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The new genetics and health: mobilizing lay expertise

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Public understanding of the new genetics is often criticized in discussions about the social and ethical issues the new genetics raise. In this paper we challenge the "deficit model" evident in this dominant discourse, and offer a constructivist approach. We explore lay expertise about the new genetics, presenting an analysis of data from ten focus group discussions with a range of lay people. After distinguishing four different types of knowledge lay people hold—technical, methodological, institutional, and cultural—we go on to consider how lay people's mobilization of this "stock of knowledge" is influenced by social location and social context, exploring in particular interviewees' perceptions of relevancy. We conclude that identifying lay people as expert in, rather than ignorant of, the way genetics may shape their lives is a fundamental first step in moving toward greater lay participation in policy discussions and, ultimately, decision making about the new genetics and health.

Introduction

The new genetics is a body of knowledge and techniques concerned with human heredity that has arisen since the invention of recombinant DNA. The search for the genetic component of a range of diseases, behaviors, and traits is now well underway. Genetic testing and screening is currently available for serious clinical conditions in Britain: for example, in some areas, pre- and post-natal testing is available for cystic fibrosis, and presymptomatic testing is available for adults with a family history of conditions such as Huntington's disease or Marfan syndrome. Research is also being conducted that could potentially develop presymptomatic genetic testing for more common, and more complex, disorders such as cancer and heart disease. Behavioral genetics is also blossoming once more, with research taking place into the genetics of IQ and homosexuality, to name two of the most controversial areas.

This explosion of genetics research coincides with a considerable discussion about the public understanding of science in general, and the new genetics in particular. Traditionally, this is based upon a "deficit model" wherein professionals bemoan the public's ignorance of, and lack of interest in, science. However, a strong critique of this position is emerging from the sociology of science,[1] in which it is argued that many different groups make up the public—and that their knowledge is not simply a matter of technical detail, but involves a broader understanding of scientific practice and institutions. The implication of this position is that we should treat the public's views about, and understanding of, the new genetics seriously—as the recent Wellcome Trust meeting, "Human Genetics: The People Decide" and our own Science Festival Event, "The Public Image of the New Human Genetics" both

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stressed.[2] This could also lead to greater public involvement in decision-making about the new genetics, through, for example, the Human Genetic Advisory Commission's taking account of the lay public's views in formulating guidelines and policy. Yet, many questions remain about which members of the public should be involved in these discussions and in what capacity. Should it be a representative sample, or one composed of people with direct experiences of genetic conditions? Should they be educated before participation? And should they come together to vote on specific policy questions, or discuss and evaluate policy via involvement in commissions and committees?

In this paper we examine the "deficit model" of public understanding and the constructivist critique of that position in relation to the new genetics. We then develop the constructivist model to provide an account of what we call "lay expertise" about the new genetics and health. After providing details of the methods we used to investigate lay expertise, we outline four different types of knowledge which people have about the new genetics—technical, methodological, institutional, and cultural. We then continue to explore the social embeddedness and relational aspects of lay people's knowledge, examining how differences in their social location and social context affect their accounts and highlighting interviewees' perceptions of the relevancy of genetics to their lives. In exploring these issues we contrast the setting of the focus groups with participants' accounts of the role of lay people in the clinic and the policy-making arena. We conclude by discussing how to mobilize lay expertise about the new genetics in order to move toward greater lay participation in policy discussions and decision making about the new genetics and health.

From the deficit to the constructivist model of the public understanding of genetics

Despite concern about the "new eugenics,"[3] the application of the new genetics in health care and the availability of genetic information in the wider public sphere (e.g. to the insurance industry) is subject to minimal regulatory controls. Informed public debate, based on sound scientific knowledge, is often cited as an appropriate regulatory brake on potential "abuse" of human genetics. For example, the Nuffield Council on Bioethics Report relies heavily on improvements in public understanding to safeguard against eugenic abuse:

> In a democracy, public understanding of human genetics should serve to create awareness of the dangers of eugenics and of the possible stigmatisation of those carrying or suffering from genetic disorders. We recommend the need for improving public understanding of human genetics should be borne in mind in any review of the National Curriculum and in the work of all public bodies concerned with the public understanding of science.[4]

In much of the governmental and medical or scientific literature about the new genetics, concerns are raised about the state of public understanding of science—in other words, about the public's ignorance. As Harper has noted:

> Future developments should be discussed and debated openly, involving the public as well as professionals. A major problem in carrying this out in Britain, as in most countries, is the poor state of education of the public regarding science in general and genetics in particular.[5]

Professionals' concern about the public's lack of knowledge about genetics is part of a much wider trend of institutionalization of the public understanding of science as proper subject matter for scientists. This can be understood as one method of bolstering the authority of science at a time when public skepticism and mistrust is high in our "risk

society."[6] Professionals downplay the public's mistrust by saying that it is unsurprising given popular ignorance of scientific facts. Public resistance to the new genetics is effectively subverted by scientists' calls for further education of the public in scientific matters. As Wynne[7] argues, it is only by engaging in research which reflexively problematizes "science as well as publics," that "potential forms of constructive public engagement with science" can be developed.

Turney[8] has noted that much of the work on the public understanding of genetics has paid little attention to why people might want to understand genetics or what it is they might wish to know.[9] Just as we must explore the ways in which scientists' accounts of lay understanding of science are a product of their professional interests in authority and autonomy, it is also important that we explore the ways in which social location shapes lay understanding of and engagement with science. Knowledge and understanding are complex, socially embedded activities.

Parsons and Atkinson[10] and Lambert and Rose[11] have begun this unpacking of lay understanding in their analysis of the views of members of families with hereditary conditions. Parsons and Atkinson (drawing on Schutz[12]) have emphasized the way in which people's "zones of relevance" determine their uptake of genetic information and services and Lambert and Rose have illustrated that people function with a "good enough" level of knowledge about genetics when affected by a hereditary condition and develop "situated understandings of medical science through intensive experiences of a specific domain."[13]

Although these challenges to the portrayal of medical knowledge as disembedded facts to be absorbed by the patient are to be welcomed, the focus within these approaches on specific "at-risk" groups leaves unchallenged the notion that people who are not "at-risk" remain ignorant. Moreover, the focus on people's accounts of the meaning of genetic information, although bringing in other types of understanding (about historical shifts in therapeutic practices, for example), leaves other layers of understanding about the new genetics unexplored. Macintyre[14] has called more generally for a scientific understanding of the public where attention would focus on the array of prior knowledge and experience present in different social groups, arguing that much that the new genetics raises is not new, and the uptake of knowledge and its application will be affected by this existing social context. Construing this as a call for a more *interpretive*, as opposed to *positivist*, approach to understanding of lay knowledge and views, we develop the following analysis.

First, drawing on the work of Wynne, we broaden the focus on lay people's understanding of technical details about their condition to consider their wider knowledge about the new genetics. Wynne[15] has emphasized that knowledge about the methods, institutions, and social implications of science also contributes to public understanding of science. Following Michael[16] we also explore the relationship between technical competence and sophisticated understanding of science. This wider knowledge can be typified as a "stock of knowledge"[17] to be drawn upon and contributed to in situationally and biographically relevant ways. What counts as valid knowledge is widened within this perspective and knowledge production and expression are understood as processes, constructed through social relations.

We then consider more fully the differences in interviewees' accounts with respect to social location and social context. We investigate further how the relevance of the new genetics to people's lives shapes these accounts. Wynne, Michael, Parsons, and Atkinson and Lambert and Rose have already shown that people's uptake of scientific knowledge is related to their perception of its relevance to their lives. Wynne and Michael also argue that relevancy is often chronically problematic because people lack the social opportunities to engage with scientific information. In other words, science is relevant to a person's life

when they think that it directly affects them and when they feel they have the opportunity to influence the way in which it affects their lives.

We explore the ways in which the new genetics becomes relevant to people in different social locations and in different social contexts. This involves a focus on people who are directly affected by hereditary conditions, but it also includes other people who are not directly affected, and who might be motivated to make sense of the new genetics for other reasons (depending on their social location and social context). We therefore broaden the traditional focus on patients and affected groups to a wider range of lay people with different levels of interests in and experiences of genetics and health and contrast their accounts in the focus groups with their accounts of the clinic and the policy-making arena.

Methodology

In order to explore lay people's views about genetics, we adopted a qualitative approach, which allows for a depth and breadth of detail and engages with the social context of knowledge. The use of surveys to access public knowledge is commonplace, but offers highly circumscribed results. As Wynne notes, "The survey method by its nature decontextualises knowledge and understanding and imposes the assumption that their meaning exists independently of human subjects interacting socially."[18] We chose focus groups because we wanted to gain an insight into the negotiations in people's accounts of their attitudes, beliefs, and values, and because the techniques of brainstorming and focusing on particular topics or vignettes allows for the articulation of a breadth of views as well as detailed exploration of relevant issues. We also felt it would be difficult to generate discussion at a personal level, and that a more general discussion around the options in hypothetical scenarios would be a more appropriate way to discuss sensitive issues such as abortion and stigma, which are likely to be raised in discussions of the new genetics. We wanted to include, as research participants, a broad range of people, thus moving away from the focus on clinic-based samples that has dominated much of the in-depth work in this field.[19] The participants were a diverse mixture and not a representative sample of the population. We nevertheless remained mindful of how people's social location—age, class, sex, occupation, and experience of health care and science more generally—was likely to shape their accounts about genetics. In general the groups were pre-formed, and participants were familiar with at least some, if not all, of the other people in the group. The reasons for this were based on a mixture of pragmatism and a deliberately flexible and open research design. In our experience, pre-formed groups are more easily accessible and more relaxed about discussing sensitive and complicated topics than groups of strangers.

Here we draw on data from ten focus groups carried out in central Scotland from February to July 1996. This is part of a larger research project in which interviews have been carried out with scientists and clinicians working on the new genetics, and written media coverage and journalists' views have been analyzed. In the recursive process typical of qualitative research, we used this analysis to inform the collection of more data using focus group techniques, which will provide further analyses. Anne Kerr led the focus group discussion in each case, and either Sarah Cunningham-Burley or Amanda Amos was also present, to take notes and ask follow-up questions where appropriate. The group discussions were tape-recorded and transcribed for analysis.

The focus groups, averaging about six participants, fall into three broad categories. The first set of groups were of a general nature, and the research team was initially unaware of any participant having direct experience of genetics or a genetics-related health concern. There was a mixed-sex group of working-class elderly people; a group of working-class

new mothers; a mixed-sex group of secondary-school teachers, one of whom was a science teacher; and a working-class youth group (of six girls). The second set had some experience of a genetics-related health concern: this set included a group of mainly middle-class women with personal experience of breast cancer; a mixed-sex group of working-class people with experience of heart disease either directly or in the family; a mixed-sex, mainly middle-class, group of people with a range of disabilities; and one mixed-sex group of nurses. The third set had direct experience of a genetics health concern, and involved a mixed-sex group of mainly middle-class relatives of children with cystic fibrosis and a mainly middle-class group of women who had undergone terminations as a result of diagnosis of fetal abnormality. The groups concerned with breast cancer, heart disease, cystic fibrosis, and terminations due to fetal abnormality were support groups. Group categories were not rigid, demonstrating the difficulties inherent in generalizing about people's previous experiences and knowledge in this area. For example, one teacher had taught genetics, and not all the people in the group with disabilities had experience of an inherited condition.

A mixture of questions on general knowledge about, and views of, genetics, inheritance, and genetic testing were followed by a set of vignettes that explored specific examples of prenatal and pre-symptomatic testing. The analysis was based on careful and repeated readings of the transcripts which led us to identify and agree on significant themes in lay people's accounts: their sources of knowledge and expertise; issues of choice; progress and reliability of the new genetics; views of "public understanding" and professional expertise; responsibility; nature/nurture; and eugenics. The transcripts were then "cut and pasted" into separate files around these main themes. These files were then read through and broken down into sub-themes, while retaining an analytical focus on the interview as a whole, and a recognition of the diversity present in the discussions. We use extracts from the interviews to illustrate the analytical themes we explore. Because the data are drawn from focus groups, the extracts include contributions from several participants and are therefore often quite lengthy. Short excerpts would not provide sufficient detail about the different aspects of people's understanding of the new genetics or about the influence of their social location and social context.

Lay understanding

The groups we interviewed displayed several types of knowledge about the new genetics, and in our analysis of this we elaborate on previous classifications where, in addition to technical knowledge, understanding based on science's institutional characteristics, and on its methods have been recognized.[20] This stock of knowledge is made apparent through the process of making sense of, or interpreting, the new genetics.

Technical knowledge

The participants had a basic technical knowledge of genetics, generally centered around notions of heredity of physical characteristics and disease. This technical knowledge was, not surprisingly, greater and more accurate in groups where participants had experience of genetic conditions, either directly or indirectly as the following quote demonstrates:

G7R38 I had a friend who had two PKU children. It was quite a devastating genetic problem to have. You know just by chance, she and her husband meeting up and marrying, and having these two children, it was quite a devasting. . . the older one was quite badly affected because he was about a year or more

> when they discovered what was actually wrong with him and the proteins had caused brain damage by then and he's got quite serious behavioral problems. So if they could eradicate things like that. Not try to make a master-race but horrible things like that. If they could try to do something about it and change, perhaps. . . add something. They are talking about adding to the genes to try and help. Like with cystic fibrosis what they are trying to do. . . not forbidding a couple to marry but to try and help them.

In other groups, technical knowledge relied on vaguer notions of genes and inheritance. It is interesting to note that in most cases, the groups discussed issues around the new genetics and health in a sophisticated manner, without need of high levels of technical competence. When technical issues were important in clarifying the discussion, the interviewer or other participants could provide the details (for example, about the statistical risk of a fetus having cystic fibrosis when both parents are carriers). At other times, discussions were not hindered by technical inaccuracies, as the following example from the interview with a support group for people with heart disease and their families in a working-class area of Edinburgh illustrates:

AK You mentioned Nazi Germany and the "master race". . . I wonder what you think about some of the genetic research that is getting done—if you think that the scientists are interfering with nature or they are going too far or that. . .

G4R59 I think they definitely are.

G4R60 Yeah. I think the idea of that mouse on the telly with a human ear or what they are doing up in Dalkeith with the sheep that are being fed human genes. They are going a little far. If they want to go an' investigate the DNA system and find oot that OK somebody's gay because there is a little slip-up in the XY hormone, we can do an injection and fix that, or a kid's going to be born mongoloid, rather than abort we may be able to find a way that we can actually sort the gene out. We are getting to the part with genetic engineering if somebody is going to get a deformed child then they just get rid of it and say "right the next one that you produce will be". . . There is always the fear in genetics that somebody comes along and tries to build the superman.

G4R61 Too many supermen would make an awful world.

In this example, participants are discussing "where to draw the line" with genetic research and technology—a frequent theme in the focus group interviews. The discussion concerns the acceptability or otherwise of research and clinical practice that is actually taking place: genetic engineering of human and animal DNA; cloning; prenatal diagnosis; gene therapy; and research into the genetics of human behavior. In essence, the sophistication of the discussion is not compromised by the inaccuracy of some of the technical details involved—the sheep were not "fed human genes" and hormones or flaws in the sex chromosomes (X and Y) are not involved in geneticists' (current) accounts of the genetics of homosexuality. While we would not wish to suggest that technical competence is irrelevant to sophisticated understandings of the new genetics and health, we do wish to stress that its role should not be over-emphasized. Instead, our research suggests that we should recognize that lay people can address complex social and ethical questions without a full and detailed understanding of the technical processes involved. Moreover, a focus on technical knowledge deficiencies obscures the other aspects of lay people's knowledge—aspects which we now go on to discuss in more detail.

Methodological knowledge

As with technical knowledge, knowledge about the methods of science was not always strictly accurate, but study participants displayed a general awareness of methodological issues, particularly around the fallibility of testing, the iatrogenic effects of prenatal testing (for example the risk of miscarriage associated with amniocentesis), and the difficulties associated with scientific proof. This knowledge about the methods of science cannot be clearly distinguished from technical understanding, in the same way that knowledge itself cannot be understood as apart from its production. For example, the following excerpt is from a discussion about nature and nurture that took place among a group of secondary school teachers in Edinburgh. They assessed the difficulties in reaching conclusions from the available evidence in genetic research by drawing on their knowledge and experience of teaching children from the same families:

G3R126 So what about the family with the four children and obviously presumably the genetics are similar and,

G3R127 One of them's a rogue.

G3R128 . . . and yet a couple of them turn out to be quite bright and normally socialized people and a couple end up to be totally anti-social [with] criminal tendencies. . .

G3R129 Well, that is again hereditary overtakes nurturing, that proves my case, because the genes that interact between male and female and link up. . . you've just proven my case. . . the genes have taken over and not the nurturing.

G3R130 Because if they all had the same. . .

G3R131 Because they've all had the same nurturing.

G3R132 You can't say they've all had the same nurturing 'cause they're all [at] different places in the family, some are boys, some are girls. . . I just don't think it's as simple and I think we do disservice to, to try and simplify it to that level. . . I accept a large part of what you're saying but I don't think it's as simple as that, I don't think you can say these two people have been brought up in exactly the same way.

G3R133 Even within one family. You couldn't say within one family. . .

G3R134 I mean, without doing it as a scientific experiment, you couldn't ever put that to the test, you couldn't say, well here's a control, here's, you know. . .

G3R135 Well, they have, they have done one. . .

G3R136 They have done.

G3R137 . . . where they take, you know, identical twins who have been split up and adopted by separate families and then looked at them.

G3R138 And the conclusion?

G3R139 No. (laughs). . .

This discussion summarizes important debates about the methods of studying the influence of nature and nurture on behavior, specifically, the ability to "measure" the influence of genetics on an individual's behavior and the equal plausibility of contrary explanations for behavior. Technical knowledge, about nurturing in particular, is clearly a feature of this discussion about methods, for example knowledge about the "pecking order" of siblings and its effects on personality.

Institutional knowledge

Participants also demonstrated knowledge of the institutional aspects of science and medicine that are relevant to the new genetics. Discussion here was about competition and cooperation among scientists; sources of funding, especially the relationship between the new genetics, pharmaceutical companies, and government; and the relationship between geneticists and the media. For example, a group of elderly people from a working-class area of Edinburgh discussed their lack of influence on genetic research:

AK Do you think that you have got enough say in the kind of research that gets done?

G2R296 No. (General agreement among other members of the group.)

G2R297 No.

G2R298 We never ever have had.

G2R299 We have never ever had any say in any kind of. . .

G2R300 They give you a few details but they never go into it in depth.

G2R301 You will never get to know the full details.

G2R302 There is too much secrecy.

AK Why is there secrecy?

G2R303 So that we dinnae ken what they are daein'.

G2R304 Everything is put in Latin so you canny understand it anyway.

G2R305 Even the prescriptions.

G2R306 They dinnae want ye to know what they are up to. Like the Government, that shower.

G2R307 Well when it comes to cancer. . . they have been doing it for years and years and they have had one or two breakthroughs but they still need money, money—it's money that's the root of everything.

G2R308 Do you no' think there is an awful lot of waste of money in research?

G2R309 Possibly, yes.

G2R310 It think it would be better putting it into the practical side of it.

G2R311 It's very difficult to judge, isn't it. . . .

G2R312 I mean there is that many different cancer researches. Why can't they amalgamate into one worldwide research fund. You've got the Imperial one and another one. I get letters from them so I ken what I am talking aboot.

G2R313 Aye there's Cancer Research and Imperial Cancer Research.

G2R314 Aye there's Marie Curie and. . .

G2R315 That's a good idea. . . they should put research all into the one building and keep them all in the one hall.

G2R316 Aye, that's it.

G2R317 The right hand telling the left hand. . .

G2R318 The only thing is that if somebody comes up with something there's somebody comes with something against it.

G2R319 But it could be worldwide. . . Concentrated in one place where all these clever men or supposedly clever men are all working on the actual same research.

G2R320 Well I think in a way especially between Cancer Research and Imperial Cancer Research they do. . .

G2R321 What together?

G2R322 Well they print papers and the other ones see it and they get the knowledge from that, [and it's] the same back the way.

G2R323 But I am talking aboot. . . work in the same laboratory.

G2R324 Well everybody works different.

G2R325 Oh aye, in research.

G2R326 And they've got different opinions.

G2R327 It doesn't mean that they are all working in one big place and they are all in different sections.

G2R328 But there is always this possibility that [the] one that discovers it will want to get the [credit].

G2R329 Aye and the other one stealing it from them. They are trying to make oot that Fleming didnae discover penicillin now, that an American did the work on it. Did you read that?

G2R330 I seen that.

G2R331 Yes.

G2R332 It was on television last week.

This conversation draws on experience with general practitioners and knowledge gleaned from the media. The issues covered are: the role of esoteric knowledge in maintaining professional power; the pros and cons of funding basic and applied research; the relations between scientists, in particular the processes whereby knowledge "advances"—for example, the publication procedure and peer review, international competition, and government funding. This is all from a group of people with no formal science education or direct contact with the scientific profession. Once more, completely accurate knowledge about the technical, methodological or institutional details is not necessary for the expression of opinions about these fundamental features of the scientific enterprise—opinions that are pertinent, critical, and inherently sociological.

Cultural knowledge

The understanding of the new genetics that the groups we interviewed demonstrated also involved what we call "cultural knowledge"—in other words, knowledge not specifically about genetic science or its institutions, but concerning the wider social and cultural context in which these are located.[21] As the new genetics is particularly pertinent to health and disability, typically this took the form of understanding about stigma and discrimination against people with disabilities, and specific knowledge about family histories, for example:

AK Do you think then that there is a kind of, because these tests are there, that there is a kind of pressure on people to go ahead and have them. . .

G4155 Well the only time that I would ever have considered having a test was if I had fell pregnant over the age of 40.

AK Uhuh.

G4156 Prior to that, no.

G4R157 Well I think it's a very special breed of person that can have a Mongoloid child, right, God rest them but I mean, if my child had been born Mongoloid he wouldn't have been aborted or put down, there's no way. He would have been loved just the same but I would have always felt jealous of other people that had normal children I think. People are always kind to Mongoloid children, they are awful loving children, but. . . I don't know really. . .

This discussion shows an understanding of the way in which attitudes to people with disabilities in our society may be related to the provision of prenatal testing for certain disabilities. An understanding of the processes of government was also part of this wider context. For example, participants drawn from a youth group (including young people and youth workers) from a working-class area of Edinburgh discuss their level of influence on genetic research:

AK . . . I'm interested in how much of say people think they have about what genetic research gets done and what tests are offered. . . who would decide about what tests get offered to people and if. . . it's OK to do research. . . Who do you think. . . decides about that? Do you think you've got any say in it? No.

G9R344 Nut.

G9R345 A lot of people are. . .

G9R346 We've no goat enough money to say how it goes and 'aw that.

AK Yes.

G9R347 Do you think if you knew more about it you could have more of a say? [youth worker]

G9R348 Nuh.

G9R349 You're still. . .

G9R350 'Cause we're just bairns.

G9R341 People dinnae listen to you though.

AK Uhuh. Who is it up to then to make sure that bad things don't happen?

G9R352 The Government.

AK The Government. Do you. . . not feel you should get any influence over what they do?

G9R353 Nut. . . look at animal rights and aw that. . . they're still daein' it and there's thousands o' people that are against it.

These interviewees expressed the view that the amount of influence people have depends on their financial status, their age, and how close they are to government decision making. In contrast, popular disapproval (or for that matter, approval) is not perceived as a major influence on science or government. Interviewees therefore demonstrated a reflexive awareness of the role of social position and social relations in this context. Michael[22] has also emphasized the importance of understanding how people's perception of their social agency and the processes of identification or alienation with scientific institutions shape their responses to experts.

Social location

To analyze fully the different ways in which people understand the new genetics, it is important to take account of these different types of knowledge—technical, methodological, institutional, and cultural—and to recognize their interdependence. We have shown the breadth and depth of understanding that a range of people have and can draw on when discussing the new genetics. This is true for people with and without direct experience of a hereditary condition or scientific training. However, it is also important to recognize the variety in peoples' understandings of the new genetics, and how this relates to their social location and personal experiences. From the above examples, we can compare the teachers' confident and articulate discussion about nature/nurture, which draws on knowledge of scientific research and their own professional experience, with the discussion by the group of elderly people whose views on the dynamics of science as an institution were unspecified and vague (but not unsophisticated). In addition to professional experience, people may draw on direct personal experience or on knowledge derived from the media and other sources. People hold their own stock of technical, methodological, institutional, and cultural knowledge for a critical understanding of the new genetics, and this is a product of their past experiences, both unique and culturally shared. Experiences that were treated as relevant in people's accounts of the new genetics mainly concerned health care, particularly prenatal care and visits to the GP; experience of friends and families' reactions to their health behavior; health experiences of family and friends; and knowledge of others' health experiences gleaned from the media.

Broadly speaking, we can say that people's accounts of the new genetics are related to their health (including their hereditary status), their class, age, and gender, and that these aspects of people's social location interfuse in shaping their accounts. For example, the group of elderly working-class people made sense of questions about genetic stigma by discussing their attitudes to people in their own community who had disabled children. They viewed children with cystic fibrosis as a greater burden and more likely to be aborted than children with Down's syndrome. This contrasts with the views of the relatives of children with cystic fibrosis who felt that Down's was more socially stigmatized because it involved mental disability and obviously different physical characteristics. Elderly people had grown up with children with Down's, at a time when children with CF were much more likely to die. Nowadays there are fewer children with Down's because of terminations and more children with CF because of better treatment of the condition. Relatives of children with CF are much more knowledgeable about the condition than other people who do not have children with CF.

It is also the case that gender plays an important role in shaping people's accounts of the new genetics. For obvious reasons, women have more experiences of prenatal testing than men, and this often featured in their accounts of their views about genetic testing. Women's primary role as caregivers also gives them particular insight into the social context in which genetic testing takes place. Health experiences more broadly are an important aspect of people's accounts of the new genetics. The groups of people with experience of heart disease and breast cancer (either directly or in the family) clearly felt a debt to the medical profession for saving their lives or the lives of their loved ones. A strong theme in their views on the responsibility of patients was their need to participate in clinical trials (and even our own research in the case of the group of women with experience of breast cancer). The group of people with disabilities, on the other hand, shared unpleasant memories of their experiences of being disregarded or devalued by medical professionals. This came through in their views on eugenics in particular. The group of nurses also drew

on both professional and personal experiences. For example, in discussing their views on the expansion of genetic research they raised general concerns about objectification and lack of consultation with patients, and in discussing the value of presymptomatic testing they drew on personal experience of ill health and challenged what they perceived to be inappropriate medicalization.

We argue that this range of understanding constitutes lay expertise about the new genetics. People are all experts about their own lives. And as social actors we engage with a range of other actors and institutions and therefore develop a unique set of knowledge from which to judge new experiences. Expertise is therefore not solely the province of professionals, but lay people have valuable knowledge and understanding of the social world which equips them to discuss the new genetics in a sophisticated and reflexive manner. As we have already argued, technical details are but a small part of this "stock of knowledge" and are far from fundamental to lay people's sociological intellect and imagination.

Social context

We now go on to explore further the way in which differences in social context shape people's accounts of the new genetics. In focus groups we have deliberately made the new genetics relevant and this allows us to access the lay expertise we have outlined above. However, lay people's mobilization or utilization of their available "stock of knowledge" is not straightforward but influenced by their perception of relevancy, social opportunity, and power relations in certain contexts.

Focus groups

These lay people's accounts of the new genetics articulate rich and diverse understandings of medicine, science, and society. Yet there is a strong resistance among lay people and professionals alike to recognize that this constitutes a form of expertise that places a positive value on their opinions and experiences. Invariably when we were setting up the focus groups, people expressed anxieties about their lack of relevant knowledge and we had to work hard to reassure them that they would be able to talk about the new genetics, and that we did not require a high level of technical proficiency. However, in most groups some participants expressed doubts about their own competence in speaking about genetics, particularly in response to the first question where interviewees were asked to say what genes or genetics meant to them. One interviewee asked if she had to speak and others asked for more specific questions and apologized for their lack of technical know-how. To offset this we deliberately emphasized our own lack of technical expertise at the start of each interview; for example, we said that we were not medical experts, and asked about personal experiences or ideas and issues that genetics raised. Once this initial wariness had passed the groups provided a supportive environment for people to discuss their views and to be reflexive about their own social position in relation to the new genetics.

Clinic

It seems likely that this difficulty in accessing or mobilizing lay expertise is a product of general devaluation of lay people's knowledge. This is experienced by lay people in encounters with a range of professionals, including medical professionals. The people we spoke to often found that their expertise came into conflict with professional definitions and knowledge. Several respondents gave examples where their own knowledge of their

bodies and emotions, or of their children's health, conflicted with medical opinion. The most striking instance of this was related by a parent who was convinced that their child had cystic fibrosis, but a diagnosis was not given until the child was two and a half years old. The group of disabled people told the most poignant stories of misunderstanding. One woman who had cerebral palsy, and her partner who had muscular dystrophy, told of their experiences in relation to the woman's pregnancy, and their struggle to convince medical professionals that she did not require or wish prenatal testing because of her different view of disability. In another excerpt the group discuss their rejection of dominant medical views of disability:

G5R39 I think it's unfair on the parents as well, 'cos they're getting told, "well, it's a genetic problem," and it's like, "it's your fault, 'cos you've got the faulty gene." Which is a bit harsh if you ask me.

G5R40 And surely what parents are wanting to be doing is loving that child that they have and not worrying themselves, feeling guilty themselves... there are so relatively few of us I think who... have become involved in the disability movement or whatever, and do feel that that, what our medical condition is important... it is an important whole part of us... [but] we've been denied that, it hasn't been recognized, it's been recognized as a *problem* by clinicians. It's not something that we should be valuing, whereas, ... I feel, yes my medical condition is important, it's an important part of me, I wouldn't be like I am without it.

G5R41 Yes... I've heard that from so many people and myself included, some of us have got to this stage... we now share experiences and have gathered experiences which are rich, just because of the actual condition that we happen to have.

G5R42 And... clinicians should not be putting this guilt trip on people, shouldn't be saying, "if you have a child with Down's Syndrome... or if you have this faulty gene and you are going to have... or you have a fifty percent chance of having a child with... then we're advising you against it." Parents... don't get the opportunity to see the positive side...

G5R43 I think they do sometimes but it's very rare.

G5R44 ... occasionally, it's very rare.

G5R45 But they don't ever get to meet... maybe families that have gone through it that are coping and think, "well, it's no different."

G5R46 I mean, in response to your question... (giggles)... I guess I understand the scientific need to explore, to understand what happens genetically... and to gather more knowledge, I understand that and I think it's valuable so long as it is done by including parents and families and individuals as partners in all of that... by valuing people... the guilt thing is so common, and if ... that is understood by researchers and doctors... for the power it holds... and is used in a different way, then I don't see anything wrong with genetic research, I think the end result of it is the more contentious side, what is done with the research.

G5R47 And I think also [there is] the difference between... a genetic disability and a person who's got a congenital disability but it's not genetic. If it's genetic... like you were saying N., the parents... it's as if it's their fault,

but if. . . you have a child and it's just. . . a congenital disability then it's not genetically related, then it's like a quirk. . . of nature and. . . the guilt is lifted off the parents whereas. . . if you've made a conscious decision to have a child knowing that you've got a genetic condition, then it's. . . almost as if. . .

G5R48 The thing that incenses me I suppose is the words that they use, if, it's something that comes out the blue, I'm a "spontaneous mutation" (giggles) according to certain. . . consultants.

G5R49 I guess I must be too.

G5R50 . . . and I think, wow!?. . .

G5R52 . . . I wear a badge, I've come from Star Trek or whatever. . . I am not me. I'm a spontaneous mutation.

This example starkly illustrates the way in which encounters with the medical profession can make people feel objectified and dehumanized when a medical or genetic condition is treated as an illness, separated from either that person's identity or their everyday life. In these situations any mobilization of lay expertise is effectively stifled. However, as this group readily admitted at another point in the discussion, their experiences can serve as resources from which a critical, alternative perspective is developed. The Disability Movement is one example where alternative versions of impairment and disability seriously challenge the medical and reductionist model of the new genetics.

On a more routine basis, people also make small challenges to medical expertise. Here this group of new mothers from a working-class area of Edinburgh are discussing prenatal testing:

G1R112 I don't think I would go through it again if I were pregnant like. . . .

G1R113 Um, well I did.

G1R114 Naw.

G1R115 I learnt a lot the first time, I was going there and just sort of, stick the arm out for the blood test or whatever, without actually sitting back and thinking.

G1R116 But I think a lot of people do J., like you believe in the medical profession and if they say you've to get this you say, well give me it, so you say, you dinnae ask any questions, they're supposed to be the ones that ken everything.

AK Uhuh, so you trust them?

G1R117 Aye, well. . . (giggles)

G1R118 You're meant to be able to trust them but the, the test results aren't always that. . . .

G1R119 Well, I think it depends on how, sort o' experienced, how many children you've got, 'cos I mean I think every first time mother's just like a guinea pig, so you're saying "aye, aye, aye." Whereas I think maybe your second and third child. . .

G1R120 Yeah, you know a bit more as well.

G1R121 Uhum.

Experience of childbirth, coupled with maturity, made these mothers feel better able to challenge their medical treatment. However, the low validity and status accorded to lay knowledge and expertise, along with the difficulty in gaining access to professionals' knowledge, either because of the incomprehensible nature of professional publications to

a lay audience, or deliberate withholding of information by professionals, means that lay people often do not readily challenge professional expertise.

Dependence on the medical profession, evident in a general acceptance of members' status as experts, therefore sits in a delicate balance with a more critical view. The following excerpt is from a conversation among a group of mainly middle-class Edinburgh women who had experienced breast cancer:

AK So it's. . . important to trust the doctors then?

G7R110 I think it's very important.

G7R111 Does anyone have a different view on that?

G7R112 No.

G7R113 I agree with all that.

G7R114 I think that you have got to go by your own instincts as well.

G7R115 Mmh. Mmh.

G7R116 Well, personally. . . when I thought I had a lump they said it wasn't a lump, it was part of my ribs sticking out. And I said, "that's not my ribs that's something else," and they only decided to give me a test just to keep me happy and if I had accepted that he had said it was part of my ribs I would have been walking about two years later with [it]. Well I don't know if I would have been walking about two years later.

G7R117 I thought that the test you were talking about was the genetic test?

AK Uhuh. Yes.

G7R118 Sorry we have moved off a bit.

AK Yes. . . I suppose [it is] the issue [of]. . . informed choice that we are talking about here. It applies to every test. . .

G7R119 I suppose with the tests. . . the number of people taking the test. . . it's got to be good for research purposes anyhow. It's not just for your own good. [It's] for the good of everybody, from the medical research being done. Obviously I've got an interest in it myself. . . but I don't really look upon it just doing it for me and my children. I'm in this for everyone. I'm no trying to be ultra-noble or anything like that but that's what I'm doing it for because. . . children used to die with leukemia. . . now most children are cured. . . 9 out of 10 and that's obviously been through lots of research and things coming on. So maybe with breast cancer in 15 years' time it would be very different.

Later on the discussion returned to clinical trials:

G7R315 The other thing is that you don't know whether [you] are on trials or not or. . . you go in and you are being given treatment and you just don't know whether. . . you might be in a. . . trial group or. . .

G7R316 Yes I must say because I originally agreed to be part of the trial that is on running and I hadn't really thought of the consequences of that until. . . I went back after my op. and they'd had all the pathology results back. Dr L. then said you can't stay in the trial because we can do better for you. Now if I'd been somewhere else would I have been left in the trial?. . . all of a sudden I thought "they had actually predestined. . . ."

G7R318 Yes and it's a computer isn't it that's chosen.

G7R319 No the computer picked whether you had conventional treatment or the trial which was surgery before your treatment or treatment first and surgery afterwards.

AK Right.

G7R320 . . . mine came out for conventional treatment but it was after all the results were in and the regime of chemotherapy I would have had within the trial wasn't as heavy as the regime they felt I needed. Now if I had been somewhere else or not in a hospital that was really dedicated to the patient rather than the trial I then thought, "goodness it makes you think twice about going into a trial." Because you are really very very much at the mercy of the doctors.

G7R321 They asked me to go into a trial and I said, "OK," but then when I got home and started thinking about it I decided, "no I don't want to go on a trial," I went back and I said, "it's maybe selfish but," I says, "I want the best possible treatment for myself whether it's a trial or not." So they weren't pleased. I came out of the trial and they gave me. . . what they considered was the best possible treatment without the trial.

From these two quotes we can see how it seems necessary for people to trust their doctors, given their own lack of professional expertise, but that this trust is not unconditional. The examples we have provided show that people's "intuitive" understanding of their own bodies might conflict with professional expertise. There is a feeling of obligation to participate in clinical trials to advance knowledge, but once again this is not an uncritical position: it must be balanced by the drawbacks of participating and ensuring personal survival. As Wynne has noted people have to act "as if"[23] they trust institutions or experts in some contexts, whereas in others they may display ambivalence or skepticism, or indeed seriously challenge dominant views. There was some evidence that the more relevant professionals' expertise was to them, the more people felt they had to trust them, as the following quote suggests:

G2R404 You have got to trust your doctor but scientists, no, I wouldn't trust them as far as that door. Well no, after this cloning caper no.

Here doctors are pointedly distinguished from more remote scientists.

The public arena

Interviewees also tended to denigrate the public for being ignorant about genetics, thus replicating the dominant "deficit model." For example:

G1R171 Again it's, the general public are basically afraid of what we don't know, I think, a lot of people are afraid, you know, if you turn round and say, "oh, I carry this gene that might cause cystic fibrosis," people might think it might be catching 'cos a lot of people just don't know.

G6R31 There's quite a lot in the media about. . . especially in the last few years of development in genetic research. It's usually quite interesting but I think a lot of people see it as kind of almost like science fiction or like a pure science that you can't really relate to every day. . . or people think that something miraculous is going to come out of it like genetic cures, sorry genetic treatment for illnesses which. . . is not going to happen like tomorrow or next month or even next year.

However, interviewees also argued that they had little influence on any public decision making about the new genetics. Lack of public involvement in decision making was not solely put down to public unwillingness or inability to learn:

G8R336 But I think my biggest worry about this whole issue, you know the general thing and that is that there is an awful lot of good science that goes around—there is some bad science as well of course—but either way it's much more often what Government then chooses to do with it. . . it's only really the Government that can force it out into the open and it's no use saying that the average Joe Public, sorry Josephine Public can't understand it. We can all read you know we've all coped here. You can understand anything if it's explained in reasonable terms. You can understand enough to make up your mind about how you feel about it can't you?

We found a significant level of skepticism about the government's accountability—particularly the lack of openness in terms of provision of information and access to members of parliament. Although drawing on the deficit model of public ignorance, participants were nevertheless critical of the opportunities for lay participation and decision making about genetics. This shifts the focus away from lay people's unwillingness or inability to learn about the new genetics to scientific and governmental institutions' unwillingness to facilitate and utilize lay people's critical understanding of the new genetics.

This research shows that people are motivated to discuss genetics-related issues in focus groups, thus expressing their expertise: lack of directly relevant experience does not preclude discussion. We argue that people hold their own resources for a critical engagement with the new genetics and its clinical context. However, this may be articulated differently in different circumstances and contexts. What stops people fully mobilizing their expertise is their lack of power in encounters with medical professionals and their alienation from traditional legislative and regulatory bodies. Although there are various barriers which demotivate people from expressing their expertise, in sufficiently supportive and unintimidating environments the new genetics can become relevant to a broad range of lay people. The tension between dependence and passivity on the one hand, and assertiveness and an appreciation of self-worth on the other (both in the clinic and the wider public arenas), may also be productive, as opposed to stultifying, in the right context.

Conclusion: mobilizing lay expertise

Calls for a more informed public to participate in debates about the new genetics are clearly based on the errant assumptions of public ignorance and inability or unwillingness to participate. These calls also serve a particular rhetorical function. In a similar fashion to scientists' appeals to the responsibility for the application of their knowledge lying with an abstract and amorphous society, they deflect attention away from the development of publicly accountable and democratic mechanisms and structures in which scientists and lay people can come together to take responsibility for the social impact of the new genetics. Indeed, as the members of the public whom we interviewed well know, the institutional structures of science are such that public opinion is not a feature of decision making in or about science, and the new genetics is no different in that regard. Truly inclusive and meaningful discussion and decision making about the new genetics requires that scientists' and doctors' professional autonomy and power be lessened. Moreover, true public participation in science would require broader reforms of the current democratic process and therefore further weaken and subvert the political power of the government.

Given that the status quo is unlikely to change in any radical way, increased public involvement in discussions about the new genetics that might influence policy will have to take place at a more modest level. This is, of course, no more essential for the new genetics than for any other social policy issue. However, given the potentially wide-ranging

impact of the new genetics on individuals and social groups, it is important to capitalize on the current interest in public consultation about the new genetics. As we have already mentioned, the Human Genetics Advisory Commission plans to consult the public about the social and ethical issues involved with the new genetics; and the Medical Research Council is currently assessing ways to consult the public about genetic research into IQ. It is important to encourage these bodies to take the public's views into account when formulating policy, and to challenge the underlying urge to simply quell public disquiet. This requires imaginative and creative thought about how to set up supportive arenas where the broad range of groups that make up the public can express and formulate their opinion through discussion and debate. It must be recognized, for example, that the differences, ambivalence, and contradictions in people's views means that any resolute expression of "public opinion" is implausible. This suggests that we need to find a way for policy and practice to cope more adequately with ambivalence and difference. Open contestation of knowledge should also be a feature of these types of discussions.

Our research experience would suggest that focus groups, based on respect for all the participants' views, are a better model for public consultation than either the medical encounter, where lay people's expertise is often denigrated, or formal public debates, where deferment to scientific expertise is likely.[24] Locally organized groups would both support the expression of lay expertise and enable documentation of views. In order to prevent an imbalance toward already-educated and middle-class people controlling any such discussion, people with less formal education or experience in expressing their views in public would have to be encouraged and supported in their participation—again, something easier to achieve at local level. In the event we organized at the Edinburgh International Science Festival, we found that, despite the easy way in which professionals, especially geneticists, can contribute to and thus dominate public discussion, we also witnessed contributions from those whose voices are usually silenced. We also argue that the public is not simply in need of facts about genes or chromosomes in order to participate in such forums, but that the general availability of a wide range of information and opinion would develop their already sophisticated level of knowledge and variety of views.

If this process were to be replicated nationally and take place outside the traditional rubric of the "Public Understanding of Science," it might lead on to more equitable participation in other arenas—public debate, committees, and advisory groups. Discussions such as these can also support the mobilization of lay expertise more effectively, and lead on to more direct lobbying of scientists and government on particular topics. We could foresee, for example, larger lay representation on committees and advisory commissions, or the calling of *lay experts* to act as special advisors. It is, for example, a cause for real concern that people with genetic disabilities are currently completely unrepresented on committees and advisory groups concerned with the new genetics. Of course, what we are advocating is a long way off from truly publicly accountable science, or more grass-roots forms of social organization based on the principle of participatory democracy. It is, however, a step in the right direction, and as such we hope it will stimulate fellow readers to respond to calls in the pages of *Public Understanding of Science* for more public consultation and representation with respect to decision making about the new genetics.

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