance in general practice from a large database of general practice consultations using two definitions of frequent attendance	Secondary analyses of data from the Fourth National Survey of Morbidity in General Practice	283 842 adult patients and their consultations between September 1991 and August 1992
Sefton, 2002	Report: Recent changes in the distribution of the social wage	N / a	N / a	N / a
Seymour and Garthwaite, 1999	QN	To study trends in hospital admissions for inguinal hernia surgery in men, examining relationships between age, deprivation and rate of surgery	Retrospective data collection	Men undergoing inguinal hernia surgery in Scotland in 1982 – 84, 1987 – 89 and 1992 – 94
Sharp and Hamilton, 2001	Review	To explore the statement 'Non-attendance at NHS outpatient clinics and at general practices is more common in deprived populations, it results from the organisation of these services, which currently puts the needs of staff before those of patients'	N / a	N / a
Shipman <i>et al.</i> , 2000	QN	To compare patient satisfaction with GP out-of-hours services in a locale with a newly introduced (15 months ago) GP co-operative, a deputising service, and GP practice-based arrangements. For those using the co-operative, to explore satisfaction with different kinds of service delivery provided	Questionnaire Satisfaction survey	Stratified sample (by organisational contact: co-operative, deputising service, practice-based). Overall 53.2 per cent response rate (n=1,823)

Author, year	Type of paper	Aim of study	Study design	Sample / participants
Shipman <i>et al.</i> , 2001	QL	To understand patients' views, expectations and experiences of attending an out-of-hours primary care centre which was part of an inner-London GP co-operative	Semi-structured telephone interviews	72 primary care centre attendees
Smith <i>et al.</i> , 1994	QN	To explore the hypothesis that social deprivation might be associated with later presentation of amblyopia, particularly of anisometropic amblyopia which depends on vision screening for referral	Secondary analysis of historical cohort data	897 children with amblyopia from seven UK orthoptic clinics
Somerset <i>et al.</i> , 1999	QL	To explore understandings concerning referral to and re-attendance at outpatient clinics and to elicit detailed descriptions of the complexities of the outpatient experience for both providers and recipients of care at the primary / secondary interface, given the policy commitment to a 'primary-care led National Health Service'	Semi-structured interviews	Individuals from three groups involved in the provision of care across the primary / secondary interface: nine patients attending as outpatients, ten general practitioners and ten consultants
Stirling <i>et al.</i> , 2001		To examine factors associated with presentation and recognition of psychological distress in GP surgeries and the interaction of these factors with consultation length	Cross-sectional study	Nine general practices in the West of Scotland, involving 1075 consultations of 21 full-time GPs

Author, year	Type of paper	Aim of study	Study design	Sample / participants
Sutton <i>et al.</i> , 2002	Report: Allocation of resources to English areas: individual and small area determinants of morbidity and health care use of health care resources	N / a	N / a	N / a
Sutton, 2002	Review	To propose a framework for incorporating the implications of vertical inequity for the socio-economic distribution of health care	N / a	N / a
Sword, 1999	Review	To critically examine the notion of barriers as conceptualised in the literature and suggests an expanded orientation to more fully appreciate its complexity	N / a	N / a
Taylor <i>et al.</i> , 2003	QN	To investigate the effects of socio-economic deprivation on clinical outcomes of patients undergoing coronary artery bypass grafting (CBAG)	Retrospective analysis of prospectively collected data	Data on 3578 consecutive patients undergoing CBAG
Thorsen <i>et al.</i> , 2000	Review	To propose theoretical clarification of the concept of the patients' purpose of a consultation by presenting a patient-centred definition, applicable for clinical work and research in general practice	N / a	N / a

Author, year	Type of paper	Aim of study	Study design	Sample / participants
Tod <i>et al.</i> , 2001	QL	To identify factors within the south Yorkshire coalfields that influence use of health services by people with angina	Individual and group interviews Field notes and diagrams	14 patients with stable angina (seven men, seven women aged 52 to 73), nine primary care staff, five community groups and one group of GPs
Trevena <i>et al.</i> , (2003)	QN	To examine the health services utilisation patterns of a seriously disadvantaged population and to document the participants' point of view on difficulties in accessing healthcare when needed, adhering to prescribed treatment and in maintaining continuity of care in follow-up	Cross-sectional case study	100 users of a charity-run soup kitchen in urban Sydney
Van Cleemput <i>et al.</i> , 2000	Review	To discuss the healthcare needs of travellers	N / a	N / a
Victor, 1997	Review	To explore the health of homeless people in Britain	N / a	N / a
Vostanis <i>et al.</i> , 1998		To establish the mental health needs of homeless children and families before and after rehousing	Cross sectional, longitudinal study	Eight rehoused families with 103 children aged two to -16 years and 21 comparison families of low socioeconomic status in stable housing, with 54 children
Watt, 2002	Review	To put Tudor-Hart's inverse care law in a modern context	N / a	N / a

Author, year	Type of paper	Aim of study	Study design	Sample / participants
Wyke <i>et al.</i> , 1992	QN	To investigate provision of and patient satisfaction with primary care services	Survey	The general practice survey data gathered in 1989 were supplemented with data from a survey of residents of the localities in three age cohorts carried out in 1987 – 88, which provided information on use of services, as well as perceived accessibility of and satisfaction with them
Wyke <i>et al.</i> , 2003	QN	To investigate whether associations between frequent attendance in general practice and socio-economic circumstances remain significant after taking detailed account of underlying ill health, perceived social support and social isolation	Retrospective data collection	1477 people in their late forties and late sixties
Young and Leese, 1999	Review	To review the literature and explore the problems and instabilities surrounding recruitment and retention of GPs	N / a	N / a
Young, 2004	Review	To show that singular and segmented approaches to illness behaviour have not clearly elucidated the complexity of the phenomenon	N / a	N / a

Appendix 4A Studies included in synthesis of literature on minority ethnic groups and access to health care

Author, year	Type of paper	Aim of study	Study design	Sample / participants
Adamson <i>et al.</i> , 2003	QN	To examine the influence of ethnicity, socio-economic position and gender on an individual's perception of need and urgency to seek health care	Questionnaire	A stratified sample of 1500 individuals (18 to 75 years) selected from two primary care practices in South West England
Ahmad, 1995	Review	To discuss issues related to race and health care	N / a	N / a
Ahmad and Walker, 1997	QN	To explore housing conditions, health and access to health and social care services	Detailed questionnaire survey	104 older Asian people
Ahmad <i>et al.</i> , 1991	QN	To examine GPs' attitudes towards Asian and Non-Asian	Postal survey	Survey sent to 182 GPs. 141 GPs replied-response rate of 78 per cent
Allison <i>et al.</i> , 2000	QN	To describe current levels, nature and access to primary care use and explore lay knowledge and experience of musculoskeletal problems and self-management strategies among South Asian and Black Caribbean populations	Questionnaire	1876 people in Manchester with musculoskeletal symptoms
Anie <i>et al.</i> , 2002	QN	To assess sickle cell pain and coping in children and to examine the relation between these factors and the utilisation of health services	Interviews Questionnaire	67 children with sickle cell disease attending three London hospitals

Author, year	Type of paper	Aim of study	Study design	Sample / participants
Arai and Farrow, 1995	QL	To assess access to British GPs among Japanese mothers, to describe what Japanese mothers expect from a consultation with a GP and to understand what the barriers are for Japanese mothers in communicating with GPs	Semi-structured interviews	18 Japanese mothers, who have been in the UK for between eight to 66 months; caring for children aged up to five years
Atkin and Ahmad, 1998	Theoretical	To explore the ethical and practical issues raised by genetic screening for sickle cell thalassaemia	N / a	N / a
Atkin <i>et al.</i> , 1998	QL	To examine both mothers' and fathers' perspectives on the nature and appropriateness of service provision for their disabled child and relate these to the views of service practitioners and managers	In-depth qualitative interviews	37 parents of a child with thalassaemia and 25 parents of a child with a SCD. 51 key service providers, managers, commissioners, and representatives from the voluntary sector in seven purchasing localities in the North of England
Atkinson <i>et al.</i> , 2001	Review	To produce an overview of current findings in relation to ethnicity and access to services and identify any gaps	N / a	N / a
Balarajan <i>et al.</i> , 1989	QN	To examine the levels of general practitioner consultations among the different ethnic groups resident in Britain	Retrospective survey of GHS data	63 966 people aged up to 64
Balarajan <i>et al.</i> , 1992	QN	To investigate the effects on GP workload of demographic and socio-economic factors using the British General Household Survey for 1983 – 87	GHS survey (information on GP consultation)	129 987 individuals from random households interviewed in the GHS survey 1983 – 87

Author, year	Type of paper	Aim of study	Study design	Sample / participants
Bebbington <i>et al.</i> , 2000	QN	To examine how people with neurotic disorders receive professional evaluation, and how this is affected by clinical and socio-demographic differences	Secondary analysis of survey data and patient records	Data from the National Survey of Psychiatric Morbidity involving over 10 000 subjects
Bhopal, 1998	Review	To explore issues of racism in health and health care	Review	N / a
Bhui and Bhugra, 1998	Review	To explore training and supervision in cross-cultural mental health services	N / a	N / a
Bhui and Sashidharan, 2003	Theoretical	To present the arguments for and against separate psychiatric services for ethnic minority groups	N / a	N / a
Bhui <i>et al.</i> , 2001	QN	To determine whether culture influences symptom presentation and help-seeking behaviour and GPs assessments	Two-phase survey: clinical interviews; interviews with patients	209 Punjabi and 180 English GP attenders at five practices in London
Bhui <i>et al.</i> , 2003	Review	To identify ethnic variations in pathways to specialist mental health care, continuity of contact, voluntary and compulsory psychiatric in-patient admissions; to assess the methodological strength of the findings	N / a	N / a
Blackledge <i>et al.</i> , 2003	QN	To compare patterns of admission to hospital and prognosis in White and South Asian patients newly admitted with heart failure, and to evaluate the effect of personal characteristics and co-morbidity on outcome	Historical cohort study	5789 consecutive patients newly admitted with heart failure

Author, year	Type of paper	Aim of study	Study design	Sample / participants
Bowler, 1993	QL	To examine the stereotypes of South Asian descent women held by midwives in a British hospital	Direct observation Interviews	South Asian maternity patients and 25 midwives
Bradley and Fredman, 1993	QN	To investigate the response of 'Asian' and 'Non-Asian' women to a computer-generated invitation to attend for a cervical smear during a one-year period	Comparative study	158 Asian women and 158 Non-Asian women aged 50 to 64 years from four general practices in Oldham
Bulman and McCourt, 1997	QL	To explore Somali women's experiences of maternity care	In-depth individual interviews Focus groups	Snowball sample of 12 Somali women who had had contact with maternity services in west London
Burnett <i>et al.</i> , 1999	QN	To understand the relationship between ethnicity, socio-demographic factors and pathways to care in the context of first engagement with psychiatric services	Interviews	Patients aged 16 to 65 from two psychiatric hospitals in London
Burr, 2002	QL	To explore the perceptions and understandings that members of the mental health care professions have about women from South Asian communities	Focus groups Semi-structured interviews	29 mental health care professionals
Carter and Bannon, 1997	QLQN	To ascertain the views of a sample of mothers of children aged three about the child health surveillance programme	Survey	Ten per cent random sample of mothers of children aged three in two West Midlands health authority areas
Carter <i>et al.</i> , 2001	Review	To explore access to and uptake of cardiovascular and mental health services among the minority ethnic community	N / a	N / a

Author, year	Type of paper	Aim of study	Study design	Sample / participants
Chan 2000	QL	To examine the views of users and providers of primary health care services for the Chinese minority in Manchester	Structured interviews Unstructured discussion Semi-structured interviews	30 Chinese mothers, 38 GPs with the largest numbers of Chinese patients registered with them and 26 health visitors
Chapple, 2001	QL	To report the perceptions and experiences of women of South Asian descent living in England, who were suffering or had suffered from thrush	Semi-structured interviews	20 women of South Asian descent who had suffered from thrush
Chaturvedi <i>et al.</i> , 1997	QN	To investigate whether South Asians and European interpret and act upon angina symptoms differently	Questionnaire Case study	Random sample of 2000 people from general practices in London
Chevannes, 1991	Theoretical	To explore access to health care for black people and to emphasise the need for understanding of the ethnic and racial composition of the population and their health needs	N / a	N / a
Chew-Graham <i>et al.</i> , 2002	QL	To conduct a qualitative study of suicide and self-harm services in relation to South Asian women in a Health Action Zone area	Focus groups	Asian women who were members of existing women's groups in Manchester
Chui <i>et al.</i> , 1999	QL	To identify barriers to the promotion of cervical screening amongst minority ethnic women, and to overcome these barriers by collaboratively, formulating, implementing and evaluating an intervention strategy	Participatory action research Focus groups	Women from six language groups, one professional group

Author, year	Type of paper	Aim of study	Study design	Sample / participants
Cole <i>et al.</i> , 1995	QN	To determine whether ethnicity significantly affected the type of pathway into care for patients with a first onset of psychosis	Semi-structured Interviews	93 ethnic minority patients, 50 men and 43 women with first onset of psychosis with an age range of 17 to 53
Cooke <i>et al.</i> , 2000	QN	To determine the general public's understanding of the term unconscious	Interviews	700 adult patients attending an inner city A&E department
Cooper and Roter, 2003	Review	To further the understanding of ethnic disparities in health outcomes through investigation of the interpersonal processes related to the provision of healthcare	N / a	N / a
Cooper <i>et al.</i> , 1998	QN	To assess whether equity is achieved in use of GP, outpatient and in-patient services by children and young people according to ethnic group and socio-economic background	Secondary analysis of the British General Household Survey (GHS) 1991 – 94	20 473 children and young people aged between up to 19 years
Coyle, 1999	QL	To explore the meaning of dissatisfaction with health care through the stories or narratives that people tell about their untoward experiences	In depth interviews	41 individuals (carers, patients, relatives, potential users, complainers and non-complainers) from inner city London and Salisbury
Crowley <i>et al.</i> , 2002	QLQN	To assess the practice and impact of a community development initiative in Newcastle	Interviews Questionnaire Direct observation	A community in Newcastle with a six per cent black and ethnic minority component and high levels of social and economic disadvantage

Author, year	Type of paper	Aim of study	Study design	Sample / participants
Davies and Webb, 2000	Theoretical	To explore the mental health needs of Somali refugee children in Wales and the difficulties for service provision	Discussion paper including some case study examples	N / a
Douglas, 1998	Review	N / a	N / a	N / a
Feder <i>et al.</i> , 2002	QN	To compare rates of revascularisation in South Asian and white patients undergoing coronary angiography in relation to the appropriateness of re-vascularisation and clinical outcome	Prospective cohort study	Consecutive patients (502 South Asian, 2974 white) undergoing coronary angiography in the ACRE study
Free, 1999	QL	To describe the experiences and perceptions of members of Vietnamese community groups in seeking out-of-hours health services and to identify potential solutions from participants' perspectives	Focus groups	Members of three established Vietnamese community groups in South London
Gaffin <i>et al.</i> , 1996	Review	To define palliative care and the current scope of services available in the UK in order to put the Council's project on improving access to hospice and specialist palliative care services for black and ethnic minority communities in context	N / a	N / a
Gammell <i>et al.</i> , 1993	QL	To discover existing patterns of the health in the refugee population, to identify how refugees use the health services available, and to identify the health service needs of refugees	Focus groups Questionnaire survey In-depth interviews	Refugees and political asylum seeker from the six communities living in the borough and professionals working with refugees
Gatrad, 2000	QN	To audit characteristics of non-attenders at a paediatric outpatient department	Prospective audit	1118 non-attenders at a paediatric outpatient department

Author, year	Type of paper	Aim of study	Study design	Sample / participants
Gatrell <i>et al.</i> , 2002	QN	To assess the extent to which the need for tertiary cardiac care is being met uniformly within two Health Authorities in North West England	Retrospective survey	Electoral ward-level data from Regional NHS office
George and Rubin, 2003	Review	To review non-attendance in general practice and its implications for access to primary health care	N / a	N / a
Ghebrehewet <i>et al.</i> , 2002	Review	To discuss some of the support arrangements available to asylum seekers, the problems encountered by primary care providers and health authorities, and the lessons learnt from arrangements for Kosovan refugees	N / a	N / a
Gillam and Levenson, 1999	Review	To explore the role and effectiveness of link-workers in primary care	N / a	N / a
Gillam <i>et al.</i> , 1989	QN	To determine the patterns of consultation with the GP among different ethnic groups and the outcome of these consultations	Retrospective data collection	Patients registered with the practice during the 23 months study period
Gilthorpe <i>et al.</i> , 1998	QN	To identify whether significant variations in hospitalisation rates among minority ethnic groups exist for asthma, and if so, which factors account for them, and in what way might they be modified	Retrospective data collection	10 444 in-patient admissions with primary diagnosis of asthma were selected
Goddard and Smith, 1998	Report: Equity of access to health care	To explore theory and evidence in relation to equity of access to healthcare in the UK	N / a	N / a

Author, year	Type of paper	Aim of study	Study design	Sample / participants
Green <i>et al.</i> , 2002	QL	To identify barriers to communication between health care workers and Chinese women living in England, to consider whether such barriers lead to inequitable access to NHS mental health treatment; and to determine the extent to which this results from institutional racism	In depth interviews	A purposive sample of 42 Chinese women living in South East England aged 29 to 60 years derived from a primary care group, two secondary mental health service providers and three Chinese associations
Griffiths <i>et al.</i> , 2001	QL	To explore reasons for the increased risk of hospital admission among south Asian patients with asthma	Interview	58 South Asian and White adults with asthma; 17 GPs; five A&E doctors; two out-of-hours GPs and one asthma specialist nurse
Hawthorne, 1990	QN	To explore and evaluate diabetes care for Asian and Non-Asian patients	Survey questionnaire	40 Asian and 31 British non-insulin dependent diabetics attending a hospital clinic
Hawthorne, 1994	Review	To examine evidence that Asian people living in Britain have difficulty obtaining good quality health care appropriate to their needs	N / a	N / a
Hoare <i>et al.</i> , 1994	QN	To investigate the effectiveness of a linkworker intervention, giving encouragement and explanations about breast screening, on the subsequent attendance for screening by 'Asian' women	Trial	'Asian' women registered with general practices
Hoare <i>et al.</i> , 1998	Review	N / a	N / a	N / a

Author, year	Type of paper	Aim of study	Study design	Sample / participants
Jack <i>et al.</i> , 2001	Review	To present the important elements related to equal access to specialist palliative care and the provision of culturally sensitive services and to examine the role of the Macmillan Ethnic Minorities Liaison Officer in the Bradford community palliative care team	N / a	N / a
Joseph Rowntree Trust, 2002	Report: - Mental health advocacy for black and minority ethnic users and carers	N / a	N / a	N / a
Kai and Hedges, 1999	QL	To promote community participation in exploring perceptions of psychological distress amongst Pakistani and Bangladeshi people, in order to develop appropriate services	Training and facilitation of resident community members (as community project workers), to define and conduct qualitative research involving semistructured interviews in their own communities	One-hundred and four South Asian people in a socio-economically disadvantaged city
Karim <i>et al.</i> , 1996	Report: Access to accident and emergency services for minority ethnic residents	N / a	N / a	N / a

Author, year	Type of paper	Aim of study	Study design	Sample / participants
Karim <i>et al.</i> , 2000	QL	To examine use of palliative care services by black and ethnic minority groups, attitudes of consultants and their influence	Semi-structured interviews	27 doctors (15 consultants and 12 GPs) records of 1681 patients referred to the hospice between 1996 – 97
Katbamna, 2002	QL	To explore the role of the primary health care team (PHCT) in supporting carers from British South Asian communities	Focus groups In-depth interviews	South Asian carers and carees from Leicestershire and West Yorkshire
Khanchandani and Gillam, 1999	QL	To evaluate the role of link-worker	Random case analyses Video role-plays Assessment schedules Questionnaire Audits	Service evaluation
Kupek <i>et al.</i> , 2002	QN	To identify factors that are predictive of late initiation of antenatal care in England and Wales	Retrospective data collection	Nine maternity units in Northern England & North Wales. The study was based on 17 765 (85.5 per cent) women
Lear <i>et al.</i> , 1994	QN	To compare morbidity and treatment for myocardial infarction and thrombolysis among Indian and European population on a coronary care unit	Survey of patient records	211 Indian and 192 European patients admitted over a period of 12 months to a coronary care unit

Author, year	Type of paper	Aim of study	Study design	Sample / participants
Li <i>et al.</i> , 1999	QL	To identify the barriers encountered by Chinese people with mental health needs in England, which hindered their obtaining appropriate help from the NHS	Questionnaire Semi-structured interviews	Attendees at Chinese community centres in health authority regions with Chinese populations in excess of 2000
Lindesay <i>et al.</i> , 1997	QN	To investigate factors affecting the uptake of health and social services by elderly Asian Gujaratis	Two-stage prevalence study initial screen with selective follow-up. Interviewer administered questionnaires	149 Hindu Gujaratis and 148 whites aged over 65 living in Leicester
Lipley and Parish, 1999	QL	To ask nurses in Harrogate how they thought racism could be stamped out in health services	Informal interviewing	Nurses in Harrogate
Littlewood, 2000	QL	To explore the reasons for delay in help-seeking for breast cancer among African and Afro-Caribbean women	Interviews Follow-up interviews	34 African and African-Caribbean women attending a South London screening clinic (aged 40 to 75 years)
Livingston <i>et al.</i> , 2002	QN	To examine service utilisation of older immigrants compared with their UK-born counterparts and relate it to health difficulties	Cross-sectional survey Interviewer administered questionnaire	Random selection of 1085 people aged over 65 in Islington, London

Author, year	Type of paper	Aim of study	Study design	Sample / participants
Lowry <i>et al.</i> , 1984	QN	To compare the severity and pattern of coronary artery disease in patients referred for investigation of the disease between Asian and white patients living in Birmingham	Survey of patient records	34 Asian and 68 White patients who had undergone coronary angiograms
Lynch and Cunninghame, 2002	Review	To explore the importance of understanding the needs of young asylum seekers in the health care system	N / a	N / a
MacKintosh <i>et al.</i> , 1999	Report: Step by step guide to epidemiological health needs assessment for ethnic minority groups	N / a	N / a	N / a
Majeed <i>et al.</i> , 1994	QN	To determine the importance of patient variables and practice characteristics for explaining variation in cervical smear uptake rates	Population based study of 126 general practices	126 general practices in outer London
Majeed <i>et al.</i> , 1995	QN	To produce practice and patient variables for general practices from census and family health services authority data, and to determine the importance of these variables in explaining variation in cervical smear uptake rates between practices	Population based study examining variations in cervical smear uptake rates among 126 general practices using routine data	Routine data from 126 general practices in London
Manthorpe and Hettiaratchy, 1993	Review	To look at the current literature on minority ethnic elders and mental health problems	N / a	N / a

Author, year	Type of paper	Aim of study	Study design	Sample / participants
Maxwell <i>et al.</i> , 1999	QLQN	To investigate how socio-cultural factors influence pain management for sickle cell disease	Structured questionnaire Focus groups	57 participants with sickle cell disease across Greater London
McAvoy and Raza, 1991	QN	To determine the effects of three different methods of providing health education on the uptake of cervical smear testing among Asian women and to evaluate the acceptability of different health education materials	Prospective cohort study Questionnaire	737 randomly selected Asian women aged 18 to 52 who were not recorded on the central cytology laboratory's computer as ever having had a cervical smear test (159 declined to take part)
McLean, 2003	QL	To elicit African-Caribbean perspectives on mental health treatment and promotion	Focus groups Face-to-face interviews	A purposeful sample of 30 individual from, or working with, the African-Caribbean community in the town
Memon <i>et al.</i> , 2001	QN	To explore access issues for minority ethnic groups and efforts made by PCGs in England to improve access for these groups	Survey	Health authorities and primary care groups with high ethnic minority populations
Menon <i>et al.</i> , 2001	QN	To assess health professionals' knowledge of ethnic minority cultures and lifestyles and its affect on delivery of health care and to assess the need for training	Questionnaire	20 community and 19 hospital paediatricians in Manchester, and 13 other community doctors from the North West Region attending the University of Manchester's Developmental Paediatrics Course

Author, year	Type of paper	Aim of study	Study design	Sample / participants
Morris <i>et al.</i> , 2003	Report: -Inequity and inequality in use of health care in England: an empirical investigation	N / a	N / a	N / a
Naish <i>et al.</i> , 1994	QL	To determine the factors that deter ethnic minority women living in East London from attending their GP for cervical cytology screening	Focus groups	Established community groups and specially convened groups of Bengali, Kurdish, Turkish, Urdu, Punjabi and Chinese speaking women
Nguyen-Van-Tam <i>et al.</i> , 1995	QN	To determine the health care experiences and health-related behaviour of Vietnamese adults living in Nottingham Health District.	Structured interview	135 adults, 66 women and 69 men ranging from 18 to 78 years old, identified from 81 Vietnamese households living in deprived inner city areas of Nottingham
Pahl and Vaile, 1988	QL	To document the health problems of traveller women and children and to make recommendations for improvements in health and welfare services for this group	Face-to-face interviews	263 traveller women with at least one child under the age of 15 living at known traveller sites in Kent in September 1984
Petrou <i>et al.</i> , 2001	QN	To measure the independent effects of clinical factors and non-clinical factors, such as provider and socio-demographic characteristics, on the number of antenatal visits made by women in England and Wales	Survey of secondary case records	20 771 women with singleton pregnancies

Author, year	Type of paper	Aim of study	Study design	Sample / participants
Ramirez <i>et al.</i> , 1999	Review	Systematic review to assess the quality and strength of evidence on risk factors for delays by patients and providers	N / a	N / a
Rashid <i>et al.</i> , 1992	QN	To examine the attitudes to and perceived use of primary health care services, including access to GPs and hospital services, telephone advice, home visiting, deputising services and out-of-hours care, among age matched populations of Asian and non-Asian patients in Leicester	Questionnaire Interviews	A random sample from the FHSA of 449 Asian and 447 non-Asian patients in Leicester
Saxena <i>et al.</i> , 2002	QN	To examine whether self-reported health status and use of services varies in children of different social class and ethnic group	Cross-sectional survey	6648 children and young adults aged 2 to 20 years from the 1999 health survey of Britain
Sharma, 1994	QN	To examine the infant feeding practices in the Vietnamese community and assess the need for advice regarding infant feeding and suitable ways of offering such advice to Vietnamese mothers. To examine health visitors' perceptions of this community's need for advice and the way it's being met	Survey questionnaire Interview Postal questionnaire	Random sample of parents of 43 Vietnamese babies taken from all those born in Lewisham and North Southwark health authority between Dec 1988 and Dec 1989. 85 health visitors working in this authority
Smaje, 1998	QN	To investigate the nature of the GP consultation as the possible occasion of inequity in health care between ethnic groups and the source of differential ethnic filtering into secondary care	Secondary analysis of GHS interview data	All respondents (1984 – 91) reporting a GP consultation in the two weeks prior to the GHS interview (3527 respondents, including 1330 from ethnic groups other than white)

Author, year	Type of paper	Aim of study	Study design	Sample / participants
Smaje <i>et al.</i> , 1997	QN	To investigate whether the NHS provides equal treatment for equal need to different ethnic groups	Secondary analysis of aggregated data of GHS	Random selection from 12 000 households in Great Britain of ethnic minority respondents and ten per cent of white respondents
Sutton <i>et al.</i> , 2002	Report: - Allocation of resources to English areas: individual and small area determinants of morbidity and health care use of health care resources	N / a	N / a	N / a
Sutton, 2002	Review	To propose a framework for incorporating the implications of vertical inequity for the socio-economic distribution of health care	N / a	N / a
Tang, 1994	QL	Exploring the health status of Vietnamese refugees and their under-use of local health services	Focus groups	12 Female Vietnamese refugees including eight elderly ladies

Author, year	Type of paper	Aim of study	Study design	Sample / participants
Tod and Lacey, 2002	QL	To identify what currently prevents people accessing cardiac rehabilitation in the South Yorkshire coalfields	Semi-structured interviews	20 people who had been admitted with an acute MI to one of the three acute hospitals in the SYCHAZ area and 15 people who were involved in cardiac rehabilitation
Uddin <i>et al.</i> , 1998	Book chapter	N / a	N / a	N / a
Webb, 2000	Review	Discussion of health care issues for minority ethnic groups	N / a	N / a
Webb and Sergison, 2003	QLQN	To evaluate the acceptability and effectiveness of cultural competence and anti-racism training to professionals providing services to ill or disabled children	Retrospective postal questionnaire survey	Staff members of the multi-disciplinary team providing care to ill or disabled children who had attended training in Cardiff and child health professionals who had completed the multidisciplinary MSc, into which the training was incorporated
Webb, Maddocks and Bongilli, 2002	Review	To explore the barriers to effective protection of black and minority ethnic children who are at risk of harm	Narrative review article with reference to some case studies	N / a
Wright, 1983	Review	To highlight language and communication problems in an Asian community	N / a	N / a

Appendix 5A Studies included in synthesis of literature on children and access to health care

<i>Author, year</i>	<i>Type of paper</i>	<i>Aim of study</i>	<i>Study design</i>	<i>Sample / participants</i>
Anderson <i>et al.</i> , 1997	QN	To identify the health perceptions of young families with different lifestyles and from different environments	Questionnaire	50 traveller families (38 interviewed) 50 affluent families (44 interviewed) and 50 from a deprived inner city area (44 interviewed)
Anie <i>et al.</i> , 2002	QN	To assess sickle cell pain and coping in children and to examine the relation between these factors and the utilisation of health services	Interviews Questionnaire	Cross sectional study with 67 children with sickle cell disease attending three London hospitals
Arksey and Sloper, 1999	QLQN	To explore lay perspectives and empowerment in relation to obtaining a diagnosis for repetitive strain injury and childhood cancer	Postal questionnaire Structured interviews	278 men and women with RSI, 98 families affected by childhood cancer
Armon <i>et al.</i> , 2001	QN	To determine the common medical presenting problems to an accident and emergency department	Audit Data collected prospectively	Data were collected on children attending a paediatric A&E department in Nottingham between February 1997 and February 1998
Arul and Spicer, 1998	Review	To review the literature on the way in which paediatric surgical care is provided throughout a region and how the service should ideally be organised	N / a	N / a

Author, year	Type of paper	Aim of study	Study design	Sample / participants
Aynsley-Green <i>et al.</i> , 2000	Review	To explore issues of advocacy and giving children a voice in modernisation of services for children and young people	N / a	N / a
Bailey and Pain, 2001	QL	To explore the socio-cultural context of women's decisions about infant feeding, including the influence of personal histories, family and friends, workplace practices, experiences of public and private spaces and beliefs and feelings about different modes of infant feeding	Qualitative interviews Focus groups	11 first-time mothers, aged 27 to 35, 12 members of their informal network of family and friends
Bloor, 1976	QL	To explore the issue of variations in the assessment of children for adeno-tonsillectomy	Observational study	Outpatient clinics of 11 ENT specialists
Bowling <i>et al.</i> , 1987	QN	To examine the factors influencing patients' attendance and frequency of attendance at the A&E of the Queen Elizabeth hospital for children	Documentary analysis Questionnaire	968 attendances by 938 attendees at A&E between Sept 1984 and Sept 1985. Also, a questionnaire was filled out by doctor attending patients over two two week periods during November 1983 and February 1984
Boylan, 2004	Report: Children's Voices Project: Feedback from children and young people about their experience and expectations of healthcare	N / a	N / a	N / a

Author, year	Type of paper	Aim of study	Study design	Sample / participants
Brooks <i>et al.</i> , 1998	QN	To determine immunisation and pre-school surveillance coverage of children who had been resident in a refuge for women victims of domestic violence	71 children resident in a refuge in a one-year period	Retrospective audit
Bryce and Gordon, 2000	QN	To investigate issues influencing the role of GPs in managing child and adolescent mental health problems	Postal questionnaire	Population of urban Scottish general practitioners
Burack, 2000	QN	To find out the opinions and attitudes of 13 to 15 year-olds towards G-based sexual health care services	Survey	1045 children attending eight state schools in North London borough of Barking and Havering
Carter and Bannon, 1997	QNQL	Ascertain the views of a sample of mothers of children aged three about the child health surveillance programme	Survey questionnaire	Ten per cent random sample of mothers of children aged three in two west midlands health authority areas
Carter <i>et al.</i> , 2002	QL	To explore the ways in which parents of children with profound special needs assess and manage their children's pain	Qualitative case study design using guided interviews over a three month period	15 parents / carers of 12 children aged 5 to 16 years with profound special needs
Churchill <i>et al.</i> , 2000	QN	To determine whether the attitudes of teenagers towards general practice are associated with differences in consultation patterns	Postal questionnaire survey compared with the same patients consultation data from the previous 12 months which was obtained from their medical records	Teenage patients aged between 13 and 15 registered with five practices in the East Midlands, analysed in relation to consultation data from retrospective casenote analysis for the preceding 12 months

Author, year	Type of paper	Aim of study	Study design	Sample / participants
Clinical Standards Advisory Group, 1998a	Report: Hospital Outpatient Services	N / a	N / a	N / a
Clinical Standards Advisory Group, 1998b	Report: Services for patients with epilepsy	N / a	N / a	N / a
Coleman and Findlay, 1997	QN	To examine the presenting problem of patients referred by GPs to a paediatric emergency clinic	Analysis of case notes	451 of 456 children referred to the clinic (data incomplete on five)
Cooper <i>et al.</i> , 1998	QN	To assess whether equity is achieved in use of general practitioner, outpatient and inpatient services by children and young people according to ethnic group and socio-economic background	Secondary analysis of GHS data	20 473 children and young people aged between up to 19 years
Cornford <i>et al.</i> , 1993	QL	To examine mothers' personal accounts of their concerns about their child's cough, their perceptions of the benefits in consulting and to evaluate how they assess their child's illness	In-depth interviews	30 mothers who consulted a GP for their child's (ave. 2.6 yrs old) cough living in urban Middlesbrough
Cragg <i>et al.</i> , 1994	QN	To study the number, demography, and clinical details of patients who agreed or refused to attend centralised primary care centres for out-of-hours medical care and to study the satisfaction with the service of those who attended	Questionnaire	All patients contacting the deputising service to request medical help out-of-hours who were asked to attend a primary care centre (1000 in total – 200 from each of five centres)

Author, year	Type of paper	Aim of study	Study design	Sample / participants
Cropper <i>et al.</i> , 2002	Review	To discuss the future organisation of paediatric services	N / a	N / a
Cunningham-Burley and McLean, 1987	QN	To investigate mothers' perceptions of their children's illnesses and of how they routinely coped with minor ailments in their children	Interview data Health diary material	A new town in Scotland and the sample was drawn from one health centre. 54 women with at least one child were randomly selected and interviewed
Davis, 1995	QN	To examine parental perceptions of the quality of care received and to explore whether this sphere of patient care requires further attention	Exploratory descriptive survey: postal questionnaire and follow up interviews	A retrospective postal questionnaire was administered to parents of children, under the age of ten, attending the department
Department of Health, 1997	Report: Paediatric Intensive Care: a framework for the future	N / a	N / a	N / a
Department of Health, 2003	Report: Getting the right start: National Service Framework for Children Standard for Hospital Services	N / a	N / a	N / a
Dingwall <i>et al.</i> , 1983	Review	Categorisation in accident and emergency departments: 'good' patients, 'bad' patients and 'children'	N / a	N / a

Author, year	Type of paper	Aim of study	Study design	Sample / participants
Dixon-Woods <i>et al.</i> , 2002	QL	To investigate the views of children, young people and their parents on primary care services for childhood asthma, to explain how they should be characterised as evaluators of health services, and to identify the dimensions of care which they see as important	Semi-structured interviews	20 families recruited from responders to a respiratory problems questionnaire and from two general practices in Leicestershire
Dixon-Woods <i>et al.</i> , 1999	Review	To explore issues surrounding partnerships with children in health care decision-making	N / a	N / a
Dixon-Woods <i>et al.</i> , 2001	QL	To determine how parents felt about the process of obtaining a diagnosis of childhood cancer, how it affected them and the implications of early diagnosis and referral	Semi-structured interviews	Purposive sample of 20 parents of children (four to 18 yrs) with a diagnosis of cancer
Dodd and Newton, 2001	Review	Outpatient services for children	N / a	N / a
Donovan <i>et al.</i> , 1997	QN	To discover the attitudes of 15 and 16 year olds to the GP consultation and contraceptive services	Questionnaire	4481 teenagers (15 and 16 year olds) from 30 schools in rural, semi-urban and urban areas of England
Doyle and Orr, 2002	Review	To evaluate inter-hospital transport to paediatric intensive care by specialist staff	N / a	N / a
Drummond <i>et al.</i> , 2000	QN	To identify the reasons for contact with the Glasgow Emergency Medical Services (GEMS) in relation to patient socio-demographic characteristics and the nature of the presenting problem	Postal questionnaire	Socio-demographic data and presenting problems

Author, year	Type of paper	Aim of study	Study design	Sample / participants
Edwards and Pill, 1996	QL	To assess patterns in help-seeking behaviours for common childhood symptoms	Secondary analysis of patient records	Parents of 67 children aged nine to 18 months from two child health clinics on Tyneside cared for by 28 different GP's
Esmail <i>et al.</i> , 2000	QN	To assess whether the documented rise in paediatric admissions was due to inappropriate admissions	Retrospective review of patient records	Sample of paediatric records in 13 NHS district general hospitals in South Eastern England between April 1990 and March 1991
Evans <i>et al.</i> , 2001	QL	To investigate what influences parents' decisions on whether to accept or refuse the primary MMR immunisation and the impact of the recent controversy over its safety	Focus groups	Forty-eight parents, whose youngest child was between 14 months and three years old, attended groups at community halls in six localities in Avon and Gloucestershire
Feder <i>et al.</i> , 1993	QN	To assess the immunisation status of traveller children presenting to primary care services compared with that of a control group as part of a larger project to assess the health care of traveller children	Documentary analysis Survey of hospital records	'Traveller gypsy children' aged ten months to six years presenting to A&E at the Queen Elizabeth Hospital for children or to any of the 12 GP working in two practices in Hackney between 1988 – 90

Author, year	Type of paper	Aim of study	Study design	Sample / participants
Field and Briggs, 2001	QN	To discern determinants of accessibility and utilisation and how these factors vary across a population	Postal questionnaire	Random sample of diabetics and asthmatics recruited from 13 selected GP practices in Northampton District Health Authority to reflect broad range of areas
Florentino <i>et al.</i> , 1998	QL	To assess the experiences of disabled young people and their carers in the transition between paediatric and adult services in Sheffield. They seek to highlight the gaps in provision that exist in this provision in their case study area: Sheffield	Interviews	87 disabled young people or their carers in Sheffield
Gibb <i>et al.</i> , 1997	QN	To describe a family HIV clinic in London and the characteristics of families using it	Survey of patient records	Data on family structure of 59 children from 56 families using the clinic between 1993 and 1996. Also, 185 children attending the clinic in the first five years, and 112 parents (76 per cent mothers) who were registered with the service over the first five years
Goddard and Smith, 1998	Report: Equity of access to health care	N / a	N / a	N / a

Author, year	Type of paper	Aim of study	Study design	Sample / participants
Granier <i>et al.</i> , 1998	QL	To describe the presentation of meningococcal disease in primary care; to explore how general practitioners process clinical and contextual information in children with meningococcal disease; and to describe how this information affects management	Semi-structured interviews	26 general practitioners who between January 1994 and December 1996 admitted 31 children (under 16 years of age) in whom meningococcal disease was diagnosed
Haylock <i>et al.</i> , 1993	QN	To ascertain the views of parents with four-year old children with motor disabilities to see to what extent integrated, appropriate and supportive services are being provided	Questionnaire	40 parents of four-year old children with motor disabilities
Hopton <i>et al.</i> , 1996	QL	To investigate patients' accounts of calling the doctor out-of-hours	Semi-structured interviews	23 people who had called out the doctor on their behalf or on the behalf of another adult and 23 people who had called out the doctor on behalf of a child between 6pm and 8am on a week day
Houston and Pickering, 2000	QL	To explore service users' perceptions of the circumstances in which out-of-hours GP services are used	Semi-structured interviews with parents (usually mothers)	Purposeful sample of 30 families, sampled according to frequent users, one-off callers, and non-callers to out-of-hours services
Hull <i>et al.</i> , 2000	QN	To investigate the contribution of practice-based, preventive child health services to rates of hospital utilisation in children under five years of age	A cross-sectional retrospective study	All 164 practices in four East London boroughs

Author, year	Type of paper	Aim of study	Study design	Sample / participants
Jacobson <i>et al.</i> , 2001	QL	To determine how teenagers view primary care, to discover how primary care providers view teenage patients and to note any differences of opinion between the two groups	Questionnaire Focus groups were assembled for those who completed and returned the questionnaire and wanted to take part. Semi-structured interviews with 40 health professionals	2265 teenage patients 14 to 18 years old, 16 GPs, 12 practice nurses and 12 GP receptionists
Jacobson <i>et al.</i> , 1998	Review	To evaluate health care for teenagers and examine the role of primary care and its interaction with teenage users of the service	N / a	N / a
Jefferson <i>et al.</i> , 2003	QN	To determine the current level of diabetes services and to compare the results with previous national surveys	Questionnaire	A questionnaire was mailed to all paediatricians in the UK identified as providing care for children with diabetes under 16 years
Jolley, 2001	QLQN	To investigate the teenage sexual health service provided by gynaecology nurses at Queen's Medical Centre, Nottingham, by assessing their knowledge, activities and perceptions in relation to teenage sexual health	Cross sectional survey and semi-structured interviews with sub-sample	All gynaecology nurses at QMC

<i>Author, year</i>	<i>Type of paper</i>	<i>Aim of study</i>	<i>Study design</i>	<i>Sample / participants</i>
Kai, 1996a	QL	To identify and explore difficulties parents experienced with acute illness in young children and the information they seek to help them	Qualitative study using one semi-structured one-to-one and group interviews with parents of pre-school children	95 parents of pre-school children
Kai 1996b	QL	To identify and explore parents' concerns when young children become acutely ill	Qualitative study making use of semi-structured one to one interviews and group interviews with parents of pre-school children	95 parents of pre-school children
Kennedy, 2001	Report: Learning from Bristol: the report of the public inquiry into children's heart surgery at the Bristol Royal Infirmary 1984 – 95	N / a	N / a	N / a
Klasen and Goodman, 2000	QL	To investigate the views that parents and GPs hold about hyperactivity and to explore how these views, and clashes between these views, influence access to services	Semi-structured interviews	Ten GPs and 29 volunteer parents of hyperactive children purposefully sampled from parents groups, community services and specialist clinics

Author, year	Type of paper	Aim of study	Study design	Sample / participants
Laming, 2003	Report: The Victoria Climbié Inquiry	N / a	N / a	N / a
Li and Taylor, 1993		To study factors affecting uptake of measles, mumps, and rubella immunisation	Cohort study	7841 children born in January to March 1990 and resident in the districts up till the end of October 1991
MacFaul <i>et al.</i> , 2001	Review	To review trends in use of children's wards excluding data on newborn babies	N / a	N / a
McCarlie <i>et al.</i> , 2002	QN	To consider the factors which may influence the uptake of routine diabetes care	Analysis of data from a diabetes register	All registered diabetes patient in one Scottish district
McClure <i>et al.</i> , 1996	QN	To identify the characteristics of children who do not attend appointments at general outpatient clinics	Questionnaire	Parents of children who had an appointment at a general clinic
McLellan NJ, 2004	Review	N / a	N / a	N / a
Middleton and Baker, 2003	QN	To examine and compare the social distribution of MMR immunisation	Retrospective survey	Immunisation data from 60 Health Authorities in England
Mishler, 1984	Book	The discourse of medicine: dialectics of medical interview	N / a	N / a
Morrison <i>et al.</i> , 1991	QN	To examine use and factors influencing use of out-of-hours services for children	Documentary analysis of patient records	Out-of-hours records on 147 children

Author, year	Type of paper	Aim of study	Study design	Sample / participants
Pain, 1999	QL	To explore what information the parent had received about their child's disabilities, from whom and whether they had found it useful. Information needs were also explored	Semi-structured interviews	20 parents
Peckham and Carlson, 2003	QLQN	To explore secondary school students' health knowledge, attitudes and behaviours, and to examine staff assessment of the Bodyzone project, in which confidential drop-in clinics for young people are set up at schools	Cross sectional questionnaire, assessment and interview study	Students and staff from two schools where Bodyzone has been implemented
Peile, 2004	Review	Patterns, trends, and influences in child health	N / a	N / a
Rawlinson and Williams, 2000	Review	To examine referrals from primary to secondary mental health services	N / a	N / a
Reading <i>et al.</i> , 1993	QN	To measure social inequalities in a variety of indicators of child health in a rural county in the north of England using 'small area' geographical methods of social classification	Retrospective survey	Over 21 000 children resident in Northumberland born between January 1985 and September 1990 and 9930 children aged 5 to 8.6 years in Northumberland schools
Redfern, 2001	Report: The Royal Liverpool Children's Inquiry Report	N / a	N / a	N / a

Author, year	Type of paper	Aim of study	Study design	Sample / participants
ReesJones <i>et al.</i> , 2004	QL	To explore the way in which GPs in the UK manage the dual responsibilities of treating individual patients and making the most equitable use of National Health Service (NHS) resources in the context of the policy of greater patient involvement in decision-making	Interviews and focus groups	24 GPs from two Greater London Health Authorities
Richman <i>et al.</i> , 1991	Review	To examine use of acute health services by homeless children	N / a	N / a
Robinshaw and Evans, 2001	QLQN	To explore parents' perspectives on health and social care service provision for pre-school children who are deaf	Questionnaire Focus groups	77 Parents of pre-school children who are deaf
Rogers <i>et al.</i> , 1999a	QL	To investigate patient's perceptions and experiences of rationing and the potential impact this might have on people's use of services	Interviews	Cross section of 53 primary care service users
Rogers <i>et al.</i> , 1999b	Book: Demanding patients? Analysing the use of primary care	N / a	N / a	N / a
Royal College of Paediatrics, 2002	Report: Old problems, new solutions: 21 st century children's health care	N / a	N / a	N / a
Sartain <i>et al.</i> , 2000	QL	To explore children's, parents' and health professionals' experience of childhood chronic illness	Semi-structured interviews	Seven families affected by childhood chronic illness and their professional carers

Author, year	Type of paper	Aim of study	Study design	Sample / participants
Saxena <i>et al.</i> , 2002	QN	To examine whether self reported health status and use of health services varies in children of different social class and ethnic group	Cross sectional survey	6648 children and young adults aged 2 to 20 years
Sayal <i>et al.</i> , 2002	QLQN	To apply a pathways of care model to children with pervasive hyperactivity in order to provide a quantitative description of the filters in help-seeking pathway through primary care, and to investigate the relative contributions of child, parent and GP factors in determining service use	Questionnaire Semi-structured interviews	Parents, teachers and GPs of children aged 5 to 11 identified from a community sample screened for pervasive hyperactivity and children with a clinical diagnosis of ADHD
Shah, 1997	Review	To highlight areas for improvement of services to Asian children with a disability and their families	N / a	N / a
Shipman <i>et al.</i> , 1997	QLQN	To examine people's attitudes towards and use of out-of-hours services	Audit Interviews	Out-of-hours services users
Shipman <i>et al.</i> , 2001	QL	This study was designed to understand patients' views, expectations and experiences of attending an out-of-hours primary care centre which was part of an inner London GP co-operative	Semi-structured telephone interviews	72 primary care centre attendees
Silverman, 1987	Review	N / a	N / a	N / a
Simpson and Stallard, 2004	Review	Referral and access to children's health services	N / a	N / a
Sloper, 1999	Review	To explore models of support for parents of disabled children and what we can learn from them	N / a	N / a

Author, year	Type of paper	Aim of study	Study design	Sample / participants
Smith <i>et al.</i> , 1994	QN	To identify whether there is a relationship between social deprivation and access to health care and screening services	Cohort study	897 children with amblyopia, from seven UK orthoptic clinics
Spencer and Battye, 2001	QL	To examine palliative care services available in the region, exploring attitudes to both current provision and possible service improvements	In-depth interviews	40 different professionals in South East England involved in managing palliative care for children with cancer in the community
Stephen <i>et al.</i> , 2003	QN	To report on patient outcomes from a nurse-led clinic for young people with suspected or diagnosed epilepsy	Audit	All patients referred during the first four years after its inception
Stern and Brown, 1994	QN	To investigate the effect of a waiting list on attendance at initial appointments in a child and family health clinic	Questionnaire	Attendees at a child and family health clinic
Stewart <i>et al.</i> , 1998	QN	To examine medical and socio-demographic factors involved in acute paediatric admission and to compare outcome of admission with factors present at time of admission	Questionnaire	Prospective study of 887 consecutive emergency general paediatric admissions to five Yorkshire hospitals during two separate three week periods in summer and winter
Streetly <i>et al.</i> , 1994	QN	To determine whether coverage of the neonatal (Guthrie) screening programme in Britain is different for groups at highest risk of sickle cell disease and to identify possible reasons for incomplete coverage	Retrospective survey	1727 infants born between 1 October and 31 December 1991 from the former West Lambeth and Camberwell District Health Authorities, London
Strong, 1979	Review	N / a	N / a	N / a

Author, year	Type of paper	Aim of study	Study design	Sample / participants
Sweeting, 1995	Review	Review of findings on sex differences in health among children and adolescents, concentrating on ages 7 to 15 years	N / a	N / a
Tang and Cunninghame, 1994	QL	To look at the health status of Vietnamese refugees and their under-use of local health services	Focus groups	12 Vietnamese refugees
Thomas, 2000	QN	To investigate the asthma-related morbidity and the reasons for discontinuation of asthma care in children who have been diagnosed as having asthma but had discontinued asthma treatment and care in a UK general practice	Postal questionnaire	Households of all children aged 15 or less with a diagnosis of asthma who had neither received a prescription for asthma related medication nor consulted a doctor or a nurse with an asthma related problem in the previous 12 months
Tickle <i>et al.</i> , 2000	QN	Firstly, to compare the socio-economic profiles of children registered with GDS, with those using the CDS services and unregistered children. Secondly, to examine the effects of socio-economic status on travelling to access primary dental care and finally to map out the location of unregistered children in relation to primary dental care services	Secondary analysis of dental patient records	All children younger than six years who used primary dental care services in, or were residents of, Ellesmere Port
Tilstone, 2004	Review	To discuss the issue that adolescent health care needs are ignored and neglected	N / a	N / a

Author, year	Type of paper	Aim of study	Study design	Sample / participants
Victor <i>et al.</i> , 1989	QN	Describe use of hospital services made by homeless families compared with that made by local residents	Analysis of patient records	In patient admissions to two non-psychiatric hospitals, attenders at a paediatric walk-in centre and a hospital casualty department
Walker and Townsend, 1999	Review	To review literature on health promotion interventions for teenagers in general practice	N / a	N / a
Webb <i>et al.</i> , 2001	QN	To describe the health and developmental status of children living in refuges for women victims of domestic violence and to investigate their access to primary care healthcare services	Cross sectional survey	148 resident children aged under 16 years and their mothers
Whitehead and Gosling, 2003	QL	To examine the lived experience of parents' perceptions of interactions with health professionals before, during and after diagnosis of tuberous-sclerosis (TS)	Interview study	109 participants from 40 families with children with a diagnosis of TS
Williams <i>et al.</i> , 1995	QN	To survey cleft and palate surgical activity in England Wales	Survey	89 surgeons (a 93 per cent response rate out of sample of 96 identified)
Young <i>et al.</i> , 2003	QN	To examine young people's and parents' accounts of communication about cancer in childhood	Semistructured interviews	13 families, comprising 19 parents and 13 patients aged 8 to 17 years, recruited from one paediatric oncology unit

<i>Author, year</i>	<i>Type of paper</i>	<i>Aim of study</i>	<i>Study design</i>	<i>Sample / participants</i>
Young <i>et al.</i> , 2002	QL	To examine parents' accounts of how they recognise and judge respiratory symptoms in children, and to investigate their interpretations of respiratory survey questions about wheeze, shortness of breath, and cough	Semi-structured interviews	19 parents of children aged under six years were recruited from a cohort of parents

Appendix 6A Studies included in synthesis of literature on older people and access to healthcare

Author, year	Type of paper	Aim of study	Study design	Sample / Participants
Adamson <i>et al.</i> , 2003	QN	To examine the influence of ethnicity, socio-economic position and gender on an individuals perception of need and urgency to seek health care	Questionnaire survey using vignettes	2500 individuals (18 to 75 years) selected from two primary care practices in South West England. From these, a random sample of 1500 and a stratified sample (for ethnicity) were selected to take part in the study
Addington-Hall <i>et al.</i> , 2000	QN	To investigate how cancer patients who receive care from community specialist palliative care (CSPS) nurses differ from those who do not	Interview survey	2074 survey interviews with an informant about the last year of a person's life who died from cancer
Age Concern, 1999	Report: Turning your back on us: Older people and the NHS	N / a	N / a	N / a
Ambery and Donald, 2000	QN	To explain variation in admission rates for elderly people	A retrospective review of admissions to DGH and CH and a survey of GP attitudes to emergency admissions	Patients over 75 from 53 general practices admitted to DGH and CH in West Gloucester during three years

Author, year	Type of paper	Aim of study	Study design	Sample / Participants
Arthur <i>et al.</i> , 2002	QN	To evaluate a follow-up assessment by the community mental health team for older people with depressive symptoms	RCT	Patients over 75 receiving a health check from one large general practice in Leicestershire
Banerjee <i>et al.</i> , 1996	QN	To assess the effectiveness of different interventions on depression of frail elderly people at home	RCT	Frail elderly people living at home
Barker <i>et al.</i> , 1990	QN	To identify the pattern of overall help seeking and coping in the UK and examine whether there are any differences in help-seeking and coping behaviour with respect to demographic variables or level of psychological complaints	Survey interview	1040 adults with a mean age of 45 (498 men, 542 women) quota sampled from the general population
Bayer and Tadd, 2000	Review	To assess whether there is an unjustified exclusion of elderly people from studies submitted to research ethics committee for approval	N / a	N / a
Beekham <i>et al.</i> , 1995	QN	To report on the course of depressive symptoms in a community-based sample of older people	Cohort survey	238 older people in a Netherlands community
Bentley, 2003	QL	To explore the extent to which there is a consumerist ethos among elderly people in a village community & factors influencing access	Interviews	Nine older villagers
Blanchard <i>et al.</i> , 1994	QN	To explore the nature of depression among older people in inner-London and their contact with primary care	Survey	96 people of pensionable age from an inner-London electoral ward

Author, year	Type of paper	Aim of study	Study design	Sample / Participants
Blanchard <i>et al.</i> , 1995	QN	To examine the effect of primary care nurses on interventions upon older people screened as depressed	RCT	96 older people over 65 years from inner city London
Bollam <i>et al.</i> , 1988	QN	To describe patients' assessment to aspects of a recent out-of-hours call; to assess whether needs are met equally across ages; to examine the acceptability of different types of out-of-hours care	Interview survey	177 patients after making out-of-hours call
Bond <i>et al.</i> , 2003	QN	To analyse access by age to exercise testing, coronary angioplasty, revascularisation and thrombolysis	Retrospective case note analysis	712 case notes of inpatients and outpatients with IHD
Bouman and Arcelus, 2001	QN	To determine the current perceived practice of consultant psychiatrists regarding taking sexual history and management of dysfunction of their patients	Postal questionnaire	Old-age general consultant psychiatrists
Brown <i>et al.</i> , 1992	QN	To investigate the annual health checks for patients over 75 years required by the 1990 GP contract	Audit of assessments and patient questionnaire	Patients of 75 years and above in 20 general practices in Nottinghamshire
Brown <i>et al.</i> , 1997	QN	To investigate the problems found by general practice contractual annual checks of the over 75s and the consequent action taken and to identify the patient and practice associated with the discovery of these problems	Survey and staff interviews	Information on patients and staff from 40 general practices
Bruce <i>et al.</i> , 1999	Review	To explore issues surrounding attitudes towards depression of people over 65 years	N / a	N / a

Author, year	Type of paper	Aim of study	Study design	Sample / Participants
Bugeja <i>et al.</i> , 1997	Report: - Exclusion of elderly people from clinical research	N / a	N / a	N / a
Callahan <i>et al.</i> , 1996	Review	To review the validity of the assumption that primary care physicians underutilise currently available and effective treatments for later-life depression	N / a	N / a
Calnan, 2003	Review	To explore the question of whether those brought up under the NHS have a more critical perspective on their health care provision in old age and have adopted a more consumerist position as opposed to being grateful	N / a	N / a
Challis <i>et al.</i> , 2002	QN	Describe and compare old-age psychiatry services in England in terms of professional autonomy, community orientation and health and social care integration	Postal survey	318 / 438 old-age psychiatrists
Chew <i>et al.</i> , 1994	QN	To investigate elderly patients' views and experiences of the annual health check and to compare these with previously reported views of GPs and practice nurses	Patient interviews	664 elderly patients from 20 FHSAs
Conway and Hockey, 1998	QL	Critically examines the value of using ideas from postmodernism in the context of the lay health beliefs of older people	Biographical interviews and a group discussion	15 older people
Cooper and Coleman, 2001	QL	To discover nurses' perceptions of the elderly patients in their care	Interviews Observation	26 nurses working in elderly care rehabilitation hospitals

Author, year	Type of paper	Aim of study	Study design	Sample / Participants
Cooper and Roter, 2003	Review	To further the understanding of ethnic disparities in health outcomes through investigation of the interpersonal processes related to the provision of health care	N / a	N / a
Cornford and Morgan, 1999	QN/QL	To examine beliefs about influenza vaccination in elderly patients at risk from influenza	Semi-structured interviews	50 patients aged over 75 years at risk from influenza, equally divided between vaccinated and non-vaccinated groups
Crawford <i>et al.</i> , 1998	QN	To examine the GPs' awareness of depression in their elderly patients and identify the characteristics of those patients least likely to be recognised and treated	Cross-sectional survey	510 elderly resident in the Gospel Oak area of Camden registered with 28 GPs at 13 practices
Croxson S, 2002	Review	To explore diabetes in the elderly: problems of care and service provision	N / a	N / a
Delaney <i>et al.</i> , 1998	QL	To construct an explanatory model of the decision to consult with dyspepsia in older patients	Qualitative interviews	31 patients consulting their GP with dyspepsia (16 men, 15 women – mean age 64 years)
Department of Health, 2001	Report: National Service Framework for older people	N / a	N / a	N / a
Department of Health / ONS, 2002	Report: The general health of older people and their use of services	N / a	N / a	N / a

Author, year	Type of paper	Aim of study	Study design	Sample / Participants
Dixon-Woods <i>et al.</i> , 2004	QLQN	To follow up trial of home-administered influenza vaccination of older people to explore reasons for their immunisation behaviour, including their views on the organisation of services	Semi-structured interviews	Analysis of records of 1865 older people and interviews of 25 people
Ebrahim <i>et al.</i> , 1984	QN	To compare the characteristics of elderly patients designated as 'consulters' and 'non-consulters'	Postal questionnaire	200 consulters and 196 non-consulters aged over 65 (90 per cent response rate)
Elkan <i>et al.</i> , 2001	QN / Review	To evaluate the effectiveness of home visiting programmes that offer health promotion and preventative care for older people	Systematic review and meta-analysis	Frail older people living at home
Evans and Katona, 1993	QN	To assess the epidemiology of depressive symptoms in elderly primary care attenders	Survey	408 elderly primary care attenders
Evans <i>et al.</i> , 2003	QN	To explore views about influenza vaccine and identify ways of improving uptake in people aged over 65 and living in the community	Postal questionnaire	Completed questionnaires were returned by 1468 / 2553 (57.5 per cent)
Fahey <i>et al.</i> , 2003	QN	To assess the quality of care given to elderly people and compare the care given to residents in nursing homes with those living in their own homes	Controlled observation study	Elderly individuals (over 65) registered with one of three general practices in Bristol. 172 were residents in care homes and 526 lived at home
Fordyce and Hunter, 1987	QN	To assess variations in service provision for older people in rural and urban areas	Interview survey	Random sample of 997 people aged over 75 living at home in rural (491) or urban areas (506)

Author, year	Type of paper	Aim of study	Study design	Sample / Participants
Foster <i>et al.</i> , 2001	QL	To explore the views of older people on out-of-hours services	Focus groups	30 participants – 26 women and four men aged between 65 and 81 years, mostly white and living alone
Freeman and Richards, 1993	QN	To find out whether patients could identify a usual doctor, patients' rationings of the importance of seeing the same doctor each time, characteristics of patients receiving high or low continuity of care, whether those desiring continuity were receiving it, patients' reactions to seeing different doctors, patients' awareness of and satisfaction with practice policy on appointments, and how patients had chosen their practice	Interview survey	111 patients from three group practices in Southampton
Glendinning <i>et al.</i> , 2002	Review	A critical review of recent policy developments in England aimed at improving health and social services for older people	N / a	N / a
Glendinning <i>et al.</i> , 2002	QN	To investigate patterns of access to medical services for residents in homes for older people	Telephone survey	All nursing and dual registered homes and one in four residential homes located in a stratified random sample of 72 English primary care groups / trust areas

Author, year	Type of paper	Aim of study	Study design	Sample / Participants
Grant <i>et al.</i> , 2000	QN	To determine the in-hospital mortality for injured elderly patients and ascertain whether they were managed less aggressively than their younger counterparts	Retrospective data collection	Trauma patients
Green <i>et al.</i> , 2002	QL	To identify triggers to self-referral for glaucoma symptoms and to explore the meaning of symptoms for people living with moderate to severe glaucoma	In-depth one-to one interviews and group interviews	28 glaucoma patients (14 men, 14 women) sampled from two hospitals
Greenlund <i>et al.</i> , 2003	QN	Examination of recognition of stroke symptoms and awareness of the need to call 911 for acute stroke events among the general population	Telephone survey	61 019 people taking part in the 2001 Behavioural risk factor surveillance system
Grimley Evans and Tallis, 2001	Review	To look at the implications of the national service framework for older people on care of the elderly	N / a	N / a
Guadagnoli <i>et al.</i> , 1997	QN	To assess whether the use of adjuvant systematic therapy in postmenopausal women with early -stage breast cancer is influenced by patient age	Retrospective cohort study	Data on 746 breast cancer patients and their surgeons
Hart, 2001	QL	To report research on experiences of stroke survivors and their informal carers who are receiving stroke services in the community	Interviews	57 stroke survivors and six carers
Hausdorff <i>et al.</i> , 1999	QN	To test the hypothesis that age-associated changes in physical function, particularly walking performance, are influenced by ageism and that positive stereotypes could be used to reverse these changes	Randomised intervention study	47 community-dwelling men and women (63 to 82 years old) who walk independently and describe themselves as healthy

Author, year	Type of paper	Aim of study	Study design	Sample / Participants
Helmes and Duggan, 2001	QN	To evaluate whether the combination of age and the presence of a physical illness would influence the recognition, treatment and further investigation by GPs of possible depression in older males	Questionnaire using four vignettes of males with depression	189 Perth GPs
Help the Aged, 2000	Report: Not because they're old. Dignity on the wards	N / a	N / a	N / a
Honkanen <i>et al.</i> , 1996	QN	To investigate factors associated with acceptance of influenza vaccination in an elderly population in order to find ways if improving coverage	Postal questionnaire	Random sample of 497 elderly patients from three administrative districts with different vaccination coverages
Hubbard <i>et al.</i> , 2004	QN	To assess whether there is discrimination against older people in access to these critical care beds	Survey	All sick people in five hospitals in a South Wales Health Authority were studied every 12 th day for one calendar year. Demographic, clinical and physiological data were collected
Iliffe <i>et al.</i> , 1991	QN	To investigate cognitive impairment among older people in north and north west London and explore related social circumstances	Survey	Patients aged 75 years and above registered with a GP in north and north west London

Author, year	Type of paper	Aim of study	Study design	Sample / Participants
Illife <i>et al.</i> , 1992	QN	To test the hypothesis that elderly people living alone are an at-risk group with a high level of morbidity that makes high demands on health and social services	Survey	239 people aged 75 and over, identified from general practitioners' age-sex registers
Jacobs <i>et al.</i> , 2003	QL	To investigate the perceptions and experiences of home managers and GPs of the provision of general medical services for older residents	Interview survey	42 interviews with nursing/residential home managers and eight resident GPs
Jagger <i>et al.</i> , 1996	QN	To describe the characteristics of elderly people who declined the offer of an annual home visit	Prospective cohort study	All elderly people aged 75 and above registered with a general practice of 13 full time and three part-time doctors with a list size of 33 000
Jenkins <i>et al.</i> , 1994	Review	To evaluate problems encountered by general practitioners when arranging hospital admission for acutely ill patients		65 elderly depressed GP attenders
Kalra <i>et al.</i> , 2004	QN	To evaluate the effectiveness of training care givers in reducing burden of stroke in patients and their care givers	RCT	300 Stroke patients and their care givers
Katona and Livingston, 2000	Review	N / a	N / a	N / a
Katz <i>et al.</i> , 2000	Review	To introduce a 'Council of Elders' providing a forum for health professionals can present their dilemmas in caring for older people to a panel of community elders	N / a	N / a

Author, year	Type of paper	Aim of study	Study design	Sample / Participants
Kavanagh <i>et al.</i> , 1998	QN	To describe utilisation of general practitioners by elderly people resident in communal establishments; to examine variations in general practitioner utilisation and estimate the likely impact of the 'downsizing' of long stay provision in NHS hospitals	Secondary analysis of survey	Disabled residents aged 65 or more without mental handicap
Kerrison and Pollock, 2001	Review	To examine policies and issues related to caring for older people in the private sector in England	N / a	N / a
Kite and Johnson, 1988	QN	To examine the attitudes towards older and young adults	Meta-analysis	All literature on young and elderly people
Lamping <i>et al.</i> , 2000	QN	To assess clinical outcomes of renal dialysis and replacement therapy among patients aged 70 and above	12-month cohort study	221 patients aged over 70 with end-stage renal failure
Lindesay <i>et al.</i> , 1997	QN	To investigate factors affecting the uptake of health and social services by elderly Asian Gujaratis	Interview survey	149 Hindu Gujaratis and 148 whites aged over 65 living in Leicester
Livingston <i>et al.</i> , 1990	QN	To assess prevalence rates of dementia, depression and activity limitation among elderly residents in inner-London	Survey using the Short CARE questionnaire	87.2 per cent of elderly residents of an inner-city electoral area
Livingston <i>et al.</i> , 2002	QN	To examine service utilisation of older immigrants compared with their UK-born counterparts and relate it to health difficulties	Interview survey	1085 people aged over 65 in Islington, London (randomly selected including those in residential settings)

Author, year	Type of paper	Aim of study	Study design	Sample / Participants
Madan <i>et al.</i> , 2001	QN	To investigate age bias among physicians in training in their treatment recommendations for breast-conserving procedures	Questionnaire	116 second year medical students
Majeed <i>et al.</i> , 1996	QN	To investigate age and sex differences in the utilisation of hospital services for ischemic heart disease (IHD)	Mortality and hospital episode data	8278 IHD deaths and 10 808 IHD consultant episodes
Mandelblatt <i>et al.</i> , 2003	QN	To evaluate breast cancer post-treatment quality of life and satisfaction in a national population	Telephone survey	Random cross-section of 1812 Medicare beneficiaries aged 67 and above who were three, four and five years post-treatment for stage I and II breast cancer
Manthorpe <i>et al.</i> , 1993	Review	To look at the current literature on minority ethnic elders and mental health problems	N / a	N / a
Marks <i>et al.</i> , 2002	QN	To describe the demographic and clinical characteristics of patients who are not transported to hospital after an emergency 999 call to East Midlands Ambulance Service	Retrospective review	Data extracted from reports of 500 consecutive non-transported patients
Marwaha and Livingston, 2002	QL	To explore and compare the views of White British and Black African Caribbean older people on depression as an illness, avenues of help and the place of the mental health services	Semi-structured interviews	Purposive sample of 40 older people from White British and Black African Caribbean, half of whom had been depressed

Author, year	Type of paper	Aim of study	Study design	Sample / Participants
McNiece <i>et al.</i> , 1999	QN	To examine socio-economic differences in general practice consultation rates among patients aged 65 years and over	Secondary analysis of data	60 general practices in England and Wales 71 984 people aged 65 and over
Mitchell <i>et al.</i> , 1997	Review	To determine whether subjects older than 75 years are included in the randomised controlled trials of anti-parkinsonian medications conducted during the last 30 years and to identify study characteristics that are associated with the exclusion of patients of advanced age	N / a	N / a
Morgan <i>et al.</i> , 1997	QN	To investigate the perceptions of older people about the significance of symptoms and what action they would take in response to particular symptoms	Assisted questionnaire	33 men and 77 women (67 to 98 years old, mean age 78 years)
Nelson <i>et al.</i> , 2001	QL	Views of frail elderly people on a nurse case managed system in the community	Interviews	11 older people – eight women and three men
Nelson <i>et al.</i> , 2002	QN	To describe the pattern and predictors of service usage, by a representative sample of people aged 65 and over	Interview	1085 people were interviewed at home
Nuckton <i>et al.</i> , 1995	QN	To determine the importance of patient age as a factor in the admission of acutely ill medical patients to critical care units	Questionnaire	Physicians were asked to admit one of two patients to a last available critical care unit bed

Author, year	Type of paper	Aim of study	Study design	Sample / Participants
O'Dea <i>et al.</i> , 2000	QN	To establish the arrangements (including charging) for provision of general practitioner (GP), nursing advice, chiropody, physiotherapy & speech and language services to nursing homes	Telephone survey	Managers of 49 nursing homes
Owens and Batchelor, 1996	QL	To examine assumptions with regard to the use of patient satisfaction surveys	Semi-structured interviews	60 patients from a District Nurse patient population using quota sampling
Palmore, 2001	QLQN	To develop an instrument that can be used to answer three questions: What is the prevalence of ageism? Which types are more prevalent? Which subgroups of older people report ageism?	Survey	Convenience sample of 84 people over 60 years old
Peake <i>et al.</i> , 2003	QN	To report age-related differences in treatment for lung cancer, including case-mix factors and impact on survival	Questionnaire	1652 lung cancer patients
Percival <i>et al.</i> , 2003	QLQN	To investigate the care, support and housing needs of people over 55 with visual impairment	Survey Interviews	400 people across Plymouth, Birmingham and London over 55 with visual impairment
Pond <i>et al.</i> , 1994	QN	To improve the ability of GPs to diagnose depression and dementia compared with standard screening measures	Intervention study, pre-post design with six-month follow-up	Patients and GPs at a retirement village on the outskirts of Sydney, Australia
Reid <i>et al.</i> , 2002	QN	To investigate possible inequities in the use of statins for people with coronary heart disease according to a wide range of social and clinical factors	Cross-sectional data	760 adults with coronary heart disease

Author, year	Type of paper	Aim of study	Study design	Sample / Participants
Rodgers <i>et al.</i> , 2003	QN	To describe the organisation and staffing of specialist hospital based stroke services in the UK	Postal survey	91 consultant stroke specialists
Rogers <i>et al.</i> , 1999	Book	N / a	N / a	N / a
Ross <i>et al.</i> , 2003	QN	To investigate the relative importance that older people attach to waiting lists, surgical complications, junior surgeons when given theoretical choices over options for cataract surgery	Interview survey	194 aged 60 to 84 from general practice register
Shah R <i>et al.</i> , 2001	QN	To examine consultation rates for psychiatric disorder in general practice among patients aged 65 and over; and to examine the effect of socio-demographic factors on consultation rates	Prospective cohort study	Sixty volunteer practices in England and Wales, study population comprised a one per cent sample of the population (502 493 patients)
Shaw <i>et al.</i> , 2001	QL	The aim of the study was to explore help-seeking behaviour in people with urinary symptoms such as leakage, frequency, nocturia and urgency in order to identify barriers to service use	Unstructured, taped interviews	Thirty-one people who either had agreed to treatment as part of an intervention study or who were receiving treatment at a hospital outpatient clinic for their urinary problems took part in interviews
Shaw <i>et al.</i> , 2001	Review	A review of the psychosocial predictors of help-seeking behaviour and impact on quality of life in people with urinary incontinence		

Author, year	Type of paper	Aim of study	Study design	Sample / Participants
Shepperd and Illiffe, 1998	Review	To explore whether hospital at-home services represent an effective way to manage patients compared with in-patient hospital care	N / a	N / a
Smeeth <i>et al.</i> , 2001	QN	To compare three different methods of administering a brief screening questionnaire to elderly people	Randomised comparison within a cluster randomised trial	32 990 people aged 75 and above registered with one of 106 participating general practices
Stark <i>et al.</i> , 1997	QN	Effect of access factors on attenders and non-attenders of the National Breast Screening Programme in a rural area (Islay and Jura)	Questionnaire survey	313 women invited for breast cancer screening
Swift, 2002	Review	To explore issues around the English National Service Framework for older people	N / a	N / a
The Audit Commission, 2000	Report: Forget me not: mental health services for the elderly in London	N / a	N / a	N / a
Tod <i>et al.</i> , 2002	QL	To identify what currently prevents people accessing cardiac rehabilitation in the South Yorkshire coalfields	Interviews	20 people who had been admitted with an acute MI to one of the three acute hospitals in the SYCHAZ area and 15 people who were involved in cardiac rehabilitation

Author, year	Type of paper	Aim of study	Study design	Sample / Participants
Tremellen, 1992	QN	To evaluate the assessment scheme for people aged 75 and above to establish doctors' and nurses' views on the value of the assessment scheme and to seek opinions on elderly assessments	Questionnaire and secondary data assessment	31 565 patients aged 75 and over and all doctors registered with Wiltshire FHSA and practice nurses assessing elderly patients
Turrell, 2001	Review	To explore the literature on whether nursing homes provide a suitable alternative to hospital care for older people	N / a	N / a
Van Essen <i>et al.</i> , 1997	QN	To assess motivating factors of elderly people to comply with influenza vaccination	Survey	Healthy elderly people invited to come for a flu vaccine by their GP
Varekamp <i>et al.</i> , 1998	QL	To explore age rationing in daily medical practice	Observation Interviews	Observations were made at two renal transplantation centres and people professionally involved in decision making about transplantation were interviewed.
Walters <i>et al.</i> , 2001	QL	To explore patients and carers help-seeking behaviour and perceived barriers to meeting unmet needs	Interviews	31 patients and 11 carers
Wilkieson <i>et al.</i> , 1996	QN	To determine if three years' experience had resulted in standardisation of the way in which health assessments for patients over 75 are carried out	Questionnaire	Principal partners from all 55 general practices in the Forth Valley Health Board Area
Williams, 1984	QN	To determine the number of people over 75 years who had no contact with primary care and to examine their medical and social characteristics	Survey	Patients over 75 from two urban general practices

Author, year	Type of paper	Aim of study	Study design	Sample / Participants
Wolf and Li, 1999	QN	To determine the factors that influence elder abuse reporting rates	Survey	Data from 27 geographical areas in Massachusetts served by protective services agencies. Number of reports of elder abuse per 1000 persons aged 60 years and above received during 1994
Zung <i>et al.</i> , 1993	QN	To estimate the prevalence of depressive symptoms in primary care patients across the United States, and to describe the patient characteristics that may be associated with increased likelihood of them	Survey	75 858 patients who visited one of 765 participating primary care physicians between February and September 1991

Appendix 7A Studies included in synthesis of literature on gender and access to healthcare

Author, year	Type of paper	Aim of study	Study design	Sample / Participants
Annadale and Clark, 1996	Review	What is gender? Feminist theory and the sociology of human reproduction	N / a	N / a
Bacchus <i>et al.</i> , 2003	QLQN	To explore help-seeking and to assess the psychological health of women who have experienced domestic violence	In-depth semi-structured interviews Questionnaire	Purposive sample of 16 women selected during post-partum period
Baider and Bengel, 2001	Review	To research outcomes and theoretical issues of gender differentiation in illness behaviour and psychological behaviour of cancer patients and their partners	N / a	N / a
Baker and Middleton, 2003	QN	To examine changing inequality in the coverage of cervical screening and its relation to organisational aspects of primary care and to inequality in cervical cancer incidence and mortality	Retrospective time trends analysis	Women aged below 35 and 35 to 64 were selected from health authority populations
Barker <i>et al.</i> , 1990	QN	To identify the pattern of overall help seeking and coping in the UK and to examine whether there are any differences in help-seeking and coping behaviour with respect to demographic variables or level of psychological complaints	Interview	1040 adults with a mean age of 45 (498 men, 542 women) quota sampled from the general population

Author, year	Type of paper	Aim of study	Study design	Sample / Participants
Bebbington <i>et al.</i> , 2000	QN	To examine how people with neurotic disorders receive professional evaluation, and how this is affected by clinical and socio-demographic differences	Symptom score ADL deficit score and demographic variables	Data from the National Survey of Psychiatric Morbidity involving over 10 000 subjects
Bendelow G, 1993	QN	To explore the relationship between perceptions of pain and the social characteristics of the individual, with a focus on the role of gender in the process, with an emphasis on the meaning of 'lay' understanding of the phenomena of pain	Questionnaire	107 men and women agreed to fill in the questionnaire
Bentham <i>et al.</i> , 1995	QN	To identify and compare the factors affecting non-response before and after the introduction of the new cervical cytology screening programme	Population study	Cohort of women aged 35 to 64 receiving invitations between Nov 1988 and October 1989. 72 practices included in the study
Bird and Rieker, 1999	Review	A discussion of why gender matters: an integrated model for understanding men's and women's health	N / a	N / a
Bowling and Bond, 2001	QN	To evaluate the costs, processes and benefits of specialists' outreach clinics held in GPs' surgeries, compared with hospital outpatient clinics	Questionnaire	Thirty -eight outreach clinics, compared with 38 matched outpatient clinics as controls, covering 14 hospital trust areas across England
Bunce, 2000	Review	To identify health problems of homeless men and highlight changes in health services needed to meet their health needs	N / a	N / a
Bury M, 1991	Review	The sociology of illness: a review of research and prospects	N / a	N / a

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Cameron and Bernardes, 1998	QN (QL)	To explore 'hidden' health disadvantages in men, drawing on a study of prostate ill health	Postal survey In-depth interviews	Men who had contacted the British Prostate Help Association
Campbell and MacDonald, 1996	QN	To evaluate two drop-in centres located in a local community centre and a primary care clinic, staffed by health visitors, social workers and staff from the community education dept	Survey	Community survey involving a random sample of 370 women taken from the community health index and a register of attendance. 265 women were successfully interviewed (72 per cent response rate)
Chapple <i>et al.</i> , 2002	QL	To explore attitudes of men with confirmed or suspected prostate cancer to testing for prostate specific antigen	Interviews	Purposive sample of 52 men with suspected for confirmed prostate cancer
Charturvedi and Ben-Schlomo, 1997	QN	N / a	N / a	N / a
Chaturvedi <i>et al.</i> , 1997	QN	We investigated whether south Asians and Europeans interpret and act upon anigal symptoms differently	Questionnaire	Randomly selection of 2000 people from general practitioners' (family physicians) lists in London, UK, to receive a questionnaire
Corne,y 1990	QN	To explore the variables associated with GP consultation and help seeking behaviour for minor illness among women and men	Postal questionnaire	Low and high attenders aged between 20 and 45 (without major life threatening illness) in one general practice in middle class area of London

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Courtenay W, 2000	Review	A social constructionist examination & review of men's health beliefs & behaviors & gender differences in social experiences & cultural representations of gender & media & health care system influences	N / a	N / a
Cunningham-Burley <i>et al.</i> , 1996	QL	To document men's perceptions of urinary symptoms and to increase their understanding of health-care-seeking behaviour	Semi-structured interviews Questionnaire	Stratified random sample of men aged 40 to 79 drawn from age – sex register of a health centre
Department of Health, 1999	Report: Saving Lives: Our Healthier Nation	N / a	N / a	N / a
Department of Health, 2000	Report: The NHS Plan	N / a	N / a	N / a
Department of Health, 2001	Report: Tackling Health Inequalities	N / a	N / a	N / a
Dixon-Woods <i>et al.</i> , 2001	QL	To explore women's accounts of choosing and using specialist services for sexual health	Semi-structured interviews	37 women screened for chlamydia trachomatis attending genitourinary medicine and family planning clinics in East Midlands

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Dong <i>et al.</i> , 1996	QN	To examine whether the sex difference in access to cardiac surgery reported using routine health service data is observed in a nationally representative sample of English adults	Survey	Stratified random sample of 32 378 people aged 16 and above living in private households who participated in the 1993 and 1995 health surveys for England. This constituted 1708 subjects (6.3 per cent of all men and 4.4 per cent of all women) who reported a history of either angina or heart attack diagnosed by a doctor who were asked about impending surgery
Doyal, 2000	Review	To argue that gender equity in health is a legitimate goal of health policy and that the health of women (and maybe men) could be improved as a result	N / a	N / a
Doyal <i>et al.</i> , 2003	Review	To review the case for including gender issues within the wider government Modernisation Agenda with reference to health	N / a	N / a
Elderkin-Thompson and Waitzkin, 1999	Review	What is known about gender differences in communication and explores the extent to which those differences might be implicated in the reported gender bias in clinical diagnosis and treatment	N / a	N / a
Emslie <i>et al.</i> , 2003	QL	To explore lay understandings among respondents from 'ordinary' families	Semi-structured interviews	61 men and women sub-sampled from a large community-based study

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Emslie <i>et al.</i> , 2001	QL	To explore the importance of gender in lay beliefs about heart problems	Semi-structured interviews	61 men and women
Fenton K, 2000	Review	Screening men for <i>Chlamydia trachomatis</i> infection: have we fully explored the possibilities?	N / a	N / a
Free <i>et al.</i> , 2002	QL	To explore young women's accounts of their use and non-use of emergency contraception	In-depth interviews	30 women aged 16 to 25; participants from socially deprived inner city areas were specifically included
Good <i>et al.</i> , 1989	QN	To examine both attitudes towards the male role and factors associated with men's gender role and the conflict for their relation to men's help-seeking attitudes and behaviour in respect of use psychological counselling	Battery of attitudinal scales	401 male undergraduates (average age 19.3 years. 91.5 per cent Caucasian) enrolled in introductory psychology courses at a large midwestern university in 1986
Hart and Lockey, 2002	QL	The project addresses inequalities in health from the point of view of new directions in midwifery education and practice	Case studies Focus groups In depth interviews	Midwifery education and practice and service provision in three 'very different' parts of England
Hurdle, 2001	Review	To discuss the role of social support in health with a particular focus on health promotion efforts with women that incorporate the elements of social support	N / a	N / a
Karasz and Anderson, 2003	QL	To study the experiences of women diagnosed with vaginitis	Semi-structured interviews	44 women in New York City, USA attending a Family Health Centre

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Khoury and Weisman, 2002	Review	To argue that 'gender sensitivity' holds the greatest potential for improving the health of both men and women. The article focuses on potential for understanding women's health	N / a	N / a
Kupek <i>et al.</i> , 2002	QN	To identify factors that are predictive of late initiation of antenatal care in England and Wales.	Retrospective survey	The project involved 20 771 women with a singleton pregnancy who delivered a liveborn or stillborn baby between 1.8.94 and 21.7.95
Lockyer and Bury, 2002	Review	To critically examine the implications for women of a gendered construction of coronary heart disease (CHD)	N / a	N / a
Macintyre <i>et al.</i> , 1999	QN	To evaluate the assumption that women's higher rates of morbidity result in gender differences in the ways symptoms are perceived, evaluated and acted upon	Survey	Two adult cohorts (in late 30s and late 50s in 1991) of the West of Scotland
Majeed and Cook, 1996	QN	To investigate age and sex differences in the utilisation of hospital services for ischaemic heart disease (IHD)	Mortality and hospital episode data	8278 IHD deaths and 10 808 IHD consultant episodes
Majeed <i>et al.</i> , 1994	QN	To determine the importance of patient variables and practice factors in explaining the variation in cervical smear uptake rates	Cross-sectional study	128 practices in Merton, Sutton and Wandsworth

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Martin <i>et al.</i> , 1991	QN	To study patients' perspectives of why they consulted the doctor, how ill they thought they were, and what happened in the consultation. To compare patients' perspectives before and after the consultation and to compare these perceptions to those of the doctor	Questionnaire	1972 patients across all ages and social class from general practices in Bedfordshire (three) and Hertfordshire (one) plus the GPs from these practices
McQueen and Henwood, 2002	QL	To consider two young men's use of language to highlight the cultural ideas and concepts they draw upon to describe the experiences which led them into the mental health system	Case studies Two open-ended interviews with each participant	Accounts of two young men (actual age not given, but between 14 and 17 years) in receipt of psychiatric services in adolescent unit in Wales
Men's Health Forum, 2002	QL	To explore ways in which young men deal with their emotions; explore with agencies how they target and work with young men; identify any mismatch between young men and agencies; develop strategies that will impact on young men's help-seeking behaviour and in turn on the level of male suicides	25 interviews	25 interviews, interviewees from Newham, East London aged between 15 and 22 years. Ten agencies were interviewed about their provision
Miers, 2002	Review	To develop an understanding of possibilities for gender sensitive care through exploring concepts of gender and gender sensitivity and through reviewing relevant knowledge about gender and health	N / a	N / a
Moller - Leimkuhler, 2002	Review	To identify from the literature barriers to help-seeking by men, particularly with reference to depression	N / a	N / a

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Moynihan, 2002	Review	To argue for a 'gender relational' approach to understanding cancer and cancer care	N / a	N / a
Petticrew <i>et al.</i> , 1993	QN	To determine whether the sex differences in access to cardiac surgery observed in the US exists in the UK	Retrospective analysis of routinely collected data	8564 patients discharged from hospital with principle diagnosis of CHD (MI, angina or chronic ischaemia) in 1987 – 88 in SW Thames region (36 per cent women) and 15 243 discharges in NW Thames region in 1990 – 91 (35 per cent women)
Raine, 2000	Review	To investigate the evidence of gender bias (defined as care provided independently of clinical need) in use of specialist services by critically appraising the literature	N / a	N / a
Raine <i>et al.</i> , 2003	QN	To demonstrate the importance of measuring both the horizontal and vertical components of equity in order to examine whether patients are receiving the health care that they need	Prospective data collection	1064 patients under 70 years
Richards <i>et al.</i> , 2000	QN	To describe prevalence of angina and chest pain in men and women in socio-economically contrasting areas; proportions of men and women who present with symptoms and who receive preliminary diagnosis of CHD, to assess effects of gender and deprivation	Questionnaire	Random general population samples from contrasting SES areas surveyed using Rose angina questionnaire. (n=1107 men and women aged 45 to 64)

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Richardson and Raibee, 2001	QL	To explore the experiences, feelings, attitudes and beliefs of a sample of young men from Corby about their use of health services	Focus groups	14 Males age 15 to 19, including four attending a school exclusion project
Riska E, 2003	Review	Gendering the medicalisation thesis	N / a	N / a
Rogers <i>et al.</i> , 1999	QL	To investigate patient's perceptions and experiences of rationing and the potential impact this might have on people's use of services	Interviews	Cross section of 53 primary care service users
Sabo D, 2000	Review	Men's Health Studies: Origins and Trends: A development of men's health studies in the United States	N / a	N / a
Saltonstall, 1993	QL	To explore embodied aspects of health (as distinct from illness / sickness) in relation to gender	Convenience sample Qualitative interviews	Men and women (white, urban, middle class) aged 35 to 55 (n=21)
Schoenberg <i>et al.</i> , 2002	QL	To explore factors and circumstances that may shape CHD time to treatment	In-depth interviews and focus groups	40 middle age and older women living in Kentucky, USA, half with diagnosed CHD and half with chronic conditions considered to be risk factors for CHD
Shaw <i>et al.</i> , 2001	QL	To explore help-seeking behaviour in people with urinary symptoms such as leakage, frequency, nocturia and urgency in order to identify barriers to service use	Unstructured, taped interviews	Thirty-one people who either had agreed to treatment as part of an intervention study or who were receiving treatment at a hospital outpatient clinic for their urinary problems took part in interviews

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Stark <i>et al.</i> , 1997	QN	To measure the effect of access factors on attenders and non-attenders of the National Breast Screening Programme in a rural area (Islay and Jura)	Prospective postal questionnaire survey Interviews using a structured questionnaire	313 women invited for breast cancer screening
Sword, 1999	Review	Critical examination of the notion of barriers as conceptualised in the literature	N / a	N / a
Tudiver and Talbot, 1999	QL	To report on family physicians' perspectives on why men do not access the health system for medical problems	Focus groups	Family physicians (n= 18) in Canada, sample randomly selected from a master list of practitioners from University of Toronto Faculty of Family and Community Medicine
Ubido <i>et al.</i> , 2002	QLQN	To explore inequalities of access to healthcare of women who are deaf	Group discussions	13 women who were hard of hearing (all over age 65) and 14 who were deaf sign language users (aged 20 to 50 years), backed up by survey evidence (37 per cent RR)
Vlassoff <i>et al.</i> , 2002	Review	Definition and discussion of gender and gender related concepts including equity and equality. Discussion of why gender should be key to discussions re health	N / a	N / a
White R, 2002	Review	To examine social and political aspects of men's health	N / a	N / a

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Wyke <i>et al.</i> , 1998	QN	An examination of whether in response to the same symptoms of minor illness, women reported a greater propensity to consult a GP than men	Interview	Respondents taking part in the West of Scotland Twenty-07 Study (853 aged 39 and 858 aged 58)