National Diabetes Strategy
And Implementation Plan

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National Diabetes Strategy and Implementation Plan

Prepared for: The Ministerial Advisory Committee on Diabetes

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Dedication

The ***National Diabetes Strategy and Implementation Plan***

is dedicated to all people in Australia who have diabetes,
those who care for people with diabetes
and people who are at risk of developing diabetes.

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Foreword

The National Diabetes Strategy and Implementation Plan is the first comprehensive plan to address what has become a major public health concern.

In early 1996 the Government made a strong commitment to address this disease in all its major forms (type 1 diabetes, type 2 diabetes, and gestational diabetes mellitus), acknowledging that 85-90% of diabetes is type 2 and that this form of diabetes is reaching epidemic proportions.

In that year agreement was reached with the State and Territory health ministers to make diabetes mellitus the fifth National Health Priority Area and I also announced the establishment of the Ministerial Advisory Committee on Diabetes to provide the Government with independent advice on the management of diabetes in Australia. The *National Diabetes Strategy and Implementation Plan* is an initiative of this committee.

Diabetes mellitus affects more than half a million Australians, many of whom do not know they have the disease. The estimated cost of diabetes (all forms) to the national health budget is about $1 billion per year while the human and social costs are incalculable.

Because of the ageing of the population and die increasing frequency of risk factors (such as overweight and physical inactivity) the prevalence of type 2 diabetes will almost certainly double in the next 10 to 15 years if the strategies detailed in this document are not acted upon with great urgency.

Recent times have seen developments in our understanding of diabetes and the ability to manage it. Such advances have given us renewed hope. Exciting developments are taking place in research, particularly relevant to type 1 diabetes. There is also now sufficient support to show that with evidence-based medical intervention, combined with good education, and early diagnosis of type 2 diabetes, we can reduce or even prevent complications associated with both type 1 and type 2 diabetes.

Possibly the greatest public health challenge is how best to approach the prevention of type 2 diabetes, which will require a committed and co-ordinated effort to address the rapid increase in the prevalence of risk factors for diabetes.

I extend thanks to Dr John Carter (Chairman) and members of my Ministerial Advisory Committee on Diabetes, Associate Professor Stephen Colagiuri, Ms Ruth Colagiuri and Associate Professor Jeanette Ward for their major contribution to this document.

I believe *The National Diabetes Strategy and Implementation Plan* will place Australia at the forefront of worldwide efforts to control diabetes. I urge all governments, health professionals, health consumer groups and all Australians to embrace the recommendations of this important strategy.

Dr Michael Wooldridge
Minister for Health and Family Services

Glossary of acronyms

ABS	Australian Bureau of Statistics
ACCHS	Aboriginal Community Controlled Health Service
ADEA	Australian Diabetes Educators Association
ADA	American Diabetes Association
ADS	Australian Diabetes Society
ADIPS	The Australian Diabetes in Pregnancy Society
AHMAC	Australian Health Ministers Advisory Committee
AIHW	Australian Institute of Health and Welfare
APEG	The Australian Paediatric Endocrine Group
APodC	Australian Podiatry Council
ASCPIGM	Australian Society of Consultant Physicians in General Practice
ASSO	Australasian Society for the Study of Obesity
ATSIC	Aboriginal and Torres Strait Islander Commission
BMI	Body mass index
CME	Continuing medical education
COAG	Council of Australian Governments
DA	Diabetes Australia
DAA	Dietitians Association of Australia
DCCT	Diabetes Control and Complications Trial
DGP	Divisions of General Practice
DH&FS	Commonwealth Department of Health and Family Services
FECCA	Federation of Ethnic Communities' Councils of Australia
GDM	Gestational diabetes mellitus
GP	General Practitioner
HbA_{1c}	Glycohaemoglobin
HIC	Health Insurance Commission
IGT	Impaired glucose tolerance
MACOD	Ministerial Advisory Committee on Diabetes
MBS	Medical Benefits Scheme
MESAG	Medical Education and Scientific Advisory Group
NACCHO	National Aboriginal Community Controlled Health Organisation
NADC	National Association of Diabetes Centres
NAP	National Action Plan
NDDP	National Divisions Diabetes Program
NDOQRIN	National Diabetes Outcomes and Quality Review Initiative
NDSS	National Diabetic Services Scheme
NESB	Non-English Speaking Background
NHF	National Heart Foundation of Australia
NHMRC	National Health and Medical Research Council of Australia
NHPC	National Health Priorities Committee
NPHP	National Public Health Partnership
PBS	Pharmaceutical Benefits Scheme
RACGP	Royal Australian College of General Practitioners
SERU	Support, Evaluation and Resource Unit
UKPDS	United Kingdom Diabetes Prospective Study
WHO	World Health Organization

Executive summary

Why do we need a *National Diabetes Strategy and Implementation Plan*?

Diabetes is a significant and growing global public health problem. It affects over 4% of the Australian population, at least 10% of older people, up to 30% of some Aboriginal communities, and has a high prevalence in people from the Pacific Islands, the Middle East, Southern Europe and some Asian counties. Diabetes causes a substantial burden of illness and premature mortality and is among the major causes of death. In Australia it is:

- the second most common reason for commencing renal dialysis
- the most common cause of blindness in people aged less than 60 years
- the most common cause of non-traumatic amputation
- the most common chronic disease in children

Recognising the extent of personal suffering and the high public cost attributable to diabetes, in 1996, the Australian Health Ministers agreed to include diabetes as the fifth National Health Priority Area. Since then additional funding has been allocated to initiate and support improvements to the outcomes of diabetes care and prevention, and a Ministerial Advisory Committee on Diabetes (MACOD) has been established to oversee the process. The purpose of the *National Diabetes Strategy and Implementation Plan* is to guide the allocation of these funds and suggest structural and functional reorganisation to ensure and sustain equitable access to effective, efficient and economically viable diabetes services for all Australians, focussing on:

- Type 1 Diabetes
- Type 2 Diabetes
- Gestational Diabetes

The *National Diabetes Strategy and Implementation Plan* presents a population focussed, evidence based rationale and short and long terms plans for reducing the personal and public burden of diabetes in Australia to the year 2010. The goals cover the continuum of diabetes care and the structures which underpin health care, ie research and the health system.

The goals

1. Prevent or delay the development of type 1 diabetes and type 2 diabetes
2. Improve health related quality of life, and reduce complications and premature mortality in people with type 1 and type 2 diabetes
3. Achieve maternal and child outcomes for gestational diabetes and for women with pre-existing diabetes equivalent to those of non-diabetic pregnancies
4. Achieve progress towards a cure for type 1 diabetes
5. Advance knowledge and understanding about the prevention, cure, and care of diabetes through a comprehensive research effort
6. Improve the capacity of the health system to deliver, manage and monitor services for the prevention of diabetes and the care of people with diabetes

What are the major issues?

Notwithstanding acknowledged information deficits, there are well defined processes of diabetes care supported by evidence of effectiveness. With adequate training, any health professional can apply most aspects of effective routine diabetes care. Expensive 'high tech' equipment is not required for this level of care, and Australia has an enviable system of primary physicians who are, in the main, organised and organisable through the infrastructure provided by Divisions of General Practice (DGP). A system of interdisciplinary, specialist ambulatory care centres exists which can be accessed free of charge to the consumer. This model has demonstrated effectiveness in improving the health outcomes of people with diabetes and reducing the cost of diabetes care. In addition, all Australians are covered by universal health insurance for access to public health services.

The problem therefore is not so much one of ‘W*hat to do’* but requires answers to the question of ‘*how to do it’* in the Australian context where barriers to optimising diabetes services and outcomes include:

- enormous cultural diversity including an Indigenous population with a record of ill health and living conditions equivalent to that found in underdeveloped countries
- an ageing, increasingly overweight and physically inactive population which is widely geographically dispersed
- uneven and inequitable distribution of services making access both geographically and culturally problematic
- a complex health system with poorly defined Commonwealth and State/Territory roles and responsibilities
- fragmentation of services and lack of cohesive policy and planning exist in many areas
- unprecedented demands on the health system which must be met with limited resources
- substantial deficiencies in our ability to collect and link data to monitor the processes, outcomes, and cost of health care
- deficits in our knowledge of some aspects of diabetes prevention and care which need to be addressed through a systematic and rigorous research effort

The framework and structure of the document

The *National Diabetes Strategy and Implementation Plan* illustrates some of the ways in which these issues might be addressed. The goals centre on primary prevention, diagnosing and managing diabetes, maintaining health status and preventing progression to end stage diabetes complications. Secondary to this, but no less vital, is the aim of increasing the capacity of the existing infrastructure to maximise our knowledge of diabetes, and act on this knowledge effectively and efficiently. The overall framework identifies three fundamental needs to which efforts must be directed in order to achieve the goals. They are:

- consumer, provider, and public *awareness* about diabetes
- the *quality and effectiveness* of diabetes prevention and care
- *access* to effective health services

These needs are addressed by focussing on *people*, *providers,* and *policy and programs* to:

- identify and disseminate appropriate *information*
- define and implement '*best practice'*
- reduce inefficiency and duplication through improved *coordination*

Specific strategies which flow from this approach are detailed throughout the document. They include the identification of, and recommendations about issues concerning service provision, provider training and incentives, consumer and public education, research prioritisation, and funding. The framework describes, in broad terms, the key outcomes and indicators relevant to the goals. It does not stipulate population targets due to the lack of accurate Australian baseline data on diabetes but identifies process targets for specific implementation plans in relevant sections of the document. The document is divided into seven sections:

Section 1: The framework

Describes the overarching framework for the *National Diabetes Strategy and Implementation Plan* and the rationale for operationalising the goals into a strategic implementation plan.

Section 2: The current situation

Provides a brief overview of type 1 diabetes, type 2 diabetes, and gestational diabetes, including the associated personal impact and public cost, and an outline of the general Australian population size and trends. Key diabetes care providers and organisations involved in diabetes care are listed in this Section and described more fully in Appendix 2. Existing models of diabetes care and recent policies and programs are outlined, concluding with a summary of the barriers to be overcome and the strengths of the current system.

Section 3: Imperatives for change

Explores infrastructure and development issues centred round the key needs. It argues for improvements to:

- *information* - data collection and management, public, consumer and provider awareness
- *'best practice'* - underpinned by systematic training and implementation
- *coordination* - including role delineation and integration at both local and national levels and an organisational structure for sustaining the *National Diabetes Strategy and Implementation Plan.*

Section 4: The focus

Centres on the goals of the *National Diabetes Strategy and Implementation Plan,* highlighting the rationale for intervening, explicit objectives, and specific requirements for improving the prevention and management of type 1 diabetes, type 2 diabetes, and gestational diabetes. It contains recommendations for these 3 main type of diabetes, for research, and for improving the ability of the health system to bring about and sustain diabetes health gain.

Section 5: Priority programs

Outlines a rationale and implementation plans for priority action areas.

Section 6: *Groups with special needs*

Describes and makes recommendations about groups which may be disadvantaged in accessing services for diabetes prevention and care by virtue of cultural grouping, ethnic origin, geographical isolation, or who may have particular needs due to either very young or increasing age. It encompasses Indigenous Australians, people from non-English speaking backgrounds, people living in rural and remote regions of Australia, children and adolescents, and the elderly.

Section 7: *Economic considerations*

Explores the cost implications of diabetes and its complications by assessing the available literature on the financial burden of diabetes and the likely cost benefits which could be achieved by systematic and comprehensive implementation of interventions with proven effectiveness.

Recommendations

Through wide consultation with stakeholder organisations and individuals, clinical and public health experts, and Commonwealth, State, and Territory Health Departments, and an extensive review of the national and international diabetes literature, a series of recommendations have been formulated. Sixty two recommendations are listed on pages xii to xvi, and repeated in the relevant Section throughout the document (Sections 3 - 6). From these a list of Priority Recommendations has been extracted (px - xii) relating to issues which require immediate consideration. These recommendations focus on *information, 'best practice', coordination, research, and the health system*.

Priority recommendations

The Priority Recommendations include the Priority Programs from Section 5 of the document which have been identified on the basis of:

- the impact and extent of the diabetes problem ie the overall health and cost burden
- the feasibility of intervening successfully including the availability of effective interventions
- the potential health improvement and cost benefits to be gained by intervening

The Priority Programs are designed to improve access to health care processes with demonstrated potential to reduce long term irreversible diabetes complications and the financial burden of diabetes. They are a national:

- Program for Improving the Quality of Diabetes Care
- Diabetes Visual Impairment Prevention Program
- Diabetes End Stage Renal Disease Prevention Program
- Diabetic Foot Disease Management Program
- Diabetes Cardiovascular Disease Prevention Program
- Early Detection of Type 2 Diabetes Program
- Type 2 Diabetes Prevention Program

Other **Priority Recommendations** include:

- optimising the quality and accessibility of diabetes prevention and care for Indigenous Australians, and for people from non-English speaking backgrounds
- implementing national initiatives for the detection and management of diabetes in pregnancy
- assessing the needs of children and adolescents with diabetes
- developing a prioritised diabetes research agenda
- improving the available data for monitoring the outcomes of diabetes prevention and care
- improving the capacity of the health system to optimise the sustainability of improvements to diabetes care by ensuring that recommended processes are encouraged and followed, and by exploring and capitalising on funding opportunities
- establishing an appropriate organisational structure and coordinating mechanisms for the *National Diabetes Strategy and Implementation Plan* overall, and for its implementation in Indigenous and non-English speaking communities

Implementing the recommendations

Implementing the recommendations of the *National Diabetes Strategy and Implementation Plan* is a daunting task. There is an extensive range of direct stakeholders including consumers and consumer organisations, clinicians, researchers, and professional organisations, Indigenous and ethnic organisations, and Commonwealth, State and Territory Health Departments, the NHMRC, Health Insurance Commission and the Australian Institute of Health and Welfare. Resources are limited and there are structural barriers to effective implementation.

Successful implementation requires more than good intentions, although such intentions are undoubtedly an essential prerequisite. In addition to enthusiasm, good will and official endorsement, a number of other ingredients are critical including:

- commonality of purpose
- stakeholder agreement
- Commonwealth, State, and Territory commitment
- the input of expert clinicians into planning, process, and evaluation
- the involvement of general practitioners and other primary health care workers
- adequate information to guide decisions
- integration with similar national prevention and care initiatives
- a commitment to supporting 'best practice'
- coordination
- resources

The *National Diabetes Strategy and Implementation Plan* sets out common goals which have been developed in consultation with key stakeholders. Expert clinicians, organisations and Commonwealth, State and Territory health departments have had input into the development of all aspects of the *National Diabetes Strategy and Implementation Plan* document.

Information

While there are acknowledged deficits in information systems to support and evaluate the *National Diabetes Strategy and Implementation Plan*, collaboration with relevant groups has enabled the development of explicit and practical recommendations about what is required to address this deficit.

'Best practice'

Implementing 'best practice' requires governments to dedicate resources to studies to generate the required evidence and support the development and dissemination of evidence based guidelines and protocols, and the evaluation of methods for their implementation. Means of enabling and rewarding effective practice must be developed and, from a clinical perspective, providers must make a commitment to applying these guidelines and protocols in everyday practice. Consumers are an important and untapped resource for implementing 'best practice'. The development of 'best practice' guidelines to inform consumers to request appropriate levels of care, accompanied by training to enable them to participate more effectively in their health care, is an important component of implementation.

Coordination

Coordination at all levels of the health system is essential to ensure optimal implementation of the *National Diabetes Strategy and Implementation Plan*. The establishment of a national non-communicable diseases and prevention programs network would greatly enhance integration of major health strategies. Diabetes specific strategies to facilitate coordination include convening a National Diabetes Summit to gain wide endorsement of the *National Diabetes Strategy and Implementation Plan*, and establishing a:

- National Diabetes Task Force supported by an Advisory Committee, Reference Groups, a Commonwealth, State and Territory Diabetes Forum, and expert Working Parties
- National Diabetes Strategy Unit including the existing Secretariat and:
    - a Medical Director
    - an Aboriginal Coordinator for diabetes and lifestyle diseases to work with Indigenous communities
    - a Diabetes Coordinator to work with non-English speaking communities to implement the recommendations of the *Strategy*.

Funding opportunities

Increased funding is required to achieve the goals of the *National Diabetes Strategy and Implementation Plan*. The financial cost of diabetes to the Australian community is referenced throughout the document and detailed in Section 7. The situation is such that we can no longer afford not to make this investment, and there is evidence that, if made, the investment will be recouped in a relatively short timeframe.

The additional funding dedicated to diabetes by the Commonwealth Government in 1996 is already impacting favourably on certain important diabetes issues, including the establishment of a National Diabetes Register and specific diabetes prevention and care projects. However, longer term funding must rely primarily on more efficient use of available resources. Capitalising on the funding opportunities identified during the development of the *National Diabetes Strategy and Implementation Plan* requires structural alterations at the Commonwealth level.

Areas which could be explored include:

- *adjustments to Medicare Benefits* which could encourage recommended practice and enable improved monitoring of certain diabetes care processes at little or no additional cost eg creating a Medicare Item number for optometrists to screen for diabetic retinopathy, and an Item number for testing for gestational diabetes
- a *Medicare Cash Out Arrangement* to equip Indigenous Health Services with a DCA 2000 analyser to perform essential monitoring and testing of diabetes on site
- *incentives for people with diabetes* to provide financial incentives to encourage increased participation in the diabetes management cycle, especially in complication screening
- *incentives for providers* to consistently apply the recommended standards of diabetes care, thus reducing the proportion of overall health care costs spent on diabetes
- *the Healthcare Agreements* could be used as a means to earmark funding for Commonwealth and State/Territory agreements in the implementation of selected priority diabetes care and prevention programs and linked to performance indicators
- *Program Funding.* A proportion of this Commonwealth - State/Territory funding which is currently set aside to address public health problems of agreed importance could be directed towards implementation of the *Priority Programs*, eg the Diabetes Visual Impairment Prevention Program. Program costs would be recouped within a short timeframe and would result in real savings in health care costs
- *Measure and Share* to reward innovative diabetes prevention and care methods at State and Territory level which reduce the growth of the Medical Benefits and/or Pharmaceutical Benefits Schemes with the resultant savings shared between the Commonwealth and the State or Territory involved
- *research funding*. NHMRC funding for diabetes development and research should reflect the status of diabetes as a National Health Priority Area (see Section 4)

Evaluation

Evaluation of the effect of implementing the *National Diabetes Strategy and Implementation Plan* should be based on the Key Outcomes and Key Indicators listed on page 8 and 9, and the ‘expected outcomes’ specified in Sections 4 and 5. This will necessitate an initial investment in data monitoring systems, and will be aided by the establishment of the National Diabetes Register, and the collection of clinical data by the National Association of Diabetes Centres and Divisions of General Practice using the NDOQRIN minimum dataset.

Evaluation of the *Strategy* itself should be based on regular review of the recommendations and the progress made towards their implementation. Appendix 3 contains a table of recommendations and implementation indicators for this purpose. It is recommended that review of the implementation process is undertaken at 6 months, 1 year, 2, 5, and 10 years from the time of its endorsement

Priority recommendations

Each Section of the *National Diabetes Strategy and Implementation Plan* contains recommendations which are also listed collectively on the following pages and are numbered consecutively under the Section headings in which they appear in the document. The *Priority Recommendations* are derived from this list and centre on:

- *'best practice'* to improve the quality and accessibility of diabetes care
- *coordination* to optimise the processes and outcomes of diabetes care and prevention
- *information systems and data collection* on diabetes and related processes and outcomes
- *the health system* to improve *effectiveness* and capitalise on *funding opportunities* for implementing and sustaining the recommendations of the *National Diabetes Strategy and Implementation Plan*
- a *prioritised research agenda* which reflects needs and deficiencies in our knowledge of diabetes care and prevention

Best practice priorities

- Implement a national Program to Improve the Quality of Diabetes Care - *Recommendation 40*
- Implement a national Diabetes Visual Impairment Prevention Program - *Recommendation 41*
- Implement a national Diabetes End Stage Renal Disease Prevention Program *Recommendation 42*
- Implement a national Diabetic Foot Disease Management Program - *Recommendation 43*
- Implement a national Diabetes Cardiovascular Disease Prevention Program *Recommendation 44*
- Implement a national Early Detection of Type 2 Diabetes Program - *Recommendation 22*
- Implement a national Type 2 Diabetes Prevention Program - *Recommendation 23*
- Develop best practice evidence based guidelines for diabetes prevention and care for health professionals and consumers in collaboration with the NHMRC - *Recommendations 6 and 10*
- Optimise the quality and accessibility of diabetes prevention and care for Indigenous Australians - *Recommendations 45 - 51*
- Optimise the quality and accessibility of diabetes prevention and care for people from non-English speaking backgrounds - *Recommendations 52 - 55*
- Implement a national initiative for the detection and management of gestational diabetes and ongoing monitoring of women who have had gestational diabetes - *Recommendations 24 and 27*
- Conduct a national assessment of the needs of children and adolescents with diabetes *Recommendation 57*

Coordination priorities

- Hold a National Diabetes Summit to obtain wide endorsement of the *National Diabetes Strategy and Implementation Plan* and develop a consensus position on roles and responsibilities for its implementation - *Recommendation 15*
- Form a National Diabetes Task Force to oversee the implementation of the *National Diabetes Strategy and Implementation Plan* - *Recommendation 16*
- Coordinate implementation of the *National Diabetes Strategy and Implementation Plan* by:
    - establishing National Advisory Working Parties to address each of the programs detailed in the *National Diabetes Strategy and Implementation Plan*
    - appointing a *National Diabetes Strategy and Implementation Plan* Medical Director
    - appointing a National Aboriginal Co-ordinator for Diabetes and Lifestyle Diseases to work with Aboriginal and Torres Strait Island communities
    - appointing a National Diabetes Coordinator for non-English speaking communities
    - establishing a national network of programs for lifestyle related non communicable diseases and prevention programs - *Recommendations 18, 19, 39, 45 and 52*

Information priorities

- Conduct a National Diabetes Prevalence Study linked to the National Biomedical Risk Factor Survey - *Recommendation 3*
- Establish the National Diabetes Register for people with insulin treated diabetes and consider expanding it into a comprehensive National Diabetes Register - *Recommendation 1*
- Establish and maintain systems for the collection and management of information to evaluate the effect of implementing the *National Diabetes Strategy and Implementation Plan* - *Recommendations 2 and 4*

Health system priorities

- Explore mechanisms to link funding with performance indicators relevant to access, process and outcomes of diabetes care, eg contracts with State, Territory, and regional health services should include a requirement to provide services which offer the recommended processes of diabetes care and meet agreed diabetes outcome indicators *Recommendation 36*
- Develop and implement mechanisms to reward and reinforce effective practice through financial incentives and professional and organisational accreditation programs *Recommendation 37*
- Establish a Working Party to explore avenues to enhance funding for implementation of the recommendations of the *National Diabetes Strategy and Implementation Plan* *Recommendation 35*

Research priorities

- Convene a National Diabetes Research Working Party with equal representation of the various research disciplines, and consumer representation, to work with the NHMRC Strategic Research Committee to develop a prioritised research agenda for diabetes which covers all aspects of diabetes across the continuum of care - *Recommendations 32 and 33*
- Increase NHMRC research funding for diabetes to reflect its status as a National Health Priority Area - *Recommendation 31*

Recommendations

Section 3: Information

1. Establish the National Diabetes Register for people with insulin treated diabetes and consider expanding it into a comprehensive National Diabetes Register
2. Establish a National Diabetes Information Advisory Group with representation of the NDR, NPHC, NDOQRIN and AIHW to:
   - develop a set of Data Standards for diabetes for incorporation into the National Health Data Dictionary
   - develop mechanisms to promote record linkage to ensure that accurate and comprehensive diabetes data are collected on diabetes mortality and end stage complications ie cardiovascular disease, amputation, blindness and end stage renal disease
   - explore ways of nationally coordinating and pooling diabetes data collection initiatives currently being undertaken and planned for the future (eg a common death certificate throughout Australia with adequate design to allow accurate diabetes coding)
   - establish a diabetes data information clearing house to facilitate access to diabetes data information for consumers, providers and planners
3. Conduct a National Diabetes Prevalence Study linked to the National Biomedical Risk Factor Survey
4. Monitor quality of care processes, and outcomes through:
   - collection of annual cross sectional clinical outcomes information using the NDOQRIN minimum dataset through Divisions of General Practice, the NADC and the National Diabetes Register
   - the Health Insurance Commission, utilising Medicare Item numbers for HbA_{1c}, lipids, microalbuminuria, and retinal screening
5. Develop cost analysis models for utilising diabetes data to provide information about the economic burden of diabetes and cost effectiveness projections of specific interventions

Section 3: Consumer, provider, and public awareness

6. The National Diabetes Task Force to oversee in collaboration with DA, JDFA, the Diabetes Task Force Consumer Reference Group, and NHMRC, the development of:
   - evidence based diabetes guidelines for consumers, or the adaptation of the NSW Health Department Consumer Guidelines, for national application
   - a dissemination strategy which takes account of existing mechanisms and networks such as the NDSS distribution, local pharmacies, and diabetes educational literature and product information prepared by pharmaceutical companies
7. DA to establish a formal mechanism for consumer advocacy, and the handling of complaints, which includes appointing appropriately trained consumer advocates and complaints officers to the National Office and each State and Territory Association.

8. The National Diabetes Task Force to approach undergraduate medical, nursing, and allied health schools across Australia, and the RACGP Training Program, to include core standardised information on diabetes which:
    - clearly differentiates between type 1 diabetes and type 2 diabetes
    - emphasises the serious consequences of undetected or poorly controlled diabetes
    - highlights risk factors, symptoms and diagnostic criteria, and management principles for type 1 diabetes, type 2 diabetes, and GDM
9. Introduce cultural sensitivity training into undergraduate medical, nursing, dietetics, podiatry, and social work courses, and continuing education programs for GPs
10. Identify effective methods of raising consumer awareness of diabetes and evaluate the role of consumers in influencing providers to implement evidence based diabetes clinical practice
11. Conduct a national Community Awareness Program on Diabetes linked to the programs for the prevention and early detection of type 2 diabetes

Section 3: Best practice

12. Develop, in collaboration with the NHMRC, best practice evidence based clinical management guidelines for each of the diabetes prevention and care programs detailed in the *National Diabetes Strategy and Implementation Plan* for implementation through a structured dissemination process which includes undergraduate and relevant postgraduate training programs for medical, nursing and allied health workers throughout Australia
13. Develop and implement incentives for providers to apply the recommended standards of diabetes care
14. Provide incentives for consumers to access recommended standards of care eg discounted self-care supplies for demonstrating participation in annual complications screening

Section 3: Coordination

15. Hold a National Diabetes Summit to obtain wide endorsement of the *National Diabetes Strategy and Implementation Plan* and develop a consensus position on roles and responsibilities for its implementation
16. Form a National Diabetes Task Force to oversee the implementation of the *National Diabetes Strategy and Implementation Plan*
17. Establish the following Reference Groups to represent key stakeholders on the National Diabetes Advisory Committee - Indigenous Australians, non-English speaking background Australians, consumer, childhood and adolescent, medical and scientific, education, and general practice
18. Establish National Advisory Working Parties to address each of the programs detailed in the *National Diabetes Strategy and Implementation Plan*
19. Appoint a *National Diabetes Strategy and Implementation Plan* Medical Director

Section 4: Type 1 diabetes

20. Establish a national infrastructure to support and conduct studies aimed at preventing type 1 diabetes
21. Establish a national infrastructure to support and conduct studies aimed at curing type 1 diabetes

Section 4: Type 2 diabetes

22. Implement a national program for the early detection of type 2 diabetes linked to the Type 2 Diabetes Prevention Program and the Program to Improve the Quality of Diabetes Care
23. Implement a national program for the prevention of type 2 diabetes linked to the Early Detection of Type 2 Diabetes Program

Section 4: Gestational diabetes

24. Establish a National GDM Advisory Committee to develop a National Consensus Position on testing for GDM, and develop and disseminate recommended standards of care and a protocol for the ongoing clinical management of women following a GDM pregnancy
25. Develop a national standardised midwives minimum data set to collect data on GDM
26. Expand the National Diabetes Register to include women with a GDM pregnancy
27. Develop a recall system for targeting women with a GDM pregnancy for ongoing lifestyle advice and monitoring for the future development of glucose intolerance

Section 4: Pregnancy in women with pre-existing diabetes

28. Develop national guidelines for the clinical management of pregnant women with pre-existing diabetes
29. Ensure that diabetic women of child bearing age have access to pre-pregnancy counselling and optimised diabetes control prior to conception
30. Monitor the outcomes of pregnancies in women with pre-existing diabetes through the National Diabetes Register

Section 4: Research

31. Increase NHMRC research funding for diabetes to reflect its status as a National Health Priority Area
32. Convene a National Diabetes Research Working Party with equal representation of the various research disciplines and consumer representation
33. Commission the NHMRC Strategic Research Committee to work with the National Diabetes Research Working Party to develop a prioritised research agenda for diabetes which covers all aspects of the continuum of care
34. Use the agreed research agenda to inform diabetes research funding from government and non-government sources and evaluate and review the research agenda every 5 years

Section 4: Health system

35. Establish a Working Party to explore opportunities to enhance funding for implementation of the recommendations of the *National Diabetes Strategy and Implementation Plan*
36. Explore mechanisms to link funding with performance indicators relevant to access, process and outcomes of diabetes care eg, contracts with State, Territory, and regional health services should include a requirement to provide services which offer the recommended processes of diabetes care and meet agreed diabetes outcome indicators
37. Develop and implement mechanisms to reward and reinforce effective practice through financial incentives and professional and organisational accreditation programs
38. Explore mechanisms to provide incentives to increase consumer participation in best practice
39. Establish a national network of lifestyle related non-communicable diseases and prevention programs

Section 5: Priority programs

40. Implement a national Program to Improve the Quality of Diabetes Care
41. Implement a national Diabetes Visual Impairment Prevention Program
42. Implement a national Diabetes End Stage Renal Disease Prevention Program
43. Implement a national Diabetic Foot Disease Management Program
44. Implement a national Diabetes Cardiovascular Disease Prevention Program

Implement a national Early detection of Type 2 Diabetes Program - *Recommendation 22*
Implement a national Type 2 Diabetes Prevention Program - *Recommendation 23*

Section 6: Indigenous Australians

45. Establish and fund a position for a National Aboriginal Coordinator for Diabetes and Lifestyle Diseases to work closely with the National Diabetes Strategy Secretariat and Working Groups, and Indigenous communities and organisations to implement the recommendations of the *National Diabetes Strategy and Implementation Plan* for Indigenous Australians
46. Strengthen the capacity of Indigenous health services and Aboriginal health workers to provide effective diabetes care and prevention services and monitor the outcomes. This should include:
    - examining the clinical utility and cost effectiveness of providing Indigenous health services with a DCA 2000 analyser and cartridges to perform near patient HbA_{1c} measurement
    - the provision of equipment for :
        - testing for microalbuminuria (Micral strips, DCA 2000 analyser)
        - screening for foot problems
    - the development and implementation of local plans for:
        - screening and treatment of diabetic retinopathy and access to equipment required for screening, and local or regional laser therapy
        - screening of people with diabetes for foot problems

  - screening pregnant women for undiagnosed diabetes and GDM training Aboriginal health workers in diabetes prevention and care and providing them with appropriate resource materials

47. Conduct periodic general health checks to identify a range of disorders, including diabetes and associated health problems (eg overweight, hypertension, microalbuminuria and hyperlipidaemia) every 1-2 years from age 18
48. Improve access to medications and supplies provided under the Pharmaceutical Benefits Scheme and the National Diabetic Services Scheme for rural and remote Indigenous communities
49. Reduce structural and environmental impediments in the food distribution system to increase access to healthy and affordable food. Addressing problems in food distribution should be undertaken in collaboration with the National Public Health Nutrition Strategy
50. Increase levels of physical activity through the provision of recreational facilities, sports and other activities that are community based. Planning and implementation of initiatives to address this recommendation should be linked with the Active Australia campaign
51. Establish principles regarding the choice of treatment of end stage renal disease for Indigenous peoples and improve the provision of, and access to, dialysis and transplantation

Section 6: People from non-English speaking backgrounds

52. Establish and fund a position for a National NESB Diabetes Coordinator to work closely with the National Diabetes Strategy Secretariat and Working Groups, and NESB communities, to implement the recommendations of the *National Diabetes Strategy and Implementation Plan* for people from non-English speaking backgrounds
53. Disseminate information about the current recommendations for diabetes clinical care and self-care in community languages eg:
    - translate into the major community languages the ‘best practice’ consumer diabetes guidelines developed under the *National Diabetes Strategy and Implementation Plan*
    - advertise diabetes clinical care and self-care recommendations through community language newspapers nationally
54. Diabetes Australia to print the National Diabetic Services Scheme forms into the major community languages
55. Establish and maintain a clearing house and resource directory of teaching materials and other resources for the care of non-English speaking people with diabetes. Diabetes Australia would be an appropriate organisation to operate this service

Section 6: People living in rural and remote Australia

56. Regional health services to develop local strategies to implement the *National Diabetes Strategy and Implementation Plan* including:
    - coordination of regional activities to prevent fragmented service delivery
    - ensuring access for people with diabetes living in rural and remote areas to support services similar to those available to their urban counterparts
    - collection of local diabetes information
    - provision of training programs for local health professionals
    - development of partnerships between local clinicians and major specialist centres

Section 6: Children and adolescents

57. Conduct a national assessment of the needs of children and adolescents with diabetes
58. Develop specific guidelines and protocols on the clinical care, monitoring, and complication screening and treatment for children and adolescents with type 1 diabetes. This should include recommendations for transition from paediatric to adult services and protocols for diabetes management in children attending school
59. Conduct regular collection and national pooling of glycaemic control and complications data on children and adolescents with diabetes every 5 years using standardised data sets
60. Ensure that diabetes care for children and adolescents with type 1 diabetes is provided by a specialist team with expertise in the management of children with type 1 diabetes
61. Focus research efforts on:
    - the prevention and cure of type 1 diabetes
    - complication prevention and reduction
    - reducing the impact of diabetes on quality of life
    - developing non-invasive blood glucose monitoring technology
    - improving monitoring to detect and prevent severe hypoglycaemia

Section 6: The elderly

62. Implement strategies to improve the quality of care of elderly people with diabetes admitted to hospital and who reside in aged care facilities or hostels

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Section 1 The framework

- **Introduction**
- **Mission**
- **Vision**
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- **The Framework**

The framework

Introduction

Why do we need a National Diabetes Strategy and Implementation Plan?

Diabetes is a common, chronic and costly disease which incurs an enormous personal and public health burden. If undetected or poorly controlled, it can result in debilitating long term complications such as blindness, kidney failure, amputation, heart attack, stroke and erectile dysfunction. An estimated 780,000 Australians have diabetes (ABS 1997). Of these approximately 430,000 have diagnosed diabetes and another 350,000 have undiagnosed diabetes. McCarty et al (1996) predict that diabetes is likely to affect 900,000 Australians by the year 2000 and 1.2 million by 2010. Further, they estimate the direct annual health care costs for diabetes in Australia may have been as high as $1.4 billion in 1995 and may reach $2.3 billion by the year 2010.

In an effort to focus attention on this problem**,** the ADS initiated the development of the *National Action Plan to the Year 2000 and Beyond* (NAP) which was published in 1993. This document put forward a well researched rationale and proposed goals and associated general strategies for reducing the burden of type 2 diabetes. It was responsible for raising government and public consciousness of the national burden imposed by diabetes but initially had no assurance of specific funding for implementation.

The NAP did not include type 1 diabetes or gestational diabetes. Since 1993, there have been advances in research which have improved the status of knowledge about diabetes. In addition, a number of Australian initiatives which impact substantially on the organisation and delivery of diabetes prevention and care have been introduced or expanded. Some of these are outlined in Section 2 under current policies and programs.

Policy context

The *National Diabetes Strategy and Implementation Plan* was conceived and developed in consciousness of the need for accountability for both the public cost and the effectiveness of health services and the need for improved coordination and integration at all levels of the health system.

There has been a growing perception that the health and financial burden of diabetes warrants the same level of strategic planning and coordination as cancer, cardiovascular disease, injury and mental health. In 1996, recognising the impact of diabetes on the Australian community, the Australian Health Ministers agreed to the inclusion of diabetes as the fifth National Health Priority Area and additional funding was allocated to support a national initiative to improve the health outcomes of people with diabetes. Given the status of diabetes as a National Health Priority Area, and the changes which have occurred over the past few years, the development of a *National Diabetes Strategy and Implementation Plan* to include type 1 diabetes and gestational diabetes as well as type 2 diabetes is indeed timely.

What is the National Diabetes Strategy and Implementation Plan for?

The purpose of the *National Diabetes Strategy and Implementation Plan* is to provide a strategic evidence based framework to guide the funding, planning, provision, organisation, and monitoring of services for people with or at risk of type 1 diabetes, type 2 diabetes, and gestational diabetes.

The *National Diabetes Strategy and Implementation Plan:*

- defines broad goals
- outlines effective strategies for specific intervention points
- describes models to optimise the availability and effectiveness of care
- highlights areas which require further research and development
- suggests an organisational structure for sustaining and integrating diabetes prevention and care services and policy, and linking these with initiatives for related health problems

Who is the National Diabetes Strategy and Implementation Plan written for?

It is recognised that the sphere of influence and action varies among the different components of our health and health support systems. For example, policy makers, funders, public health practitioners, public and private clinicians and educators, researchers, consumer and professional bodies, non-government organisations, commercial interests such as pharmaceutical companies, and local health planners and administrators all have widely diverse needs for information and guidance.

The *National Diabetes Strategy and Implementation Plan* is designed to illustrate the way forward for all these groups by proposing a core set of common goals, recommendations and practical implementation plans to guide collective national action, at both the practice and the policy level, towards reducing the personal and public impact of diabetes in Australia.

The document does not specifically target people with diabetes as a reader audience but, ultimately, the *National Diabetes Strategy and Implementation Plan* is not about health bureaucracies, organisations, or stakeholder groups. Rather, it is about people who have diabetes, those who care for people with diabetes, and people who are at risk of developing diabetes in the future.

What is its focus?

While there are some deficiencies in the available information, there is a good evidence base and body of expert knowledge about what is required to improve diabetes outcomes. It is time to act to ensure that the recommended standards are available to all Australians who need care, and to decrease the gaps in our knowledge about what works and what does not.

The focus of the *National Diabetes Strategy and Implementation Plan* is on motivating purposeful and cohesive action by defining what needs to be done to improve outcomes for type 1 diabetes, type 2 diabetes, gestational diabetes, establishing a goal directed and appropriately resourced research program for diabetes, and improving the effectiveness of the health system.

The emphasis of the *National Diabetes Strategy and Implementation Plan* is on information, ‘best practice’, and coordination. It seeks to bridge the gap between intellectual rationale and implementation by suggesting practical, planned, strategic and coordinated, task oriented action to achieve the goals and improve the effectiveness and accessibility of diabetes prevention and care services across the nation.

Mission

The mission of the *National Diabetes Strategy and Implementation Plan* is:

> to ensure socially equitable access to effective, efficient, evidence based, and economically viable services and programs for diabetes prevention and care for all people living in Australia

Vision

It is anticipated that pursuit of this mission will result in a system of diabetes prevention and care in the future which:

- is efficient, responsive, outcomes oriented and based on evidence of effectiveness
- is population focussed but also addresses the needs of individual consumers and communities and encourages their participation in decision making about the nature of the health services they require
- places greater emphasis on prevention and population risk reduction by involving the wider community in creating an environment which makes healthy lifestyle choices not just available but the easy option
- recognises the role of primary health care providers in the prevention and care of diabetes
- moves from traditional models of professional role delineation between the health disciplines to truly interdisciplinary care which first identifies the task to be done, then defines the level of competency required to perform the task, and next asks who is able, available or can be suitably re-skilled to deliver the required level of care
- accommodates social, cultural, demographic and geographic variations by maintaining choice from a range of models, methods, activities and resources which produce similarly positive outcomes but may be more or less suited to different circumstances
- is underpinned by comprehensive and coordinated research programs which systematically identify and address deficits in knowledge about all aspects of diabetes prevention and care, and which seek and reflect consumer perspectives
- makes relevant clinical information available to the full range of health carers providing continuing and episodic care to individuals with diabetes or with risk factors for diabetes
- links effective processes to effective outcomes through comprehensive monitoring and reporting systems
- can be evaluated on a range of relevant indicators against standardised outcome criteria including risk reduction, morbidity, mortality, health related quality of life, functional status, satisfaction, and cost

Goals

The goals of the *National Diabetes Strategy and Implementation Plan* are designed to reflect and focus attention on the key areas which need to be addressed to reduce the impact of diabetes on individuals with or at risk of diabetes, and the Australian community.

Goal 1: Prevent or delay the development of type 1 diabetes and type 2 diabetes

Goal 2: Improve health related quality of life, and reduce complications and premature mortality in people with type 1 diabetes and type 2 diabetes

Goal 3: Achieve maternal and child outcomes for gestational diabetes, and for women with pre-existing diabetes, equivalent to those of non-diabetic pregnancies

Goal 4: Achieve progress towards a cure for type 1 diabetes

Goal 5: Advance knowledge and understanding about the prevention, cure, and care of diabetes through a comprehensive research effort

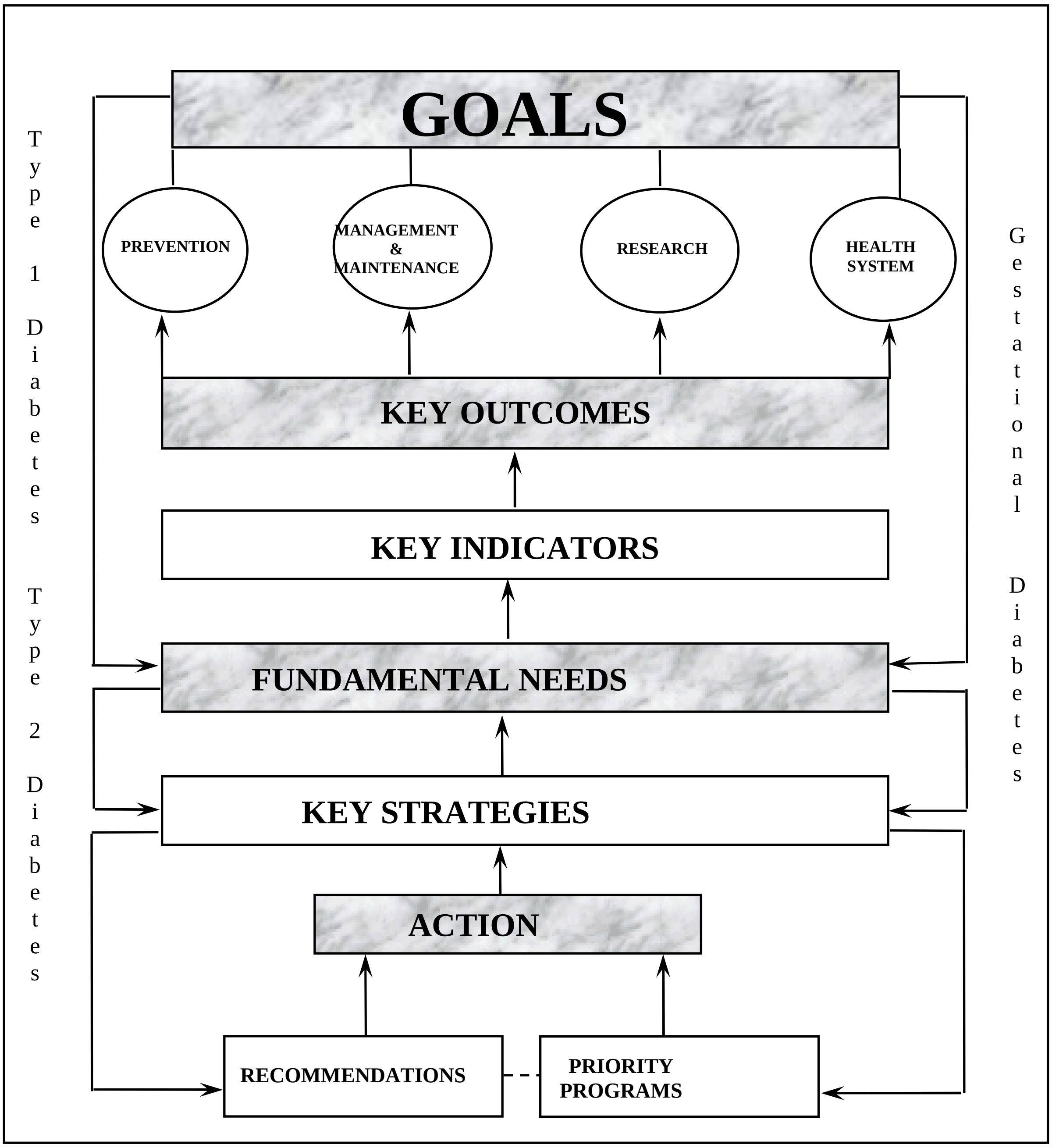
Goal 6: Improve the capacity of the health system to deliver, manage and monitor services for the prevention of diabetes and the care of people with diabetes

Note: *The Goals are numbered for convenience only. The numbering does not denote a hierarchy of importance and has no implications for priority.*

The Framework

The framework for the *National Diabetes Strategy and Implementation Plan* (Figure 1) consists of broad goals, key outcomes, indicators, needs and intervention points, generic strategies, and general recommendations which point to the required action. As a focus for this action a number of priority programs, each of which contributes to one or more of the goals and includes a range of strategies, have been developed in an 'action plan' format. These priority programs are designed to clearly define the tasks that need to be undertaken. While they illuminate specific pathways for addressing identified problems, there is flexibility to allow for local variations in population needs and practice contexts.

Figure 1: National Diabetes Strategy Framework



Goals

The goals centre on attaining health gain for diabetes through primary prevention; improving health and related quality of life, ie reducing premature morbidity and mortality by delaying or preventing the onset of diabetes complications; curing type 1 diabetes; increasing our knowledge about improving diabetes outcomes; and increasing the capacity of the health system to deliver, and monitor diabetes prevention and care services with optimal effectiveness and efficiency. Rather than classifying the stages of the health care continuum under the traditional headings of primary, secondary, and tertiary prevention, the framework has adopted the concept of (primary) prevention, (disease) management, (health status) maintenance, and systems (NHIMG, 1997).

The order in which the goals appear does not relate to their value. Goals 1 to 4 are *primary goals* which focus on type 1, type 2 and gestational diabetes across the continuum of care. Goals 5 and 6 are *systems goals*, and are no less important as they concentrate on research and health system organisation which underpin achievement of the primary goals. Together, the goals represent a strong statement of intent to crystallise attention on what needs to be achieved, and provide a foundation for the operational framework and implementation plans which follow.

Primary goals

Goal 1: Prevent or delay the development of type 1 diabetes and type 2 diabetes

Goal 2: Improve health related quality of life, and reduce complications and premature mortality in people with type 1 diabetes and type 2 diabetes

Goal 3: Achieve maternal and child outcomes for gestational diabetes, and for women with pre-existing diabetes, equivalent to those of non-diabetic pregnancies

Goal 4: Achieve progress towards a cure for type 1 diabetes

Systems goals

Goal 5: Advance knowledge and understanding about the prevention, cure, and care of diabetes through a comprehensive research effort

Goal 6: Improve the capacity of the health system to deliver, manage and monitor services for the prevention of diabetes and the care of people with diabetes

Key outcomes

A general description of the key outcomes which can be anticipated as a result of achieving the goals of the *National Diabetes Strategy and Implementation Plan* is provided.

Due to the deficiencies in the available baseline information, targets have not been set at this level of the framework. Instead they have been articulated as ‘Expected Outcomes’ which encompass the key outcomes and processes relevant to each priority program described in Section 5, and the areas on which the goals of the *National Diabetes Strategy and Implementation Plan* are focussed (see Section 4).

Key Outcomes

- A reduction in the development of risk factors for diabetes in the healthy population
- A reduction in modifiable risk factors for diabetes in the at risk population
- A reduction in the prevalence and incidence of type 1 diabetes and type 2 diabetes
- A reduction in the incidence of complications in people at diagnosis of type 2 diabetes
- A reduction in blindness, amputation, end stage renal disease, cardiovascular disease in people with diabetes
- A reduction in complications of pregnancy associated with diabetes
- Progress towards a cure for type 1 diabetes
- A comprehensive national information system to monitor the processes, outcomes, and cost of diabetes
- A sound evidence base of knowledge about the effectiveness of interventions and models for diabetes prevention, cure, and care including educational and psychosocial aspects
- An integrated, effective and efficient health system for diabetes

Key indicators

Following from the key outcomes, key indicators to measure progress towards attainment of the goals of the *National Diabetes Strategy and Implementation Plan* will include:

- the prevalence of overweight, physical inactivity and inappropriate nutrition in the general population
- the proportion of the “at risk” population in whom modifiable risk factors are reduced
- the incidence and prevalence of type 1, type 2, and gestational diabetes
- the proportion of people with diabetes who:
    - have heart disease
    - have strokes
    - have impaired vision
    - have end stage renal disease
    - have amputations
    - die as a result of diabetes

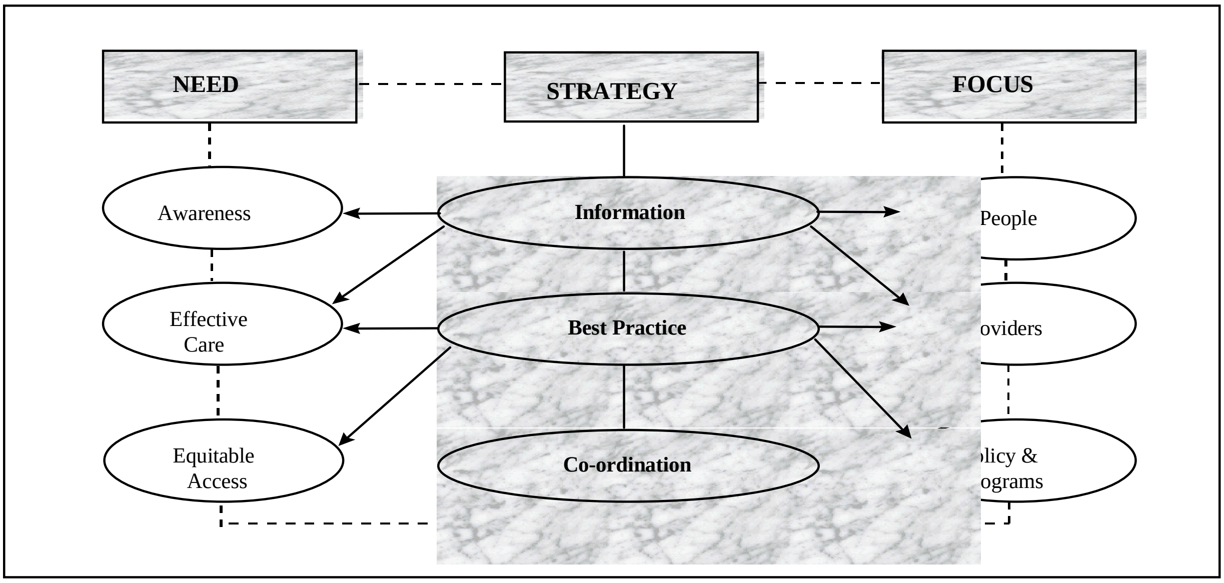
- The outcomes of pregnancies complicated by diabetes
- A prioritised research agenda for diabetes which addresses prevention, cure and care
- The status of diabetes and related data collection, linkage, and use
- The extent of the coordination and integration of diabetes prevention and care, and linkages between diabetes and related major health improvement initiatives

Fundamental needs

Figure 2 illustrates the relationship of fundamental needs, key generic strategies and their focus or target areas. Broad strategies for creating positive shifts in the indicators listed above are based on the identification of three fundamental needs which must be addressed. They are the need to:

- promote consumer and provider *awareness* of diabetes prevention and care
- improve the *quality and effectiveness* of diabetes prevention and care
- increase *access* to effective services and programs for diabetes prevention and care

Figure 2: The relationship of needs, strategies and focus areas



Key strategies

Consistent with the National Health Information Management Group Framework (NHIMG, 1997) the key, generic strategies cross the continuum of care from *primary prevention*, the *management* and *maintenance* of health problems, and include the *systems* which underpin the provision of health care. They target *people* ie the general population, the high risk population, and people with diabetes; *providers*, including clinicians and public health practitioners; and *policy and programs* to address the key needs by focussing on:

- information
- best practice
- coordination

More specific strategies which flow from these generic components include informing and skilling the health and related workforce to develop and implement 'best practice', and the establishment of mechanisms for developing, enabling and rewarding effective practices.

The role of *information* is multi-faceted. It encompasses creating public awareness of diabetes, risk reduction strategies, symptoms, screening points and criteria; educating consumers about self-care and their entitlement to appropriate professional care and support services; ensuring that information is culturally sensitive and geographically accessible; raising provider consciousness of the impact of diabetes; collecting, assessing, and disseminating information on health care processes and outcomes, and generating rigorous scientific, clinical, psychosocial, educational and service organisation data to inform best practice and policy.

Evidence based practice refers to applying interventions and methods which are grounded in evidence of effectiveness as measured by health gain. The cost of some effective interventions may be substantially higher than others in which case the extent of the health improvement must be evaluated against financial costs on a population basis. Evidence based practice has significant implications for provider accountability and improving access to effective and timely care, and should apply equally to clinical practice, health and related policy, and resource allocation. However, 'best' or evidence based practice is currently limited by information deficits which may be difficult to address in some instances due to practical or ethical constraints or because of a lack of suitable methods for addressing issues and aspects of health care which do not readily lend themselves to traditional methods of analysis.

Monitoring the implementation of 'best practice' presents methodological challenges and there needs to be continuing commitment to the generation of new treatments and interventions and the evaluation of their effectiveness in comparison to currently accepted 'best practice'. In the interim, where evidence of effectiveness is weak or absent, consensus expert opinion can be utilised as a guide while strategic research is directed towards filling knowledge gaps.

Systematic *coordination* of services, policy, and planning across the continuum of care within and between government, and non-government organisations, and across disease entities and health disciplines may be the most essential ingredient for improving awareness, effectiveness of care, and access to care. The focus should be on producing tangible outcomes through the definition of common goals and objectives and agreed indicators.

Obtaining optimal results will depend largely on our ability to reduce duplication and fragmentation and will require systematic:

- delineation of roles between Commonwealth and State/Territory Health Departments; primary, secondary and tertiary health services; and between health disciplines
- collaboration within the health sector, between related government jurisdictions
- vertical (within disease entities) and horizontal (across disease entities) integration of policy, planning, and service provision
- collecting and sharing audit and research information.

Key intervention points

Classically, the key intervention points for diabetes follow the continuum of care. They are listed below with specific strategies aimed at optimising the outcomes of each phase of the disease process. Table 1 illustrates key intervention points and proposes the associated action required by defining 'key tasks' for each stage of the continuum. For example:

No diabetes

- Population strategies to prevent the development of risk factors in healthy people
- Public awareness of risks
- Risk identification and risk reduction interventions

Pre diabetes

- Identification of susceptible individuals
- Research and preventative interventions targeting the at risk population

Undiagnosed diabetes

- Public awareness of symptoms
- Early detection ie identifying and screening people with risk factors

Known diabetes

- Access to quality clinical care and education at diagnosis and on an ongoing basis
- Access to regular monitoring of diabetic and general health status and appropriate management of problems as they arise
- Active identification and reduction of risk factors for diabetes complications
- Active identification and treatment of diabetes complications
- Rehabilitation of people with complications
- Palliation of end stage complications

Table 1: Key intervention points and associated required action and tasks

KEY INTERVENTION POINTS	ACTION - KEY TASKS
No diabetes*	Prevent the healthy population from developing risk factors Increase public awareness of risk factors, the significance of risk factors, and risk reduction strategies
Pre diabetes	Reduce risk factors in the 'at risk' population * Support goal directed research into causes and preventative interventions
Undiagnosed diabetes*	Increase public awareness of symptoms, risk factors and screening points Implement programs for: - active identification and screening of people with risk factors - opportunistic screening of people with risk factors - population screening for high risk groups
Known diabetes	
• At diagnosis	Provide: - clinical care according to guidelines - education in self care - information about recommendations for clinical care
• Established uncomplicated diabetes	Provide services for: - routine monitoring of diabetic and general health status - regular screening for complications - management of problems as they arise - reinforcement of self care education Implement programs for: - identification and reduction of risks for diabetes complications including assessment of diabetic status in people with diabetes who are admitted to hospital for any reason - self care education and psychosocial support Support goal directed research aimed at curing diabetes
• Diabetes with complications	Provide services for: - prevention of the progression of complications - self care education and psychosocial support - rehabilitation of people with disabilities - palliation for people with end stage complications Support goal directed research aimed at the reversal of complications

**Note: Given the current status of knowledge these cannot yet be usefully applied to type 1 diabetes*

Action

Recommendations

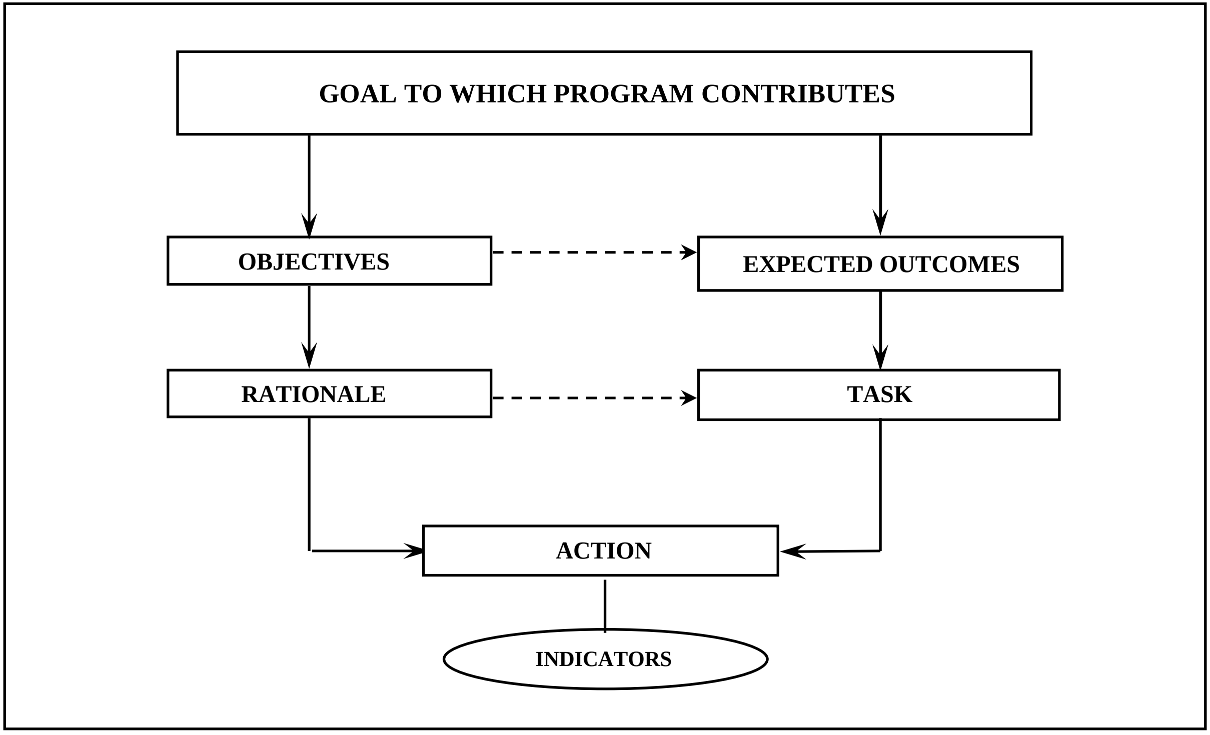
The recommendations of the *National Diabetes Strategy and Implementation Plan* are based on the key needs across the continuum of prevention, management and maintenance, and by addressing deficiencies in the health system. These recommendations are aimed at bringing about sustainable long term changes to the structure and organisation of care and target improvements in information, best practice and coordination.

Priority programs

For the most part, the purpose of the *National Diabetes Strategy and Implementation Plan* is to make recommendations which include priorities for action but leave explicit implementation plans to be developed by the appropriate organisation, expert advisory group, or agency. However, to demonstrate clearly defined pathways and processes for making progress towards the achievement of the stated goals, specific plans for priorities and programs which encompass a range of more detailed strategies are included in Section 5 and follow the format shown in Figure 3. These are based on a prioritisation framework (adapted from DHS&H, 1994) which examines:

- the impact and extent of the problem
- the feasibility of intervening successfully
- the potential benefit to be gained by intervening

Figure 3: Format for priority programs



Structure of the document

The *National Diabetes Strategy and Implementation Plan* document is divided into separate sections which can be accessed independently. They are:

- **Section 1** *The Framework* for the strategic implementation plan based on the broad goals
- **Section 2** *The Current Situation* with regard to diabetes in the Australian context
- **Section 3** *Imperatives for Change* which examines policy and infrastructure issues
- **Section 4** *Type 1 Diabetes, Type 2 Diabetes, GDM*, *Research,* and the *Health System*
- **Section 5** *Priority Programs*, outlining a rationale and plans for priority action areas
- **Section 6** *Groups with Special Needs*, focussing on disadvantaged groups
- **Section 7** *Economic Considerations*, exploring the cost implications of diabetes, its complications, and intervention programs

Section 2 The current situation

- **Introduction**
- **About diabetes: an overview**
- **People**
- **Providers and organisations**
- **How diabetes services are delivered now**
- **Policy and programs**
- **Barriers and strengths of the current system**

The current situation

Introduction

Planning for improvements to the outcomes of diabetes prevention and care necessitates an understanding of how and by whom diabetes services are delivered now, and awareness of existing or planned policies and programs with potential to impact on diabetes outcomes. This Section of the *National Diabetes Strategy and Implementation Plan* presents a brief overview of the current situation including:

- ***About diabetes*** summarising the three main types of diabetes found in Australia and which are the subject of the *National Diabetes Strategy and Implementation Plan*
- ***People*** briefly describing the size and general composition of the Australian population, and highlighting some relevant population trends
- ***Providers and organisations*** list the main categories of health professionals directly involved in the care of people with diabetes. Providers and diabetes specific services are described more fully in Appendix 2 which also presents a profile of the range, roles, and relationship of the professional and consumer organisations for diabetes in Australia
- ***How are diabetes services delivered now*** listing the main models for the delivery of diabetes care commonly used in Australia and in most Western countries
- ***Policy and programs*** illustrating some of the key initiatives which have developed since the NAP was published in 1993, and highlighting the important potential of these developments to increase coordination and integration of diabetes prevention and care services and initiatives
- ***Barriers and strengths*** summarising the principal obstacles and limitations to be negotiated in the current system in order to achieve improved diabetes outcomes, and outlines positive aspects of the present system

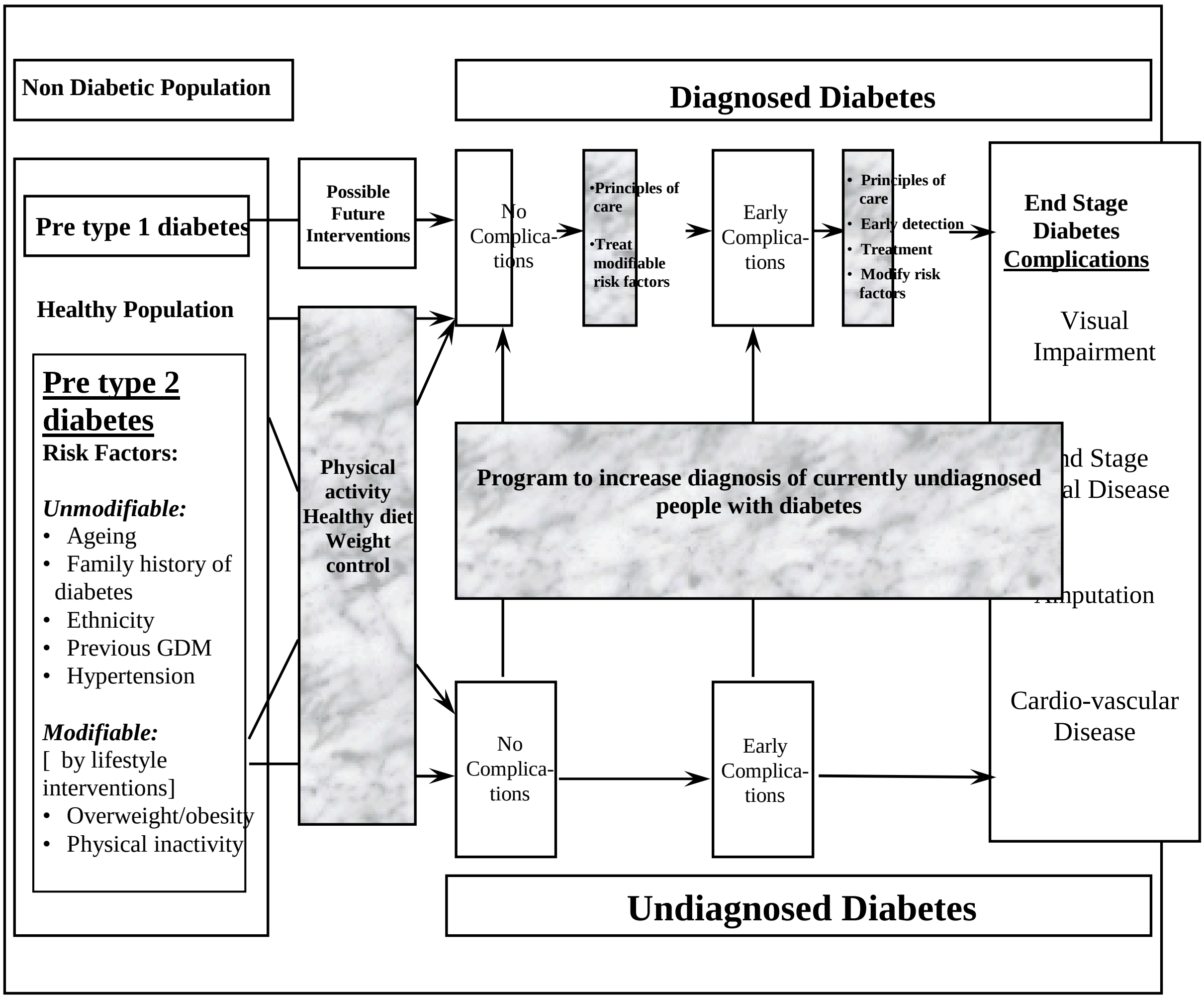
About diabetes: an overview

Diabetes mellitus is a serious and growing health problem in Australia and can result in major irreversible long term microvascular, macrovascular and neuropathic complications. These complications are predominantly due to persistent hyperglycaemia, however, lipid disturbances and hypertension are important contributing factors. There are three main types of diabetes which affect people living in Australia - type 1 or insulin dependent diabetes, type 2 or non-insulin dependent diabetes, and gestational diabetes (GDM).

The natural history of diabetes includes a number of distinct stages which provide an opportunity for intervention (Figure 4). Both type 1 diabetes and type 2 diabetes have a pre diabetic state, and stages in which there are:

- no diabetes specific complications
- early complications
- end stage complications

Figure 4: Stages of diabetes and associated population interventions



Progression through these stages is not inevitable. Improving the quality of diabetes care, including the identification and reduction of risk factors for complications, can prevent the development or progression of complications. In addition, the primary prevention of diabetes is becoming increasingly viable.

Type 1 diabetes

Type 1 diabetes is an auto-immune disease in which the body’s immune system reacts against and destroys the insulin-producing beta cells in the islets of the pancreas. Type 1 diabetes accounts for 10-15% of all people with diabetes and, although it is one of the most common chronic conditions of childhood, can occur at any age. It results in significant public and personal health problems and it is essential that this burden is considered in population focussed approaches to improving diabetes outcomes.

Despite a lack of known modifiable risk factors, the current state of knowledge about the primary mechanisms for the development of type 1 diabetes and recent research into the identification of early markers and immune therapy to prevent its clinical manifestation, combine to make type 1 diabetes increasingly amenable to future preventative interventions.

Type 2 diabetes

Type 2 diabetes is the commonest form of diabetes, affecting 85-90% of all people with diabetes. It is characterised by insulin resistance and relative insulin deficiency. Lifestyle factors such as overweight, inactivity and diet predispose to its development. While the prevalence varies among different populations, type 2 diabetes is one of the most common chronic diseases in the world and is increasing at an alarming rate, especially in developing countries. Its overall prevalence in Australia is approximately 4%, increasing towards 10% in people over the age of 65 years and up to 20% in some Aboriginal communities. Surveys suggest that there are as many people with undiagnosed as with diagnosed type 2 diabetes. People with type 2 diabetes are at high risk of macrovascular disease, having a twofold incidence of cardiovascular disease compared to the non-diabetic population. They are also prone to the full range of microvascular complications.

There is growing evidence that the onset of type 2 diabetes can be prevented or delayed, and several major studies are currently assessing the relative merits of a variety of interventions aimed at improving nutrition, reducing overweight and obesity, and increasing physical activity. A number of pharmacological interventions aimed at the primary prevention of type 2 diabetes are also being studied.

Treatment of type 1 diabetes and type 2 diabetes

Dietary modification is the cornerstone of the treatment of all diabetes but pharmacological therapy differs according to the type of diabetes. Type 1 diabetes requires the self administration of insulin, usually two to four times daily, while type 2 diabetes may be treated by dietary modification alone or in combination with oral hypoglycaemic agents. For many people with type 2 diabetes, oral therapy becomes ineffective after a time and insulin injections are required.

Gestational diabetes mellitus

GDM is carbohydrate intolerance of variable severity which is first diagnosed during pregnancy, and is frequently cited as the commonest complication of pregnancy. The diagnosis is established by performing an oral glucose tolerance test during the pregnancy. In Australia, current rates of GDM range from 5.5% to 8.8%, with women from a Caucasian background having rates of 3% to 5%. GDM rates may be as high as 20% in Aboriginal women and in women from high risk ethnic populations e.g. India, Asia, Pacific Islands. Risk factors for GDM include a history of diabetes in a first degree relative, increasing maternal age, obesity and being a member of a community/ethnic group with a high risk of developing type 2 diabetes.

While the carbohydrate intolerance usually returns to normal in the immediate postpartum period there is a significant chance of the subsequent development of permanent diabetes in the mother, and an increased chance of the baby developing obesity and impaired glucose tolerance and/or diabetes later in life. Women affected by GDM and their children are an important target for diabetes prevention programs.

Treatment of gestational diabetes

In addition to appropriate obstretric management of the pregnancy, careful monitoring of diabetes control is required to guide the clinical care of GDM. Self care education and dietary management are integral to the achievement of optimal outcomes. Because oral hypoglycaemic medications are contra-indicated during pregnancy, insulin is required to treat women with GDM if normoglycaemia cannot be achieved by dietary modification.

Prevalence of diabetes

The 1995 ABS National Health Survey indicates that 430,700 Australians have self reported diabetes (ABS, 1997). In addition there is an estimated one undiagnosed person with type 2 diabetes for each diagnosed person. Therefore, the total diabetic population is estimated to be 780,000 (4.3% of the total population) of whom approximately 80,000 have type 1 diabetes and 700,000 have type 2 diabetes. Since 1990 the number of people with diabetes has increased from 650,000 (3.8%). By the year 2000 diabetes is predicted to affect 900,000 Australians and 1.15 million by 2010 (McCarty et al, 1996).

Personal impact of diabetes

For the individual, the impact of a diagnosis of diabetes is substantial and dictates the need for considerable lifestyle modification. This includes the planning and timing of meals, frequent self measurement of blood glucose, the administration of insulin or hypoglycaemic tablets, adjustments and precautions for exercise, and the avoidance of short term complications such as hypoglycaemic episodes. In addition to the health threats diabetes imposes on the individual, quality of life and personal confidence are also threatened by issues such as:

- the need to depend on others for assistance
- public confusion between type 1 diabetes and type 2 diabetes
- public misconceptions about dietary requirements, the misconception that diabetes is ‘catching’, or is ‘self inflicted’ eg by eating too much sugar
- deciding ‘who to tell’ about having diabetes eg family, friends, co-workers, employers
- feelings of loss of control and embarrassment associated with ‘hypos’, particularly when they occur in social situations or the workplace
- having to inject or self test blood glucose away from home
- inflexible self care requirements which interfere with work, sporting, or social activities eg having to eat at regular intervals
- difficulties with obtaining and renewing drivers licences
- ‘out of pocket’ costs for medications, supplies, and equipment
- discrimination in life and travel insurance, and in the workplace
- exclusion from certain sports and from employment in certain job categories, eg people treated with insulin are precluded from scuba diving and from driving public passenger vehicles

The public cost of diabetes

The direct cost of diabetes in Australia has been estimated at $1.2 billion per year and is predicted to reach at least $2.3 billion by the year 2010 (McCarty et al, 1996). The complications of diabetes are responsible for most of this cost. Achieving early diagnosis, and improving the effectiveness and accessibility of diabetes care to prevent, or at least delay, complications will have the greatest immediate impact on the community burden of diabetes related human and economic costs. In the longer term, strategies to prevent the development of diabetes will also contribute to reducing the financial and personal impact of diabetes.

What is required for effective diabetes care

From the literature and from expert consensus, three main areas of diabetes care have been identified as the key components of effective diabetes care. Colagiuri R et al, (1995) postulated that the health outcomes of people with diabetes could be significantly improved if all people with diabetes have access to:

- opportunities for self care education and skills training
- routine monitoring of clinical status to promote optimal diabetes control
- regular screening to facilitate the early detection and appropriate management of complications

While many people with diabetes are already able to access this level of care, many are not. The task therefore, is to ensure socially, culturally, and geographically equitable access to recommended standards of diabetes care for all Australians. The background population context in which the task must be accomplished is described in the next segment.

The people

The size of the population

The estimated resident population of Australia at 31 March 1997 was 18,492,000 (ABS, 1997). Australia’s population is small in world terms at 0.3% of the world’s population in 1994. This is in contrast to the USA which had 5% and China with 21% of the world’s population.

The Indigenous population

The Indigenous population is estimated at 2% of the total Australian population (372,100 individuals at 30 June 1996). NSW has the highest number of Indigenous people (106,300) which is 1.7% of the total NSW population. The Northern Territory has the highest Indigenous population as a proportion of the total population (27.7% ie. 49,600 individuals).

The immigrant population

The overseas born population was estimated at 4.2 million in 1996 which was 23% of the total Australian population. The proportion of the total Australian population born overseas has increased since 1976 (20%) and the make-up of the overseas born population has changed. People from UK and Ireland still form the largest group, however, their number as a proportion of the total overseas born population has fallen from 41% in 1976 to 29% in 1996. There has also been a decline in the size of populations from other European countries. The Asian born population has grown rapidly. In 1996, 22% of all people born overseas but now residing in Australia were from Asian countries with Vietnam providing the largest Asian birthplace group.

Growth of the population

The average annual rate of growth in the Australian population (1.1%) is lower than the world population growth rate of 1.6%, and lower than most of our neighbouring countries in Southeast Asia and Oceania (ABS,1997). Australia s population is projected to grow to between 22.5 and 23.9 million in 2021.

Trends in ageing

The already evident ageing of the Australian population is set to continue with the population aged 65 years and over projected to increase substantially in the next century. As population growth slows, the population progressively ages and the median age will increase from 34 years in 1995 to between 40 and 41 years in 2021. By 2021 approximately 17.5 % of Australia's population are predicted to be aged 65 years or over. As a result of declining mortality and increase in life expectancy, the proportion of these people aged 85 years and over is also projected to increase significantly since the 6% growth rate in this group is well above the growth rate for the Australian population as a whole (ABS 1997).

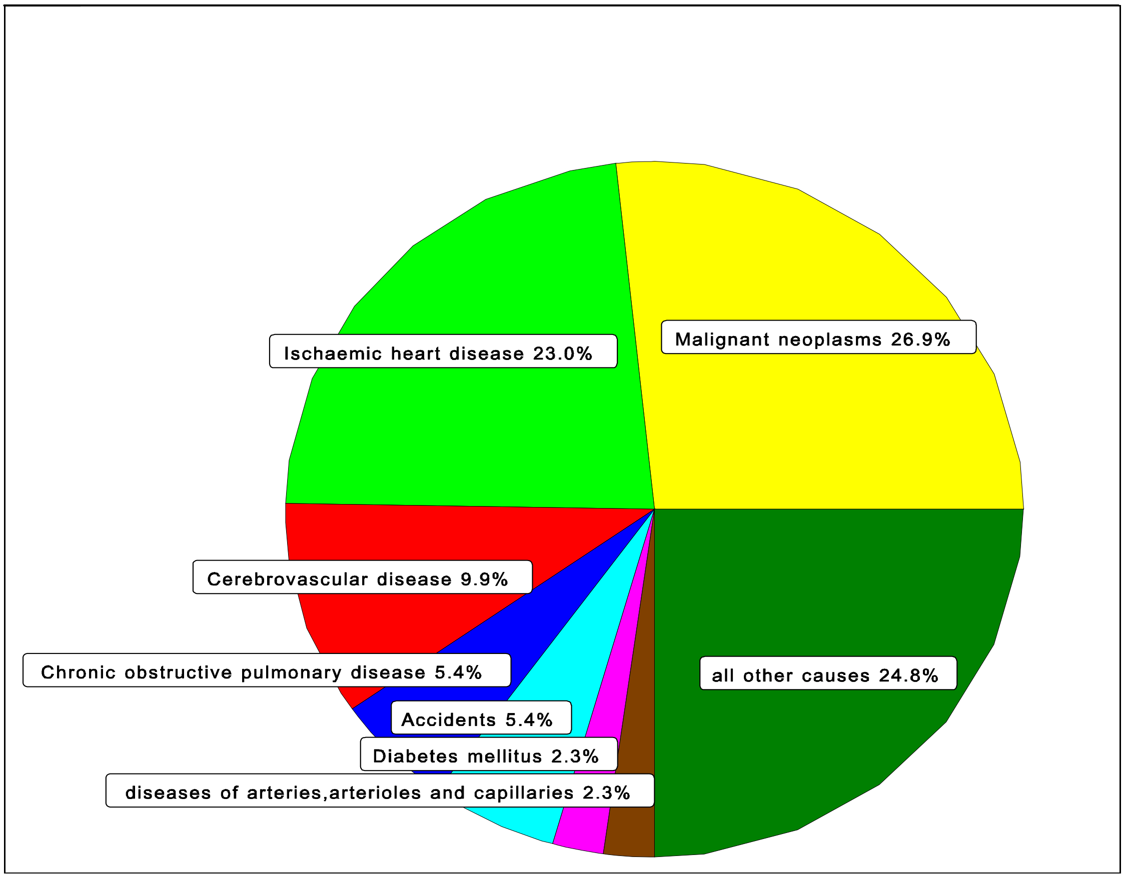
Distribution of the population

The population of Australia is concentrated in urban areas in two main coastal strips which are located in a crescent shape in the east and south-east through Queensland, NSW, Victoria and South Australia; and a smaller region in the south west coast of Western Australia. These regions are widely separated by 3,000 kilometres of sparsely populated land with neither extending more than about 300 kilometres inland. Within these regions, the population is mainly concentrated in the capital cities and large conurbations. The most urbanised states are NSW with 88% of the population living in urban areas at the 1991 census, Victoria with 87% and Western Australia with 86% (ABS, 1997) .

Mortality

Despite the high mortality rates of Indigenous Australians, overall Australian mortality rates are low by world standards. Australia has a higher than average life expectancy, and in 1990 ranked ninth and seventh of 24 countries for males and females respectively; this is approximately equal to Canada, but ahead of both the United States and the United Kingdom (Taylor & Salkeld, 1996). Cancer and ischaemic heart disease have remained the two leading causes of death in Australia in the last decade (Figure 5) although the standardised death rate for ischaemic heart disease continues a long term decline. There has been an increase in the standardised death rate for diabetes, consistent with the higher contribution to the total number of deaths in 1996 than in 1987 (ABS, 1996). The ABS currently reports only underlying causes of death, which refers to the disease or complication which led directly to death. With an ageing Australian population, conditions commonly found in older persons are increasingly important causes of death. The ABS is currently developing an approach to the analysis and presentation of multiple causes of death data to better examine mortality patterns.

Figure 5: Leading Causes of death as a proportion of total deaths



Deaths due to diabetes

Diabetes was identified as the direct cause of death for 2,708 persons, accounting for around 2% of deaths in 1995 making it the seventh leading cause of death that year (ABS, 1997). This represents only the deaths directly attributable to diabetes, and is therefore an underestimate of the true mortality due to diabetes because it is recognised that diabetes is substantially under-reported in mortality data (Whittall et al, 1990). Diabetes is often mentioned as a contributory cause on death certificates, but the underlying cause is more frequently coded as cardiovascular disease or renal disease. Diabetes was mentioned on 8,839 death certificates in 1995, and therefore may have contributed to 49.0 deaths/100,000 population (ABS, 1997).

Providers and organisations

It is widely recognised that optimal diabetes care should be person centred and requires an interdisciplinary team approach. This includes input from an endocrinologist or diabetologist, general practitioner, diabetes educator, dietitian, podiatrist, and, ideally, a psychologist or social worker. In some communities, Aboriginal and ethnic health workers will also be an important part of the team. A range of other health professionals may be engaged in caring for people with diabetes, particularly if long-term complications develop. These may include ophthalmologists, renal physicians, and vascular surgeons. Due to the high prevalence, chronic nature and the additional health risks imposed by a diagnosis of diabetes, all health service providers commonly encounter people with diabetes and are important target groups for skills training programs, and the dissemination of 'best practice' standards for diabetes.

Services specific to diabetes are mainly provided by private endocrinologists or in publicly funded specialist Diabetes Centres. Subsidised insulin needles and injection devices, and blood and urine testing reagents are distributed by DA under a Commonwealth funded scheme and a number of diabetes organisations have evolved to support consumers and health professionals including:

- The Australian Diabetes Society
- The Australian Diabetes Educators Association
- The Australasian Diabetes in Pregnancy Society
- The Australasian Paediatric Endocrine Group
- Diabetes Australia
- The Juvenile Diabetes Foundation Australia
- The National Association of Diabetes Centres

Appendix 2 contains a profile of these organisations and the providers who are the most common sources of health care for people with diabetes. However, it should be noted that the major stakeholders in diabetes are the people who have diabetes and their families.

The person with diabetes

The central person in the diabetes team is the person with diabetes. Compared to people with other chronic diseases, people with diabetes are expected to take considerable responsibility for their own health care and must make multiple and often complex daily decisions regarding the taking and timing of their meals, exercise and medications. It is essential that people with diabetes, their families and friends are afforded opportunities to learn self-care recommendations and skills, and are actively involved in decisions about the management of their diabetes.

Families and other significant social contacts

Families, carers, partners, and friends play a substantial role in the care of people with diabetes and are entitled to opportunities for education, support and participation in decisions about diabetes care. In the case of very young children, parents bear the full burden of responsibility with significant others requiring education to equip them to help care for the child and provide support to the parents. In the elderly, circumstances may also require carers or adult children to assume entire responsibility for diabetes care. For young and mature adults, partners are a vital resource in managing or reducing the risk of 'hypos' and/or ketoacidosis, and providing psychological support.

How are diabetes services delivered now

Several models of care are available for the management of people with diabetes. The particular model of care used is often determined by the availability and accessibility of local resources rather than clinical considerations. Determining the appropriateness of services and models for diabetes care requires consideration of clinical issues such as the type of diabetes, the presence or absence of complications, and psychosocial issues such as the age and culture related needs of the individual.

All models of diabetes care should have the capacity to apply accepted principles of diabetes care which include:

- ongoing routine clinical care
- regular screening for complications, and appropriate treatment of detected complications
- diabetes education
- dietary assessment and education

A benchmarking survey was recently conducted by the NADC to establish best practice recommendations for diabetes education and dietary advice. The need for these services was dependent on the type and stage of diabetes, but the survey concluded that 2-4 consultations with a diabetes educator and dietitian were required at the time of diagnosis (more for people with type 1 diabetes) and annual review by an educator and dietitian was desirable for people with established diabetes. The availability of and access to these services is an issue which must be addressed, and people with diabetes, their carers and primary care health professionals should be aware of these principals of care.

Models of care

Care by General Practitioner alone

The majority of adults visit a general practitioner at least once a year. It is estimated that the care of many people with type 2 diabetes is provided solely by the GP often without the involvement of a diabetes educator or dietitian.

The current health care system in Australia fails to discourage 'doctor shopping'. This practice involves frequent changing of GPs, regular attendance at more than one GP for the same health problem, and in some instances concurrent attendance at several GPs. The burgeoning of after hours GP medical centres in recent years has exacerbated this problem. ‘Doctor shopping’ impacts negatively on continuity and coordination of care, increases duplication of services and therefore health care costs, and may also result in the omission of important assessments for diabetes. Structural deterrents are required to reduce this practice and promote improved continuity of contact with a central provider.

Specialist care

Specialist care is provided either in the public sector through the traditional Diabetes Clinic or in private practice. This is usually in addition to the care provided by the GP but invariably the diabetes is managed predominantly by the specialist. Specialist care is essential for children and adolescents with type 1 diabetes, and pregnant women with diabetes.

Ambulatory care

Diabetes care is now almost exclusively provided on an ambulatory basis and in most metropolitan locations diabetes ambulatory care centres, staffed by interdisciplinary teams, have replaced traditional in-hospital services eg insulin initiation, diabetes stabilisation, specialist foot care clinics. These services are provided by Diabetes Centres, the majority of which are co-located with public hospitals but there are also some private centres. Diabetes ambulatory care centres have traditionally been concentrated in or near major cities but are beginning to be established in rural and also remote centres.

Shared care

Shared care evolved from recognition of deficiencies in the care provided solely by the GP or a specialist service. Essentially shared care arrangements aim to provide the person with diabetes with integrated and better quality of care by:

- improving communication between primary and specialist services
- improving coordination in the planning and delivery of diabetes care
- increasing the involvement and skills of GPs in caring for people with diabetes
- promoting consistent standards of care
- avoiding duplication of services

Many DGP have implemented diabetes shared care programs in conjunction with local diabetes services. Integrated care is a variation of shared care and is currently being formally evaluated in NSW.

Specialist outreach services

Specialist outreach clinics have evolved in an attempt to increase access for people with diabetes who require specialist advice but are geographically isolated. They involve visiting specialist medical practitioners or teams who provide specialist assessment and treatment which is not locally available eg laser therapy for retinopathy. Specialist outreach services fulfil an important function. However, they have traditionally evolved on an ad hoc basis with no formal agreement identifying and documenting principles or conditions of operation. Clear specification of the roles and responsibilities of both visiting specialist and local clinicians is required to optimise the success of outreach arrangements.

Patient education

Access to information about one’s health problem is a fundamental entitlement. The provision of information about diabetes, self care education and skills training for people with diabetes has long been accepted as a key tool in the successful management of diabetes. The integral role of patient education as an essential component in intensive therapy, aimed at optimising diabetes control and outcomes, was confirmed by the DCCT (1993), and a recent editorial claims that patient education is as important as insulin in the management of diabetes (Jervell, 1996).

Diabetes patient education has been shown to improve metabolic control (Redhead et al, 1993), and reduce mortality (Verlato et al, 1996). Alone or in combination with other interventions it has a well demonstrated ability to reduce the number and duration of hospital stays and the likelihood of re-admission especially with regard to amputation (Miller & Goldstein, 1972; Edmonds et al

1986; Malone et al, 1989: Assal, 1991; Davidson, 1991).

Education may be delivered on an individual basis, through ‘one-off’ group education programs, or by means of support groups, which are conducted on an ongoing basis. Of these, individual education remains by far the most common method. Improvements in patient knowledge, confidence and adherence to self care recommendations have been widely reported as a result of group education (Padgett et al, 1998; Brown, 1990) and, although less frequently studied, individual education (Colagiuri R et al, 1994).

Policy and programs

Relevant developments since the release of the NAP in 1993

Recent policy and program initiatives across Australia reflect a heightened national awareness of the need for a coordinated approach to preventing and managing health problems. Some of the newer developments which have the potential to impact substantially on the way in which diabetes prevention and care services are funded, organised and delivered include:

Information

NDOQRIN

NDOQRIN (pronounced ‘endocrine’) is a *National Diabetes Outcomes and Quality Review Initiative* which is auspiced by the ADS and links with the National Diabetes Indicators initiative described below. Its aim is to promote the collection and management of nationally standardised clinical diabetes information based on a core minimum dataset (See Section 3: p34). During 1998 the NDOQRIN dataset will be used by the NADC and DGP to collect diabetes complications data on a broad scale in a variety of practice settings across Australia.

National indicator development

Following extensive consultation, a set of national diabetes indicators has been agreed for initial reporting to the Australian Health Ministers in 1998. This process is part of the overall reporting on the five National Health Priority Areas and is supervised by the National Health Priorities Committee (See Section 3, p39).

The National Diabetes Register

Since the adoption of diabetes as a National Health Priority Area, the establishment of a National Diabetes Register (NDR) has been approved. The proposed NDR will be managed by the AIHW and will initially include people with type 1 diabetes and people with type 2 diabetes who are treated with insulin (See Section 3, p37)

Community awareness campaign on Diabetes

In 1997, following the pre-election commitment made by the Federal Minister for Health to raise awareness of diabetes and achieve earlier diagnosis of people with type 2 diabetes, the MACOD approved National Diabetes Strategy funding for a project to explore the feasibility of conducting an effective public awareness campaign for diabetes. Subsequent engagement of a consultancy team to undertake stakeholder and community consultation has resulted in the submission to the MACOD in December 1997 of a draft report entitled *Raising Awareness About Diabetes* for possible launching in 1998.

Best practice

NHMRC Retinopathy Guidelines

Evidence based guidelines for the detection and management of diabetic retinopathy have been developed under the auspices of the NHMRC. Four publications targeting specialist medical practitioners; GPs; optometrists, nurses and other non-medical health professionals; and consumers (NHMRC, 1997) have been distributed nationally with National Diabetes Strategy funding.

NSWH Clinical Management Guidelines

The NSW Health Department Diabetes Outcomes Project, which commenced in late 1994, led to the development of ‘best practice’ guidelines for diabetes. The evidence and consensus based Principles of Care and Guidelines for the Clinical Management of Diabetes in Adults (NSW Health 1996) focussing on 7 key areas of diabetes management were developed by an Expert Working Group convened by NSW Health and were launched in November 1996. Implementation of these Guidelines is being evaluated through the NSW Health Integrated Diabetes Care Pilot Projects and through the Statewide Implementation Program conducted by the NSW & ACT Section of the NADC in rural NSW. A set of consensus guidelines on diabetes patient education (NSW Health, 1997) and the dietary management of diabetes was released recently (NSW Health, 1997). A guideline for GDM is planned.

Increasing physical activity

Active Australia is the product of a partnership between the Australian Sports Commission and the DH&FS. By involving government, industry, business and community in a coordinated approach, *Active Australia* is developing a national framework and infrastructure to ensure opportunities for increasing individual and community participation in physical activity with a view to maximising the concomitant social, health, and economic benefits. Guidelines for physical activity are being developed and a public education campaign has begun. An education package and approved provider status will be available to clubs and organisations in early 1998.

Nutrition

Australia's National Food and Nutrition Policy was released in 1992. A new phase of policy implementation will begin shortly, with the development of a National Public Health Nutrition Strategy. Implementation of this strategy will be coordinated through a new partnership between the Commonwealth, State and Territory health authorities to be known as the Strategic Inter-governmental Nutrition Alliance (SIGNAL). Following the establishment of SIGNAL, an extensive process of consultation will occur. This will provide the basis for the creation of structures and processes designed to enable close collaboration between government health services and non-government agencies, the food industry and consumer and community organisations. A number of national nutrition promotion priorities are currently under consideration. These are:

- prevention of overweight and obesity
- increasing consumption of vegetables, legumes and fruit
- promotion of optimal nutrition for women, infants and children
- improving access to healthy food choices and nutrition education for vulnerable groups

Prevention of overweight and obesity

A national strategic plan for the prevention of overweight and obesity, Acting *on Australia's Weight*, was released by the NHMRC in 1996. The goals are to prevent further weight gain in adults and eventually reduce the proportion of the adult population that is overweight or obese; and to ensure the healthy growth of children. The report places major emphasis on sustainable intervention strategies which focus on primary prevention, such as the identification and modification of environmental barriers to physical activity and healthy eating. A national implementation strategy designed to turn the recommendations of *Acting on Australia's Weight* into action is currently under development by the DH&FS. Another initiative, *Healthy Weight Australia - a National Strategy*, was published by ASSO in 1995.

Ambulatory diabetes casemix classification and shadow payment project

This project was undertaken in 1996-97 with joint Commonwealth and NSW Ambulatory Care Reform funding to develop a casemix classification system for the full range of ambulatory diabetes services. Ten Diabetes Centres participated in coding and costing of major occasions of ambulatory diabetes services including:

- episodes of diabetes care such as visits required to commence insulin therapy
- routine medical, education and dietary consultation services
- single, multidisciplinary, labour intensive services such as complications screening

Coordination

COAG Coordinated Care Trials

Initiated by the Council of Australian Governments (COAG), coordinated care trials across Australia are currently testing service and funding models as part of an overall strategic plan for improving the accessibility and quality of care for people with chronic conditions through the integration, coordination, and streaming of health care within and between disciplines and between public and private services. Healthplus, the SA Coordinated Care Trial includes a focus on diabetes with the GP as the care coordinator, and will include measures of patient satisfaction, functional status and clinical outcomes in its evaluation.

General practice

Funding arrangements for DGP are moving towards outcomes-based contracts creating an ideal opportunity to introduce diabetes specific strategies into the broader reforms in general practice in order to improve outcomes for people with diabetes.

Integration Support and Evaluation Resource Unit

The Integration SERU was established in 1996 with funding from the Commonwealth Government. Its role is to support the development and evaluation of Divisions of GP ‘integration’ projects and programs focussing on activities such as joint service planning, liaison and shared care for the areas of diabetes, obstetrics, mental health, aged and extended care, palliative care and GP involvement in acute (hospital) care by:

- reviewing literature and learning from Divisional projects and programs
- developing support materials, including literature reviews, case studies, currently accepted practice guides and sets of outcomes and indicators for specific issues

- coordinating a national program approach through initiatives such as the NDDP
- commissioning or carrying out strategic evaluations on critical issues
- providing advice to stakeholders, including Divisions, Commonwealth, State and Territory Health Departments, committees overseeing the Divisions Program, and others
- maintaining networks of individuals and groups involved in its focus areas.

National Divisions Diabetes Program

The NDDP is a coordinated national approach to diabetes care in Australian general practice, which is being developed under the umbrella of the Integration SERU. The program consists of modules on planning, evaluation and core and optional activities. These modules are designed to facilitate the implementation and evaluation of 'best practice' diabetes care through GPs and DGP working in collaboration with diabetes care providers and organisations. The aims of the NDDP are to:

- improve the quality of diabetes care in general practice
- improve the health outcomes of people with diabetes
- identify type 1 diabetes and type 2 early
- prevent type 2 diabetes

The NDDP attempts to maintain consistency with other national diabetes initiatives. For example, the NDOQRIN dataset is incorporated into the program evaluation module, and where possible, NDDP outcomes and indicators are consistent with the National Health Priority Area indicators and are defined under the quadrants of *Division, GP, patient,* and *population* used by the DH&FS Outcomes Based Funding framework.

National Aboriginal Community Controlled Health Organisation

NACCHO is the national peak body representing approximately 100 Aboriginal community controlled health services across Australia on matters relating to Aboriginal health and well being. While NACCHO and its predecessor, the National Aboriginal and Islander Health Organisation (NAIHO) have been active for some years, in 1997 the allocation of Commonwealth funding has enabled the establishment of a national NACCHO Secretariat in Canberra. This improved infrastructure has increased NACCHO's capacity to enhance collaboration and consistency in the work of ACCHs.

National Public Health Partnership

Formed in late 1996 by Australian Health Ministers, the National Public Health Partnership (NPHP) is a partnership arrangement between the Commonwealth, States and Territories for the purpose of:

- improving public health sector collaboration, particularly with regard to priority setting
- enhancing coordination and sustainability of public health strategies
- strengthening public health infrastructure and activity

The Partnership is being implemented by the National Public Health Partnership Group which comprises the Chief Health Officers or Directors of Public Health of each of the jurisdictions plus senior representatives of the NHMRC and AIHW.

Through the Partnership, the NPHP seeks to encourage greater coordination in research, improved consistency of public health data collection and utilisation, and improved integration of public health strategies. Other priorities of the NPHP include attention to legislation issues, examining the role of ‘best practice’ in the public health arena, and assessing public health financing methods.

National Association of Diabetes Centres

This national network of Diabetes Centres and Services was formed in 1994 with the aim of promulgating uniform standards of care in order to promote improved access to high quality services for people with diabetes. The NADC provides an ideal mechanism for coordinating a collaborative approach to addressing diabetes service issues eg data collection, and providing systematic professional support and training to non-diabetes personnel.

Barriers and strengths of the current system

There are substantial barriers within the present system, which hinder efforts to improve diabetes prevention, care, and outcomes. There are also considerable strengths which can be built on and used as exemplars. The key barriers and strengths of the current system include:

Current barriers to improving the outcomes of diabetes care

- Fragmentation and lack of coordination at all levels of disease prevention and health care planning, funding, and provision result in inefficiencies and deficiencies in the system
- Standards of diabetes care are variable and many providers do not appreciate the seriousness of diabetes and the magnitude of the health threat posed by undiagnosed or poorly controlled diabetes
- Despite evidence that the care and outcomes of diabetes improve if practice systems include mechanisms for patient identification and recall, and management checklists, too few primary practitioners use disease registers and management protocols
- Reliable and comprehensive Australian baseline data is not available on many aspects of diabetes, and there are global deficiencies in information about the effectiveness of some interventions and models of prevention and care
- Funding and resource allocation mechanisms fail to encourage and reward effective policy and practice
- There is little incentive for GPs to provide a comprehensive diabetes service
- There are no disincentives to discourage patients from 'doctor shopping' ie changing GPs frequently, or attending more than one GP for the same problem
- Integration between GP services and publicly funded hospital and community services is less than optimal, and there are insufficient diabetes educators and allied health workers in the community

Strengths of the current system

- Coordination is improving in policy, planning, service provision, and health surveillance with a number of national initiatives capable of impacting favourably on the outcomes of diabetes prevention and care recently established or under development
- Increasing information about prevention and management of diabetes resulting from national and international research is expanding the available evidence base of knowledge in these areas
- There is already sound evidence for some aspects of care which are manifest in general international consensus about the requirements for good diabetes care, and locally developed evidence and consensus based diabetes guidelines
- Good examples of high quality multidisciplinary and interdisciplinary diabetes care exist which can be widely extrapolated or can be modified to accommodate a diversity of cultural and geographical needs
- ‘Free’ access to publicly funded interdisciplinary specialist diabetes services is available in most metropolitan and some urban areas, and are beginning to be established in a few rural centres
- Reagents strips for self blood glucose testing, insulin and other relevant medications, and insulin syringes and needles are subsidised by the Commonwealth Government through the NDSS
- There is increasing interest in diabetes nationally, and improved awareness among governments, and public health practitioners of the magnitude of the health and financial burden of diabetes and the need to reduce its impact on the Australian community

Section 3 Imperatives for change

- **Introduction**
- **Information**
- **Best practice**
- **Coordination**

Imperatives for change

Introduction

In comparison with other nations Australians enjoy relatively good health as measured by life expectancy, peri-natal mortality and similar standards. Maintaining and improving our health in the face of growing costs and increasing demands will necessitate improving the efficiency and effectiveness of the health system. Imperatives for effecting such changes include:

Improving information

Comprehensive *information* systems are required to underpin improvements to the effectiveness of health care. Such systems are critical to the provision of information:

- about health care processes and outcomes against which evaluations of health interventions can be made
- to guide policy and practice
- to guide decisions about the effectiveness and efficiency of resource allocation
- to predict future health trends and identify prevention and health care priorities

Consumers and the general public are increasingly demanding information on which to base health care decisions. Many health care providers do not fully appreciate the serious nature of diabetes and the debilitating complications which can result from undetected or poorly controlled diabetes. Strategic dissemination of appropriately tailored information to these groups is critical to driving improvements to diabetes outcomes.

Implementing 'best practice'

'Best' or evidence based practice is central to increasing our ability to provide effective disease prevention and health care services within an affordable budget. Few would deny that, where evidence of effective interventions is available, it should be adopted preferentially provided that the interventions are safe, ethical and acceptable to consumers. For many aspects of diabetes prevention and care there is substantial and growing evidence about effective interventions. The issues then, are to i) direct research toward addressing deficits in the information about 'best practice', and ii) explore and assess methods of implementing '*best practice*'. Broad implementation of 'best practice' standards is crucial to increasing access to quality services and will require attention to enabling mechanisms including training, incentives, and integration/coordination; and the development of appropriate evaluation methodologies.

Improving coordination

Coordination at all levels of disease prevention and health care policy development, planning, funding, and service delivery is central to optimising the use of resources and reducing duplication and fragmentation. Co-ordination is enhanced by the setting of common goals and the establishment of communication mechanisms to promote a 'seamless' approach to the provision of health care. Integration and continuity of care does not imply the discontinuation of disease specific health care programs but focuses on ensuring organisational and operational structures and methods which provide a strengthened generic infrastructure and enhanced collaboration at all levels.

This Section makes recommendations for *improving information*, *implementing 'best practice*', and *improving coordination*.

Information systems

Information is a key component of any health strategy and is essential for:

- informing providers and consumers about the magnitude of the problem
- monitoring progress against defined indicators and targets
- developing best practice
- providing data to evaluate the cost effectiveness of interventional strategies

Surveillance data describing diabetes and its complications are critical to increasing recognition of the public health burden of diabetes, formulating health care policy, identifying high risk groups, developing strategies to reduce the burden of diabetes, and in evaluating progress in disease prevention and control.

To date there has been little systematic Australian diabetes data collected and there is an urgent need for an effective and efficient national diabetes monitoring system to provide accurate and reliable data. Although some data are collected, Australia lacks an integrated system which coordinates these efforts. An integrated system would allow cost effective decisions to be made, planning preventive and treatment services and targeting priority groups. A coordinated effort is required nationally to monitor diabetes, its risk factors and complications.

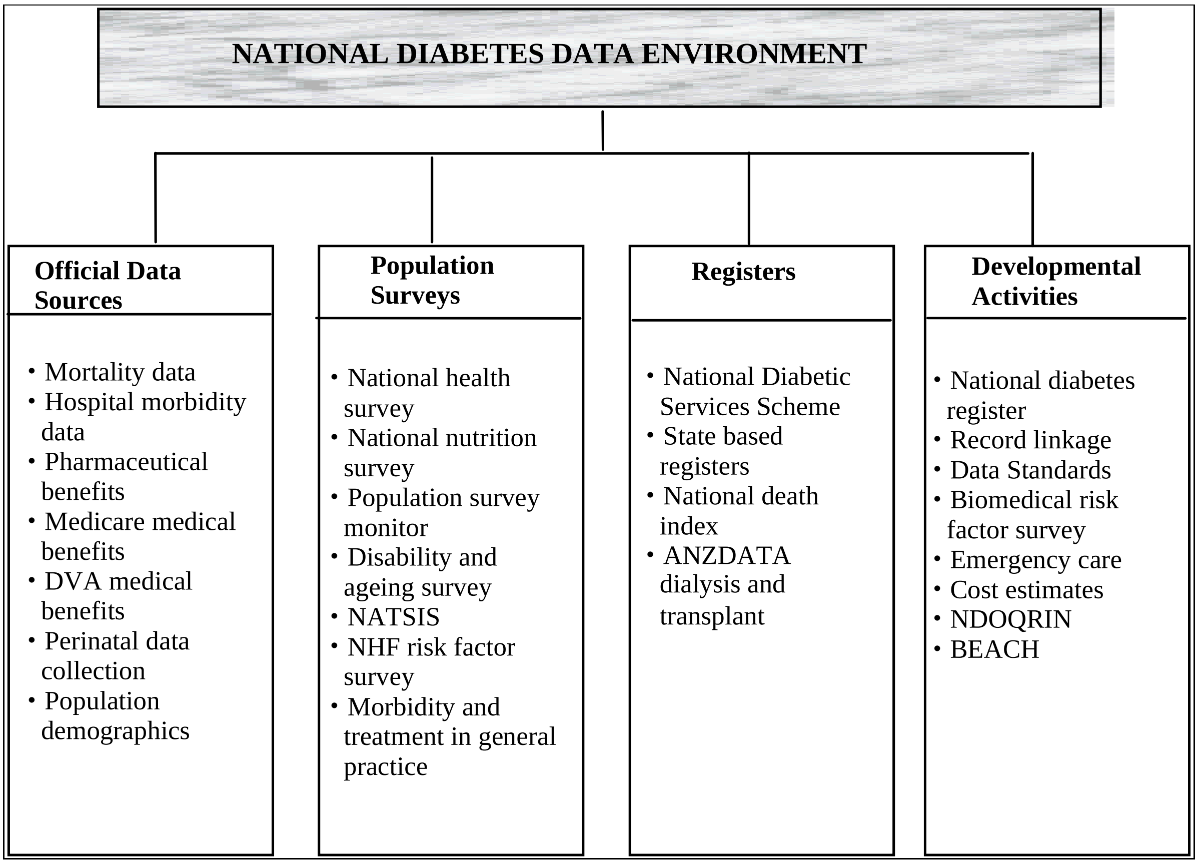
International and Australian diabetes data development activities

The 1989 St Vincent Declaration recognised the importance of data collection and information surveillance which lead to the formation of the Diabetes Care Optimisation for Information Technology (DOIT) group. This group has been very active in generating systems and collecting data throughout Europe which have provided new information about quality of diabetes care and the extent of complications. The Australian Diabetes Society established an Australian counterpart of DOIT called OZDOIT. More recently this activity has been extended into the *National Diabetes Outcomes Quality Review Initiative* (NDOQRIN - pronounced ‘endocrine’). Both of these activities are coordinated by subcommittees of the ADS.

NDOQRIN is a national initiative and the management committee includes representation of the NHPC secretariat and the AIHW. The aim of NDOQRIN is to promote the development of quality diabetes care in Australia through the development of a national standard diabetes dataset and the promulgation, collection, management and aggregation of data collected through this standard dataset. The NDOQRIN dataset is being used by the National Association of Diabetes Centres to collect nationally pooled data on diabetes care and complications in people attending specialist services. Also the dataset is now linked with the National Divisions Diabetes Program and forms a program evaluation module and will be used to collect data on people with diabetes being managed in the primary care setting.

More recently a decision has been made to establish a National Diabetes Register for people with insulin treated diabetes. This has the potential to be expanded in the future into a comprehensive register of all people with diabetes.

Figure 6: National diabetes data environment



Current potential or available sources of diabetes related data

Figure 6 details the national data environment for the population health monitoring of diabetes (Bennett, 1997).

The usefulness of routinely collected data and registers can be enhanced by record linkage and by the development and implementation of standard methods and definitions. Other issues relevant to the data environment include ethical, privacy and confidentiality issues.

Limitations of current official data sources relevant to diabetes

- ***Mortality data*** relating to diabetes are considerably under-reported on the doctor’s death certificate and in official mortality figures which are based on a single underlying cause of death. This is being partially addressed by multiple cause of death coding which commenced in 1997.
- ***Hospital morbidity data*** are currently derived from national hospitalisation statistics, which provides information on inpatient episodes. Separation rates are reported by cause, but are limited to the principal diagnosis. Not only is diabetes rarely a principal diagnosis but it is frequently not recorded as an associated underlying condition.
- ***Pharmaceutical Benefits Scheme (PBS)*** data provide limited information because medications supplied from government hospitals is not covered and also no information is collected on the disease condition. It is useful in monitoring total specific medication use eg insulin use.

- ***Medicare data*** are collected by the Health Insurance Commission on professional services rendered by registered medical practitioners, dental practitioners and optometrists. The data cover approximately 75% of services but does not include inpatient or outpatient services provided by public hospitals. No information is collected on the medical condition. Some information is available on diabetes related diagnostic procedures eg the number of HbA_{1c} measurements.

- ***Department of Veterans' Affairs*** (DVA) collects data on medical, hospital, pharmaceutical, community nursing, respite care and allied health services provided to eligible veterans. Considering the older age group of the veteran population, DVA is a potentially useful source of data regarding the management of diabetes in an elderly population.

- ***Perinatal data collection:*** information on diabetes and GDM is included in the perinatal data collections of all States and Territories, but is not part of the perinatal minimum dataset. These data are routinely collected in Western Australia and Tasmania whereas its collection in NSW, Queensland, South Australia, ACT & Northern Territory is optional. National data on maternal diabetes and GDM are available from the AIHW/National Perinatal Statistics Unit.

- ***National Health Surveys*** (1984, 1990, 1995) included a suite of questions on self reported diabetes diagnosis, complication rates, health service usage, self assessed health status, functional health status (SF36 on half the sample), and cardiovascular risk factor behaviours (smoking and inactivity) and a range of demographic information. The 1995 survey included 54,000 people of whom 2100 were Indigenous Australians.

- ***National Nutrition Survey*** was conducted on a subset (40%) of 1995 National Health Survey respondents and collected information on the prevalence of cardiovascular risk factors (obesity, fat intake, hypertension). No blood sample was taken but weight, height, waist, hip and blood pressure were measured in participants older than 16 years of age.

- ***Population Survey Monitor*** is conducted quarterly by the ABS and independent surveys can be combined to give annual estimates. Questionnaire space or interview time may be purchased.

- ***Disability, Ageing and Hazards Surveys*** collect diabetes data where diabetes contributed to the disabling condition or underlying cause of the main condition about issues such as difficulties experienced and help required. The next survey is due to be conducted in 1998.

- ***National Aboriginal and Torres Strait Islander Survey*** *(NATSIS)* was conducted by the ABS in 1994 and covered all ages. It provided self reported diabetes prevalence estimates and limited complications data.

- ***NHF Risk Factor Surveys*** have been conducted periodically since 1983 with the last being performed in 1989. The 1983 survey collected blood for measurement of fasting glucose, while subsequent surveys collected data on self reported diabetes.

- ***Survey of Morbidity and Treatment in General Practice*** collected data by general practitioners recording all surgery and home doctor-patient encounters for two one week periods 6 months apart in 1990-1991. The survey provided some information on diabetes in general practice.

Registers

- ***National Diabetic Services Scheme*** (NDSS) is a Commonwealth funded subsidy scheme operated under contract by DA and provides syringes, needles and reagent strips to people with diabetes. The register contains 300,000 names of which 127,000 are insulin treated and 173,000 are non insulin using. Currently new registrants average 3,600 per month (600 insulin and 3000 non-insulin using). It is estimated that the NDSS coverage is 90-95% for insulin treated and 50-60% for non insulin using people with diabetes.

- ***State Based Registers*** operate under the auspices of APEG in New South Wales, South Australia and Western Australia and are under development in other states. These registers include people with type 1 diabetes under 15 years of age.

- ***National Death Index*** (NDI) is housed at the AIHW and contains information on all deaths occurring in Australia since 1980 obtained from Registries of Births, Deaths and Marriages in each State and Territory. Its use is strictly confined to medical research and could be used for data linkage with the National Diabetes Register.

- ***ANZDATA*** has collected data since 1963 on people with end stage renal disease proceeding to dialysis or kidney transplantation. Diabetes specific data are recorded.

Developmental activities

- ***National Diabetes Register*** (NDR) will be housed at the AIHW and will collect data on people with insulin treated diabetes using the NDSS and APEG state based registers as sources of ascertainment. Inclusion on the NDR will be voluntary. These data will be used to monitor national diabetes indicators, and will provide samples for epidemiological and clinical studies on the aetiology, prevention and complications of diabetes. Although the NDR will be initially restricted to people with insulin treated diabetes, it is anticipated that it will be extended in the future to include all people with diabetes.

- ***Record Linkage*** is important because diabetes is currently inadequately reported. Potential linkages with the NDR include the NDI, Medicare benefits database, the PBS and hospital morbidity database. The Privacy Commissioner has endorsed guidelines developed by the NHMRC to protect privacy in medical research, which allows, with ethic committee approval, health records to be linked for statistical and research purposes without informed consent of the information providers (Section 95 of the Privacy Act).

- ***Data Standards*** for diabetes data should conform to data item definitions in the National Health Data Dictionary. A current activity of the ADS NDOQRIN Management Committee is to have its standard diabetes data definitions incorporated into the National Health Data Dictionary. Also standards and definitions for overweight and obesity, smoking and physical activity are being developed under the umbrella of the National Health Information Agreement as part of a national cardiovascular monitoring activity. The proposed linkage of these activities is shown in Figure 7.

- ***National Biomedical Risk Factor Survey*** is currently being planned. This survey will include blood sampling and provides an ideal opportunity to perform a true diabetes prevalence study by including glucose tolerance testing on a representative subset of the study population. A feasibility study is currently being supported through the National Diabetes Strategy.

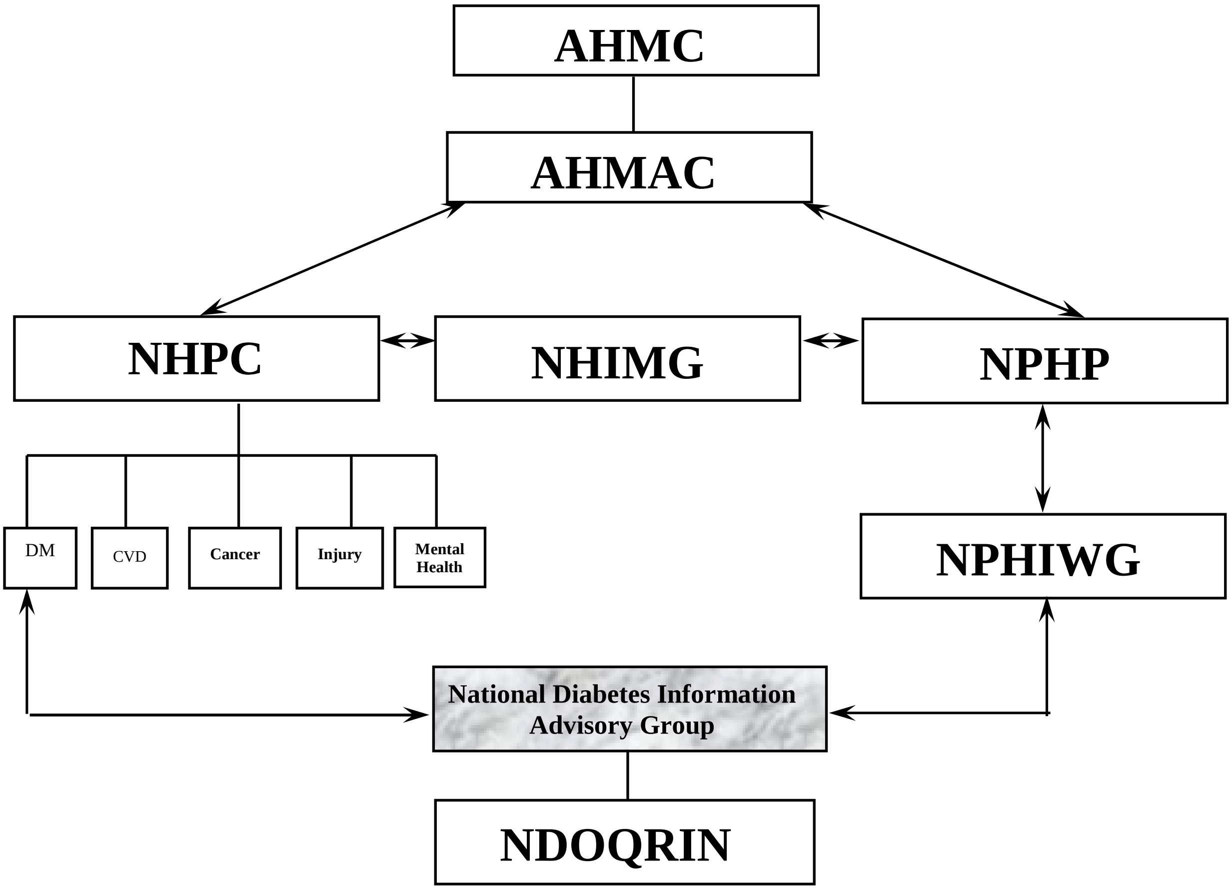
- ***PreHospital Emergency Care Survey*** is being developed to combine State and Territory ambulance service emergency data into a national minimum dataset which will include identification of people with diabetes.

- ***Disease Costs and Impact Study*** conducted within the AIHW provides estimates of the direct costs of disease, including diabetes. Data include hospital, home, medical, other health professionals and pharmaceutical costs.

- ***NDOQRIN*** is a national initiative which will collect Australia-wide cross-sectional diabetes care data on people attending diabetes specialist services in March, 1998. It is also planned to collect similar data on people attending GPs.

- ***BEACH*** (Bettering the Evaluation and the Care of Health) is a program of annual collection of information about patients seen, and problems managed and the management techniques provided in general practice in Australia. It will be conducted in collaboration with AIHW.

Figure 7: Diabetes information pathways



Legend:

AHMC	-	Australian Health Ministers' Council
AHMAC	-	Australian Health Ministers' Advisory Council
NHPC	-	National Health Priority Committee
NHIMG	-	National Health Information Management Group
NPHP	-	National Public Health Partnership
NPHIWP	-	National Public Health Information Working Party
NDOQRIN	-	National Diabetes Outcomes and Quality Review Initiative

National diabetes indicators

The National Health Priority Area initiative is focussing on the five identified priority areas, including diabetes. By the end of 1998 a report is due to the Health Ministers providing baseline data using a set of indicators that will give some indication of the impact of diabetes on the health of Australians. These data will be useful not only for health policy planners but also for clinicians and providers. The National Health Priority Committee is overseeing the development of a set of indicators for this purpose.

The initial draft indicators were developed using the health outcomes framework of the NHIMG (van Ommeren & Bhatia, 1997). Potential indicators were evaluated using a set of evaluation criteria - importance (priority), feasibility (cost, time frames), scientific validity (credibility), usefulness (policy and clinical relevance), distribution (spatio-temporal, regional, jurisdictional), comprehensibility (standard operational definitions) and being sensitive enough to detect change. Following an extensive consultation process, a set of *Agreed Indicators* have been proposed for use in the first report to Health Ministers due this year. They are:

Agreed Indicators: Outcomes

Prevalence rates of complications

- end stage renal disease
- eye complications
- foot problems
- coronary heart disease

Hospital separations for

- end stage renal disease
- eye complications
- foot problems
- coronary heart disease where diabetes is one of the principal diagnoses

Age specific prevalence rates for type 1 and 2 diabetes (initially will be self reported)

- in total population
- in Indigenous population
- among people from non-English speaking backgrounds

Agreed Indicators: Risk factors

Prevalence of obesity and being overweight (as measured by BMI) **in:**

- general population
- among people with type 2 diabetes

Non participation by the total population in regular sustained moderate aerobic exercise

Prevalence of blood pressure above 140 mm Hg systolic and/or 90 mm Hg diastolic among people with type 2 diabetes under the age of 60 years, and above 160 mm Hg systolic and/or 90 mm Hg diastolic for those aged 60 years and over

Agreed Indicators: Health status

Age-standardised death rates (total population, Indigenous people and people with non-English speaking backgrounds) **for**

- all causes
- cardiovascular disease
- end stage renal disease
- stroke
- deaths under 45 years of age
- where type 1 diabetes or type 2 diabetes is a specific cause of death

Self assessed health status of people with diabetes (as measured by using the National Health Survey five point scale or SF 36)

Labour force participation rates for people with diabetes and the general population

Days off work for people with diabetes and the general population

The *National Diabetes Strategy and Implementation Plan* specifies ‘Potential Indicators’ which are broadly consistent with the diabetes indicators proposed for reporting to Health Ministers. Additional potential indicators relevant to the goals of the *National Diabetes Strategy and Implementation Plan* are also included. It is intended that the potential indicators be reviewed as part of the program development process in order to derive specific indicators for the program.

Target setting

Target setting is used to assess progress towards desired health goals, the essence of which is to demonstrate a change in an indicator. Target values can be specified in a number of ways:

- to indicate a movement in a certain direction
- to indicate a desired trend but not quantified
- quantified as a single specific numerical value
- related to 'process' rather than direct improvement in health outcome

The aim is to set a target for each indicator which is challenging yet realistic and achievable. The way this is done for an individual indicator will vary and is dependent on the desired outcome. A major issue is whether the target should be quantified by a single numerical value. Finland and the Netherlands have chosen not to quantify any targets, whereas other countries consider specific quantified targets as essential.

Quantifying targets presents difficulties unless certain prerequisites are met. These include:

- the availability of sound baseline data
- the potential to monitor progress
- the availability of, and the status of knowledge about, effective interventions
- a realistic time period for the intervention to demonstrate effectiveness

In countries which have set targets, the magnitude of the expected change has been based on a combination of scientific evidence, informed judgement and statistical modelling. This has resulted in a variation of the type of target chosen for a particular indicator (Reddy, 1997).

The approach adopted in the *National Diabetes Strategy and Implementation Plan* has been to use a combination of available evidence, informed judgement and precedents set by other international initiatives such as the St Vincent Declaration, to derive a mixture of quantitative and qualitative end points which are referred to as 'Expected Outcomes'. As knowledge about these clinical areas advances, especially the availability of accurate baseline data, and as progress is made in implementing the recommendations of this document, it is anticipated that the 'Expected Outcomes' will be reviewed, modified and further developed and may then be specified as 'Targets'.

Recommendations

1. Establish the National Diabetes Register for people with insulin treated diabetes and consider expanding it into a comprehensive National Diabetes Register

2. Establish a National Diabetes Information Advisory Group with representation of the NDR, NPHC, NDOQRIN and AIHW to:
   - develop a set of Data Standards for diabetes for incorporation into the National Health Data Dictionary
   - develop mechanisms to promote record linkage to ensure that accurate and comprehensive diabetes data are collected on diabetes mortality and end stage complications ie cardiovascular disease, amputation, blindness and end stage renal disease
   - explore ways of nationally coordinating and pooling diabetes data collection initiatives currently being undertaken and planned for the future (eg a common death certificate throughout Australia with adequate design to allow accurate diabetes coding)
   - establish a diabetes data information clearing house to facilitate access to diabetes data information for consumers, providers and planners

3. Conduct a National Diabetes Prevalence Study linked to the National Biomedical Risk Factor Survey

4. Monitor quality of care processes and outcomes through:
   - collection of annual cross sectional clinical outcomes information using the NDOQRIN minimum dataset through Divisions of General Practice, the NADC and the National Diabetes Register
   - the Health Insurance Commission, utilising Medicare Item numbers for HbA_{1c}, lipids, microalbuminuria, and retinal screening

5. Develop models for utilising diabetes data to provide information about the cost of diabetes and cost effectiveness of specific interventions.

Informing consumers, providers and the general public

This segment argues for the strategic dissemination of information to:

- inform and empower consumers to request the recommended standards of care from their health professionals
- raise awareness among providers of the serious nature of diabetes, the importance of early detection and appropriate management, and current recommendations for reducing risk factors for the development of type 2 diabetes
- enhance public awareness of risk factors, recommendations for risk reduction, and symptoms of diabetes

Consumer awareness and participation in diabetes care and decision making

The Final Report of the Taskforce on Quality in Australian Health Care recommends a number of measures to increase consumer education and involvement in health care including the establishment of local complaints mechanisms (AHMAC, 1996). A handbook for implementing national diabetes programs (WHO, 1995) emphasises the right of people with diabetes to information, education, social equity, consideration of their emotional needs, empowerment and involvement in health care. Prior to this, the National Health Strategy published a background paper proposing that the key objectives of the health system should include:

- a focus on the needs of the population and specific groups within it
- reducing inequalities in health particularly for disadvantaged groups
- the provision of effective efficient health resources and services
- a process for public debate about health system priorities
- recognition, respect and assurance of the rights of people

This increasing interest in consumer involvement is manifest in many ways including a protocol for consumer participation (DOCS, 1994), and attempts to measure patient satisfaction and perspectives on health services and health care quality (Draper & Hill, 1995; Frank Small & Associates, 1995; Consumers' Health Forum & DH&HS, 1996). While progress is being made in this area, there are inherent difficulties in measuring consumer satisfaction. For example, a literature review by Thompson & Sunol (1995) highlights variations in the meaning of satisfaction and questions conceptual agreement and consistency in approaches to understanding the nature of patient satisfaction. Despite an emerging body of literature, methods for assessing consumer satisfaction are relatively new and require evaluation and refinement. Further, many of the available assessment tools have been developed overseas and are not culturally or linguistically appropriate for Australians.

Patient held diabetes record cards have traditionally provided one means of informing and involving people with diabetes in their clinical care. These have been available in a variety of forms and are frequently used in Diabetes Shared Care programs to facilitate communication between specialist and primary physicians, and promote patient attendance for clinical review of their diabetes.

Despite their popularity with patients, the success of such cards as a diabetes information record and communication mechanism has not been adequately assessed and may be almost entirely determined by the commitment of the patient's medical carers to updating the information on a continuing basis.

A review of the international literature about the effect of patient participation in medical decision making and patient-provider communication on diabetes management provides some evidence that patient adherence to diabetes self-care recommendations improves with increased patient involvement (Golin et al, 1996). Wredling et al (1996) urge consideration of patient perspectives in planning and delivery of diabetes services, citing patient opinions and experience of continuity of care, unfulfilled desire for access to carers, and discontinuity of physician care as negatively influencing glycaemic control. Further, self-rated health has been found to be a significant predictor of mortality in people with older onset of diabetes (Dasbach et al, 1994). In view of this, and the finding that quality of life issues identified by clinicians as important, did not accord well with those identified by people with type 2 diabetes (Griffiths et al, 1997), the incorporation of patient perspectives in the assessment of quality of life, health, and health care is undoubtedly critical to obtaining meaningful results.

Despite recent interest in consumer awareness and participation, the role of people with diabetes in bringing about improvements to the standard of clinical care they receive and in driving the implementation of 'best practice' guidelines and protocols is relatively unexplored. Anecdotal Australian information suggests that while consumers may be keen to access information on recommendations about the clinical standards of care which should be practised by their health care providers, many are reluctant to present this information to their medical practitioners or to question them about the standard of care they provide.

It is commonly contended that consumers do not necessarily have the content knowledge or technical expertise to make judicious assessments of the quality of their clinical care. In some instances this may be true as exemplified by a study in which a sample of people with diabetes reported a high level of satisfaction with the services of general practitioners whose care did not meet even the basic recommended standards for diabetes (Kamien, 1994). Another Australian study (Colagiuri R et al, 1995) demonstrated that basing diabetes education solely on educational priorities selected by patients may result in patient knowledge deficits of sufficient magnitude to compromise diabetes control.

Rather than arguing against the inclusion of consumer perspectives and the involvement of consumers in health care decision making, these examples illustrate the need for the strategic dissemination of consistent, accurate, and understandable information to empower people with diabetes to:

- appraise the quality of diabetes care they receive
- seek appropriate services
- make informed decisions about their diabetes management

The European Patients' Charter is based on the premise that many people with diabetes receive suboptimal health care and are entitled to know what level of care they should expect to receive (The Subcommittee of the European Region of the International Diabetes Federation and the St Vincent Declaration of the WHO, 1991). This document has been published for distribution to consumers in mini-booklet form under pharmaceutical industry sponsorship. The American Diabetes Association (ADA), the British

Diabetic Association (BDA) and DA have published similar policy documents covering the rights, roles and responsibilities of consumers with regard to their diabetes care. However, none of these initiatives appear to have been underpinned by a strategically planned dissemination process or subjected to systematic evaluation of their impact on consumer and/or provider behaviour.

In a more active approach to consumer empowerment, the National Breast Cancer Coalition (USA) has developed a training program for breast cancer consumer advocates. The program, known as Project LEAD (Leadership Education Advocacy and Development), offers basic scientific and leadership training to increase the ability of advocates to participate effectively in decisions about breast cancer research (Liberati, 1997). This model may be well suited to diabetes and warrants further exploration. Current local efforts aimed at raising the awareness of people with diabetes about the quality of clinical care they should expect to receive include the NSW Health Department Consumer Guidelines for Diabetes (1996). The Consumer Guidelines follow the recommendations in the NSW Health Department Principles of Care and Guidelines for the Clinical Management of Diabetes Mellitus in Adults (NSW Health , 1996). Preliminary results of evaluations of the impact of disseminating these documents to consumers are expected to be available in late 1998.

Provider awareness

Provider awareness of the potential health and social repercussions of diabetes and the needs of people with diabetes for information and support is reported to be poor in some instances and the implementation of clinical guidelines is less than optimal. Assal & Golay (1995) claim that health care providers are not aware of the inadequacies of the care and education they provide, are reluctant to undertake audit and self-assessment and do not link effectively with centres of excellence.

Referral rates from primary care physicians to diabetes educators and diabetes dietitians indicate that GPs may not be conscious of the vital role of patient education in optimising the outcomes of diabetes care. Australian reports indicate low awareness of, or referral rates to, education and support services such as those supplied by DA (Blades & Morgan, 1996; Eigenmann, 1995).

Deficiencies in inpatient care of diabetes

Evidence about deficiencies in the inpatient care of diabetes is becoming increasingly available. Several studies demonstrate less than optimal attention to poor diabetes control, low referral rates for diabetes education and specialist assessment of diabetes status, poor documentation and inadequate assessment of diabetes complications and metabolic control, and lack of recognition of undiagnosed type 2 diabetes (Sinha & Gill, 1996; Colagiuri R et al, 1996; Hudson et al, 1996; Davis & Hughes-Anderson, 1996; Sunder et al, 1997; Middleton et al, 1997). While such deficiencies are not specifically attributed to lack of provider awareness, it would appear that providers of inpatient care to people with diabetes are not conscious of either the potential seriousness of diabetes or the currently accepted standards and recommendations for care.

To date most efforts to improve the inpatient care of diabetes consist of protocols developed and used in individual health facilities. There is a need to develop and implement national principles of inpatient care including indications for referral for diabetes specialist assessment, and principles for perioperative management of diabetes.

What is required of providers?

To manage diabetes effectively, health professionals need appropriate initial training in their respective disciplines and continuing professional education and skills training in diabetes in order to ensure timely monitoring of:

- metabolic control
- general physical status
- educational needs
- psychological needs

To know when and how to apply suitable interventions, providers need to be aware of:

- currently available interventions and models of care
- currently recommended standards of diabetes care
- the implications of diabetes regimens for the patient's daily lifestyle
- the potential health consequences of inadequately managed diabetes

Basic principles for educating health professionals are needed

Fundamental to this is the need for health professionals to be able to distinguish between the nature and treatment requirements of type 1 diabetes and type 2 diabetes. Efforts should be made to develop and base undergraduate health professional training on a set of agreed principles which include this distinction, along with basic guidelines and protocols based on current evidence about the prevention, early detection and management of diabetes. A national effort could be developed in partnership with ADS, ADEA, DAA, A PodC, DA and undergraduate medical, nursing, dietetic and podiatry schools and the RACGP Training Program.

Diabetes simulation

Effective self-care of diabetes requires the patient to acquire a complex and wide range of technical knowledge and skills. To communicate these, set realistic goals and promote patient adherence to treatment regimens, health carers need in depth understanding of the psychosocial and practical implications of diabetes on the lifestyle of individuals and their families.

Simulating diabetes as a method of enhancing formal diabetes teaching for health professionals was first described in 1980 (Welborn & Duncan, 1980). Other studies have also described its usefulness in improving the insight and understanding of a variety of health professionals into the daily difficulties and lifestyle adjustments encountered by people with diabetes (Warren-Boulton et al, 1982; McBride & Mallon, 1987; Michael & Bull, 1988; Cotunga & Vickery, 1990; Colagiuri S et al, 1994). Another study has reported improved metabolic control in children whose parents took part in a diabetes simulation intervention (Satin et al, 1989).

Consideration should be given to incorporating diabetes simulation exercises into routine training and inservice programs for hospital staff, community nurses, general practitioners and allied health workers, and undergraduate medical, nursing, and dietetic students.

The potential role of pharmaceutical companies in raising provider awareness of diabetes

Pharmaceutical companies involved in diabetes care can play a significant role in raising awareness of diabetes and recommendations for its management, particularly in the field of general practice. Their representatives are in frequent contact with medical and non-medical clinicians and these companies produce substantial amounts of educational resources and literature to market and support the correct use of their products. The potential for using this existing mechanism to raise provider awareness of diabetes and promulgate currently recommended and consistent diabetes care standards is relatively untapped. Closer liaison between ADS, ADEA, DA and the diabetes sector of the pharmaceutical industry on this matter is suggested.

Public awareness

The effects of public awareness campaigns on public knowledge and behaviour change with regard to health promotion and disease prevention has not been well researched. Consequently, although there is an increasingly sound evidence base for what needs to be done to prevent diseases like type 2 diabetes and cardiovascular disease, little is known about how to present public health messages in a way that will maximise their effect on public and personal motivation to act on the message and adopt healthier lifestyle choices.

The general public may have little or no basic knowledge about diabetes and is already bombarded daily by a vast array of commercial messages on billboards, neon signs, and in the electronic media. To be noticed and retained, health messages need to be succinct, easy to understand, and compelling. With this in mind the ADA recently launched a new public awareness campaign centred on a short message *'Diabetes is serious. Diabetes can be controlled'*. This campaign is aimed at alerting Americans to the significance of diabetes as a public health problem and personal health risk and will be evaluated in 1998 (Graham, 1997).

The most recent Australian attempt at raising public awareness of diabetes, the DAMM Campaign, gave a quite complex message. The evaluation of the DAMM Campaign was mainly based on process and its impact is difficult to determine. An evaluation report is available (Duckett, 1996). Evaluation of the Finnish National Awareness Program for diabetes involving a telephone survey of 700 people showed no difference in knowledge of diabetes before and after the campaign (Sampo-Mäkinen, 1997). However, this may have been due to the relatively good baseline diabetes knowledge of the Finnish public demonstrated in the pre intervention assessment.

It is not clear whether there is more benefit to be gained from planned *public awareness* campaigns or from ongoing *publicity* campaigns which report news items about diabetes on a random continuing basis to maintain public consciousness. Franz (1997) claims that the mass media are:

- the most common means of transmitting health information in the USA
- immediate and compelling
- considered credible and authoritative by the public

Ongoing publicity is opportunistic and relies on an ability to interest the media in publicising human interest stories or new information about research, costs, complications and disability or general statistics about the health burden. This method is largely reliant on the availability of well briefed spokespersons whose position in health or politics carries a degree of authority. On the other hand, awareness campaigns have the advantage of enabling their planners to:

- Determine the:
    - target group
    - message content
    - method of delivery
    - timing and frequency of messages
- Put mechanisms in place to ensure that consistent, accurate and adequate information is available to members of the public who are motivated by the campaign to seek professional advice
- Prepare providers and stakeholder organisations for the additional questions and occasions of service which are likely to result from the campaign

It is important for both methods, and imperative for planned public awareness campaigns that careful consideration is given to:

- planning for early detection and appropriate initial management and/or referral of people who are diagnosed as a result of the campaign
- the provision of appropriate advice on the need for future testing for people who are screened but do not have diabetes
- the provision of advice and services for risk factor management in people who do not have diabetes but have risk factors

The role of patient education in health promotion and primary prevention

As well as providing specific self care information and skills training, educational contacts with patients present opportunities to deliver health promotion and disease prevention messages to relatives which should not be overlooked. For example, Gnanalingham & Manns (1997), suggest that while many people with type 2 diabetes have a limited understanding of risk factors for diabetes and their significance, educating such people to inform their non-diabetic first degree relatives of i) their increased risk of developing diabetes and ii) recommendations for modifiable risk factor reduction, may be a useful primary prevention strategy. Other examples include encouraging patients attending diabetes education to improve the nutrition of their whole family, and increase the whole family’s participation in physical activity.

Recommendations

6. The National Diabetes Task Force to oversee in collaboration with DA, JDFA, the Diabetes Task Force Consumer Reference Group, and NHMRC, the development of:
   - evidence based diabetes guidelines for consumers, or the adaptation of the NSW Health Department Consumer Guidelines, for national application
   - a dissemination strategy which takes account of existing mechanisms and networks such as the NDSS distribution, local pharmacies, and diabetes educational literature and product information prepared by pharmaceutical companies

7. DA to establish a formal mechanism for consumer advocacy, and the handling of complaints, which includes appointing appropriately trained consumer advocates and complaints officers to the National Office and each State and Territory Association

8. The National Diabetes Task Force to approach undergraduate medical, nursing, and allied health schools across Australia, and the RACGP Training Program, to include core standardised information on diabetes which:
   - clearly differentiates between type 1 diabetes and type 2 diabetes
   - emphasises the serious consequences of undetected or poorly controlled diabetes
   - highlights risk factors, symptoms and diagnostic criteria, and management principles for type 1 diabetes, type 2 diabetes, and GDM

9. Introduce cultural sensitivity training into undergraduate medical, nursing, dietetics, podiatry, and social work courses, and continuing education programs for GPs

10. Identify effective methods of raising consumer awareness of diabetes and evaluate the role of consumers in influencing providers to implement evidence based diabetes clinical practice

11. Conduct a national Community Awareness Program on Diabetes linked to the programs for the prevention and early detection of type 2 diabetes

Best practice

Evidence based ‘best practice’ in the context of an outcomes orientation

For the most part, previous explications of ‘best practice’ have not been systematically derived from all available evidence. Nor have they necessarily focussed on outcomes or explicitly defined the outcomes of interest, especially consumer-oriented outcomes (Eddy, 1993). The ‘outcomes approach’ being advocated at both national and state health jurisdictions encourages a focus on patient results. There is less emphasis on measurement of inputs and activity and more overt recognition and monitoring of outcomes (Rissel et al, 1996). In chronic disease, the outcomes approach emphasises multidisciplinary care as a means to achieve better patient outcomes. This emphasis on outcomes also has strengthened the need for a more overt recognition of the underlying evidence. At any point in time, there is an existing body of knowledge about the efficacy and effectiveness of specific health care interventions. Once synthesised by accepted methods, the strength of this evidence can be ranked according to a taxonomy of evidence as shown in Table 2.

Table 2: Levels of evidence for health care interventions (treatment / screening)*

Level I	Evidence of effectiveness obtained from a systematic review of all relevant randomised controlled trials
Level II	Evidence of effectiveness obtained from at least one properly designed randomised trial
Level III-1	Evidence of effectiveness obtained from well-designed controlled trials without randomisation
Level III-2	Evidence of effectiveness obtained from well-designed cohort or case-controlled analytic studies preferably from more than one centre or research group
Level III-3	Evidence of effectiveness obtained from multiple time series or pre/post designs
Level IV-1	Evidence of effectiveness from descriptive studies including case reports with or without empirical evaluation data
Level IV-2	Published recommendations or opinions of effectiveness from groups of recognised experts, organisations or learned colleges including their endorsement of IV-3 evidence
Level IV-3	Consensus judgment of effectiveness by individuals or other groups not based on higher levels of evidence

**Adapted from NHMRC 1995*

Interventions for which there is Level I or Level II evidence can be implemented with confidence, knowing that there is compelling *a priori* evidence that patient outcomes will improve. If the case for an intervention is less convincing because the evidence is weak (eg consensus opinion of experts or uncontrolled clinical series), then the case for implementation is less justified.

Clinical practice guidelines and protocols

It is becoming increasingly recognised that individual clinicians are not always aware of the full body of knowledge pertinent to a specific clinical decision. Clinical practice guidelines are systematically developed statements to assist practitioners and patient decisions about appropriate health care for specific clinical circumstances (Field & Lohr, 1992). Evidence based clinical practice guidelines are developed from replicable and comprehensive methods to identify and synthesise all available evidence and are explicit in the levels of evidence to support specific clinical actions (Hayward & Laupacis, 1993). No guidelines produced by national and state organisations up to 1993 fully described the processes for retrieving and synthesising evidence to permit replication (Ward & Grieco, 1996). Despite an increasing number of guidelines even within NSW alone, there is little evidence of evaluation or monitoring of clinical behaviour or patient outcomes (Holt et al, 1996).

Currently available guidelines are described elsewhere in this document. Future guideline development in diabetes should respond to documented variation in practice and clinical controversy (Holt et al, 1996). In the interim, local dissemination and implementation of available guidelines will undoubtedly enhance outcomes for people with diabetes. It has become increasingly recognised that local ownership of guidelines is an important prerequisite for implementation.

A survey of general practitioners in 1995 found high regard in principle for guidelines but some ambivalence about their utility in the everyday clinical practice (Gupta et al, 1997a). Innovative implementation strategies were not highly rated by general practitioners (Gupta et al, 1997b) despite the substantial evidence that intensive, individualised, locally-based strategies are necessary to ensure that guidelines are adopted in practice (Grimshaw & Russell, 1994).

Implementation principles and models

A prototype for guideline implementation is yet to be developed and rigorously tested in Australian conditions. Until that time, implementation efforts should be derived from systematic reviews of overseas implementation projects (Davis et al, 1995; Grimshaw & Russell, 1994). Specific elements will likely include:

- the development of a local dissemination and implementation plan
- ‘user friendly’ versions of guidelines and protocols, and consumer versions
- local engagement and commitment, most likely obtained by the identification and support of a recognised peer (Hiss et al, 1978)
- identification and involvement of all local stakeholders, including consumers
- a comprehensive communication strategy to ensure all aspects of implementation are understood and agreed
- alignment with other initiatives or requirements likely to strengthen guidelines implementation at the local level eg hospital or facility accreditation, professional quality assurance programs
- recognition of the need to change through baseline audit, surveillance data or other means of quantifying current practice and/or outcomes
- local modification without compromise to the implications of the available evidence for care eg protocols, local policies

- a local formative evaluation plan to document the impact of implementation on practice and/or outcomes and identify deficient aspects summative evaluation to inform ongoing implementation initiatives (Muir-Gray 1997)

Incentives

It is not always easy to distinguish ‘sticks’ and ‘carrots’ in a complex system such as health. It has been recommended that:

> ‘The most important step in facilitating change is to ensure that professionals want to change ... It is much more effective to stimulate professionals to grow their own carrots than to force them into behaving like donkeys, enticed by a carrot dangling in front and threatened by a stick held behind’ (Muir-Gray 1997).

As described elsewhere (Muir-Gray 1997), financial incentives are likely to work only in fee-for-service health care systems. Their potential in Australia is not well understood. The effectiveness and longevity of financial strategies, such as withdrawal of scheduled rebates, are not always evaluated and are rarely reported or published. Non-financial incentives, such as professional training, are described below.

Provider training

Continuing education has the potential to improve practice and outcomes (Davis et al, 1995). Largely uncoordinated at present, there is advantage in developing core curricula, common resources and clinical audit packages to support provider training. However, system reform and external support for better individual clinical practice is essential. If structures do not change, then well-intended efforts in professional training will be undermined by larger, more influential barriers to ‘best practice’. Provider training needs to be based on a comprehensive needs assessment; principles of adult learning; participatory models of teaching and evaluation. In diabetes, knowledge, skills and attitudes to multidisciplinary care can be improved.

RACGP training program

Recognition of postgraduate training for GPs has only recently become mandatory for entry into general practice through a national vocational register (Knight, 1997). Vocational postgraduate training of GPs is conducted and coordinated by the RACGP Training Program through a state based structured program involving academic and practical experience for medical graduates wishing to enter general practice. This program already includes a diabetes component and is ideally situated to promulgate consistent and recommended standards of diabetes care in general practice.

*Continuing medical education for GP*s

Requirements to maintain vocational registration now include ongoing participation in a three-year QA & CE Program (Table 3).The RACGP considers its role primarily as an arbiter and advocate for professional standards in general practice. In contrast, DGP were created in 1992 as part of the GP Strategy to strengthen local identification and organisation of general practice (Knight, 1997).

The development of a Practice Assessment Activity in diabetes which provides feedback through audit could be implemented by individual GPs (Ward et al 1996; Ward et al, 1997). Divisional diabetes registers are currently being evaluated (Harris & Powell-Davies, 1996). A framework for performance monitoring known as the National Divisions Diabetes Program is being developed by the Integration SERU (see Section 2: p28).

Table 3: Quality assurance and continuing education program requirements for 1996-1998

Components	**Points Required**		
	1996	1997	1998
Practice Assessment Activity	< ------------20 minimum------------>		
Continuing Medical Education	20	20	20
Professional Development	< --------------up to 50-------------->		

Source: *RACGP Quality Assurance and Continuing Education Program.* RACGP, 1996

Involving General Practitioners in implementing ‘best practice’

Linking with general practice organisations is a key element in the implementation of many aspects of the *National Diabetes Strategy and Implementation Plan.* The Organisational Section of this *Strategy* recommends the formation of a General Practice Reference Group to work with the National Diabetes Advisory Committee on issues relating to diabetes and general practice.

Given the number of people with diabetes in the community, and the nature of primary care, GP involvement is crucial to any strategy aimed at improving diabetes care, especially for people with type 2 diabetes. The responsibility for caring for people with diabetes must be accompanied by appropriate knowledge about diabetes management, skills to implement best practice guidelines, and systems to support and reward ‘best practice’.

The involvement of DGP in diabetes care projects and the recent move to outcomes oriented DGP block grant funding provides additional opportunity to address these issues (Weller et al, 1997). The establishment of the SERU for Integration has resulted in the development of the NDDP which contains a number of modules covering general practice diabetes activities including GP education, clinical management and patient recall, and screening for diabetes and provides a blueprint for Divisions participating in diabetes care programs. The NDDP recognises the need for monitoring process and health outcomes and recommends the NDOQRIN minimum data set for this purpose.

Opportunities for providing ‘best practice’ incentives to GPs

Incentives should be an integral part of encouraging GPs to actively participate in programs to improve the health outcomes of their diabetic patients. To date, these have been mainly in the form of CME or Practice Assessment points although Divisional diabetes projects have offered GPs direct financial rewards or access to allied health professional staff. The current Medicare Benefits Schedule Review may provide a platform for more appropriate remuneration for aspects of general practice diabetes care such as annual complication screening.

Table 4: Options to support the implementation of Clinical Management Guidelines (CMG) for diabetes

Strategy	Target Group	Implementation
Influence professional education and provide skills training	Undergraduate medical students	• Incorporate CMG into undergraduate teaching in medical schools
	Advanced medical trainees	• Incorporate CMG into RACGP Training Program • Incorporate CMG into training program for generalist specialist physicians (ASCPIGM) • Incorporate CMG into training and programs provided by Rural Health Training Units
	Divisions of General Practice	• Conduct workshops (using recognised expert clinicians) for rural and urban GPs to introduce the CMG and explore issues related to implementing the CMG into routine clinical practice
	Non-medical diabetes clinicians	• Incorporate CMG into undergraduate and continuing education programs
	All clinicians	• Incorporate CMG in promotional and educational material produced by pharmaceutical companies • Promote CMG through articles in the medical press • Distribute CMG to clinical directors of public hospitals and community health centres
Provide clinicians with access to professional support	Relevant clinicians	• Make available practical and relevant practice and care organisation aids eg patient ID and recall systems, care plans, referral criteria, information systems • Provide 24 Hour telephone access to specialist advice for urgent clinical problems • Offer training attachments to specialist services • Develop telemedicine links between rural and metropolitan health facilities • Offer satellite teletutorials for rural and isolated clinicians on specific clinical issues relating to the CMG
Provide incentives for clinicians to implement CMG	General practitioners General physicians & Pharmacists	• Develop professional continuing education and quality assurance points packages based on the CMG, obtain appropriate accreditation and make available through professional colleges and associations ('rewards' may also be appropriate)
Inform and empower consumers to seek appropriate care	People with diabetes	• Advertise recommended standards of care to people with diabetes through consumer journals, community language press • Provide incentives for consumers demonstrating participation in recommended processes of care • Develop a 'best practice consumer card' for systematic distribution through NDSS, DA State and Territory Associations and local branches, health professionals, community health centres and hospitals • Develop and conduct training programs to equip consumer advocates to participate effectively in CMG implementation

Source: National Association of Diabetes Centres (NSW & ACT Section), 1996

Future opportunities include the possibility of tying Divisional Block Grant Programs and individual practice grants to processes and/or outcomes related to diabetes and other National Health Priority Areas. Activities currently in the planning stages may also be relevant eg the Health Insurance Commission's disease management demonstration projects.

Accreditation of individual GPs could also be considered as a stand-alone program or preferably linked to incentives. The American Diabetes Association (ADA) has recently launched a Provider Recognition Program, a voluntary program whereby physicians who care for people with diabetes can achieve Recognition by submitting data to demonstrate they are providing quality diabetes care which meets criteria established in best practice guidelines (ADA, 1996). Recognition is acknowledged by a certificate to display in the office and the physician's name is listed in the ADA's website and journals.

Consumers

In parallel with activities to improve the care provided by health professionals, considerable effort is being directed to ensure that people with diabetes and their carers are aware of the standards of care which they should expect to receive and patient charters have been prepared by many national associations (St Vincent Declaration Steering Committee, 1991). In Australia, DA has documented consumer rights and responsibilities and NSW Health produced a Consumer Guideline (NSW Health, 1996). With this increased focus on consumer awareness comes an increased possibility of litigation for practices which do not conform with recommended clinical practice. Already in the UK there has been an instance of successful litigation for blindness resulting from diabetic retinopathy where the health carers were deemed to be at fault because the retinopathy had not been adequately detected or treated (Brahams, 1992).

Recommendations

12. Develop, in collaboration with the NHMRC, best practice, evidence based clinical management guidelines for each of the diabetes prevention and care programs detailed in the *National Diabetes Strategy and Implementation Plan* for implementation through a structured dissemination process which includes undergraduate and relevant postgraduate training programs for medical, nursing and allied health workers throughout Australia
13. Develop and implement incentives for providers to apply the recommended standards of diabetes care
14. Provide incentives for consumers to access recommended standards of care eg discounted self-care supplies for demonstrating participation in annual complications screening

Coordination

The health system is struggling to meet increasing demands on resources, ensure socially and culturally equitable access to, and appropriate geographical distribution of, health services. The importance of coordination in reducing fragmentation and unnecessary duplication in the health system generally was recognised by the COAG which, in 1995, announced a decision to reduce 60 different and poorly connected health care programs to three streams of care, ie general care, acute care, and coordinated care. What needs to be coordinated for diabetes includes:

- services aimed at primary prevention and early diagnosis
- the care of people with diagnosed diabetes
- the implementation of the National Diabetes Strategy

Primary prevention and early detection services

As discussed in Type 1 Diabetes (Section 4), considerable recent advances have been made in the field of primary prevention for type 1 diabetes and the identification of people at risk. However, insufficient is yet known to warrant the application of broad population approaches. This leaves research as the key area requiring coordination for this aspect of type 1 diabetes. Recommendations for developing a strategic research agenda and the commitment of an appropriate proportion of public research funding to diabetes are outlined in Section 4 of this document, under Research. On the other hand, type 2 diabetes is a model condition for health promotion and disease prevention since it encompasses many generic population health issues, for example:

- obesity
- smoking
- nutrition
- hypertension
- physical inactivity
- dyslipidaemia

Several approaches are being implemented to address these modifiable risks including the *QUIT* program for smoking cessation and, as outlined in Best Practice (Section 3), *Active Australia* to combat physical inactivity, and the National Nutrition Strategy ie *Acting on Australia's Weight*. No health program operates in isolation and all initiatives stand to benefit from linkages with other similar programs. Outcomes can undoubtedly be enhanced by the associated reduction of duplication, increased coverage and consistency, and additional value for money.

The MACOD has contracted for the development of a *Community Awareness Campaign on Diabetes*, and a key recommendation of the *National Diabetes Strategy and Implementation Plan* is the implementation of a:

- National Type 2 Diabetes Prevention Program
- National Early Detection of Type 2 Diabetes Program

It cannot be emphasised strongly enough that these initiatives should be integrated horizontally and an organisational structure developed which facilitates planning, communication, and consistency of core, key elements such as basic health messages. Nor can the need for common core indicators and datasets to facilitate outcomes evaluation across these programs be overstated.

The care of people with diabetes

To deliver consistent and recommended standards of diabetes care to people with either type 1 or type 2 diabetes, the task is to ensure that everyone with diabetes has access to:

- information and education about self-care
- self-care equipment and supplies
- routine clinical care and monitoring to ensure opportunities for optimal blood glucose control
- regular clinical review and screening for the early detection of complications
- clinical and support services for the management of complications if complications develop
- rehabilitation services for those with irreversible disabling complications
- palliative care services for those with end stage complications

Diabetes is a complex disease which can affect all systems of the body. People with diabetes encounter a wide array of health services and providers in the course of their health care. Even at diagnosis GP, diabetes education, dietary, pathology, and pharmacy services are required. Specialist medical services including those of an endocrinologist and ophthalmologist may be indicated as may psychology and social services. Figure 8 shows the range of services which must be negotiated by the newly diagnosed; for complications screening; and for people with identified complications. Ensuring an interface between these services in order to provide ‘seamless’ care to consumers is a major challenge and crosses a range of issues including:

Information systems

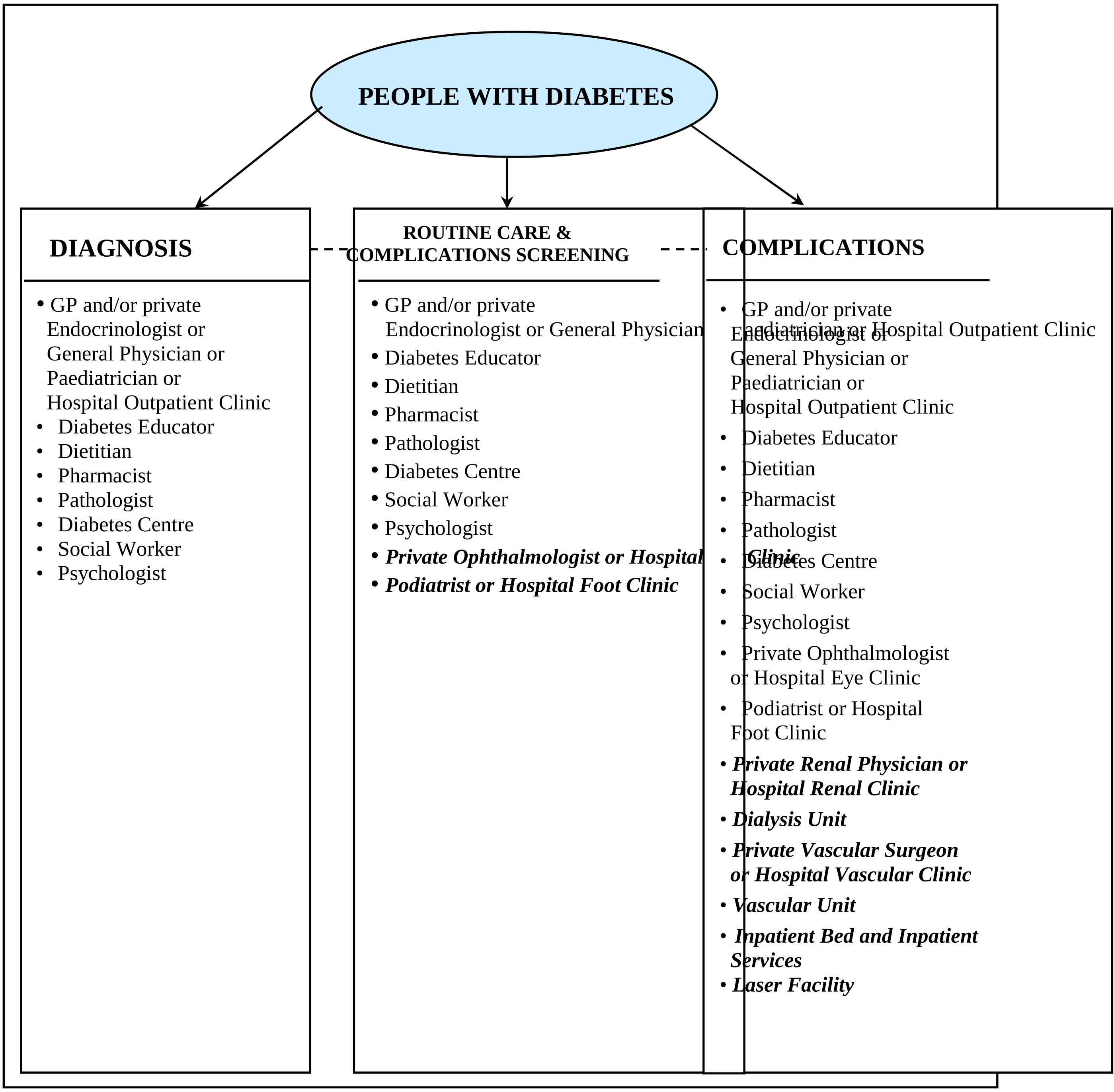
Data monitoring systems and record linkages are pivotal to coordination of health care and are discussed earlier in this Section, and the piloting of patient held, portable, electronic smart cards was recommended by the Taskforce on Quality in Australian Health Care (AHMAC, 1996).

Professional role delineation and collaboration

Role delineation between health disciplines is an important aspect of professional regulation and accountability. There are also functional distinctions between primary and specialist domains. However, there are many aspects of diabetes care which can be carried out by any health professional ranging from an individual with specialist medical qualifications to Aboriginal health workers and enrolled nurses. Professional regulations relating to the roles and responsibilities of each health discipline need to build in flexibility to cover the wide variations in practice settings and available resources dictated by Australia’s vastness and population distribution.

Diabetes has been a pathfinder in multidisciplinary, or what is more correctly termed *interdisciplinary* care, to the extent that there is substantial overlap in the function of the various disciplines involved. For example, diabetes (nurse) educators initiating and adjusting insulin, nurse run complications screening, the operation of nonmydriatic fundus cameras by Aboriginal health workers, the provision of advice to patients about clinical aspects of care by dietitians, and the self-care education of patients by medical staff. Despite these exemplars, there is still much resistance to breaking down traditional dominance among health disciplines and it is justifiably argued that changes to current roles could compromise the quality of care provided to consumers unless adequate attention is paid to training, experience and competence, accreditation and accountability issues.

Figure 8: Examples of services required by people with diabetes



Structural barriers to professional overlap are gradually being removed as evidenced by the NSW Nurse Practitioner Project which explored and piloted an extended role for nurses in the clinical arena. This addressed some aspects of the unnecessary division between the roles of nurses and doctors but many more need to be addressed.

One example relevant to diabetes is the contention that nurses should not perform basic podiatry procedures such as toenail cutting. As suggested in the Vision statement of this document, the expedient and correct approach to such problems is to i) define what is the task to be done and the level of competency required to do it and, ii) ask who is available or can be suitably re-skilled to perform the task.

Using podiatry services for diabetes, a framework based on the components of assessment of the diabetic foot can be developed ie:

- obtaining a history - questioning the patient regarding the health status of their feet
- visual assessment - looking at the foot and noting its condition
- physical assessment - examining the foot manually
- mechanical assessment - examining the foot with the aid of instruments
- laboratory assessment - assessing the foot by means of biomedical methods

Table 5 illustrates what might reasonably be done by a variety of health professionals in the physical examination of the foot. Clearly a wide range of health professionals can perform this task and such a framework could be used as the basis for developing competencies for undergraduate training, continuing education, and for re-negotiating professionals' roles, especially in settings where some categories of service providers are unavailable or scarce.

Shared care, and more recently integrated care, has provided a better coordinated and more cohesive approach to the care of people with diabetes but appears to have fallen short of achieving a seamless interface. An emerging model which extends these concepts a step further is *collaborative care* which is based on:

- definition of roles and responsibilities of all concerned including the patient
- identification of the task which needs to be done ie principles and protocols of care
- the provision of support in the form of education, training, documentation, communication, and information systems
- an organisational structure, ie a steering committee representing the 'collaborating' clinicians, and consumers

Organisational role delineation and collaboration

The delineation of roles between Commonwealth and State and Territory Health Departments is critical to coherent and cohesive policy, planning, implementation, and monitoring for any national strategy. Intersectoral collaboration both within the health system, and between the health system and other government and private sectors is a key strategy for optimising the effectiveness of primary prevention and health care programs.

Table 5: Draft components of and professional roles in the assessment of the diabetic foot

Components of Foot Assessment	Role of the Health Professionals							
	Aboriginal Health Worker	Enrolled Nurse	Community Health Nurse (registered)	General Practitioner	Diabetes Educator	Podiatrist	Endocrin-ologist	Vascular Surgeon
Physical Examination								
Skin temperature, areas of erythaemia	✓	✓	✓	✓	✓	✓	✓	✓
Interdigital problems (including maceration, fissures)	✓	✓	✓	✓	✓	✓	✓	✓
Pitting oedema	✓	✓	✓	✓	✓	✓	✓	✓
Footwear: Check fit, support, quality and design (wide heels base, firm heel counter, resilient soles, activity appropriate)	✓	✓	✓	✓	✓	✓	✓	✓
Footwear: Check points of possible irritation inside and outside	✓	✓	✓	✓	✓	✓	✓	✓
Blanching on elevation/dependent rubor	✓	N	✓	✓	✓	✓	✓	✓
Dorsalis pedis and posterior tibial pulses	✓	N	✓	✓	✓	✓	✓	✓
Capillary filling time	✓	N	✓	✓	✓	✓	✓	✓
Wound classification (presence, type of exudate, odour)	✓	N	✓	✓	✓	✓	✓	✓

Sources: 1. The Framework - R. Colagiuri 1995
2. Draft content - NSW Health Diabetes Foot Problems Working Group 1996

Organisational structure for the *National Diabetes Strategy and Implementation Plan*

An appropriate organisational structure for managing the *National Diabetes Strategy and Implementation Plan* is critical to progress the recommendations of this document.

The current structure

Ministerial Advisory Committee on Diabetes (MACOD)

MACOD was established following the addition of diabetes as a National Health Priority. The terms of reference of MACOD include responsibility for providing expert advice to the Minister for Health and Family Services on all matters relating to the development and implementation of a national diabetes strategy and implementation plan, and providing diabetes advice to the National Health Priority Committee. The committee membership includes Commonwealth and two State Government representatives, representatives of consumer and professional diabetes organisations, NACCHO, Centre for Culture, Ethnicity and Health, AIHW, NHMRC and individual health professionals involved in diabetes care.

Medical, Education and Scientific Advisory Group (MESAG)

This committee was formed to provide advice on medical, scientific, education and public health aspects of diabetes as requested by MACOD and to facilitate peer review of proposals submitted to MACOD for funding through the National Diabetes Strategy. The committee membership consists of expert diabetes health professionals several of whom are also members of MACOD.

While recognising and acknowledging the contribution of MACOD in developing the national diabetes strategy to its current position, a revision of the current structure is considered necessary and desirable to facilitate the implementation stage of the strategy.

Principles for the proposed organisational structure

The following principles were considered in recommending the proposed organisational restructuring for managing the *National Diabetes Strategy and Implementation Plan.*

- **Ensure representation of key stakeholders**

  The key stakeholders which should be represented include:
  - Commonwealth Government
  - States and Territory Governments
  - Aboriginal and Torres Strait Islander communities
  - Non-English speaking background communities
  - Diabetes consumer organisations - DA, JDFA
  - Diabetes professional organisations - ADS, ADEA
  - General Practitioners
  - AIHW
  - NHMRC

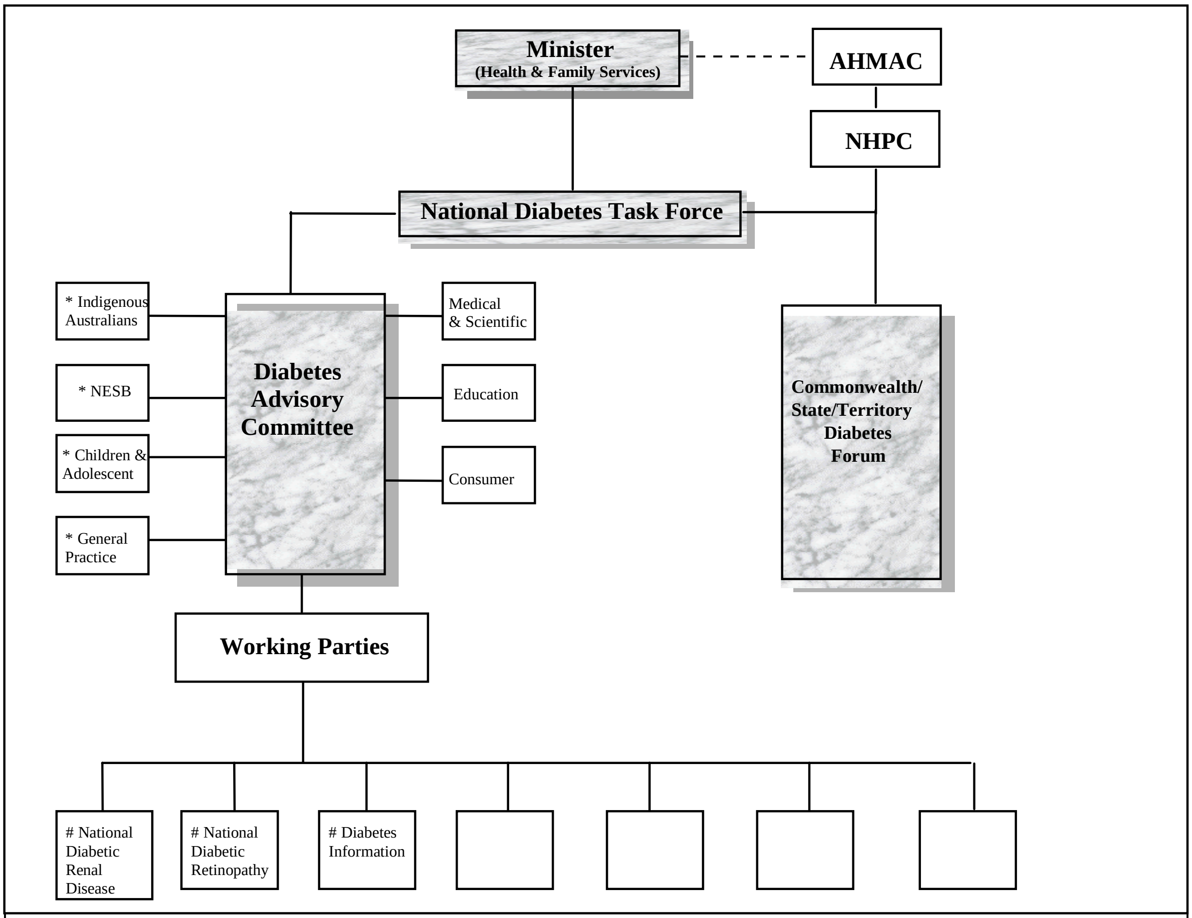
- **A comprehensive and effective management, coordination and implementation structure**
  Successful implementation will require broad ranging input at Commonwealth, State/Territory and local/regional levels. Specific working parties will need to be set up to further develop and oversee the implementation of priority recommendations.

- **A structure with the capacity and authority to make decisions and ensure action**
  This aspect is important to ensure that decisions can be implemented.

Proposed new organisational structure

It is proposed that the management of the *National Diabetes Strategy and Implementation Plan* be divided between two sections - a National Diabetes Advisory Committee and a Commonwealth/ State/Territory Diabetes Forum. The activities of these two groups would be coordinated by a National Diabetes Task Force under the direction of the Minister for Health and Family Services. The proposed structure is shown in Figure 9.

Figure 9: Organisational structure for the National Diabetes Strategy and Implementation Plan



Diabetes Advisory Committee Reference Groups

* Indigenous Australians' Diabetes Reference Group
* NESB Australians' Diabetes Reference Group
* Children and Adolescent Diabetes Reference Group
* General Practice Diabetes Reference Group
* Medical and Scientific Diabetes Reference Group
* Education Diabetes Reference Group
* Consumer Reference Group

Working Parties

\# National Diabetic Renal Disease Advisory Group
\# National Diabetic Retinopathy Advisory Group
\# Diabetes Information Advisory Group
\# Others

AHMAC - Australian Health Ministers Advisory Committee
NHPC - National Health Priority Committee

National Diabetes Task Force

This group would coordinate the activities of the National Diabetes Advisory Committee Group and a Commonwealth/State/Territory Diabetes Forum.

Suggested representation

- Chair and two members of the National Diabetes Advisory Committee
- Chair and two members of the Commonwealth/State/Territory Diabetes Forum

Functional brief

- coordinating the implementation of the *National Diabetes Strategy and Implementation Plan*
- responsibility for recommending and allocating funding for implementation of the *National Diabetes Strategy and Implementation Plan*
- reporting to the Minister of Health and Family Services
- advising bodies such as the National Health Priority Committee

National Diabetes Advisory Committee

This committee would be representative of diabetes health care delivery and consumer organisations.

Suggested representation

- Chair and two members of the Commonwealth/State/Territory Diabetes Forum
- Chairpersons of the following Reference Groups:
  - Indigenous Australians’ Diabetes Reference Group
  - Non-English Speaking Background Australians’ Diabetes Reference Group
  - Consumer Reference Group
  - Childhood and Adolescent Reference Group
  - Medical and Scientific Reference Group
  - Education Reference Group
  - General Practice Diabetes Reference Group

Reference Groups

It is proposed that several Reference Groups are established to represent specific interest groups and content areas. These Groups should be widely representative and gender balanced and should include:

- Indigenous Australians’ Diabetes Reference Group: - established under the auspices of NACCHO
- Non-English Speaking Background Australians’ Diabetes Reference Group
- Consumer Reference Group: established under the auspices of DA
- Childhood and Adolescent Reference Group: established under the auspices of JDFA
- Medical and Scientific Reference Group: established under the auspices of ADS
- Education Reference Group: established under the auspices of ADEA
- General Practice Diabetes Reference Group

The Chairpersons of these Reference Groups would serve as members of the National Diabetes Advisory Committee. The organisations under which these Reference Groups are formed would be responsible for membership of the group, providing the secretariat and arranging and funding their Reference Group meetings.

Functional brief

- provide expert diabetes advice to the National Diabetes Task Force
- report to the National Diabetes Task Force
- recommend strategy priorities
- oversee specific Working Parties.

Commonwealth/State and Territory Diabetes Forum

The establishment of such a forum has been adopted by other national health strategies and is designed to facilitate and promote Commonwealth and State/Territory agreement for the adoption and implementation of national health priorities.

Suggested representation

- Chair and two members of the National Diabetes Advisory Committee
- Public Health Division, Commonwealth Department of Health and Family Services
- National Health Priority Area
- each State and Territory
- AIHW
- NHMRC
- GP Branch, Commonwealth Department of Health and Family Services

Functional brief

- facilitate the adoption of strategies recommended by the National Diabetes Task Force at a State/Territory and local/regional level.

Working Parties

A number of Working Parties will be required to perform specific tasks related to the implementation of the programs and strategies recommended in the *National Diabetes Strategy and Implementation Plan*. Examples of Working Parties are the National Diabetic Renal Disease Advisory Group, the National Diabetic Retinopathy Advisory Group, and the Diabetes Information Advisory Group.

Stakeholder involvement in implementation

Additional to a strong organisational structure and commitment from government, successful implementation of the *National Diabetes Strategy and Implementation Plan* requires wide endorsement. It is critical to:

- ensure a sense of ownership and responsibility for the Strategy among key stakeholder groups
- identify clear implementation pathways
- define roles and responsibilities for the various facets of the implementation and evaluation process

One way to achieve this would be to bring key stakeholders together in a national summit to endorse the *National Diabetes Strategy and Implementation Plan* and develop a consensus position on implementation.

Recommendations

15. Hold a National Diabetes Summit to obtain wide endorsement of the *National Diabetes Strategy and Implementation Plan* and develop a consensus position on roles and responsibilities for its implementation

16. Form a National Diabetes Task Force to oversee the implementation of the *National Diabetes Strategy and Implementation Plan*

17. Establish the following Reference Groups to represent key stakeholders on the National Diabetes Advisory Committee - Indigenous Australians, non-English Speaking Background Australians, Consumer, Childhood and Adolescent, Medical and Scientific, Education, and General Practice

18. Establish National Advisory Working Parties to address each of the programs detailed in the *National Diabetes Strategy and Implementation Plan*

19. Appoint a *National Diabetes Strategy and Implementation Plan* Medical Director

Section 4 The focus

- **Introduction**
- **Type 1 diabetes**
- **Type 2 diabetes**
- **Gestational diabetes and management of pregnancy in women with pre-existing diabetes**
- **Research**
- **The health system**

The focus

Introduction

This Section provides information on the background and issues associated with the three main types of diabetes found in Australia, research, and the health system and provides a rationale for action, and specific recommendations for:

- Type 1 diabetes
- Type 2 diabetes
- Gestational diabetes (and pregnancy in women with pre-existing diabetes)
- Research
- The health system

Goal 1:	Prevent or delay the development of type 1 diabetes and type 2 diabetes
Goal 2:	Improve health related quality of life, and reduce complications and premature mortality in people with type 1 diabetes and type 2 diabetes
Goal 3:	Achieve maternal and child outcomes for gestational diabetes, and for women with pre-existing diabetes, equivalent to those of non-diabetic pregnancies
Goal 4:	Achieve progress towards a cure for type 1 diabetes
Goal 5:	Advance knowledge and understanding about the prevention, cure, and care of diabetes through a comprehensive research effort
Goal 6:	Improve the capacity of the health system to deliver, manage and monitor services for the prevention of diabetes and the care of people with diabetes

Note: The Goals are numbered for convenience only. The numbering does not denote a hierarchy of importance and has no implications for priority.

Type 1 diabetes

Key points

- In 1995 there were an estimated 80,000 people with type 1 diabetes in Australia
- Up to the age of 20 years approximately 1 in 1,500 people has type 1 diabetes, increasing to approximately 1 in 500 in people over the age of 20
- Type 1 diabetes is one of the most common serious diseases in childhood
- Type 1 diabetes is due to an autoimmune destruction of the insulin producing beta-cell of the pancreas which results in insulin deficiency
- Diabetes has a considerable impact on quality of life for the individual with diabetes and their family
- Type 1 diabetes should be managed by a specialist team
- Transition from paediatric to adult care can be particularly difficult
- Cardiovascular disease remains the leading cause of death among people with diabetes
- Ischaemic heart disease accounts for at least 50% of the mortality in people with diabetes compared with 23% in the general population
- Renal disease accounts for between 8% and 14% of deaths in people with diabetes
- Type 1 diabetes may result in blindness, end stage renal disease, foot ulcers and amputations
- Severe hypoglycaemia is an ever present concern, especially when striving for optimal blood glucose control
- A pre type 1 diabetic state can be identified by blood testing for antibodies which may be detectable months to years before clinical symptoms
- The ability to detect the pre-diabetic state provides the opportunity to prevent the development of type 1 diabetes in the future if a suitable therapy is developed
- Transplantation of pancreatic tissue or genetically engineered non-islet cells offers the prospect of a future cure for type 1 diabetes

Background

Type 1 diabetes, also called insulin-dependent diabetes mellitus (IDDM) or juvenile diabetes, is an autoimmune disease in which the body's immune system reacts against and destroys the insulin-producing beta cells in the islets of the pancreas (Harrison et al, 1990). Deficiency of insulin leads to elevated blood glucose and frequently to long-term complications including retinopathy, nephropathy, cardiovascular disease, and foot problems.

Type 1 diabetes is one of the most common serious diseases in childhood, with a higher incidence below the age of 20 than cancer, cystic fibrosis, multiple sclerosis, juvenile rheumatoid arthritis or muscular dystrophies. To live, but not necessarily avoid complications, people with type 1 diabetes must inject themselves with insulin several times daily and balance this with food and physical activity to minimise the risks of potentially life-threatening hypoglycaemia and long term complications.

The incidence (number of people who develop type 1 diabetes each year per 100,000 people in the general population aged under 15 years) ranges from a high of about 40 in Finland to 1 in countries such a Japan and Mexico. Australia has lacked a national register, but State-based surveys (Glatthaar et al, 1988; Verge et al, 1994) indicate an incidence of about 14 per 100,000 per annum, and there is evidence that the incidence is increasing. Up to the age of 20 years approximately 1 in 1,500 people has type 1 diabetes, increasing to approximately 1 in 500 in people over the age of 20.

Symptoms of type 1 diabetes may be acute and dramatic in childhood, but less so in people who are first diagnosed as adults. Increased awareness and improved medical care have ensured that death from acute complications such as ketoacidosis, dehydration and coma, is rare these days. The diagnosis of type 1 diabetes is confirmed by detecting hyperglycaemia in either fasting or random blood samples. Management with insulin injections is often initiated in difficult emotional circumstances for a newly-diagnosed child and his or her family. Children and their families require special understanding and emotional support, counselling and education, which must be ongoing.

About half the lifetime risk of type 1 diabetes is genetic and contributed to mainly by the HLA genes within the major histocompatibility complex (MHC) (Harrison & Tait, 1991) and by a number of other genes several of which have been identified (Morahan et al, 1996). The remaining risk is contributed to by environmental factors, for example viruses, chemical toxins or dietary components, which cannot be definitively identified in the majority of cases. Congenital rubella (German measles virus) was discovered to cause type 1 diabetes by Sydney researchers in the 1960's (Forrest et al, 1971), but other environmental agents remain elusive, probably due to their multiplicity and their involvement long before clinical symptoms appear.

The autoimmune process of beta-cell destruction begins months to years before clinical symptoms. Individuals in this pre-clinical or sub-clinical phase of type 1 diabetes can now be identified (Bingley et al, 1993) by the presence of circulating antibodies or T cells that react to antigens in beta cells, such as insulin itself (Palmer, 1993; Colman et al, submitted). Pre-clinical diagnosis and the recent success in preventing diabetes in rodent models herald interventions to prevent type 1 diabetes in humans.

Personal impact of type 1 diabetes

People with type 1 diabetes cannot take life for granted since their bodies do not function automatically and are under constant threat without external assistance. The diagnosis of type 1 diabetes is a sentence to a life of daily insulin injections juggled with diet control and frequent finger-prick blood testing to monitor and prevent the blood glucose level becoming too high (hyperglycaemia) or too low (hypoglycaemia or ‘hypo’). At either end of the spectrum, the result can be loss of consciousness (coma) and even death.

The possibility of longer-term complications leading to blindness, kidney failure, heart attack or limb amputation also presents a threat. Patients and their families are exhorted to rigorously control blood glucose levels with insulin injections, diet and exercise to minimise the risk of complications, but this is a difficult balancing act and comes at the risk of ‘hypos’. Parents of children with type 1 diabetes may suffer anxiety and guilt for not achieving recommended blood glucose targets, and about causing ‘hypos’ when attempting to follow ‘best practice’ advice. The potential benefits of good blood glucose control come at a price, on patients and their families, that is intensely personal, as well as medical and economic. A summary of the personal impact of diabetes for people with diabetes outlining additional concerns can be found in Section 2 (p 19).

Health burden of type 1 diabetes

People with type 1 diabetes have a reduced life expectancy and increased morbidity due to higher rates of cardiovascular disease (heart attack, stroke), amputations, kidney failure and blindness.

There are only limited Australian data on the specific complication rates in people with type 1 diabetes. Mortality figures do not usually differentiate between types of diabetes. The Tasmanian Insulin Treated Diabetes Register (Riley et al, 1995) provides some information, although a significant percentage of registrants have insulin treated type 2 diabetes. Mortality rates were increased two-fold compared with non diabetic Tasmanians, with women with childhood onset of diabetes having 10 times the rates of cardiovascular mortality compared with non-diabetic females (Riley et al, 1995). However the impact is certain to be greater because 16% of death certificates of people with childhood onset diabetes did not report diabetes (Riley et al, 1995).

Renal disease accounts for between 8% and 14% of deaths in people with diabetes (McCarty et al, 1996). Microalbuminuria is detected in up to 20% of people with type 1 diabetes and overt nephropathy develops in 33% of people with type 1 diabetes. Each year persistent microalbuminuria develops in 2% of people with type 1 diabetes.

Diabetic retinopathy is the commonest cause of visual loss in adults under the age of 60. In the Newcastle study, 80% of people with type 1 diabetes had evidence of retinopathy after 10 years of diabetes and almost all by 15 or more years. Proliferative diabetic retinopathy was present in 20% after 15 years, 30% after 20 years and nearly 50% after 30 years (Mitchell, 1980). The DCCT showed that in people with type 1 diabetes without retinopathy, intensive therapy reduced the risk of developing retinopathy by 76% compared with conventional therapy. In people with non-proliferative diabetic retinopathy, intensive therapy slowed progression by 54% and reduced the development of proliferative diabetic retinopathy or severe non-proliferative diabetic retinopathy by 47%. Cumulative 9 year rates of progression of retinopathy were 54% with conventional therapy and 12% with intensive therapy (DCCT Research Group, 1993).

Foot disease, including peripheral neuropathy and peripheral vascular disease which may lead to ulceration or amputation, is a common cause of morbidity in people with type 1 diabetes. An estimated 1 in 4 people with diabetes has peripheral neuropathy, intermittent claudication is experienced by 3% of men and 0.5% of women with diabetes, approximately 1 in every 100 people with diabetes has had an amputation and 5% will experience a foot ulcer.

Needs of people with type 1 diabetes

People with type 1 diabetes have essential external needs without which they cannot live. The primary lifesaving need is of course injectable insulin, but there are many secondary indirect and non-physical needs, some of which are also required by the person's family and community. In the absence of a cure, these needs are for the lifetime of someone with type 1 diabetes. They include:

- supplies of insulin and insulin delivery devices, blood glucose and ketone monitoring systems
- medical (diabetologist, general practitioner) and paramedical (diabetes educator, dietician, podiatrist) services for ongoing medical care, education and counselling
- special medical (diabetologist, ophthalmologist, nephrologist) and paramedical (diabetes educator) services for early detection and intervention/prevention of complications
- special support (children's camps, adolescent transition clinics, support networks)
- access to all the above

Studies clearly demonstrate the personal, social and economic cost-benefits of comprehensively meeting these needs, to enable useful, productive life and prevent complications.

Economic burden of type 1 diabetes

Type 1 diabetes is a major health problem and makes a significant contribution to the total cost of diabetes in Australia which is estimated to exceed $A 1 billion annually (McCarty et al, 1996).

A detailed analysis of the economic burden is presented in Section 7 and in each of the Priority Programs in Section 5.

Goal

Prevent or delay the development of type 1 diabetes

Objectives:

- Improve methods for identifying people at risk of developing type 1 diabetes
- Develop safe and effective interventions to prevent or delay development of type 1 diabetes

Expected Outcomes:

- Effective screening and intervention strategies to decrease the incidence of type 1 diabetes
- Identification of environmental trigger agents and primary prevention therapies (eg vaccination against viruses)

Rationale

The number and accuracy of methods for identifying people genetically at risk and/or having immunological and metabolic markers of pre-clinical type 1 diabetes has been steadily improving. Pre-clinical diagnosis in first degree relatives of people with type 1 diabetes is now a reality. It is based on the detection of antibodies (and immune T cells) in a blood sample that react with islet antigens (insulin, glutamic acid decarboxylase, tyrosine phosphatase IA-2) (Palmer, 1993; Colman et al, submitted). The presence of one or more antibodies to these antigens reflects the presence of underlying beta cell autoimmunity and, depending on the age of the person, denotes low, medium or high risk for the development of clinical disease. The presence of impaired insulin secretion in response to intravenous glucose adds significant predictive value for the imminent development of clinical disease. As beta cell destruction is considered to be mediated by autoimmune T cells, assays for islet antigen-reactive T cells are likely to be particularly informative for disease prediction and monitoring of potential intervention therapy (Harrison et al, 1993). T cell assays currently are a research tool only, and need to be further developed for application in routine screening of the general population. Screening for pre-clinical disease could now be extended from first degree relatives to the general population. This is necessary because 90% of people who develop type 1 diabetes do not have a first degree relative with the disease. However, screening will need to be complemented with safe, effective intervention/prevention strategies before it could become universal, and cost effective.

Identification of susceptibility genes and immunological markers of pre-clinical disease has heralded potential prevention strategies. Apart from the identification of at risk individuals, the other prerequisite for prevention of type 1 diabetes is the availability of safe, specific forms of immunotherapy. Trials of non-specific immunosuppressive agents (azathioprine, cyclosporine) during the 1980's established ‘proof of principle’ that immunological interventions would be likely to delay or prevent the onset of clinical disease. However, such non-specific treatments with potential for serious side effects if given long-term, such as susceptibility to serious infections or cancer, cannot be justified in asymptomatic individuals, many of whom would be children. Most attempts to develop specific immunotherapies centre on the use of islet antigens themselves as therapeutic tools (Harrison, 1995). These antigens, the targets of the pathological, autoimmune response, can be delivered in a “tolerizing” manner through the body’s mucous membrane after oral, aerosol or intra-nasal administration, to induce protective immunity. These approaches have been successfully tested in the NOD mouse model of type 1 diabetes (Harrison et al, 1996) and are now being trialed in at risk humans. A multicentre trial of oral insulin is being conducted in the United States and a trial of intra-nasal insulin is underway in Melbourne. Insulin is the only islet antigen that is beta cell-specific, and it has been used as a therapeutic agent in clinical type 1 diabetes for decades. Animal safety and toxicology studies will need to be undertaken with the other islet antigens before they could be applied in clinical trials in humans.

The cost benefits of future strategies will need to be assessed once the effectiveness of an intervention has been established. However, estimates of the current financial burden to the individual and the community of type 1 diabetes unequivocally predict the cost-benefit of intervening to prevent or delay the development of this disease.

Proposed indicator

- the incidence of type 1 diabetes

Strategies

Coordination

A National Advisory Group on Prevention of Type 1 Diabetes should be established which could be formed by expanding the current Australian Diabetes Intervention Group (ADIG) into a nationally representative group. The function of this group would be to oversee and coordinate type 1 diabetes prevention research, including establishment of a national reference laboratory and DNA database, a national database of research programs and a program for monitoring research outcomes.

Information

The newly established National Diabetes Register and the Australasian Paediatric Endocrine Group (APEG) databases have the capacity to accurately monitor the incidence of type 1 diabetes, thereby providing information on the outcomes of future type 1 diabetes prevention research.

Best practice

The National Advisory Group on Prevention of Type 1 Diabetes should produce and regularly update a national consensus position paper to guide health professionals, consumers, consumer organisations and funding bodies about the state-of-the-art of type 1 diabetes prevention.

Recommendation

20. Establish a national infrastructure to support and conduct studies aimed at preventing type 1 diabetes

Goal

Achieve measurable progress towards a cure for type 1 diabetes

Objective:

- Develop safe and effective methods to cure type 1 diabetes

Expected Outcomes:

- Successful transplantation of insulin-secreting tissue without the need for long-term, non-specific immunosuppressive therapy
- The development of safe, specific forms of therapy to prevent graft rejection and recurrence of islet autoimmunity
- The establishment of a standardised, quality-controlled source of pigs as donors of islet tissue for transplantation

Rationale

The considerable burden of type 1 diabetes makes its cure in people with established disease an essential goal. Cure means replacing lost insulin-secreting capacity in a way that enables insulin to be secreted in a finely tuned manner in response to natural nutrient stimuli such as glucose, amino acids and fatty acids. This may be achieved by transplanting pancreas tissue, islet or islet beta cells, or other cells into which the genetic machinery for insulin secretion has been engineered.

Human pancreas from organ donors is in short supply, and in any case could never meet requirements. The supply problem can be overcome by using animal, eg pig tissue. However, the major obstacle to successful transplantation of allografts (tissue within species) or xenografts (tissue between species) is immunological rejection of the graft and the recurrence of type 1 diabetes pathology in the graft.

At present, pancreas or islet transplantation is restricted to the small number of people with type 1 diabetes who require a kidney transplant, in whom the benefits of a life-saving kidney transplant justify the chronic use of strong non-specific immunosuppressive drugs (prednisolone, azathioprine, cyclosporine) to prevent graft rejection. The potential toxic effects of these drugs (increased risk of severe infection, cancer) cannot justify their use in the vast majority of people with type 1 diabetes. Cure by tissue transplantation will depend on research to find relatively safe and specific forms of immunotherapy.

Methods for curing type 1 diabetes in humans include:

- *transplantation of human cadaveric pancreas* is used in some people with type 1 diabetes who require kidney transplantation. Recipients are usually able to cease insulin injections within days of receiving the graft. Graft survival is now similar to that of other solid organ transplants with 76% of 8,999 pancreases grafted still functioning after one year. After 5 years, 64% have functioning grafts. Patient survival is 91% after 1 year and 80% after 5 years (Bland, 1997). At the end of 1996, 96 pancreases had been grafted in Australia, with 73% functioning and 92% of patients surviving (Bovington, 1997). Pancreas transplants are performed in the Australian Pancreas Transplant Unit at Westmead Hospital, Sydney and in the Department of Surgery, Monash Medical Centre, Melbourne. The major risk of transplantation is the ongoing use of non-specific immunosuppressive drugs to prevent rejection, which increases the risk of serious infection and cancer
- *transplantation of adult human islets* was first undertaken in 1970, but the success rate has been very low. By the end of 1995, 180 people with type 1 diabetes worldwide had received islet transplants but only 24 were able to stop insulin after 1 week; only 11 were insulin independent after 1 year, and only 5 after 3 years (Hering et al, 1996). Adult islet transplantations have not been performed in Australia
- *transplantation of human fetal pancreatic tissue* obtained from second trimester therapeutic terminations, into a small number of people with type 1 diabetes on immunosuppressive therapy, was undertaken in Australia in the 1980's but no cases of insulin independence were documented (Tuch et al, 1988)

- *transplantation of pancreatic tissue from animals,* particularly islets isolated from fetal, neonatal and adult pigs are capable of reversing diabetes in immunosuppressed rodents. In Sweden, 10 people with type 1 diabetes received fetal pig islet transplants, which, in some cases, functioned initially but did not reduce insulin requirements (Groth et al, 1994). Although the Federal Drug Administration (FDA) in the USA approves phase 1 and 2 trials of transplantation of pig tissue into humans, this form of transplantation into humans in Australia has been delayed pending the formulation of NHMRC guidelines following concerns about the potential for transmission of viruses

  A new strategy being pioneered in Australia is the engineering of pig islet cells with genes that encode proteins to make the islet resistant to immune attack after transplantation. This strategy is leading to the breeding of transgenic pigs for organ donation

- *transplantation of genetically engineered non-islet cells* is an alternative to using islets from humans or animals. This technology is not yet ready for human experimentation (Clark et al, 1997)

Proposed indicators

- the prevalence of type 1 diabetes
- the proportion of people with type 1 diabetes receiving human, animal or genetically engineered pancreatic tissue transplants resulting in reversal of diabetes at 1 and 5 years and improved quality of life

Strategies

Coordination

Establish an Australian Pancreas Transplant Advisory Group (APTAG) to develop and coordinate a national research strategy and programs to cure type 1 diabetes.

Information

Establish a database of research programs to cure type 1 diabetes and to monitor outcomes.

Best practice

APTAG should be responsible for producing and regularly updating a national consensus position paper on activities relating to the cure of type 1 diabetes and guidelines for researchers, consumers, consumer organisations and funding bodies.

Recommendation

21. Establish a national infrastructure to support and conduct studies aimed at curing type 1 diabetes

Type 2 diabetes

Key points

- In 1995 there were an estimated 780,000 people with diabetes in Australia - 430,000 diagnosed and 350,000 undiagnosed, representing 4.3% of the total population. Approximately 700,000 have type 2 diabetes
- Indigenous Australians have diabetes prevalence rates typically ranging from 7.4% to 15.6%, although higher rates have been reported in some communities
- Higher rates of diabetes are observed in Australians born overseas compared with Australian born population
- The pre diabetic state of impaired glucose tolerance (IGT) is at least as common as type 2 diabetes. IGT is associated with a significant risk of the development of type 2 diabetes and increased cardiovascular morbidity and mortality
- Glucose intolerance is a feature of the Metabolic Syndrome which affects an estimated 30% of the population
- Modifiable risk factors for type 2 diabetes, IGT and the Metabolic Syndrome include physical inactivity, unhealthy diet and obesity/overweight and all occur frequently
- Diabetes has a considerable impact on quality of life
- Cardiovascular disease remains the leading cause of death among people with diabetes
- Ischaemic heart disease accounts for at least 50% of the mortality in people with diabetes compared with 23% in the general population
- Renal disease accounts for between 8% and 14% of deaths in people with diabetes
- Type 2 diabetes may result in blindness, end stage renal failure, foot ulcers and amputations
- Lifestyle modification has the potential to prevent or delay the development of type 2 diabetes in susceptible individuals and communities
- Screening high risk individuals for the detection of undiagnosed type 2 diabetes is recommended
- Diabetes complications can be reduced by improved glycaemic control and better access to quality care

Background

Type 2 diabetes is a serious medical and social problem which places a large economic burden on individuals and society. It is the most common type of diabetes accounting for 85% to 90% of cases (McCarty et al, 1996). Type 2 diabetes is commonly considered mild, but its devastating complications are anything but mild. Large vessel disease in particular is severe and accelerated, leading to premature mortality (from cardiovascular disease) and considerable morbidity from angina, stroke, claudication and amputation. In addition, people with type 2 diabetes are subject to the development of the typical microvascular complications which can result in visual impairment, renal disease and foot problems.

Type 2 diabetes in Australia

There are only a limited number of studies, which have examined the prevalence of diabetes in Australia, and none of these has been conducted on a national sample. The 1995 ABS National Health Survey data on diabetes (ABS, 1997) indicate a self reported overall diabetes prevalence of 2.4% (430,700 Australians), increasing from 0.1% for people under age 15 to 8.9% in people aged 75 and over. This represents an increase in the proportion of people reporting diabetes in 1989-90 and may be a result of a combination of factors including increased diabetes prevalence, ageing of the population, changes in diabetes awareness, changes in medical practice/technology and improved diabetes testing methods. While the effect of ageing is significant it does not explain the total increase.

An Australian study has systematically examined the prevalence of undiagnosed diabetes and found a ratio of undiagnosed to diagnosed cases of 0.54 for Indigenous Australians and 1.1 for non Indigenous Australians (Guest et al, 1992). Applying this correction of one undiagnosed person with type 2 diabetes for each diagnosed person, the total diabetic population is estimated to be 780,000 (4.3% of the total population) of whom approximately 700,000 have type 2 diabetes. Since 1990 the number of people with diabetes has increased from 650,000 (3.8%). By the year 2000 diabetes is predicted to affect 900,000 Australians and 1.15 million by 2010 (McCarty et al, 1996).

While there is considerable variation in the prevalence of diabetes among different communities of Indigenous Australians, some communities have the fourth highest rates of type 2 diabetes in the world (McCarty et al, 1996). These differences may be genuine or reflect important differences in the design and in the reporting of results. Studies performed over the last decade show prevalence rates varying from 7.4% to 15.6% (McCarty et al, 1996). Ethnic differences in prevalence rates of type 2 diabetes have been reported from around the world but there are no good data available for Australian residents. However many of the ethnic groups with high prevalences are represented in Australia. Most of the highest rates are found in migrant populations which may have experienced a greater degree of westernisation. It is likely that ethnic people with higher genetic susceptibility to diabetes migrating to Australia will face a greater exposure to environmental factors associated with a westernised/industrialised lifestyle which will increase the risk of developing diabetes. Furthermore, these people are at greater risk of developing and experiencing adverse impacts of diabetes complications because many will lack access to health facilities (McCarty et al, 1996). The 1995 National Health Survey (ABS, 1997) reported that the age and sex standardised rate of diabetes in the overseas born population was 3.0% which is higher than that of the Australian born population (2.1%). The highest crude prevalence rates of diabetes were among people born in Europe, especially Southern Europe (7.8%).

Characteristics of type 2 diabetes

Type 2 diabetes is characterised by insulin resistance and diminished insulin secretion which result in an inability to maintain normal blood glucose levels. These abnormalities are postulated to result from genetic (Neel, 1962) and environmental influences, including intrauterine malnourishment (Hales & Barker, 1992).

The treatment of type 2 diabetes often involves weight reduction, increased physical activity and diet modification, and may include oral medications or insulin. While type 2 diabetes primarily occurs in adults over the age of 40, there is an increasing trend for the condition to develop at a younger age, particularly in communities undergoing rapid lifestyle changes, including Indigenous Australians. Unfortunately it can be asymptomatic for many years during which time undiagnosed hyperglycaemia can produce complications. Extrapolations from people with type 2 diabetes who have retinopathy at the time of diagnosis indicate that in some people type 2 diabetes may have existed undiagnosed for up to 12 years (Harris, 1993).

Beyond type 2 diabetes

Impaired Glucose Tolerance (IGT)

IGT defines a subgroup of the population which has glucose levels intermediate between normal values and those diagnostic of diabetes. People with IGT are at increased risk of the future development of type 2 diabetes and also at increased risk of cardiovascular disease morbidity and mortality. Insulin resistance is a feature of IGT and hyperinsulinaemia is also generally observed. Risk factors for IGT are similar to those for type 2 diabetes and for the pre diabetic state.

In the 1981 Busselton study 4.3% of men and 3.3% of women had IGT (Glatthaar et al, 1985) and in the Victorian country study rates of 4.0% in men and 7.8% in women were observed with similar rates in Indigenous Australians (Guest et al, 1992). There are no data on people of non-English speaking backgrounds resident in Australia. The prevalence of IGT increases with age. In the USA 6.4% of the 20-44 years age group have IGT, rising to 22% in 65-74 years (Harris et al, 1987).

Approximately one third of people with IGT will develop type 2 diabetes over a 5-10 year period (WHO, 1994). However, highly variable rates of progression have been reported ranging from 2% per year in Denmark to 16.4% in the Dutch Hoorn study (Alberti, 1996) with the median being approximately 6% per year progression to type 2 diabetes. Progression is not invariable and many will revert to normal glucose tolerance while a significant number remain with IGT. Biochemical risk factors for progression include the fasting and 2 hour blood glucose level and raised basal and low post-glucose insulin levels while increased body weight and ageing are also predictive but not independent risk factors once the biochemical parameters are considered (Harris, 1996).

IGT is associated with an increase in cardiovascular morbidity and mortality. Although there is controversy about whether this relationship is causal or due to the association of IGT with the other cardiovascular risk factors which cluster as the Metabolic Syndrome, people identified with IGT are at increased risk and strategies should be directed at minimising cardiovascular disease.

Prevention of progression of IGT to type 2 diabetes is a potential strategy in reducing the personal and societal impact of diabetes. Various interventions have been trialed including diet modification, sulphonylureas, biguanides and exercise alone or in combination (Melander, 1996). The major benefit has derived from lifestyle interventions. Reductions in progression from 29% to 13% over a 10 year period have been achieved with diet modification (Sartor et al, 1980), from 29% to 11% over 6 years with diet and exercise (Eriksson & Lindgarde, 1991) and up to 46% over a 6-year period by diet and/or exercise in the recently published DaQing study (Pan et al, 1997). A number of new pharmacological trials are underway using acarbose, metformin and troglitazone.

Also the Diabetes Prevention Program (DPP), a large multicentre study, has recently commenced in the USA to examine the effects of intensive exercise, troglitazone and metformin, but the results will not be available until 2003. As yet there are no data on any effect on changing the incidence of macrovascular disease.

The Metabolic Syndrome

The terms Metabolic Syndrome, the Insulin Resistance Syndrome or Syndrome X refer to a cluster of commonly associated clinical (central obesity, hypertension) and metabolic (glucose intolerance, dyslipidaemia, coagulation abnormalities, microalbuminuria) abnormalities which are risk factors for premature cardiovascular and atheromatous diseases. Insulin resistance is postulated as the common underlying abnormality and is accompanied by elevated insulin levels. The degree of glucose intolerance is variable ranging from normal to type 2 diabetes.

The Metabolic Syndrome is common and is estimated to affect approximately 30% of the population (Alford, 1996). Identifying individuals in the population with insulin resistance is difficult because of the lack of suitable methodologies for routine testing of individuals outside a research setting. Studies suggest that approximately 25% of the glucose tolerant population have insulin resistance (Reaven et al, 1993). This prevalence is influenced by age and weight, increasing from 22% in young normal weight men to 85% in older overweight men, and by racial background being observed in 59% of Aboriginal people (Colagiuri & Brand-Miller, 1997).

In summary, people with IGT or the Metabolic Syndrome, have increased mortality and morbidity due to cardiovascular disease. People in these categories should be encouraged to make lifestyle modifications such as reducing weight if overweight, maintaining reasonable levels of physical activities, eating a healthy diet and not smoking. In addition they should be screened and treated for cardiovascular risk factors and have annual follow up examinations which should include measurement of fasting plasma glucose (Davies & Gray, 1996).

Risk factors

Type 2 diabetes, pre diabetic states and the Metabolic Syndrome have common risk factors, some of which are modifiable and others are not (Table 6). Genetic factors are implied from the strong association of IGT and type 2 diabetes with a family history of type 2 diabetes. However despite an intense search, the genes which confer this susceptibility have not been identified. Increasing age has a deleterious effect on glucose tolerance due to a combination of increasing insulin resistance and decreasing insulin secretion. Increasing life expectancy has resulted in increasing the health burden of type 2 diabetes.

Table 6: Risk factors for glucose intolerance

Modifiable:	**Non modifiable**:
Nutrition: fat intake, glycaemic load	Age
Obesity: especially abdominal	Genetic susceptibility
Physical inactivity	Degree of modernisation
Intrauterine environment	Ethnicity
Smoking	

Modifiable risk factors

There are a number of well described modifiable risk factors which offer the potential for successful intervention.

Physical activity

Physical activity enhances insulin sensitivity and is beneficial in both non-diabetic and diabetic individuals. Cross sectional studies have shown that the least active individuals have a 2 to 4 fold increased chance of developing type 2 diabetes compared to the most active, and this holds true across a large number of populations (Zimmet, 1992). Physical activity is also inversely related to the development of IGT. In the Malta study, 16.5% of people in the lowest tertile of physical activity moved from normal glucose tolerance to IGT over a 2 year period compared with 5.2% in the most active group (Schranz et al, 1991).

Activity levels were assessed in the 1995 National Health Survey (ABS 1997). Among people with diabetes, 2% exercised at a high level, 20% at a moderate level, 36% at a low level and 41% were sedentary. Inactivity was also common among the total population with 37% of people over age 45 years not performing any regular exercise.

Nutrition

Nutrition is an important but complex risk factor in the development of type 2 diabetes. It is likely that a number of dietary factors contribute not only to diabetes but to other risk factors, such as obesity (Hamman, 1992). Dietary factors which have been most implicated in this process are energy dense foods rich in saturated fat (O'Dea, 1991), increased intakes of high glycaemic index carbohydrate (Brand Miller & Colagiuri, 1994) and reduced intakes of fibre. Two recent cohort studies which examined the relationship between dietary intake and the development of type 2 diabetes in 65,173 women and 42,759 men respectively over a 6 year follow up period reported diets with a high glycaemic load and a low cereal fibre content were associated with a 2-3 fold increase in risk of developing type 2 diabetes (Salmeron et al, 1997; Salmeron et al, 1997a). Recently breast feeding has also been proposed as a possible factor in preventing the development of type 2 diabetes (Pettitt et al, 1997).

Obesity

Increased body weight, especially centralised distribution of body fat (abdominal obesity) is an important risk factor for the development of type 2 diabetes, hypertension and cardiovascular disease. The aetiology of overweight and obesity is the complex interplay of genetic factors, food intake, physical activity and psychosocial influences. Two recent publications have detailed the extent of this problem in Australia (Healthy Weight Australia, 1995; NHMRC, 1996).

The 1989 National Heart Foundation (NHF) survey found that 40% of the adult population were overweight or obese - 48% males, 33% females (NHF & AIHW,1991). The prevalence of weight problems in the Australian population is increasing with the 1995 National Nutrition Survey finding 55.2% of adults being overweight (36.9%) or obese (18.3%) (ABS & DH&FS, 1997). The risk of obesity increases with age and weight problems are more prevalent among people in rural areas (NHF & AIHW, 1991) and the socioeconomically disadvantaged.

Weight problems are also an issue in Indigenous Australians although there is some variation in the results of different surveys (NHMRC, 1996). The 1994 National Aboriginal and Torres Strait Islander Survey conducted by the ABS showed that 38% of Aboriginal and Torres Strait Islander people aged over 13 years were overweight or obese. The Victorian country town study found that 62% of Aboriginal adult males (compared to 73% for non-Aboriginal males) and 70% of Aboriginal adult females were overweight or obese (compared to 54% for non-Aboriginal females) (Guest et al, 1992).

The problem of overweight and obesity is greatest among immigrants to Australia from Southern Europe who have 2 to 3 times greater odds of being overweight or obese compared with their Australian-born counterparts (NHF & AIHW, 1991). A higher BMI was also found in people from the Middle East and men from Eastern Europe (Bennett, 1993). However there is considerable variation in obesity among different ethnic populations. Some of this difference may be related to inherent differences in body weight measurements which equate to obesity with Asians likely to have lower cut points to define obesity and Pacific Islanders a higher cut point.

Increased body weight is commonly found in people with abnormalities of glucose tolerance compared to those with normal glucose tolerance. There is a sharp increase in IGT at a BMI in excess of 27 kg/m^2 with past and sustained high BMI being more important than current BMI alone (Alberti, 1996).

Smoking

A number of recent studies suggest that smoking may also be a modifiable independent risk factor for type 2 diabetes (Feskens & Kromhout, 1989; Rimm et al, 1993; Rimm et al, 1995; Kawakami et al, 1997). These studies have shown an approximately 2-3 times higher risk of developing type 2 diabetes in people who smoke more than 20-25 cigarettes a day. This risk can be reduced by ceasing smoking. The failure of earlier studies (Wilson et al, 1986) to show this association has been explained by a failure to take into account the amount of cigarettes smoked. Smoking has an acute effect in impairing glucose tolerance and reducing insulin sensitivity (Frati et al, 1996).

Personal impact of type 2 diabetes

While the public image of type 2 diabetes may be of a relatively non serious disease, quality of life is threatened in a number of ways. All people with type 2 diabetes are required to follow a diet, exercise regularly, and have regular retinal examination and screening for other complications from the time of diagnosis. People are affected by and cope with this in different ways, depending on treatment requirements and the presence or absence of complications.

Quality of life has not been studied as extensively as in type 1 diabetes. The 1995 National Health Survey (ABS, 1997) used the SF-36 to collect data on reported general health and well being in people with diabetes aged 18 and over and found statistically significant lower standardised mean scores than those people without diabetes for all eight SF-36 scales, especially for general health and role limitations due to physical health problems. In addition, a substantial proportion of people describe a reduction in their social life (Hornquist et al, 1995).

Health burden of type 2 diabetes

Mortality

Premature mortality can be considered the most severe complication of diabetes. Type 2 diabetes is associated with mortality rates which are 2 to 3 times higher than the rest of the population. However mortality statistics greatly underestimate the true diabetes related mortality as diabetes is always underestimated on death certificates.

The 1996 ABS report (ABS, 1997) listed diabetes as the 7th commonest cause of death, accounting for 2.3% of all deaths in Australia. Overall standardised death rate was 15 per 100,000 population, 18 per 100,000 for males and 12 per 100,000 for females. These statistics include only deaths which are directly attributable to diabetes. Since 1994, provision has been made to identify all deaths where diabetes is mentioned on the death certificate (rather than only as an underlying cause). In 1995 diabetes was mentioned on the death certificate and therefore could have contributed to 49 deaths per 100,000 population. While cancer is now the leading cause of death among Australians, cardiovascular disease remains the leading cause of death among people with diabetes.

Some Australian data are available on mortality in people with diabetes. Whittall et al (1990) reported that 63% of deaths in their cohort were due to cardiovascular disease but 37% of death certificates had not listed diabetes as direct or indirect cause of death, and McCann et al (1994) reported that 50% of deaths were due to coronary heart disease in men. This compares to the entire Australian population where ischaemic heart disease accounts for 23% of all deaths (ABS, 1997). Death rates in diabetic men of 1.8 times and in diabetic women of 1.4 times that of the Western Australian general population have been observed while females with diabetes onset under age 50 had 3 times the death rate (Knuiman et al, 1992). In the Tasmanian insulin treated diabetes register a 2-fold excess of mortality compared with the Tasmanian population has been found, with women with childhood onset of diabetes having 10 times the rates of cardiovascular mortality compared with non-diabetic females (Riley et al, 1995). Once again diabetes was not noted on 27% of death certificates (Riley et al, 1995). Renal disease accounts for between 8% and 14% of deaths (McCarty et al, 1996). The situation in Indigenous Australians is similar although renal disease is a direct cause of death in 22.3% and infection in 20.8% (Phillips et al, 1995), but diabetes was again not listed on 44% of death certificates.

This premature mortality results in a significantly shortened life expectancy. For a diabetic person of 60 years of age, life expectancy is reduced by 5 years and for females with early onset diabetes, life expectancy can be reduced by up to 16 years (Knuiman et al, 1992).

Morbidity

A range of complications can develop in people with type 2 diabetes. In the 1995 National Health Survey (ABS, 1997), the self reported crude prevalence rates were 5.7% for blindness, 6.8% for kidney disease, 14.9% for heart disease, 4.1% for stroke and 1.8% for amputation. Co-morbidities were also frequently observed - hypertension (44%) was four times more common in people with diabetes and 16.5% had high cholesterol.

Diabetic renal disease is the second most common cause in Australia of end stage renal disease requiring transplantation or dialysis and the number of people with type 2 diabetes accepted into these programs now exceeds those with type 1 diabetes (ANZDATA Report, 1996). The number of Aboriginal people and Torres Strait Islanders developing end stage renal disease is increasing at an alarming rate, with the annual incidence doubling every 3-4 years (Hoy, 1997).

Fifteen per cent of people with type 2 diabetes have evidence of retinopathy at diagnosis, with 55% developing retinopathy after 10 years of diabetes and 70% after 15 or more years (Mitchell, 1980). Overall 35% of people with type 2 diabetes have diabetic retinopathy (Mitchell et al, 1997). Using USA data adjusted for Australian Blindness criteria, ABS census data and estimates of diagnosed diabetes, it is estimated that 14,000 Australians have moderate visual impairment (corrected VA 6/24-6/60) and up to 7,200 are legally blind (corrected VA < 6/60) from diabetic retinopathy (NHMRC, 1997).

Foot disease is another major source of morbidity in people with type 2 diabetes. Amputations are 15 times more common in people with diabetes and approximately 50% of all amputations in Australia are attributable to diabetes. The number of amputations each year is approximately 2,800, the majority of which occur in people with type 2 diabetes.

Needs of people with type 2 diabetes

People with type 2 diabetes require ongoing medical, education (including diet) and personal support. The lifestyle changes, which include adhering to a diet and undertaking regular physical activity, are difficult to comply with and non adherence engenders feelings of guilt as well as admonition from others. In addition, people with type 2 diabetes must contend with the perception, often demonstrated by health professionals as well as lay people, that the condition is not particularly serious, in the face of their being constantly reminded of the devastating complications which may arise. These issues may be exacerbated by language barriers and lack of availability or access to required services.

A summary of other issues affecting people with diabetes can be found in Section 2, About diabetes: an overview.

Economic burden of type 2 diabetes

Type 2 diabetes is one of the most challenging health problems of the 21st century but its impact has been largely ignored by health care planners. The total cost of diabetes in Australia is estimated to exceed $A 1 billion annually (McCarty et al, 1996) and over 70% of health costs are consumed by people with type 2 diabetes (Alberti, 1996).

A detailed analysis of the economic burden is presented in Section 7 and in each of the Priority Programs in Section 5.

Recommendations

22. Implement a National Early Detection of Type 2 Diabetes Program linked to the National Type 2 Diabetes Prevention Program and the Program to Improve the Quality of Diabetes Care
23. Implement a National Type 2 Diabetes Prevention Program linked to the national Early Detection of Type 2 Diabetes Program

The rationale for these recommendations is detailed under Priority Programs in Section 5.

Gestational diabetes

Key points

- GDM is carbohydrate intolerance of variable severity with onset or first recognition during the current pregnancy
- The diagnosis of GDM is made by glucose tolerance testing
- ADIPS has recommended that all women should be tested for GDM in every pregnancy
- GDM is found in 5.5% to 8.8% of pregnancies. Women from a Caucasian background have an incidence rate of 3 to 5% while the incidence rate may be as high as 20% in Aboriginal women and in women from high risk ethnic populations e.g. India, Asia, Pacific Islands
- A number of studies have reported an association between GDM and increased perinatal morbidity and mortality
- GDM is more likely to be associated with an adverse pregnancy outcome in people from high risk groups, particularly if there is reduced access to effective obstetric care
- Longer term consequences of GDM include the future development of type 2 diabetes in the mother and the development of obesity, impaired glucose tolerance and/or type 2 diabetes in the offspring
- The identification of women with GDM and the offspring of GDM pregnancies may be of major importance to efforts to reduce the increasing prevalence of type 2 diabetes in the community

Background

Gestational diabetes mellitus (GDM) is carbohydrate intolerance of variable severity with onset or first recognition during the current pregnancy (Metzger, 1991). A small proportion of pregnant women will have unrecognised pre-existing diabetes or develop type 1 or type 2 diabetes during pregnancy. These can either be clinically recognised during pregnancy or determined by postpartum glucose tolerance testing. While GDM is associated with both short and long term adverse outcomes, there is controversy about some clinical aspects.

The diagnosis of GDM is made by glucose tolerance testing. The most commonly used testing procedure in Australia is based on the recommendations of the World Health Organisation (WHO) and entails a 75 gm glucose load with measurement of plasma glucose fasting and at 2 hours. The risk of an adverse pregnancy outcome increases as the maternal 2-hour glucose level increases with no apparent inflexion point. Thus the cut point for diagnosis has been determined by clinical consensus. There are international variations in this consensus cut point reflecting different populations and available resources. The Australasian Diabetes in Pregnancy Society (ADIPS) recommendations for the diagnosis of GDM are a fasting plasma glucose of 5.5 mmol/L or above and/or a 2 hour value of 8.0 mmol/L or above after a 75gm glucose load (Martin, 1991).

ADIPS has recommended that all women should be tested in every pregnancy (Martin, 1991). Selective testing of women based on risk factors will miss about one-third of all cases (Coustan, 1989; Moses et al, 1994). Testing in every pregnancy is necessary as a normal test in one pregnancy does not exclude the possibility of GDM in a subsequent pregnancy. While the definitive diagnosis of GDM is made using an oral glucose tolerance test, for logistical reasons, women may be screened by a preliminary glucose challenge test. While this is designed to reduce the number of women having an OGTT, a two stage procedure does lead to a delay in diagnosis and perhaps some anxiety to those women who are ultimately shown to have a false positive result.

Beischer et al (1991) have demonstrated over more than a quarter of a century of observation that the incidence of GDM has increased from around 1% to more than 8%. After adjustment for population variables, such as increasing maternal age and a changing ethnic mix, there was still a genuine increase and an increasing incidence. Data available from four centres in Australia report current rates of GDM ranging from 5.5% to 8.8% (Beischer et al, 1991; Martin et al, 1995; Moses et al, 1994; Yue et al, 1996). Women from a Caucasian background have an incidence rate of 3 to 5% while the incidence rate may be as high as 20% in Aboriginal women and in women from high risk ethnic populations e.g. India, Asia, Pacific Islands (Beischer et al, 1991; Yue et al, 1996). Risk factors for GDM include a history of diabetes in a first degree relative, increasing maternal age, obesity and being a member of a community/ethnic group with a high risk of developing type 2 diabetes.

The health burden of GDM

Risks to the foetus

GDM is associated with an increased perinatal morbidity and mortality. Earlier observational studies reported an increased perinatal mortality rate (PMR) in women with GDM (O'Sullivan et al, 1973; Pettitt et al, 1980) and this is still a problem in developing countries (Ramtoola & Damry,1997; Munichoodappa & Gurudas, 1997). Ongoing improvements in maternal and perinatal care have resulted in a steady overall reduction of the PMR in Western countries and it has been assumed that this would also apply to women with GDM. However recent Australian data have shown that women not tested for GDM have a PMR 2-3 times that of the tested obstetric population (Beischer et al, 1996). Babies born to mothers with undiagnosed or poorly managed GDM have a higher risk of macrosomia and delivery interventions. There is also an increased risk of neonatal hypoglycaemia, jaundice and hypocalcaemia and the need for and use of special care nursery facilities.

Risks to the offspring

Children from a pregnancy complicated by GDM have an increased risk of obesity and the early development of impaired glucose tolerance and type 2 diabetes (Silverman et al, 1995; Plagemann et al, 1997). The risk appears to be related to the maternal glucose level and is not found in women with good blood glucose control during the pregnancy (Silverman et al, 1995; Simmons et al, 1997). For obvious ethical reasons, there are only limited data from long term comparative observational studies in humans and therefore the long term effect on the offspring must be interpreted with caution. However, the evidence is consistent from both animal experiments and from human observational studies and there is so far no evidence to the contrary. Thus part of the burden of GDM, by providing an unfavourable intrauterine environment, may be to pass on to the offspring a phenotype which predisposes to the development of type 2 diabetes.

Risks to the mother

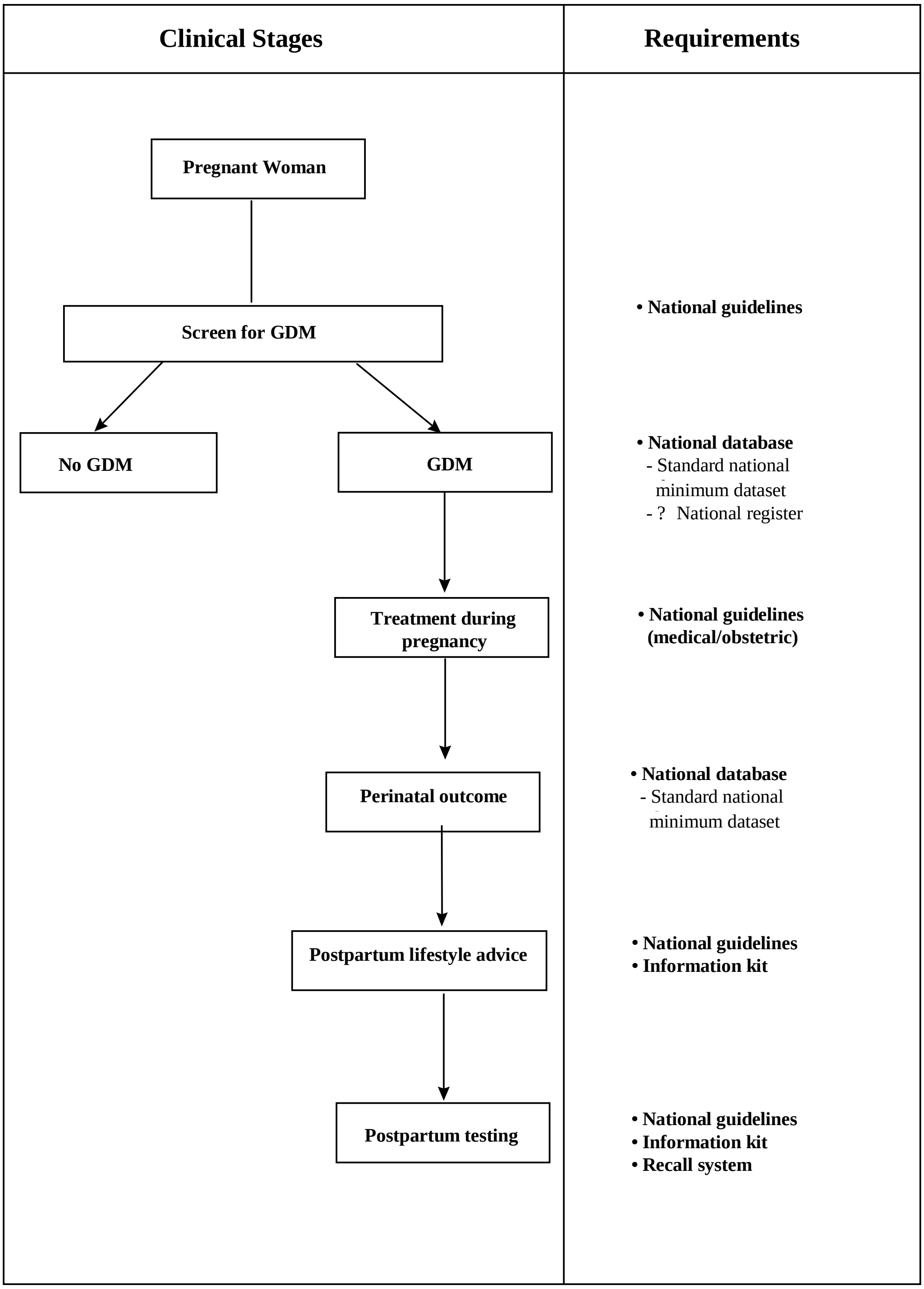
GDM is a very important risk factor for the future development of type 2 diabetes in the mother. The rate of conversion to type 2 diabetes of a woman who has had GDM will vary between population groups. In Caucasians the conversion rate is in the order of 2% per year. Women who are obese and are from a community, culture or ethnic background with a high prevalence and early age of onset of type 2 diabetes will have a more rapid conversion, perhaps as high as 5% per year.

Potential risks of management

Concern has been expressed about the potential for harmful outcomes following the management of GDM, particularly for women with a glucose level in the lower diagnostic range. Subjecting such women to intensive management with self blood glucose monitoring has been considered by some to be unnecessary and may result in unjustified anxiety in the mother. In general, the attitude of women towards the diagnosis of GDM and its treatment has been poorly researched (Griffiths et al, 1993). There is also some concern that overly aggressive management of GDM may result in a small for gestational age infant (Langer et al, 1989). A diagnosis of GDM in some centres has been associated with a greater chance of an obstetric intervention at the time of delivery.

Figure 10 summarises the general requirements for implementing a comprehensive GDM program.

Figure 10: ***Gestational diabetes program***



Economic considerations

There are few published studies which have examined the economic impact of GDM. The components which contribute to healthcare costs associated with GDM include:

- screening and diagnosing GDM
- treatment of women with GDM
- immediate and long term consequences of a diagnosis of GDM for both the mother and infant

- longer term follow up and interventions to prevent the development of type 2 diabetes

Currently approximately 50% of pregnant women are tested for GDM (Moses & Colagiuri, 1997; Wein et al, 1998), mostly using a two step procedure involving a screening test followed by an oral glucose tolerance test if the screening test is positive. Screening for GDM is relatively inexpensive and has been calculated to cost approximately $10 per person (Moses et al, 1997). However this cost is dependent on where the testing is performed, being more expensive if performed in a private pathology laboratory because of the additional cost of the patient episode initiation fee (see Early Detection of Type 2 Diabetes - Section 5).

Treatment costs for women with GDM are also dependent on how and where care is provided. Moses et al (1997) calculated a cost of care which included self monitoring of blood glucose, diabetes and dietary education, and medical consultation to be in the order of $380 for each woman not requiring insulin and $470 each for women requiring insulin treatment.

The major potential public health benefit of diagnosing GDM derives from identifying a cohort of women who are at increased risk of the future development of diabetes. It has been suggested that each woman with a previous GDM pregnancy should be assessed annually for the development of type 2 diabetes (NZSSD, 1995). The cost of ongoing annual surveillance of these women by the protocol of the Australian Diabetes Screening Survey (Welborn et al, 1997) would incur an annual cost of $102 for each woman.

Gregory et al (1993) have estimated savings of $US 32 million over 10 years with interventions which prevent 10% of US women with previous GDM developing type 2 diabetes, and savings of $US 140 million if 25% were prevented from developing type 2 diabetes, targets which are realistic and feasible given the results of recently reported intervention studies (Pan et al, 1997).

Clearly more data are required for a more detailed and comprehensive analysis of the costs associated with GDM. Such analyses would also help inform discussion and recommendations about screening and intervention programs for GDM.

Goal

Achieve maternal and child outcomes for gestational diabetes equivalent to those of non-diabetic pregnancies

Objectives:

- Develop and implement a national consensus position on the detection of GDM
- Improve the effectiveness and accessibility of services for the care of all women with GDM

Expected Outcomes:

- 80% of all pregnant women being appropriately tested for GDM
- 80% of women with GDM receiving care according to guidelines
- 80% of Aboriginal Indigenous health services having a GDM service and staff trained to provide the service

Rationale

Despite the potential for immediate advantages to the outcome of the pregnancy, and the identification of women at particularly high risk of developing type 2 diabetes in the future, an estimated half of all women are currently not being tested for GDM (Moses & Colagiuri, 1997; Wein et al, 1998). Detection of GDM is essential in order to implement appropriate interventions to ensure the best outcome for the pregnancy. While debate continues about the degree of hyperglycaemia at which the risk of perinatal morbidity and mortality increases, a testing program is necessary to detect women with unequivocal hyperglycaemia about which there is widespread consensus that intervention is indicated and beneficial.

Women diagnosed with GDM should have access to health professionals with expertise in the management of this problem. A team approach should be used and should include a dietitian, diabetes educator and a medical practitioner (and where appropriate an Aboriginal health worker). Appropriate and ongoing dietary advice is an essential aspect of treatment with insulin therapy being implemented if adequate glycaemic control is not achieved.

Proposed indicators

- the proportion of pregnant women being appropriately tested for GDM
- the proportion of women with GDM receiving care according to guidelines
- the number and distribution of facilities providing services to women with GDM

Strategies

Coordination

Establish a National GDM Advisory Committee which should be responsible for:

- developing a National Consensus Position on testing for GDM by reviewing the current ADIPS protocol, the OATSIHS recommendations on GDM screening and diagnosis, and current literature
- devising implementation strategies for achieving appropriate testing for GDM
- developing a program for increasing public awareness of GDM and about appropriate testing during pregnancy
- developing a program for increasing awareness among health professionals about testing for GDM during pregnancy and developing information kits to facilitate this in prenatal clinics and in the offices of obstetricians and GPs.

Information

- develop a national standardised midwives minimum data set to collect data on GDM, including testing for GDM
- create a Medicare Schedule Benefit Item for testing for GDM. This would not incur any additional costs and enable testing for GDM to be monitored
- Commonwealth and State/Territory Health Departments to publish data about the pattern of testing
- expand the National Diabetes Register to include women with a GDM pregnancy
- establish local GDM data bases

Best practice

- develop and disseminate standards of care and a protocol for management of women with GDM
- develop and provide training programs for health professionals (especially Aboriginal and Ethnic health workers) in the management of women with GDM
- provide advice and assistance in establishing GDM management services in Aboriginal communities and for high risk ethnic communities.

Recommendations

24. Establish a National GDM Advisory Committee to develop a National Consensus Position on testing for GDM, and develop and disseminate recommended standards of care and a protocol for the ongoing clinical management of women following a GDM pregnancy

25. Develop a national standardised midwives minimum data set to collect data on GDM

26. Expand the National Diabetes Register to include women with a GDM pregnancy

Goal

Prevent or delay the development of type 2 diabetes

Objective:

- Provide every woman after a GDM pregnancy with advice about lifestyle activities to reduce her chance of developing type 2 diabetes

Expected Outcomes:

- 50% reduction in the progression to type 2 diabetes of women who have had GDM
- 80% of women with previous GDM being regularly tested for glucose intolerance
- the establishment of a GDM register/data base
- the establishment of a mechanism for recalling women with previous GDM for glucose tolerance testing

Rationale

Women with previous GDM are at high risk of developing type 2 diabetes. Overall, 2% of Caucasian women develop type 2 diabetes each year after a pregnancy complicated by GDM. This percentage may be as high as 5% in women who are obese and who are from cultural groups with a high prevalence and early age of onset of type 2 diabetes. Lifestyle factors which are known to delay or prevent the future development of type 2 diabetes include eating a healthy diet, performing regular physical activity and achieving a healthy weight. Favourable changes to these factors are likely to have a positive effect (Rossi & Dornhorst, 1996). Therefore ongoing education about these lifestyle factors should be offered to all women after a GDM pregnancy. In addition these women should be assessed regularly for glucose intolerance to ensure early detection and treatment in women who do progress to type 2 diabetes.

Potential indicators

- the proportion of women with a previous history of GDM progressing to type 2 diabetes
- the proportion of women with GDM being regularly tested for the development of type 2 diabetes
- the proportion of women with GDM who receive advice about modifiable risk factors before discharge from hospital

Strategies

Coordination

The National GDM Advisory Committee should develop recommendations about postpartum lifestyle advice and ongoing surveillance, implementation strategies, and awareness programs for both women with a GDM pregnancy and for health professionals.

Information

Lack of information about women with previous GDM pregnancies is a significant barrier to implementing strategies for the prevention of the future development of diabetes. Information strategies which address this include:

- expand the National Diabetes Register to include women with a GDM pregnancy
- incorporate a recall system within National/State/regional/local GDM data bases

A recall system already operates through the Mercy Hospital in Victoria and could form the basis of developing and trialing a state based system for potential expansion into a national model.

Best practice

- develop and disseminate standards of care and a protocol for ongoing management of women following a GDM pregnancy
- develop and provide training programs for health professionals (especially Aboriginal health workers and Ethnic health workers) in the ongoing management of women following a GDM pregnancy
- provide women with GDM advice about modifiable risk factors before discharge from hospital
- increase community awareness that women with previous GDM need to eat a healthy diet, perform regular physical activity and maintain a healthy weight
- provide this advice in a culturally appropriate format
- inform women with previous GDM and their general practitioner/regular health carer about the importance of regular testing for glucose intolerance
- provide community education about the need for assessing glucose tolerance in women who have had GDM

Recommendation

27. Develop a recall system for targeting women with a GDM pregnancy for ongoing lifestyle advice and monitoring for the future development of glucose intolerance

Management of pregnancy in women with pre-existing diabetes

Key points

- Type 1 diabetes occurs in approximately 3.5/1,000 pregnancies and is the most common pre-existing medical disorder complicating pregnancy
- Type 2 diabetes is uncommon in Caucasian women of child bearing age but is much more common in Indigenous Australians and women from certain ethnic backgrounds
- Diabetes is a high risk state for both the mother and her foetus
- The occurrence of maternal and foetal complications is dependent on metabolic control
- Spontaneous abortions occur at double the rate and congenital anomalies at two to five times the rate of the general population
- Poorly controlled diabetes during the early weeks of pregnancy, in many cases before the women knows that she has conceived, significantly increases the risk of spontaneous abortion and major congenital anomalies
- Programs for preconceptual management of the diabetic woman planning a pregnancy, and the normalisation of blood glucose levels before conception, reduce the risk of major birth defects and the occurrence of spontaneous abortions to near that of the non-diabetic population
- Pre pregnancy counselling and management are vital components in the care of women with diabetes
- Pregnancy in diabetic women is contraindicated if the woman has clinical cardiac disease and if there is significant pre-existing renal disease
- Ideally, all pregnant women with diabetes should be cared for by an interdisciplinary team

Background

Pregnancy in women with pre-existing diabetes is a potentially serious problem for both the mother and foetus. Type 1 diabetes occurs in approximately 3.5/1,000 pregnancies and is the most common pre-existing medical disorder complicating pregnancy (SIGN 9, 1996). Type 2 diabetes is uncommon in Caucasian women of childbearing age but is much more common in Indigenous Australians and women from certain ethnic backgrounds. Oral hypoglycaemic agents are contraindicated during pregnancy and therefore women with pre-existing type 2 diabetes should be converted to insulin prior to conception.

Diabetes is a high risk state for both the mother and her foetus because of increased risks of congenital malformation, spontaneous abortion, pre-eclampsia, premature labour, polyhydramnios, maternal infection, late intrauterine death, foetal distress, obstructed labour, and neonatal complications including hypoglycaemia, respiratory distress syndrome and jaundice. In the pre-insulin era, maternal mortality was 33% and perinatal mortality was 65%. Following the discovery of insulin, maternal and foetal/neonatal survival improved dramatically. During the past decades, general advances in the care of the individual with diabetes, as well as advances in foetal surveillance and neonatal care, have continued to improve outcomes in most diabetic pregnancies (ADA, 1993). However, despite these advances, several problems remain including a high incidence of congenital anomalies and spontaneous abortions, caring for women with advanced diabetes complications, and caring for women who present late for antenatal care.

The occurrence of maternal and foetal complications is dependent on metabolic control, especially major congenital abnormalities and spontaneous abortions. The true incidence of spontaneous abortions is not known but has been estimated at 30%, double that of the general population (Miodovnik et al, 1984). The risk of congenital anomalies in type 1 diabetes ranges from 6-12%, a two to five fold increase compared to the general population (ADA, 1993) and accounts for 40% of the perinatal loss in type 1 diabetes. Congenital abnormalities vary and include cardiac, neural tube or skeletal defects and are often multiple, more serious and more often result in death compared with non diabetic women. They appear to be the direct result of the teratogenic effects of hyperglycaemia and other metabolic abnormalities.

Since foetal organogenesis is largely completed by 6 weeks after conception, poorly controlled diabetes during the early weeks of pregnancy, in many cases before the women knows that she has conceived, significantly increases the risk of first trimester spontaneous abortion or delivering an infant with a major anomaly (Greene et al, 1989). As a result of programs developed for preconceptual management of the diabetic woman planning a pregnancy, and the normalisation of blood glucose levels before conception and in the early weeks of pregnancy, studies have confirmed a reduction in the risk of major birth defects and the occurrence of spontaneous abortions to near that of the non-diabetic population (Kitzmiller et al, 1991).

Pre pregnancy counselling and management have emerged as vital components in the care of the woman with diabetes. Pre pregnancy planning programs should include assessment of the patient’s fitness for pregnancy, obstetric evaluation, intensive education of patient and partner, attainment of optimum diabetes control and timing and planning of pregnancy. A planned pregnancy is a major objective of preconception counselling.

Pregnancy in diabetic women is contraindicated if the woman has clinical cardiac disease because maternal mortality is high and if there is pre-existing renal disease (creatinine clearance < 50 ml/min or proteinuria > 300 mg/24h) because of the high risk of morbidity and mortality of the infant. Pregnancy may cause significant deterioration of diabetic retinal and renal disease, particularly in those women with a long history of poor diabetes control. Retinal problems should be treated prior to conception. Also autonomic neuropathy can be associated with intractable vomiting.

An optimal outcome may be obtained in diabetic pregnancy if good metabolic control is achieved before and during pregnancy. This requires planned management of the diabetic women of child bearing potential including contraceptive advice, pre-pregnancy counselling, early antenatal care, careful obstetric surveillance and neonatal support should be available when required. Preconception management has been shown to be cost effective (Scheffler et al, 1992). All forms of contraception carry some risk and every woman must be considered individually.

Ideally, all pregnant women with diabetes should be cared for by an interdisciplinary team including an endocrinologist or physician with expertise in diabetes care, an obstetrician with a specialist interest in diabetic pregnancy, a diabetes educator, a dietitian and a neonatal paediatrician. There is no need for routine admission other than when a diabetic or obstetric problem occurs. Self blood glucose monitoring and dietary review are essential and folate supplements (4mg/day) are advised. Hypoglycaemia is common but there is no evidence that its occurrence can cause foetal abnormalities (SIGN 9, 1996).

The timing of delivery should be individualised and the aim is to have a spontaneous vaginal delivery if possible. However this will ultimately be determined by obstetric indications and the health of the mother. Each labour ward managing women with diabetes should have a clear protocol. The recommended method of management of the diabetes during labour is an insulin-dextrose infusion. The mother’s diet and insulin will need review in the postpartum period. Breast feeding should be encouraged but care should be taken as this may increase the chance of hypoglycaemia.

Goal

Achieve maternal and child outcomes for pregnant women with pre-existing diabetes equivalent to those of non-diabetic pregnancies

Objectives:

- Pre pregnancy counselling and optimised diabetes control for all women with diabetes before and during pregnancy
- Improve the effectiveness and accessibility of services for the care of pregnant women with diabetes

Expected Outcomes:

- 80% of women with diabetes in the child bearing age group receiving pre pregnancy counselling about the management of diabetes and pregnancy
- 80% of pregnant women with pre-existing diabetes receiving care according to guidelines

Rationale

The rationale for improving the care of pregnant women with pre-existing diabetes is contained in the Background, management of pregnancy in women with pre-existing diabetes.

Proposed indicators

- the proportion of diabetic women of child bearing age receiving pre pregnancy counselling
- the proportion of diabetic women planning a pregnancy receiving preconception management according to guidelines
- the proportion of pregnant women with pre-existing diabetes receiving care according to guidelines

Strategies

Coordination

- develop national evidence based/consensus guidelines on the management of pregnancy in women with pre-existing diabetes

Information

- ensure that data on the occurrence and outcomes of pregnancy in women with pre-existing diabetes is collected by the National Diabetes Register of insulin treated diabetes
- explore mechanisms for collection of similar data for pregnant women with pre-existing non insulin treated type 2 diabetes

Best practice

- develop and disseminate standards of care and a protocol for management of pregnant women with pre-existing diabetes
- develop and provide training programs for health professionals in the management of pregnant women with pre-existing diabetes

Recommendations

28. Develop national guidelines for the clinical management of pregnant women with pre-existing diabetes

29. Ensure that diabetic women of child bearing age have access to pre-pregnancy counselling and optimised diabetes control prior to conception

30. Monitor the outcomes of pregnancies in women with pre-existing diabetes through the National Diabetes Register

Research

Key points

- Research and development has had a major impact on the health gains achieved this century
- Combatting the rapidly growing burden of diabetes requires strategic effort across the entire spectrum of research - epidemiology, behavioural, health system, biomedical and clinical
- Frameworks have been developed to address strategic issues to determining research priorities and deficiencies
- Australia does not currently have a national strategic prioritised research plan for diabetes
- In 1995 the NHMRC allocated 2.3% ($2.35 million) of its research funding to diabetes while JDFA contributed $1.94 million and DA contributed $0.6 million
- In 1995 the NHMRC directly allocated 25% of its funds to the then four Priority Health Areas - cardiovascular disease, cancer, mental health and injury
- Diabetes research funding through the NHMRC is not commensurate with its status as a National Health Priority Area.

Goal

Advance knowledge and understanding about the prevention, cure, and care of diabetes through a comprehensive research effort

Objectives:

- Develop a comprehensive prioritised research plan to improve outcomes for people with diabetes and to prevent people developing diabetes
- Increase NHMRC funding for the prioritised research program
- Implement mechanisms to provide feedback and results to the research and clinical communities to maximise the relevance of research efforts and to minimise duplication and peripheral research

Expected Outcomes:

- A comprehensive prioritised diabetes research plan
- NHMRC funding equivalent to the other National Health Priority Areas
- An accelerated, efficient and rigorous research output in Australia which addresses priority research needs in diabetes and is multidisciplinary in orientation

Background

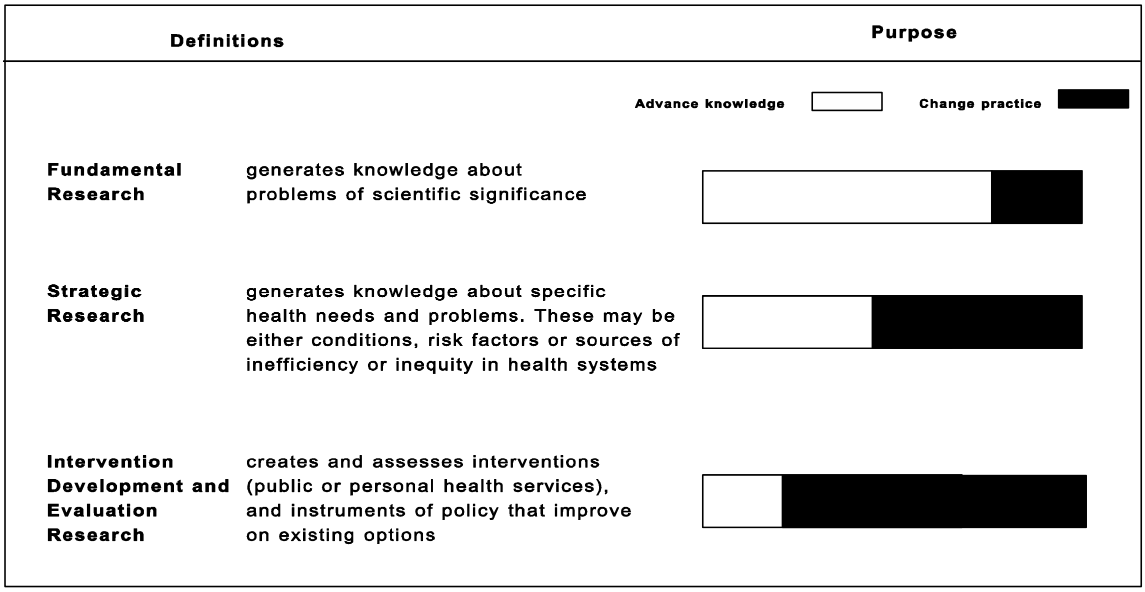
Many factors determine the health status of individuals and the variability of health within populations. It is estimated that worldwide, half of the health gains achieved this century have resulted directly from improvement in economic and educational standards. Of equal importance in achieving health gain has been the advance in scientific knowledge and its application both in creating effective interventions and in guiding behaviour (WHO, 1996).

This has significant implications for health policy and emphasises the high return achieved by investments in health research and development (R&D) on health status and economic productivity. The challenge is to develop ways to maximise R&D efforts to ensure the best use of limited resources. Since most of the gains of health R&D can be shared, an important objective is to explore mechanisms for collective action in performing research, sharing developments and creating an information environment to translate research findings into practical tools.

Health R&D must be considered in its broadest sense and include the behavioural sciences, health systems, biomedical research, clinical research, and operational research to facilitate implementation. To combat the rapidly growing burden of non communicable diseases such as diabetes requires a significant increase in strategic research in epidemiology, behavioural sciences and health policy with the aim of reliably monitoring the true prevalence and trends of these conditions in populations, and understanding their determinants. Basic data on mortality, morbidity and disability are currently inadequate as are data on determinants of environmental and behavioural risk factors (WHO, 1996).

An additional issue is the uneven distribution of funding between the various research disciplines with biomedical research being better supported than epidemiological, clinical and behavioural research. This is an important consideration for the *National Diabetes Strategy and Implementation Plan* since the contribution of the various research disciplines to health knowledge and practice differs (see Figure 11) (adapted from WHO, 1996).

Figure 11: Contribution of research to knowledge and changing practice



Definitions	
Fundamental Research	generates knowledge about problems of scientific significance
Strategic Research	generates knowledge about specific health needs and problems. These may be either conditions, risk factors or sources of inefficiency or inequity in health systems
Intervention Development and Evaluation Research	creates and assesses interventions (public or personal health services), and instruments of policy that improve on existing options

Source: Adapted from WHO, 1996

At the outset of any research initiative, two questions must be asked: ‘What do we know already? ’ and ‘What do we need to know? ’ in order that a responsive research agenda is developed, agreed and undertaken. Limited research funds can then be directed to projects which answer relevant and important questions, building on an existing knowledge base in a systematic manner. The strengths of investigator-driven research are not undermined by such an approach but the urgent research questions which need to be ‘fast tracked’, can be addressed. An example of a comprehensive review which was undertaken to identify priority issues for Australian research demonstrated the weaknesses of relying on an exclusively investigator-driven research output (NSW Cervical Screening Program, 1997). Similar approaches to the systematic synthesis of existing knowledge and the identification of research priorities have been advocated elsewhere (Peckham & Smith, 1996; Dunn et al, 1994; Muir-Gray, 1997).

Frameworks have been developed to address the strategic issues relating to determining research priorities and deficiencies. The model proposed in cancer control (Advisory Committee on Cancer Control, 1994) was itself derived from a framework to improve public health practice (Tugwell et al, 1985). This model comprises four stages through which basic research progresses to the delivery of programs to the public, emphasising evidence based decision rules to move from one stage to the next. The four main stages are fundamental research, intervention research, program delivery and surveillance/monitoring. Each of these is linked to a fifth category, knowledge synthesis and decision-making (Advisory Committee on Cancer Control, 1994). The model’s four principles are accountability, empowerment, ethics and efficiency.

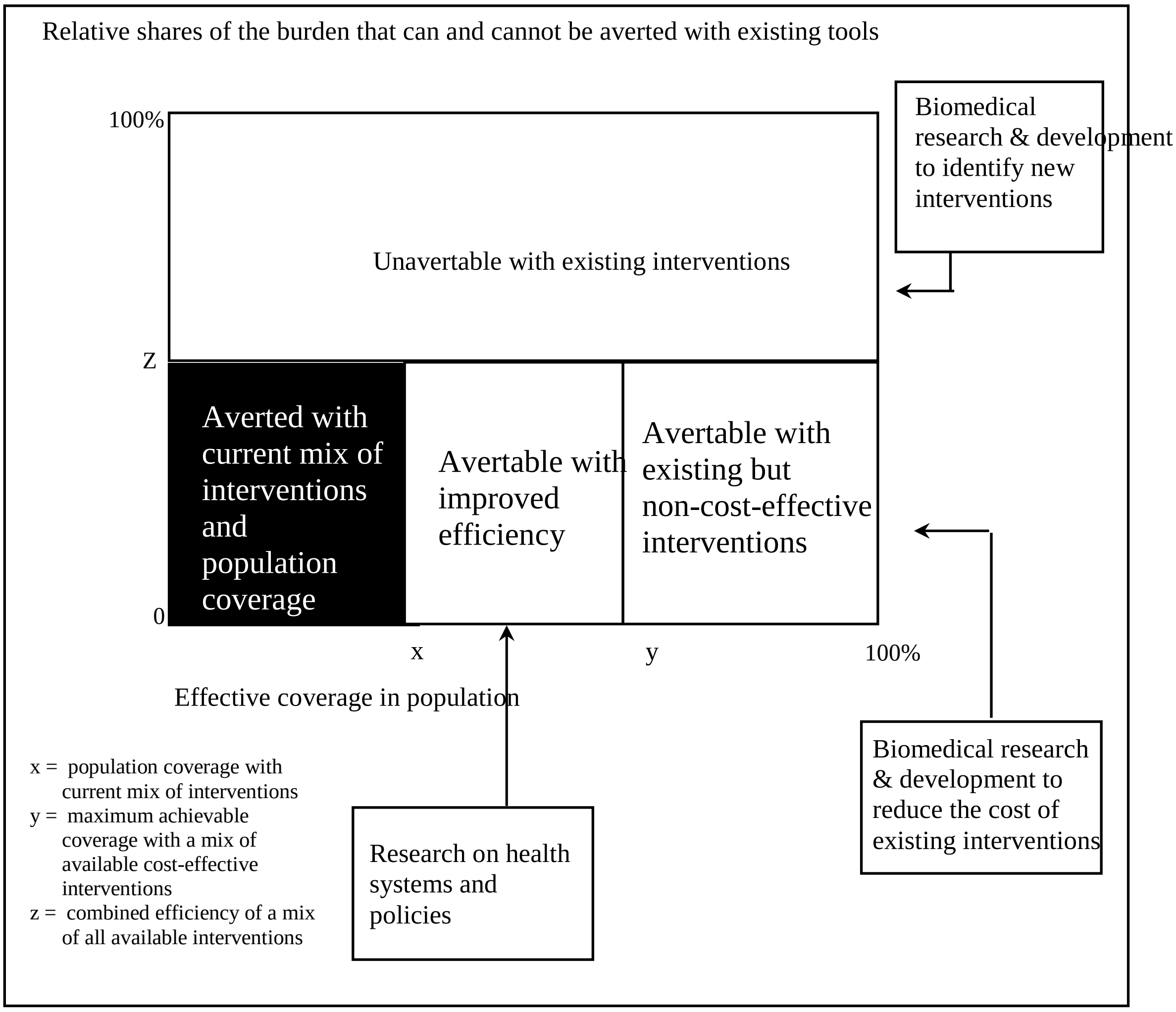
The Strategic Research Development Committee of the NHMRC has already adopted a priority setting process to develop research agendas for youth suicide, injury, and ear disease in Indigenous Australians (NHMRC, 1998). The model used by the NHMRC was initially proposed by WHO to analyse the burden of health to identify research needs (WHO, 1996) and is illustrated in Figure 12. The whole square represents the total estimated disease burden from a given condition. The horizontal axis represents the extent to which effective treatment is reaching the population and the vertical axis represents the combined efficacy of the treatment mix. The subdivisions within the square represent different portions of the burden - what is being averted now, what could be averted if existing interventions were used more efficiently, and what could be averted with existing but non-cost effective interventions.

The application of the components of this model to one aspect of diabetes, Diabetic End Stage Renal Disease, is illustrated in Table 7.

Table 7: Analysing the burden of diabetic end stage renal disease to identify research needs

Condition	Need	Opportunity: promise of R&D effort					Investment
	Disease burden	Primary reason for persistence of burden	Current knowledge base/R&D capacity	• Desired intervention • Estimated cost effectiveness	Probability of success	• Current effort • Additional cost	
End stage renal disease	high	failure to use existing tools efficiently	good	• package of integrated management • high	high	• sub optimal • low	high priority

Figure 12: Model to analyse the burden of disease to identify research needs



x = population coverage with current mix of interventions
y = maximum achievable coverage with a mix of available cost-effective interventions
z = combined efficiency of a mix of all available interventions

Diabetes research funding in Australia

Funding for diabetes R&D does not reflect the magnitude of the health burden caused by diabetes in Australia and diabetes' status as a National Health Priority Area.

Funding sources

Research in Australia is funded through two major sources, government and non-government.

Government research funding

NHMRC

The NHMRC is the Commonwealth Government's research funding mechanism. Each year the Commonwealth Government appropriates funds for research which are granted by the Minister of Health and Family Services on advice of the NHMRC. The NHMRC has a broad range of research related functions including improvement of health, prevention, diagnosis and treatment of disease, provision of health care, public health research and medical research and ethical issues relating to health.

The NHMRC Research Committee (Public Health and Medical) has members categorised with expertise in biomedical research, combined biomedical/clinical research, clinical research and public health research. In addition there is a Strategic Research Development Committee which is responsible for defining a research and training agenda based on identified gaps in knowledge and skills. This committee has a member with expertise in Endocrinology.

Research funding provided by State and Territory Government

State and Territory Governments allocate funding to support research to address specified areas of health. These arrangements are locally determined and are not administered through a mechanism as clearly defined by the NHMRC.

Non government funding

The main non government sources of research funding are the JDFA and DA (through the Diabetes Australia Research Trust, the WA Diabetes Research Fund and the Kellion Foundation).

Pharmaceutical companies also contribute to research funding as do non diabetes specific charitable organisations, other industry and individual benefactors. Another source of research funding which is likely to increase in the future is partnerships between the pharmaceutical industry and biotechnology companies, especially in arrangements which include rights to licensing discoveries.

Extent of diabetes research funding

In 1995 the NHMRC allocated 2.3% ($2.35 million) of its research funding to diabetes while JDFA contributed $1.94 million and DA contributed $0.6 million (ADS Summary Report on Diabetes Research, 1996). In the same year the NHMRC directly allocated 25% of its funds to the then four Priority Health Areas - cardiovascular disease, cancer, mental health and injury (Giusti et al, 1995). Clearly diabetes research funding through the NHMRC is not commensurate with its status as a National Health Priority Area.

Proposed indicators

- A prioritised research plan for diabetes
- A published list of priority research issues for use by researchers and investors
- The amount of NHMRC and total funding for diabetes research
- The amount of funding for biomedical, clinical, behavioural, health services and public health research
- The outcomes of research efforts such as number and quality of peer-reviewed papers originating from Australian investigators in diabetes prevention, cure, and care
- The documented use of research findings in policy development and clinical decision-making

Recommendations

31. Increase NHMRC research funding for diabetes to reflect its status as a National Health Priority Area

32. Convene a National Diabetes Research Working Party with equal representation of the various research disciplines, and consumer representation

33. Commission the NHMRC Strategic Research Committee to work with the National Diabetes Research Working Party to develop a prioritised research agenda for diabetes which covers all aspects of the continuum of care

34. Use the agreed research agenda to inform diabetes research funding from government and non government sources and evaluate and review the research agenda every 5 years

The health system

Key points

- Australia has a good and comprehensive health care system
- The relationship between Commonwealth, State/Territory and regional health services is complex. Financing, planning, health surveillance and service delivery responsibilities are divided but not always coordinated between different levels of government
- Recent innovations which address some health system issues include the COAG coordinated care trials, the National Public Health Partnership and the National Health Priority Area initiative
- Health care funding by the Commonwealth government is through Medicare, the Healthcare Agreements, the Pharmaceutical Benefits Scheme, and funding for specific programs and for general practice.
- Horizontal integration with other national initiatives is essential for improving diabetes prevention and care. Key programs to which the *National Diabetes Strategy and Implementation Plan* should be linked include:
  - Active Australia
  - Acting on Australia's Weight
  - Australia's Food and Nutrition Policy
  - NPHC Cardiovascular Disease Committee
  - National Divisions Diabetes Program
  - National Aboriginal Health Strategy
  - National Rural Health Policy
  - National Healthy Ageing Strategy
- Ongoing funding is required to implement and sustain the *National Diabetes Strategy and Implementation Plan*. Funding opportunities include:
  - Changes to Medicare Benefits Schedule for both clinical and pathology services
  - Medicare cash out arrangements
  - Incentives for consumers and providers
  - Linking part of the Healthcare Agreement funding to performance indicators for the National Health Priority Areas
  - Measure and Share arrangements for diabetes

Goal

Improve the capacity of the health system to deliver, manage and monitor services for the prevention of diabetes and the care of diabetes

Objectives:

- Develop and maintain a coordinated approach to diabetes prevention and care which is integrated across the continuum of care, and across relevant disease areas
- Ensure that health and related policy uses an evidence based approach and supports healthier environments, effective resourcing, administration, prevention services, and clinical care for diabetes
- Assure funding for implementation of the recommendations of the *National Diabetes Strategy and Implementation Plan*

Expected Outcomes:

- A coordinated and integrated approach to diabetes prevention and care
- Information systems to monitor progress
- Structural changes to provide ongoing funding to implement the recommendations of the *National Diabetes Strategy and Implementation Plan*

Background

The Commonwealth of Australia is made up of six States and two Territories. Levels of government are divided into three tiers:

- Commonwealth
- State/Territory
- Local

Overall, Australia has good and comprehensive health care. However the evolution of health care provision in Australia has resulted in a system which is complex. Financing, planning, health surveillance and service delivery responsibilities are divided but not always coordinated, between different levels of government. Further complexity is added by the coexistence of public and private systems and their respective funding arrangements. There is continuing debate, and occasionally tension, about the appropriate mix of public and private services, and Commonwealth and State/Territory funding arrangements, responsibilities and powers.

Health care structure

Commonwealth

At the Commonwealth level the health system comprises the DH&FS and three statutory bodies:

- the AIHW which is responsible for national health surveillance and monitoring socio-demographic data
- the Health Insurance Commission (HIC) which administers and monitors Medicare payments and operates Medibank Private
- the NHMRC which provides independent advice to government about health issues and funds health and medical research

The role of the DH&FS is constantly evolving and currently includes stewardship of national health policy and the identification of national health priorities; provision of funds to the States and Territories through the Healthcare Agreements and program funding; administration of Medicare and the PBS; and the monitoring of health goals and targets.

States and Territories

State and Territory Governments are concerned with administering and allocating funding to regional health services for acute care (public hospitals), community-based services (eg community nursing, early childhood centres) and traditional health protection (eg food safety; infectious disease monitoring and outbreaks). State and Territory jurisdiction also includes the licensing of private hospitals and nursing homes, registration of medical, nursing, and most categories of allied health workers; and State/Territory health policy development and implementation. Also, States and Territories are assuming an increasing role in local needs assessment, health surveillance, health promotion and disease prevention, environmental health and immunisation.

Local

Local government also contributes to health. Responsibilities vary from State to State, but usually relate to environmental control, home care services and local activities in health promotion and disease prevention. Waste disposal is a local government responsibility pertinent to people with diabetes (see below).

Health care funding arrangements

The Commonwealth is primarily responsible for the funding of health services, through direct payments to the States/Territories, Medicare and the PBS.

Medicare

The cornerstone of the Australian health financing system is the government-run national health insurance scheme, Medicare, paid for through taxation (and levy) on income. Medicare began operation in 1984 and is administered by the HIC. Medicare has been successful in containing health care costs (Taylor & Salkeld, 1996) and the experience in Australia has been similar to other countries with cost-control being more effective where a ‘single payer’ has responsibility for financing (Gray, 1996). Public support for the scheme has steadily increased, although it has been criticised for its potential for cost-shifting between State and Commonwealth governments (Macklin, 1990), patient queuing, and the lack of choice and diversity it offers patients.

The HealthCare Agreements

Formerly known as the Medicare Agreements, the Healthcare Agreements cover the distribution of funding provided by the Commonwealth to the States and Territories to support hospital and other publicly funded health facilities and services. Increasingly arrangements are being negotiated to link this funding to health outcomes.

Pharmaceutical Benefits Scheme

The PBS is designed to provide timely, reliable and affordable access to necessary and cost effective medicines (DH&FS, 1997). Medicines covered by the PBS are provided at a subsidised cost with the individual's contribution differing according to individual circumstances eg whether the person is a pensioner or health card holder. The PBS does not cover pharmaceutical items supplied by public hospital facilities which is funded by the States and Territories.

Program funding

In addition to the above funding arrangements, the Commonwealth allocates funding for specific programs. This funding is at the Commonwealth's discretion and may be linked to State/Territory bilateral agreements.

General Practice funding

General Practice illustrates the complexity of our health care system. GPs are registered by the State/Territory but are reimbursed for the services they provide by the Commonwealth through Medicare. Recently geographically co-located individual GPs have formed Divisions of General Practice, of which there were 118 throughout Australia in 1996, and Divisions receive direct Commonwealth funding. Much of this funding supports specific programs but funding arrangements are currently changing to block Outcomes Based Funding.

Recent health system initiatives

Council of Australian Governments (COAG)

The April 1995 COAG meeting announced the agreement of all jurisdictions to building a better health and community services system which meets people's needs better, delivers services efficiently and contains costs. This meeting also proposed organisation of health services into three streams - general care (which included health promotion and preventive care), acute care, and coordinated care. The latter is of direct relevance to diabetes since it focuses on health care needs which are best met by a mix of services over an extended period. Coordinated care trials have resulted from an agreement that these new arrangements need to be formally assessed. Several trials are currently in progress across Australia and diabetes is among the conditions being studied.

National Public Health Partnership (NPHP)

Formed in late 1996 by Australian Health Ministers, the NPHP is a partnership arrangement between the Commonwealth, States and Territories for the purpose of:

- improving public health sector collaboration, particularly with regard to priority setting
- enhancing coordination and sustainability of public health strategies
- strengthening public health infrastructure and activity

The Partnership is being implemented by the National Public Health Partnership Group which comprises the Chief Health Officers or Directors of Public Health of each of the jurisdictions plus senior representatives of the NHMRC and AIHW.

Through the Partnership, the NPHP seeks to encourage greater coordination in research, improved consistency of public health data collection and utilisation, and improved integration of public health strategies. Other priorities of the NPHP include attention to legislation issues, the role of 'best practice' in the public health arena, and public health financing methods.

National Health Priority Area Initiative

The objective of this initiative is to foster collaboration between Commonwealth, State and Territory governments, health professionals and others relevant to the health care industry, to identify, promote and monitor the adoption of practices of proven benefit across the continuum of care for the five Priority Health Areas, which includes diabetes. This has provided a means of assisting Health Ministers to identify and utilise mechanisms available to governments for achieving health gain.

Issues relevant to diabetes

Effective diabetes prevention and care involves a range of initiatives which in turn involve health professionals from a wide range of disciplines, all levels of government and other health areas eg nutrition, physical activity. The main structural issues which underpin the provision of effective and efficient diabetes prevention and care are:

- information
- best practice
- coordination

These issues and their relevance to diabetes are discussed in detail in Section 3.

Coordination is a key feature of the NPHP and the NHPA activities. The NPHP has recently initiated the National Strategies Coordination Project and established a National Strategies Coordination Working Group. The objective of this Group is to examine ways of achieving greater coordination and collaboration between national strategies, particularly in the area of monitoring and reporting. Two other health system issues are relevant to diabetes:

Integration

Effective diabetes prevention and care requires both vertical and horizontal integration of a range of national efforts. Public health strategies in nutrition, physical activity, overweight and obesity, and tobacco control are particularly relevant to diabetes prevention. In addition these factors also impact on the care of people with diabetes.

The development of a National Health Master Plan (as proposed in the Interim Report of Implementing Australia's Food and Nutrition Policy) would be a significant step towards achieving the level of integration necessary to provide policy direction and guide national activities which are comprehensive and avoid duplication. This approach incorporates both vertical integration of strategies addressing the specific needs of diabetes and horizontal integration across programs relevant to the prevention of diabetes.

The *National Diabetes Strategy and Implementation Plan* should be linked to the following national programs and strategies:

- Active Australia
- Acting on Australia's Weight
- Australia's Food and Nutrition Policy
- NPHC Cardiovascular Disease Committee
- National Division's Diabetes Program
- National Aboriginal Health Strategy
- National Rural Health Policy
- National Healthy Ageing Strategy

Funding opportunities

In 1996 the Commonwealth Government included diabetes as a National Health Priority Area and allocated funding of $ 7.7 million over a three year period to help reduce the burden of diabetes. This funding is already impacting favourably on certain important diabetes issues, including the establishment of an insulin treated diabetes register and supporting specific projects. However, the wider implementation and long term sustainability of the *National Diabetes Strategy and Implementation Plan* will require exploring other funding opportunities within the health care system. There are also opportunities within existing funding structures to decrease the economic burden on individuals with diabetes, their families and carers.

During the development of the *National Diabetes Strategy and Implementation Plan* many suggestions were received about potential mechanisms for enhancing funding for diabetes. This segment highlights areas and practices which could potentially be modified to increase available funding for diabetes care. The funding opportunities are grouped to reflect desired outcomes of the *National Diabetes Strategy and Implementation Plan.* Some of these proposals could be implemented with minimal changes to current funding arrangements while others would require more significant structural reform and reorientation. The rationale and justification for the funding proposals are contained in the relevant Sections of this document.

Medicare Benefits funding

The following proposals for changes to the current Medicare Benefits arrangements are evidence based, safe, efficient and cost-effective and therefore meet the criteria for consideration by the Medicare Services Advisory Committee.

Medicare Benefits Schedule - Clinical Services

Additional Medicare Benefit Schedule rebate items

- podiatry consultation for diabetic people with a foot ulcer
- non mydriatic retinal photography screening for diabetic retinopathy in people with diabetes

Both have the potential to effect a substantial improvement in the care of people with diabetes and lead to significant savings in costly complications.

Change to current Medicare Benefit Schedule items and regulations

- introduce a subset of Medicare Item 10900 to specifically cover screening for diabetic retinopathy by optometrists by measurement of visual acuity and retinal examination through dilated pupils by direct or indirect ophthalmoscopy

Medicare Benefits Schedule - Pathology services

- provide a rebate for accredited offsite laboratory performance of HbA_{1c} using a DCA 2000 analyser
- create a Medicare Item number for screening for GDM. This would not incur any additional costs and would facilitate monitoring of GDM screening
- include Micral reagent strips for the detection of microalbuminuria as a P9 MBS item
- alter Medicare rebate regulations to allow
    - screening for type 2 diabetes with fasting plasma glucose measurement
    - measurement of HDL cholesterol routinely with lipid measurement
    - a single pre-written pathology form to cover the pathology items required for annual complication screening in people with diagnosed diabetes

Medicare cash out arrangement

This mechanism could be used to fund the proposal to equip Indigenous Health Services with a DCA 2000 analyser to perform essential monitoring and near patient testing of diabetes. This arrangement would not only result in a substantial improvement in care but would be cheaper than routine pathology laboratory testing for HbA_{1c}.

Incentives for people with diabetes

The person with diabetes is the central person in the diabetes care team. Incentives to encourage increased participation in the diabetes management cycle should facilitate their more active involvement. Such incentives could include financial rewards for participation in complications screening, for example presentation of documentation of retinal assessment could entitle the person to:

- discounted NDSS items
- discounted private health insurance membership fees.

Incentives for health care providers

Incentives could also facilitate more active participation of health care professionals in providing recommended standards of diabetes care. This could occur at the system or individual level. A range of rewards could be considered including financial rewards, on-site referral access for GPs to allied health professionals and continuing medical education accreditation points. Examples include:

- rewards to health services which measure aspects of diabetes care and effect cost saving through improved diabetes care service delivery and diabetes outcomes
- using DGP Outcomes Based Funding to include financial rewards and incentives for

individual practitioners participating in Divisional Diabetes Shared Care Programs and meeting agreed standards of care (such as those set out by in the NDDP), and who demonstrate better practices to improve health outcomes of people with diabetes

Healthcare (Medicare) Agreement

The Healthcare (Medicare) Agreement could be used as a means to earmark funding for Commonwealth and State/Territory partnership agreements in the implementation of selected priority diabetes care and prevention programs. In addition, funding should be linked to a limited number of performance indicators.

Program funding

Additional Commonwealth Program funding should be allocated for the Priority Programs for reducing diabetes related end stage renal disease, visual impairment and foot problems. These cost effective programs would recoup the program costs in a short period and would improve the quality of life of people with diabetes and result in ongoing real savings in health costs.

Measure and share

The Commonwealth is exploring innovative ways of managing the boundaries between MBS and PBS and other programs with individual States and Territories through proposals which provide incentives to them to reduce growth in MBS/PBS. Where the initiative(s) contribute to a measurable reduction in the growth of MBS/PBS, an agreed proportion of the resultant savings would be made available to the participating State/Territory. This arrangement could be applied to specific aspects of diabetes prevention and care programs.

Research

The NHMRC funding of diabetes should be increased to a level commensurate with its status as a National Health Priority Area (see Section 4 p110).

DA should increase its role in endeavours to increase non-government research funding. DA should develop a national approach to increase funding for diabetes research which could include a commitment by member organisations to contribute a percentage of profits from NDSS and other income sources to be directed to supporting research.

Other issues

Other issues requiring Government policy initiatives relevant to programs for diabetes prevention and care include:

- developing incentives and sanctions within the health system to encourage ‘best practice’
- accountability of health services and providers
- consumer issues:
    - lack of a national policy on sharps disposal
    - limitations of current food labelling regulations

Opportunities for change

The development and implementation of a national diabetes strategy provides an opportunity to review health system issues which impact on the large number of people who either have diabetes or are at increased risk of developing diabetes, and consequently have poorer health outcomes than other members of the community. Highlighted throughout the document are many facets of health care delivery applicable to diabetes, which are amenable to change.

Recommendations

35. Establish a Working Party to explore opportunities to enhance funding for implementation of the recommendations of the *National Diabetes Strategy and Implementation Plan*

36. Explore mechanisms to link funding with performance indicators relevant to access, process and outcomes of diabetes care eg, contracts with State, Territory, and regional health services should include a requirement to provide services which offer recommended processes of diabetes care and meet agreed diabetes outcome indicators

37. Develop and implement mechanisms to reward and reinforce effective practice through financial incentives and professional and organisational accreditation programs

38. Explore mechanisms for incentives to increase consumer participation in best practice

39. Establish a national network of lifestyle related non-communicable diseases and prevention programs

Section 5 Priority programs

- **Introduction**
- **National Program to Improve the Quality of Diabetes Care**
- **National Diabetes Visual Impairment Prevention Program**
- **National Diabetes End Stage Renal Disease Prevention Program**
- **National Diabetic Foot Disease Management Program**
- **National Diabetes Cardiovascular Disease Prevention Program**
- **National Program for the Early Detection of Type 2 Diabetes**
- **National Type 2 Diabetes Prevention Program**

Priority programs

Introduction

The Priority Programs detailed in this Section are recommended for immediate action. They have been selected using a prioritisation framework (adapted from DHS&H, 1994) on the basis of:

- ***the impact and extent of the problem they are designed to address***, ie the burden of ill health and the financial cost attributable to the problem
- ***the feasibility of intervening successfully to reduce this burden***, ie the availability of interventions with evidence of safety and effectiveness, and the ability of the health system to implement them on a socially equitable population basis
- ***the potential benefit to be gained by intervening***, ie the magnitude of the improvement to the health and health-related quality of life of individuals, the population health gain, and the cost savings which may reasonably be expected as a result of intervening

Five of the Priority Programs address the major complications which affect people who already have either type 1 diabetes and type 2 diabetes and which cause debilitating effects on individuals with diabetes, their families, and communities. These Programs take the approach of improving the quality and accessibility of diabetes care in order to reduce complications. The remaining two Priority Programs address the problem of reducing the burden of diabetes through the prevention and early detection of type 2 diabetes. Given the current status of knowledge it is presently not feasible to implement population prevention and early detection programs for people with type 1 diabetes. However, together, these approaches have significant potential to make a short term difference to the health of all Australians with diabetes and the capacity to reap substantial long term health gain.

As indicated in this Section and in Section 7, the savings made by implementing these Programs would offset the costs within a relatively short time. The Priority Programs recommended for implementation as a matter of urgency are a national:

- Program to Improve the Quality of Diabetes Care
- Diabetes Visual Impairment Prevention Program
- Diabetes End Stage Renal Disease Prevention Program
- Diabetic Foot Disease Management Program
- Diabetes Cardiovascular Disease Prevention Program
- Early Detection of Type 2 Diabetes Program
- Type 2 Diabetes Prevention Program

The Priority Programs are presented in a format which provides an evidence based rationale for acting on the problem, including health burden, effectiveness of available interventions and financial impact, followed by a proposed plan for implementation founded on the key strategies of *information*, *best practice* and *coordination*.

National Program to Improve the Quality of Diabetes Care

Goal

Improve health related quality of life, and reduce complications and premature mortality in people with type 1 diabetes and type 2 diabetes

Objective:

- Improve the effectiveness and accessibility of care for people with diabetes

Expected Outcomes:

- 80% of people with diabetes receiving clinical care consistent with national guidelines
- 80% of general practitioners and other health professionals aware of and applying the recommended standards of diabetes care
- 80% of people with diabetes receiving self-care education and dietary advice consistent with the guideline recommendations
- 80% of people with diabetes aware of the recommended standards of diabetes care

Key points

- Diabetes is a serious health problem which places a large economic burden on individuals and society
- Diabetes is associated with mortality rates which are 2 to 3 times higher than the rest of the population
- Large vessel disease in particular is severe and accelerated, leading to premature mortality
- Specific diabetes complications result in visual impairment, renal disease and foot problems
- Considerable economic benefits would result from reducing HbA_{1c} and the resulting fewer diabetes complications
- Reducing HbA_{1c} to the level achieved in the DCCT intensively treated group (7.2%) would produce for each individual with diabetes:
  - 7.7 years of additional sight
  - 5.8 additional years free of end stage renal disease
  - 5.6 additional years free of lower extremity amputation
  - an additional 15.3 years of life free from significant microvascular or neurological complication
  - an additional 5.1 years of life

The increased treatment costs of improving diabetes control can produce positive net cost benefits after 5-7 years

Rationale

Impact

Diabetes is a serious health problem which places a large economic burden on individuals and society through its devastating complications. Large vessel disease in particular is severe and accelerated, leading to premature mortality from cardiovascular disease and considerable morbidity from angina, stroke, claudication and amputation. In addition, people with diabetes are subject to the development of the typical microvascular complications which can result in visual impairment, renal disease and foot problems.

Diabetes is associated with mortality rates which are 2 to 3 times higher than the non diabetic population. The 1996 ABS report (ABS, 1996) listed diabetes as the 7th commonest cause of death, accounting for 2.3% of all deaths in Australia. However mortality statistics greatly underestimate true diabetes related mortality as diabetes is always underestimated on death certificates. Sixty three per cent of deaths are due to cardiovascular disease (Whittall et al, 1990) compared to the entire Australian population where ischaemic heart disease accounts for 23% of all deaths (ABS, 1997). Renal disease accounts for between 8% and 14% of deaths (McCarty et al, 1996). The situation in Indigenous Australians is similar although renal disease is a direct cause of death in 22.3% and infection in 20.8% (Phillips et al, 1995). This premature mortality results in a significantly shortened life expectancy. For a diabetic person 60 years of age, life expectancy is reduced by 5 years and for females with early onset diabetes, life expectancy can be reduced by up to 16 years (Knuiman et al, 1992).

A range of complications can develop in people with diabetes. In the 1995 National Health Survey (ABS, 1997), the self reported crude prevalence rates were 5.7% for blindness, 6.8% for kidney disease, 14.9% for heart disease, 4.1% for stroke and 1.8% for amputation. Co-morbidities were also frequently observed - hypertension (44%) was four times more common in people with diabetes and 16.5% had a high cholesterol. Diabetic renal disease is the second most common cause in Australia of end stage renal disease requiring transplantation or dialysis (ANZDATA Report, 1996). The number of Aboriginal people and Torres Strait Islanders developing end stage renal failure is increasing at an alarming rate, with the annual incidence doubling every 3-4 years (Hoy, 1997). Eighty percent of people with type 1 diabetes have evidence of retinopathy after 10 years of diabetes and almost all by 15 or more years while 15% of people with type 2 diabetes have evidence of retinopathy at diagnosis with 55% developing retinopathy after 10 years of diabetes and 70% after 15 or more years (Mitchell, 1980). Overall 35% of people with diabetes have diabetic retinopathy (Mitchell et al, 1997). Using USA data adjusted for Australian Blindness criteria, ABS census data and estimates of diagnosed diabetes, it is estimated that 14,000 Australians have moderate visual impairment (corrected VA 6/24-6/60) and up to 7,200 are legally blind (corrected VA < 6/60) from diabetic retinopathy (NHMRC, 1997). Foot disease is another major source of morbidity in people with diabetes. Amputations are 15 times more common in people with diabetes and approximately 50% of all amputations in Australia are attributable to diabetes. The number of amputations each year in people with diabetes is approximately 2,800.

Special problems in children and adolescents

Young children have special needs associated with their physical, cognitive, psychological, and social development which require care from well-trained specialist health professionals. Another issue is the transition from paediatric to adult care. The gap between paediatric and adult services creates a situation whereby many adolescents do not make this transition smoothly. The situation is further complicated because it coincides with a naturally difficult period in the life of many teenagers.

The routine care of young people with type 1 diabetes at school is also a potential source of concern. There are at least 26 separate educational authorities in Australia. While many State authorities have well-developed policy and procedure manuals for the management of childhood diabetes, there is a lack of uniformity and in some cases no procedures are in place. A national approach would address this problem.

Feasibility of intervening successfully

Improving glycaemic control can prevent or delay the development of diabetes complications. The Diabetes Control and Complications Trial (DCCT) showed that in people with type 1 diabetes without retinopathy, intensive therapy reduced the risk of developing microvascular complications by approximately 65% compared with conventional therapy and in people with early retinopathy complications were reduced by approximately 50%. (DCCT, 1993). Similar data are accumulating for people with type 2 diabetes (Abraira C et al, 1995; Ohkubo Y et al, 1995). However, the results of the United Kingdom Prospective Diabetes Study are awaited to definitively answer this question (Turner et al, 1996).

Improving diabetes control requires a collaborative effort involving the person with diabetes, carers, and medical and non-medical health professionals. Guidelines universally recommend achieving an HbA_{1c} as close to normal as possible while avoiding severe hypoglycaemia. The aim is to achieve an HbA_{1c} result within 1% of the upper limit of normal but with a result within 2% of the upper limit of normal being acceptable and providing protection against complications. Reaching this latter target in routine clinical practice is feasible for most, but not all, people with diabetes.

Economic considerations

Available data suggest that considerable economic benefits result from reducing HbA_{1c} wherever possible due mainly to improved glycaemic control resulting in fewer diabetes complications. However, additional costs are incurred in improving glycaemic control and therefore is it cost effective? The DCCT Research Group assessed the lifetime benefits and costs of intensive therapy as practised in the diabetes control and complications trial (DCCT, 1996) for people with diabetes who meet eligibility criteria for the DCCT and estimated that approximately 17% of people with type 1 diabetes fulfilled these criteria - 120,000 people in USA of whom 37% of these would be in the primary prevention group and 63% in the secondary prevention cohort. Reducing HbA_{1c} to the level achieved in the DCCT intensively treated group (7.2%) would produce for each individual 7.7 years of additional sight, 5.8 additional years free of ESRD, 5.6 additional years free of LEA, an additional 15.3 years of life free from significant microvascular or neurological complication and an additional 5.1 years of life. The lifetime additional costs of intensive therapy was approximately $A52,000.

After allowances for discounting, the cost of intensive treatment was $A44,000 per year of life gained and $A31,000 per QALY, costs which are considered cost effective.

The DCCT findings also have been extrapolated to develop a model to simulate people with newly diagnosed type 2 diabetes (Eastman et al, 1997) compare treatments which achieved an HbA_{1c} of 10% or 7.2%. The predicted cost effectiveness of comprehensive treatment is approximately $A24,600/QALY gained using DCCT intensive treatment costs. The model showed the cost/QALY gained is the lowest for minorities and for those with the highest HbA_{1c} and that intervention was least cost effective in the treatment of diabetes beginning late in life.

These costs relate to intensive therapy as delivered in the DCCT and it is generally believed that similar improvements in diabetes control can be achieved far more cheaply. In fact it has been estimated that the increased treatment costs of improving diabetes control can produce positive net benefit after 5-7 years (Gilmer et al, 1997). However the main obstacle to multifactorial intervention programs to prevent complications which could potentially lead to cost savings is the large initial investment.

Extrapolation of these data to Australia is difficult because of a lack of large population studies which have assessed glycaemic control in people with diabetes. One study of 1,114 people with type 2 diabetes showed that 34% of non Indigenous Australians and 53.1% of Indigenous Australians consulting an urban diabetes service had an HbA_{1c} of more than 2% above the upper limit of normal and would qualify for programs to improve diabetes control (Colagiuri S et al, 1997). If international data for children and adolescents with type 1 diabetes are applicable to Australians, 64% with diabetes diagnosed for more than 2 years have an HbA_{1c} above 8% (Mortensen and Hougaard, 1997). Despite the lack of local data it seems likely that a significant percentage of Australians would benefit from programs to improve control and that poor glycaemic control is making a significant contribution to the excessive health care costs associated with diabetes.

Implementing a National Program to Improve the Quality of Diabetes Care

The task

- ensure that all people with diabetes have access to recommended standards of care
- improve metabolic control in people with diabetes in order to minimise diabetes complications

Essential Requirements

Guidelines

National evidence based guidelines and protocols on principles of diabetes care, and monitoring of diabetes control, complications and risk factors for complications. Guidelines have been developed by NSW Health which could be used as the basis for national guidelines. These should be developed by the Improving the Quality of Diabetes Care Advisory Group in conjunction with the NHMRC.

Separate guidelines and protocols will be required for children and adolescents with type 1 diabetes. The guidelines produced by APEG and NSW Health could be used as the basis for these national guidelines which should address the special needs of young children and include recommendations on transition from paediatric to adult services and protocols for management of children attending schools.

Proposed indicators

- the proportion of people with diabetes receiving diabetes care as defined by national guidelines including:
  - glycohaemoglobin (HbA_{1c}) measurement
  - annual complications screening
  - assessment of weight, blood pressure and lipids
  - receiving diabetes education and nutrition advice
  - review by a specialist diabetes team
- the proportion of general practitioners and other healthcare workers aware of and applying the recommended standards of diabetes care
- the proportion of health professionals trained to provide quality diabetes care
- the proportion of health facilities providing quality diabetes care

Resources

Human
Although there are sufficient numbers of primary care physicians to implement recommended principles of care for people with diabetes, type 1 diabetes requires ongoing specialist care. Routine diabetes care of children and adolescents with type 1 diabetes should be provided by a specialist team with expertise in the management of children with type 1 diabetes. There are currently insufficient numbers of diabetes educators, dietitians and podiatrists to meet the requirements of this program. Also the distribution of specialist services poses access problems.

Material
Resources would be required for the publication and distribution of the principles of care documents. In some areas, resources will be required to apply the clinical guidelines, eg HbA_{1c} measurement.

Enabling factors

Commonwealth and State/Territory Government Agreement
Commitment is required at this level to facilitate the implementation of the program and to translate the initiative into action at the regional and local level.

Funding
Financial support is required to:

- develop, produce and distribute national guidelines
- develop consumer and provider training
- establish information systems to monitor progress

Public and provider awareness of the Program

- programs are required to ensure that the message about the benefits of optimal diabetes control reaches the entire target group, especially Indigenous and non English speaking background populations, and children and adolescents
- training programs are required to update primary care health professionals about the requirements for quality diabetes care. A variety of options is available for established diabetes services to network with metropolitan and rural services eg the NADC workshops for rural general practitioners on the NSW Health Diabetes Clinical Management Guidelines
- health professional training programs should include a paediatric diabetes curriculum
- public awareness of the seriousness of diabetes and the distinction between type 1 and type 2 diabetes

Policy

- incentives to reward effective practice, such as Medicare rebate item for general practitioners to perform annual complication screening for people with type 2 diabetes
- incentives to reward consumer participation in quality programs, such as NDSS supplies provided at discounted rates for people presenting evidence of compliance with principal of care recommendations; Healthcare funds providing discounted membership for people presenting evidence of compliance with principal of care recommendations
- ensure continued access to Childhood Disability Allowance for children with type 1 diabetes

Action plan

Establish a National Improving Quality of Diabetes Care Advisory Group

This group should include representation of the ADS, ADEA, APEG, Indigenous and non-English speaking background organisations, consumers and general practice. This group should work on:

- developing national evidence based guidelines for improving the quality of diabetes care for health professionals and consumers
- workforce issues including:
  - role delineation for implementation of the principles of diabetes care including guidelines and criteria for referral to specialist care including medical, education, dietary and podiatry
  - required provider:patient ratios
  - training and accreditation of health professionals
- consumer and provider awareness program
- education of consumers in their rights and responsibilities to accessing, receiving and monitoring quality diabetes care
- accreditation of facilities providing quality diabetes care
- information systems for monitoring progress

Monitoring

- establish an information system to collect these data. For people with insulin treated diabetes link this program to the National Diabetes Register and perform 5 yearly random sampling surveys of people with type 1 diabetes. Also link to data collected by general practitioners and diabetes centres using the NDOQRIN data collection system
- regular reporting against indicators

Evaluation

- evaluate progress against the expected outcomes and proposed indicators - initially using parameters of process and ultimately on health outcomes
- analyse costs and cost effectiveness of program

Further considerations

Care of particular groups

- young children: ensure availability and access to specialist health professionals trained in the management of young children with type 1 diabetes

Transitional services

- develop systems to assist adolescents to effectively transfer their care from paediatric to adult services

Research

- non-invasive blood glucose monitoring: direct efforts to develop non-invasive blood glucose monitoring technology and target private fund raising to support this activity
- hypoglycaemia: direct and support efforts to improve monitoring to detect and prevent impending severe hypoglycaemia.

Recommendation

40. Implement a National Program to Improve the Quality of Diabetes Care

National Diabetes Visual Impairment Prevention Program

Goal

Improve health related quality of life, and reduce complications and premature mortality in people with type 1 diabetes and type 2 diabetes

Objective:

- Reduce visual impairment and new blindness in people with diabetes

Expected Outcomes:

- 50% reduction in new blindness by the year 2005
- 80% of people with diabetes being appropriately screened for retinopathy
- the majority of people with vision threatening retinopathy receiving laser therapy
- an increase in the availability of laser treatment

Key points

- Diabetic retinopathy is the commonest cause of visual loss in adults under the age of 60
- All people with diabetes are at risk of blindness and 10% will develop vision threatening retinopathy
- In Australian communities the prevalence of diabetic retinopathy ranges from 21%-36%
- The annual incidence for the development of sight threatening retinopathy is 1%
- 80% of people with type 1 diabetes have evidence of retinopathy after 10 years of diabetes and almost all by 15 or more years
- 15% of people with type 2 diabetes have evidence of retinopathy at diagnosis, 55% after 10 years and 70% after 15 or more years
- Less than one third of eligible people with blindness due to diabetes are receiving a blind or blind-age pension
- Blood glucose control is the major modifiable risk factor influencing the development and progression of retinopathy
- The DCCT showed that, in people with type 1 diabetes, intensive therapy can reduce the development of retinopathy by 76% and slow progression by 54%. Similar data are accumulating for people with type 2 diabetes
- ACE inhibitor therapy may decrease progression of retinopathy in non hypertensive people with diabetes
- Cataract is another important cause of visual loss in people with diabetes

- It has been conclusively established that successful intervention to prevent visual loss due to diabetic retinopathy is feasible
- Routine screening is essential since diabetic retinopathy is symptomless in its early and most easily treatable forms
- Screening should be part of the routine care of all people with diabetes. Australian data indicate that a significant proportion of people with diabetes are not receiving adequate screening or follow-up of retinopathy
- Screening can be performed by ophthalmologists, optometrists, general practitioners, diabetologists and other appropriately trained health workers, or technicians in the case of fundus photography using the non mydriatic camera
- Non ophthalmologist screeners should refer to an ophthalmologist people with any retinopathy other than minimal NPDR, people in whom the fundi cannot be visualised or people with decreasing visual acuity
- Laser treatment has been conclusively shown to preserve vision in people with sight threatening retinopathy
- The annual cost of diabetic eye disease in Australia is $A 193 million
- Introducing interventions to increase compliance with screening to 80% would result in annual savings of at least $A 15 million.

Rationale

Impact

Diabetic retinopathy is the commonest cause of visual loss in adults under the age of 60. All people with diabetes are at risk of blindness. Most will eventually develop some degree of retinopathy and approximately 10% will develop vision threatening retinopathy and risk significant visual loss and blindness. Sight threatening retinopathy causes no symptoms in its early stages when it is most amenable to treatment. By the time visual loss is present, there is a significantly poorer prognosis for treatment. Failure of health services to implement programs to prevent diabetic blindness was recognised in the St Vincent Declaration as an area of deficiency requiring urgent attention.

In Australia the prevalence of diabetic retinopathy ranges from 21%-36% while vision-threatening retinopathy occurs in 6%-13%. The annual incidence of retinopathy for people without retinopathy at baseline is 6%-14%, depending on the duration of diabetes and glycaemic control. The corresponding annual incidence for the development of sight threatening retinopathy is 1% (Lloyd-Smith et al 1996, Lee et al 1995, Mitchell et al 1997).

Retinopathy can be broadly categorised into the following types - non proliferative (NPDR), proliferative (PDR) and macular oedema. The Early Treatment Diabetes Retinopathy Study (ETDRS) grading system is commonly used to grade the severity of retinopathy within these categories and to assign urgency of intervention to prevent development or progression of significant visual loss. In the Newcastle study, 80% of people with type 1 diabetes had evidence of retinopathy after 10 years of diabetes and almost all by 15 or more years. PDR was present in 20% after 15 years, 30% after 20 years and nearly 50% after 30 years. In type

2 diabetes 15% had evidence of retinopathy at diagnosis, 55% after 10 years and 70% after 15 or more years (Mitchell 1980). The overall prevalence rates of diabetic retinopathy from the Blue Mountains Eye Study (BMES) was 35% in people with type 2 diabetes and 75% in people with type 1 diabetes. PDR was found in 1.6% and macular oedema in 5.5%.

Only limited data are available for Indigenous Australians. Prevalence rates in urban and rural communities similar to non-Indigenous Australians have been reported (Stanton et al, 1985), however the rates seem considerably higher in remote communities. In the Northern Territory, almost half of Aboriginal people have evidence of retinopathy at diagnosis and overall one third have retinopathy and in almost half it is vision threatening (Markey et al, 1996).

There are no reliable data on the current proportion of blindness caused by diabetic retinopathy in Australia. Available data are likely to be a significant underestimate. The Melbourne Visual Impairment Project (MVIP) and the BMES indicate that less than one third of eligible persons are receiving a blind or blind-age pension. These data are similar to the United Kingdom where prevalence rates of blindness due to diabetic retinopathy of 8% are reported but only 30% of all patients entitled to a blind registration are actually registered (SIGN 3, 1996). These statistics serve to highlight that people with diabetes and their carers are frequently unaware of practical help and support available for the visually handicapped - travel concession, support services, low visual aids.

The known duration of diabetes is important in determining the presence of retinopathy while glycaemic control is the major modifiable risk factor influencing the development and progression of retinopathy. The combined effects of duration of diabetes and glycaemic control on the development and progression of retinopathy appear similar in type 1 and 2 diabetes. Other risk factors which have been implicated include hypertension, pregnancy, nephropathy, elevated lipids, and smoking. The impact of glycaemic control has been clearly established in people with type 1 diabetes. The DCCT showed that in people with type 1 diabetes without retinopathy, intensive therapy reduced the risk of developing retinopathy by 76% compared with conventional therapy. In people with NPDR, intensive therapy slowed progression by 54% and reduced the development of PDR or severe NPDR by 47%. Cumulative 9 year rates of progression of retinopathy were 54% with conventional therapy and 12% with intensive therapy (Wang et al 1993, DCCT Research Group 1993).

Similar data are accumulating for people with type 2 diabetes (Abraira et al, 1995; Ohkubo et al, 1995). In the Wisconsin study, the effect of glycaemic control was similarly related to the incidence and progression of diabetic microvascular complications in type 1 and 2 diabetes (Klein et al, 1996). However, the results of the United Kingdom Prospective Diabetes Study are awaited to definitively answer this question.

Recent evidence suggests that treatment with an ACE inhibitor may decrease retinopathy progression in non hypertensive people with type 1 diabetes who have little or no nephropathy (Chaturvedi et al, 1998). These findings require confirmation before changes to clinical practice can be advocated.

Cataract is another important cause of visual loss in people with diabetes since it is more common in diabetes, occurs at an earlier age and is associated with less favourable outcomes of surgical intervention.

The feasibility of intervening successfully

It has been conclusively established that successful intervention to prevent visual loss due to diabetic retinopathy is feasible. In Stockholm County new blindness has been reduced by one third over a 5-year period with the annual incidence decreasing by 7% between 1991 and 1995 (Backlund LB et al, 1997). Reducing visual loss is dependent on two factors - screening, and treatment with laser therapy. Routine screening is essential since diabetic retinopathy is symptomless in its early and most easily treatable stages and this simple measure has been shown to prevent visual loss (SIGN 3, 1996). The early detection of vision threatening retinopathy (VTR) by regular eye examination conducted by trained personnel is the key to reducing visual loss and blindness from diabetic retinopathy. The essential requirements of screening are assessment of (corrected) visual acuity and examination of the fundi through dilated pupils or fundus photography using a non-mydriatic camera. Screening needs to be part of the routine care of all people with diabetes. Australian data indicate that a significant proportion of people with diabetes are not receiving adequate screening or follow-up of retinopathy.

A number of options are currently used for screening with no single modality being superior. The sensitivities and specificities of different screening methods vary widely and are closely related to the expertise and training of the person performing the screening (NHMRC, 1997). However, even relatively insensitive methods can be effective provided there is the opportunity for regular and repeated assessment. Considering the geography and population distribution of Australia, a combination of screening methods is likely to be employed in most areas based on local resources and circumstances.

The main screening options for diabetic retinopathy include direct or indirect ophthalmoscopy through dilated pupils and retinal photography with or without pupil dilatation. Personnel who could perform the screening include ophthalmologists, optometrists, general practitioners, diabetologists and other appropriately trained health workers, or technicians in the case of fundus photography using the non mydriatic camera. A combination of personnel is likely to be necessary since it is arguable as to whether specialist ophthalmologist resources should be utilised for this purpose, optometrists rarely see younger diabetic patients and diabetologists see less than half of all people with diabetes. Although general practitioners have unique access to the entire diabetic population and are the sole carer for over 50% of the diabetic population, the opportunity to acquire experience in detection and interpretation of retinal lesions is limited by other demands of their practice. Without training, their accuracy as screeners is unsatisfactory, but can reach satisfactory levels after short instructional courses (SIGN 3, 1996). The majority of Victorian general practitioners responding to a questionnaire survey said they examined none or less than half of their diabetic patients for retinopathy. Those who did rarely dilated pupils (Dickson et al, 1996). Whether general practitioners perform the screening themselves or not, they have an obligation to ensure that all their patients are screened appropriately for diabetic retinopathy. Whatever the screening option it is essential that the results are communicated to the health professional with overall responsibility for the care of the patient. In addition, patient involvement through education is crucial.

Indigenous communities have poorer access to and lower utilisation rates of mainstream services, which contribute to their higher rate of diabetic complications. Involvement of an Aboriginal health worker in community based screening for diabetic retinopathy is desirable as is establishing links between Indigenous communities and the nearest available ophthalmologist and optometrist. The use of the retinal camera in screening Indigenous populations has been shown to be less costly than yearly ophthalmological examinations by ophthalmologists (Griffith et al, 1993) and field studies have established the feasibility of training Aboriginal health workers in this technique (Keefe et al, 1996).

Non ophthalmologist screeners should refer to an ophthalmologist people with any retinopathy other than minimal NPDR, people in whom the fundi cannot be visualised or people with decreasing visual acuity (NHMRC, 1997). People with more severe forms of retinopathy and with unexplained decreased corrected visual acuity require urgent referral. Ophthalmologists should repeat eye examination every 6-12 months in people with mild NPDR, every 3-6 months if moderate or severe NPDR, and more frequently if the macular is threatened. Optometrists who detect any form of retinopathy can already refer the patient directly to an ophthalmologist with full Medicare benefits.

In managing people with retinopathy, every effort should be made to optimise glycaemic control and to correct elevated blood pressure and lipids. Laser treatment has been conclusively shown to be an effective therapy for people with sight threatening retinopathy (DRS and ETDRS). Laser therapy was associated with a 50 to 98% reduction in the development of severe visual loss in PDR and clinically significant macular oedema. Vitrectomy surgery is helpful in people with type 1 diabetes within 3 months of persistent severe vitreous haemorrhage and very severe PDR which has not responded to aggressive laser therapy. It is less beneficial in people with type 2 diabetes.

Economic considerations

There are no reliable data on the current proportion of blindness in Australia caused by diabetic retinopathy but detailed estimates have been reported in the NHMRC guidelines on the Management of Diabetic Retinopathy (NHMRC, 1997). Furthermore available data are likely to seriously underestimate the extent of the problem. Both the MVIP and the BMES indicate that less than one third of eligible persons are receiving a blind or blind-age pension. Commonwealth data indicate that in 1994 8,300 people were receiving a blind pension and 13,300 were receiving an age-blind pension, i.e. 21,600 Australians. Using US data adjusted for Australian Blindness criteria, ABS census data and estimates of diagnosed diabetes, it is estimated that up to 14,000 Australians have moderate visual impairment (corrected VA 6/24-6/60) and up to 7,200 are legally blind (corrected VA < 6/60) from diabetic retinopathy. This suggest a three-fold increase in the number of blind Australians compared with the estimated 2,000 who currently receive blind pensions for diabetic retinopathy.

The cost of providing pensions to the current 21,600 Australians receiving blind pensions is estimated at $A339 million in 1994 - $A20,200 per year for people under age 65 and $A 13,100 per year for people over age 65. For people who are blind as a result of diabetic retinopathy, the 1996 annual cost could be between $A13 and $A40 million, depending on the estimates of the proportion of pension recipients who are blind from diabetic retinopathy.

Screening costs can be estimated using Medicare rebates for examination by ophthalmologists (the most expensive scenario) for the estimated 350,000 people with diagnosed diabetes in 1996. Screening at least every 2 years, as recommended by the NHMRC, and with follow up every 3-12 months of the 35% with retinopathy, the annual Medicare cost of screening is around $A19 million with full compliance.

Vision threatening retinopathy requiring treatment is estimated to be present in 44,000 Australians (11% of known diabetes cases - 19,000 with PDR and 25,000 with macular oedema without PDR). Each year 6,900 are estimated to require laser treatment for PDR and another 7,500 for macular oedema. A conservative estimate of the Medicare cost of such laser treatment is around $A25 million plus fluorescein angiography costs of $A1.5 million and vitrectomy costs of $A0.5 million - i.e. total $A27 million. Therefore the total estimated combined screening and treatment cost is $A46 million per annum.

Modelling studies performed by the University of Melbourne Ophthalmology Department (NHMRC, 1997) indicate that the overall health care expenditure (including disability) incurred by the Commonwealth Government due to diabetic retinopathy and its associated consequences at 30% compliance was $A193 million each year. These studies confirm a substantial saving to government from screening and treatment programs for diabetic retinopathy. Introducing interventions to increase compliance to 80% would decrease expenditure to $A178 million, a saving of $A15 million. If the higher blindness costs are used the savings would amount to $A31 million.

With the low cost blindness disability estimates, the Commonwealth Government would incur increased costs of approximately $A5 million for 7 to 10 years following which significant savings would be generated thereafter. For high cost blindness disability estimates, savings would result from the first year of the program. Although the extra savings from yearly compared to second yearly eye examination are small, compliance with screening may be facilitated by including screening as part of the annual review.

Implementing a National Visual Impairment Prevention Program

The task

- screen people with diabetes for retinopathy
- provide laser therapy for people with vision threatening retinopathy
- improve metabolic control in people with diabetes

Essential requirements

National evidence based guidelines and protocols

The NHMRC has recently published guidelines for diabetic retinopathy which include evidence based recommendations for medical practitioners, optometrists, non medical health professionals and consumers. These guidelines are currently being disseminated and the effectiveness of this activity is being formally evaluated.

OATSIHS has recently completed a systematic review and produced guidelines for the management of diabetes (including retinopathy) for Indigenous Australians and this publication should guide programs being designed for addressing this problem in Indigenous communities.

Proposed indicators

- the prevalence and incidence of blindness in people with diabetes
- the proportion of people with diabetes being appropriately screened for retinopathy
- the proportion of people with vision threatening retinopathy receiving laser therapy
- the number and distribution of laser therapy facilities

Resources

Human
There are sufficient numbers of ophthalmologists, optometrists and other health professionals to perform the screening and sufficient ophthalmologists to perform laser therapy. However, inequality in distribution of these services makes access an issue.

Material
Depending on the method of screening which is appropriate for a particular region, some equipment for screening eg retinal cameras will be required. Also additional laser therapy equipment will be required in some locations. The strategic location of these additional laser services requires coordination and planning.

Enabling mechanisms

Commonwealth and State/Territory Government Agreement
Commitment is required at this level to facilitate the implementation of the program and to translate the initiative into action at the regional and local level. Involvement of representatives of Aboriginal and Torres Strait Islander Commonwealth and State/Territory organisations is essential in the planning of any program for Indigenous Australians

Funding
Financial support will be required to initiate and coordinate the program. Initial funding will be required to:

- provide equipment for screening
- establish additional laser facilities
- support training programs to improve screening proficiency
- fund a pilot state wide project on implementing this program

Public and provider awareness of the program

- this is already underway through the dissemination of the NHMRC Guidelines but further effort is required to ensure that the message reaches the entire target group, especially Indigenous and non English speaking background populations
- the screening proficiency of individual clinicians varies widely. Ongoing training programs are required to improve and maintain screening skills.

Policy
The following changes to the Medicare Benefits Schedule would facilitate implementation of this program:

- introducing a subset of Medicare item number 10900 to specifically cover screening for diabetic retinopathy by optometrists. The reimbursement rate would be identical to the current item 10900 but would specifically be for screening for retinopathy by measurement of visual acuity and retinal examination through dilated pupils by direct or indirect ophthalmoscopy
- creating a Medicare item number for fundus photography using a non mydriatic camera. Criteria could be established to limit the health professionals who would be eligible to provide this service, and the frequency with which the examination could be performed. The estimated rebate for this item is approximately $20.

Audit and Quality Assurance
Mechanisms for assuring the quality and facilitating process audit of whichever screening options are used and for the personnel performing the screening must be developed.

Action

Establish a National Diabetic Retinopathy Advisory Group

This group should include representation of the ADS Retinopathy Subcommittee, Indigenous and non-English speaking background organisations, the Royal Australian College of Ophthalmologists, the Optometrists Association of Australia, ADEA, consumers and general practice. The group should work with Commonwealth and State/Territory Governments on:

- workforce issues including:
  - role delineation for screening and treatment including guidelines and referral criteria for and between health professionals such as:
    - ophthalmologist
    - optometrist
    - specialist physicians
    - general practitioners
    - aboriginal health workers
    - nurse practitioners
  - required provider : patient ratios
  - training programs
- implementation strategies for the various screening options
- service organisation and models especially the provision of accessible laser facilities
- guideline dissemination strategies
- consumer and provider awareness program
- consumer education program
- information systems for monitoring diabetic eye disease and a follow-up and recall system

Monitoring

- establish an information system to collect baseline and annual data
- annual reporting against indicators

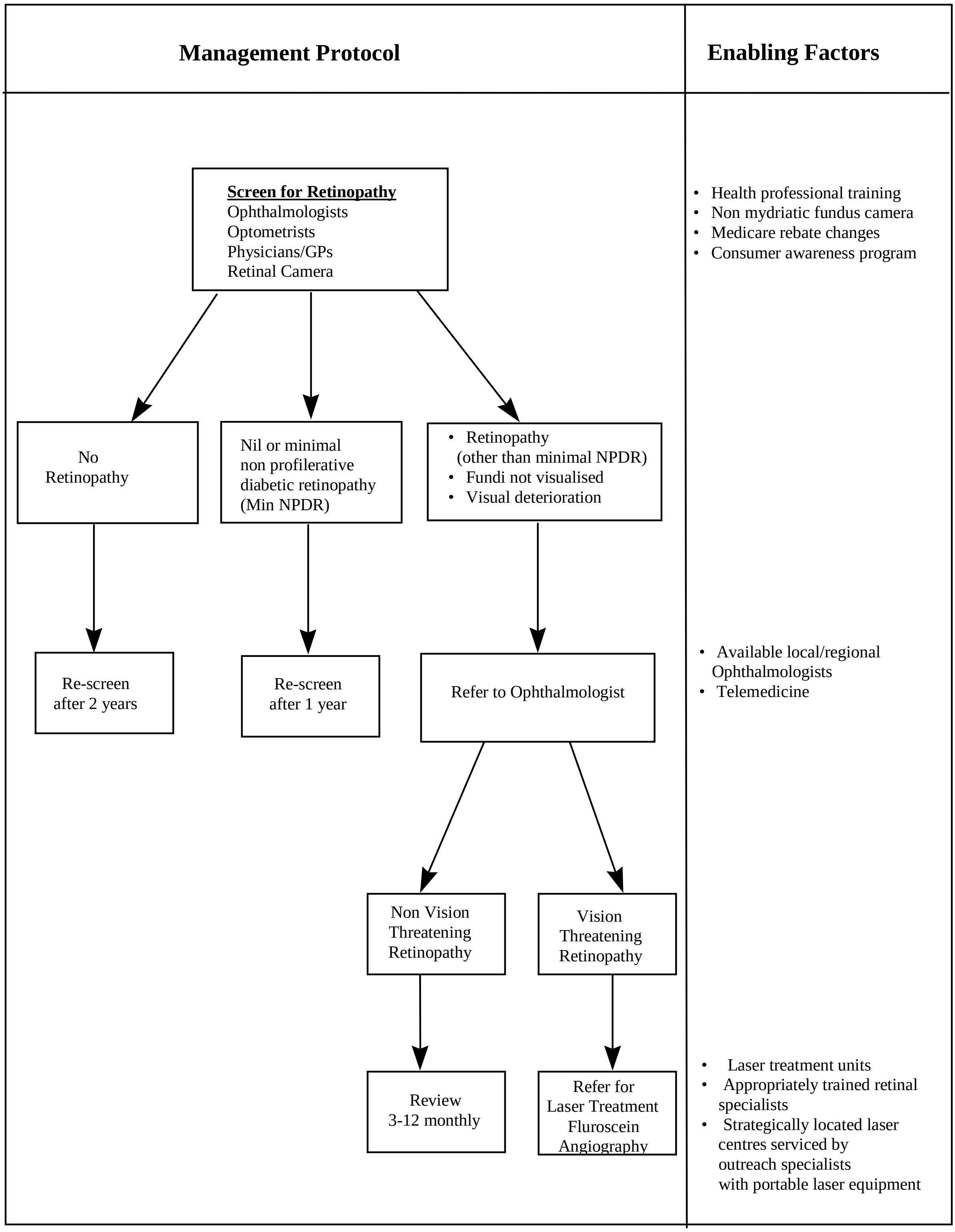
Evaluation

- evaluate progress against the expected outcomes and proposed indicators - initially using parameters of process and ultimately on health outcomes
- analyse costs and cost effectiveness of the program

Recommendation

41. Implement a national Diabetes Visual Impairment Prevention Program

Figure 13 : Diabetes Visual Impairment Prevention Program



- Health professional training
- Non mydriatic fundus camera
- Medicare rebate changes
- Consumer awareness program

- Available local/regional Ophthalmologists
- Telemedicine

- Laser treatment units
- Appropriately trained retinal specialists
- Strategically located laser centres serviced by outreach specialists with portable laser equipment

Section 6 Groups with special needs

- **Introduction**
- **Indigenous Australians**
- **People from Non-English speaking backgrounds**
- **People living in rural and remote Australia**
- **Children and adolescents**
- **The elderly**

Groups with special needs

Introduction

This Section of the *National Diabetes Strategy and Implementation Plan* highlights the groups within the Australian population who, in order to achieve significant improvement in diabetes health gain, require special consideration in the planning, delivery and coordination of diabetes prevention and care services. Special consideration is warranted:

- in the case of ***Indigenous Australians*** **and** ***people from non-English backgrounds*** for whom access to high quality services for diabetes prevention and care is hindered by cultural and/or linguistic factors and who, as a result of these factors, are more likely than other Australians to experience socio-economic disadvantage as manifested by higher unemployment rates and poorer educational opportunities. While people from non-English speaking backgrounds are concentrated mainly in and around cities, many Indigenous Australians reside in rural and remote areas and are therefore subject to geographic as well as cultural disadvantage in accessing health care services

- for ***people living in rural and remote regions*** where the sparse population dispersion precludes ready access to the full range of diabetes services which are found in urban centres. For some people in rural and remote Australia, lack of employment opportunities resulting from the depression of rural industries adds a socio-economic dimension to the already restricted geographical access they experience

- on the basis of ***age*** with respect to:
    - ***children and adolescents*** who have specific needs related to physical and psychological development. Difficulty in accessing specialised services to address the needs of children and adolescents with diabetes and their families may be further compounded by the cultural and geographical factor in children and adolescents from Indigenous, non-English speaking background or rural and remote communities

    - ***the elderly*** who may be socio-economically and/or physically disadvantaged in accessing health services, and who may be restricted in their ability to carry out the recommendations of their health carers

Some innovative methods and alternate models of care are already available. Others need to be developed and assessed in order to increase socially equitable access to a range of high quality diabetes services. In addition, determinants of health such as employment, transport, and nutrition need to be considered. In the meantime, much can be achieved by targeting the relevant primary health carers for the dissemination of consistent guidelines and protocols recommending currently accepted standards of diabetes prevention and care, and implementation strategies which include the provision of training, specialist support, and criteria and mechanisms for referral.

Indigenous Australians

Key points

- Life expectancies for Aboriginal and Torres Strait Islander men and women are 15-20 years below those of other Australians
- Diabetes, predominantly type 2 diabetes, is a major cause of morbidity and mortality for Aboriginal and Torres Strait Islander peoples
- Available data suggest that the overall prevalence rates among adults is between 10% and 30%, at least 2-4 times that of non Indigenous Australians
- The predominate form of diabetes is type 2 diabetes which occurs at an earlier age than non Indigenous Australians, including during childhood. GDM is also more common
- Aboriginal and Torres Strait Islander populations experience 12 to 17 times more deaths due to diabetes than non Indigenous Australians
- Excess mortality is mostly attributable to an increase in cardiovascular disease, although renal failure is also a significant problem
- A major barrier to improving diabetes care is limited availability and access to required and culturally appropriate health care

Background

Diabetes in the Aboriginal and Torres Strait Islander Population

The poor health status of Aboriginal and Torres Strait Islander peoples is well documented. Life expectancies for Aboriginal and Torres Strait Islander men and women are some 15-20 years below those of other Australians. Diseases of the circulatory system, respiratory illness, injury and cancer are the leading causes of death. Infant mortality rates remain 3 to 5 times higher than those of other Australians.

Diabetes, predominantly type 2 diabetes, is a major cause of morbidity and mortality for Aboriginal and Torres Strait Islander peoples. Two recent systematic reviews commissioned by OATSIHS have extensively reviewed current knowledge of diabetes in Aboriginal and Torres Strait Islander peoples and formulated diabetes management guidelines (Couzos et al, 1997; de Courten et al, 1997). The precise prevalence of diabetes among Aboriginal and Torres Strait Islander peoples is not known. Available data suggest that the overall prevalence rates among adults is between 10% and 30%, at least 2-4 times that of non Indigenous Australians (de Courten et al, 1997). Diabetes in Aboriginal and Torres Strait Islander children is due to a combination of type 1 diabetes, which has a similar or lower incidence than in non Indigenous Australian children (de Courten et al, 1997), and type 2 diabetes which is being increasingly observed at a young age. One study has documented type 2 diabetes in 2.7% of Aboriginal children and adolescents (mean age 18.5 years) (Braun et al, 1996). Gestational diabetes (GDM) is more common in Aboriginal and Torres Strait Islander women who have rates 2-3 times that of non Indigenous women (Couzos et al. 1997).

Aboriginal and Torres Strait Islander populations experience 12 to 17 times more deaths due to diabetes than non Indigenous Australian (ABS &AIHW, 1997). This excess mortality is mostly attributable to an increase in cardiovascular disease. However renal failure is also a

significant problem and accounted for the most deaths in a cohort of Aboriginal and Torres Strait Islander people in the Northern Territory (Phillips et al, 1995).

There is also a paucity of data on rates of diabetes complications among Aboriginal and Torres Strait Islander peoples. Data from the Northern Territory show that the age-adjusted risk of end stage renal failure was 17.4 times that of non Indigenous Australians and that the end stage renal failure associated with diabetes was 26.5 times higher (Hoy et al, 1995). This problem is continuing to progress at an alarming rate (Hoy, 1997).

There are a number of inter-related factors which impact on the persistent poor health among Indigenous people. The relationship between these factors is complex and current evidence does not allow an assessment of the relative importance of each factor. They include:

- socio-economic factors
- social and cultural factors
- poor access to good quality health care due to cultural and locational factors, poor linkages, lack of population health focus, workforce issues and financial barriers
- environmental factors such as housing
- specific risk factors such as poor nutrition.

Structure of health care for Indigenous Australians

This segment reviews some of the key departments and organisations crucial to the development and implementation of health policy and services for Aboriginal and Torres Strait Islander communities. Space precludes the inclusion of all of the important groups.

The Office of Aboriginal and Torres Strait Islander Health Services (OATSIHS)

This office is within the Commonwealth Department of Health and Family Services and was established in 1994 to give greater focus to Indigenous peoples' health needs in mainstream health programs. Since July 1995 the Office has had responsibility for providing funding to community controlled primary health and substance misuse organisations previously administered by ATSIC.

The OASTIHS has an important role in the implementation of diabetes strategies which will take place through the network of funded Aboriginal health services by:

- ensuring that Indigenous people participate fully in the development of appropriate programs
- ensuring that matters associated with diabetes are dealt with through States and Territories joint planning forums
- facilitating the integration of specialist diabetes programs within the primary health care setting and ensuring that policy and administrative processes support this integration
- facilitating the development of a primary care workforce skilled in diabetes management
- working with other areas within the Health and Family Services portfolio to promote policy and structural changes to remove barriers to access for Indigenous peoples
- working with organisations outside the health sector to bring about improvements in areas such as environmental infrastructure, particularly in remote areas

- working with health information and data systems to improve the quality and appropriateness of Indigenous health data

To facilitate coherent policy development and to support evidence based strategic planning, the OATSIHS commissioned a series of reviews into a number of key health areas in Aboriginal and Torres Strait Islander health. Two reviews into all aspects of type 2 diabetes in Aboriginal and Torres Strait Islander populations have been completed (de Courten et al, 1997; Couzos et al, 1997). Two further reviews which focus on nutrition and healthy food supply programs, and breastfeeding and early infant nutrition, and the recently published eye health review (Taylor, 1997) have relevance to the prevention and management of diabetes.

The outcomes from these reviews and consultations facilitated through NACCHO and OATSIHS have provided the basis for developing strategies and recommendations for improving the diabetes related health outcomes of Aboriginal peoples and Torres Strait Islanders

The National Aboriginal and Torres Strait Islander Health Council (NATSIHC)

The Commonwealth Government has established NATSIHC to provide advice to the Minister of Health and Family Services on strategies, priorities and policies to improve the health status of Aboriginal and Torres Strait Islander peoples.

The Aboriginal and Torres Strait Islander Commission (ATSIC)

ATSIC continues to have a vital role in the provision of community infrastructure such as housing and community support facilities, and environmental health problems eg disposal systems which are integral to improving the health status of Indigenous people.

State and Territory Governments Aboriginal and Torres Strait Islander Advisory Forums

These have already been established in some States and Territories. It is important for all States and Territories to develop a strategic framework for diabetes prevention and care consistent with the recommendations of the *National Diabetes Strategy and Implementation Plan* at all levels of health policy and service delivery, while taking account of local diversity and priorities.

Aboriginal Community Controlled Health Services (ACCHS)

These health facilities have been established to provide primary health care for Aboriginal and Torres Strait Islander people. There are approximately 100 health services funded through the OATSIHS. Others are funded through State and Territory Governments eg in Northern Queensland and the Torres Strait, which are funded by the Queensland Government. Their role is to provide the Aboriginal and Torres Strait Islander population with:

- clinical and population health services
- culturally appropriate health promotion programs
- coordination of health service and monitoring of health status
- a framework through which local and regional community health action is developed

National Aboriginal Community Controlled Health Organisations (NACCHO)

NACCHO is the umbrella organisation for the OATSIHS funded Aboriginal Community Controlled Health Services. It has a policy, priority setting and coordinating role for the community controlled Aboriginal health sector.

Aboriginal Health Workers (AHW)

Aboriginal Health Workers have an important role in the provision of health care to Indigenous communities. They provide an essential link between traditional and mainstream perceptions of health and health care, and often have strong links with the community. They are usually the first point of contact for advice and health care.

Strategies to improve access to effective culturally appropriate diabetes care for Aboriginal peoples and Torres Strait Islanders

Principles on which the strategies are based

- all diabetes specific strategies for Aboriginal and Torres Strait Islander communities should be part of an holistic approach to health care
- wherever possible diabetes and related health services for Aboriginal and Torres Strait Islander communities should be delivered within the community
- training of AHWs and all staff of Indigenous health services (IHS) should be an integral part of all diabetes programs
- all training and/or outreach services are conducted with the primary aim of supporting IHSs and AHWs, and building on their capacity to conduct the required services with a minimum of external intervention
- the need for services should be determined by the community

Areas of particular need

Strategies for the prevention and care of type 2 diabetes in Aboriginal and Torres Strait Islander populations should include increased emphasis on disease prevention, systematic early detection services, increased access to effective community based services; and improved access to specialist services, particularly in rural and remote areas.

Primary prevention of diabetes and related health problems

A range of policies and strategies both within and outside the health sector are required to address issues of employment, education, transport, food storage and costs. Links with national prevention and health promotion initiatives such as Active Australia and the National Nutrition Strategy are essential to ensure culturally appropriate approaches to the implementation of these programs in Aboriginal and Torres Strait Islander communities. In the meantime, healthy lifestyle and risk reduction advice should be given to all people at risk of diabetes as part of their total package of care.

Early diagnosis

Early diagnosis is vital to the prevention of diabetes complications. It is common for people to have type 2 diabetes for a number of years without knowing it (Harris et al, 1992). Consequently, many people already have established complications by the time they are diagnosed. In addition, detection of GDM requires active screening programs.

Quality and effectiveness of diabetes care

The development and impact of diabetes complications can be significantly reduced if everyone with diabetes received the recommended standards of care, including the implementation of well documented evidence based guidelines for the clinical management of diabetes to guide ongoing monitoring and annual review of people with diabetes. Since Indigenous Australians are less likely to access mainstream specialist services, it is imperative that IHSs provide ongoing monitoring and annual screening for complications.

Special considerations

Priority programs for:

- Improving the Quality of Diabetes Care,
- Visual Impairment Prevention,
- End Stage Renal Disease Prevention,
- Diabetic Foot Disease Management,
- Cardiovascular Disease Prevention
- Early Detection of Type 2 Diabetes and
- Type 2 Diabetes prevention

are detailed in Section 5 of this document. The following points serve to highlight additional particular considerations and special needs of Indigenous Australians.

Prevention and detection of type 2 diabetes

In Aboriginal and Torres Strait Islander populations a large proportion of the community may have undiagnosed diabetes and there is a high prevalence of diabetes risk factors. Effective strategies for detection should combine opportunistic as well as a population health approach to case finding but individual services should make strategic judgements on the balance to be struck between targeting those displaying risk factors versus a total population approach.

Primary prevention interventions seek to promote and encourage a healthy living approach to disease prevention, recognising that risk factors for several diseases overlap and that health promotion and care should be enacted through an holistic health framework.

Nutrition studies in Aboriginal communities have commonly shown excessive intakes of dietary sugars and fats and low intakes of micronutrients. A major contributor to this nutritional problem is the lack of availability and cost of healthy foods. Potential ways of improving access to healthy foods include initiating and supporting new distributing chains and/or buying cooperatives, local food production and models of successful community store operation. Food supply issues in rural/remote and urban areas also need to be addressed.

Improve quality of care of people with diabetes

Diabetes control

The impact of glycaemic control has been clearly established in people with type 1 diabetes and similar data are accumulating for people with type 2 diabetes. Clinical management guidelines universally recommend regular assessment of diabetes control by measurement of glycohaemoglobin (HbA_{1c}) and implementation of measures to achieve an HbA_{1c} result of within 1% of the upper limit of normal while avoiding severe hypoglycaemia.

HbA_{1c} is measured in a pathology laboratory on blood collected by venipuncture or on capillary blood using a DCA 2000 analyser. The DCA 2000 analyser provides an on-the-spot (within 6 minutes) result which is accurate for routine clinical practice and can be operated by a range of health professionals after a short training period. Measurement of HbA_{1c} using the DCA 2000 analyser is considerably cheaper than laboratory HbA_{1c} measurement ($6 for the DCA 2000 test vs $16.60 and a patient episode initiation fee for the laboratory test). These instruments can also be used to screen for microalbuminuria (see below).

This technology would allow the tests to be performed by the health practitioner in the presence of the patient and provides immediate feedback of the result. This is in contrast to sending specimens away to laboratories with the inherent delays in obtaining results and subsequent difficulties in contacting patients. The technology could be particularly useful to services with limited or no access to a laboratory.

Indigenous health services should have a DCA 2000 analyser. Potential ways of funding the purchase of the DCA 2000 analysers and consumables include:

- Medicare cash out arrangement based on the savings which will accrue from the lower cost of performing DCA 2000 analyser compared to laboratory HbA_{1c} measurement
- enabling IHSs to recover the consumable costs of the DCA 2000 cartridges by accreditation as off-site laboratories which would allow them to claim a Medicare rebate (but not a patient episode initiation fee) for performing an HbA_{1c} measurement

Renal disease

Renal disease is a major problem in Aboriginal and Torres Strait Islander peoples who have a considerably higher rate of end stage renal failure, with limited access to dialysis facilities, and a higher prevalence of microalbuminuria, a precursor to more advanced stages of renal disease. Implementation of the *End Stage Renal Disease Prevention Program* (Section 5) is urgently needed in Aboriginal and Torres Strait Islander communities.

On site screening for microalbuminuria incurs consumable costs which could be funded by:

- supplying Micral reagent strips under the National Diabetic Services Scheme to IHSs
- making Micral reagent strips a P9 MBS item
- providing IHSs with a DCA 2000 analyser through a Medicare cash out arrangement based on the savings which will accrue from the reduced cost of laboratory tests for microalbuminuria

Key issues for the provision of dialysis and renal transplant for Aboriginal and Torres Strait Islander peoples include an evaluation of the use of continuous ambulatory peritoneal dialysis (CAPD) for patients remote from dialysis units, the provision and use of satellite and mobile renal dialysis units, and barriers to renal transplantation. Agreement should be negotiated with States/Territories Health Departments regarding dialysis and renal transplantation for Aboriginal and Torres Strait Islander peoples. The principles of care for end stage renal disease should be defined in consultation with Aboriginal and Torres Strait Islander communities, especially people with renal disease, and primary and specialist care services.

Diabetic retinopathy

All people with diabetes are at risk of developing diabetic retinopathy, visual impairment and blindness. Regular screening for retinopathy for the detection of vision threatening retinopathy requiring laser treatment is essential to prevent serious visual impairment.

Prevalence rates of retinopathy in urban and rural communities similar to non Indigenous Australians have been reported (Stanton, 1985). However the rates seem considerably higher in remote communities. In the Northern Territory, almost half of aboriginal people have evidence of retinopathy at diagnosis and overall one third have retinopathy, and in almost half it is vision threatening (Markey, 1996).

The screening option will vary according to the location of the community and available local services. Where the community option is to use a non mydriatic fundus camera, Recommendations 10 to 12 of the Eye Health in Aboriginal and Torres Strait Islander Communities Report (Taylor, 1997) should be considered:

- provision of regionally based non mydriatic fundus cameras and portable laser facilities
- local recall systems
- Medicare rebates for non mydriatic fundus photography by practitioners other than ophthalmologists and optometrists

Diabetic foot disease

Foot problems account for considerable morbidity in people with diabetes and may result in ulceration and amputation. Most of these problems are preventable with foot protection, routine foot care, and early detection and treatment of problems when they occur.

Foot examination to detect people with diabetes at high risk of developing serious foot problems can be performed by any health professional, including Aboriginal health workers, who have received basic training and have the appropriate equipment.

The basic equipment for screening for foot problems is the 10g monofilament which is inexpensive. Some communities may wish to acquire more sophisticated equipment such as a portable Doppler.

Training packages have been developed by the ADEA and on-site training of health workers within IHSs could be achieved with the assistance of local/regional specialist diabetes services or as part of the National Footcare Project currently being conducted by the National Association of Diabetes Centres as part of the National Diabetes Strategy.

The following segment outlines implementation strategies designed to improve diabetes prevention and care and provide an infrastructure to coordinate these activities.

Strengthen the capacity of Aboriginal health workers to provide quality diabetes care and prevention services

AHWs provide holistic care for their clients. Within this framework specific problems, such as diabetes, are addressed. In addition to participation in accredited training programs, the following strategy is intended to assist AHWs, and other staff of IHSs, to reduce the impact of diabetes through early diagnosis and detection of people at high risk of foot problems.

Develop

Diabetes Detection Assessment Kit for Type 2 diabetes and GDM, including

- checklist of symptoms and risk factors
- referral criteria for diagnostic testing of people with positive screening results
- guidelines for providing educational information on modifiable risk factors for diabetes and cardiovascular disease and key messages about diet, physical activity, smoking and alcohol

High Risk Foot Kit, including

- 10g monofilament
- checklist for identifying at risk feet
- basic dressing pack
- protocol for basic wound management
- checklist of referral criteria
- guidelines for patient education on self care of the feet

Note: The Australian Diabetes Educators Association has developed National Action Plan Foot Assessment Guidelines and a training program which could easily be adapted for use by Aboriginal health workers

Train Aboriginal health workers to use the kits

Develop and implement training programs on the use of the Kits

Strengthen the capacity of Indigenous health services to deliver effective diabetes care and monitor outcomes

The two systematic reviews undertaken by OATSIHS in 1997 have provided a sound scientific basis for prevention, management and treatment of type 2 diabetes in Aboriginal and Torres Strait Islander populations.

A set of recommendations for clinical care guidelines for the management of type 2 diabetes has been extracted from these systematic reviews to underpin the process of developing locally appropriate clinical care guidelines.

Support and evaluate the development of locally appropriate clinical care guidelines

Ensure availability of equipment for monitoring diabetes and complications screening

Most of the routine monitoring of diabetes and annual screening for complications can be performed within community health services provided the following equipment is available:

- DCA 2000 analyser for assessment of blood glucose control (HbA_{1c})
- weighing scales, height measure and tape measure, for assessment of body mass index and waist:hip ratio
- sphygmomanometer and stethoscope for measurement of blood pressure
- monofilament for assessment of diabetic foot problems (some IHSs might also acquire a portable Doppler)
- assessment for diabetic kidney disease
  - urine protein test strips
  - Micral reagent strips or DCA 2000 analyser and microalbumin cartridges
- assessment for diabetic retinopathy
  - Snellen chart to test visual acuity
  - ophthalmoscope
  - access to non mydriatic fundus camera or telemedicine facility

This strategy would constitute a major step in building on the capacity of IHSs to deliver increasingly comprehensive and specialised levels of diabetes and related care, thus decreasing the need for routine referral to outside services.

Protocols for follow up and management of identified clinical problems

Local protocols and training will be required for health workers to:

- interpret results of physical examination and biochemical tests
- identify problems and potential problems
- take appropriate remedial action or
- initiate referral appropriately

Access

Each service should have access to at least one Aboriginal Health Worker who has training as a diabetes educator. This requires increasing the opportunities and funding for AHWs to participate in accredited diabetes educator training programs.

Training and support

Support, training and development in the initial stages of implementation may be facilitated by links between community controlled health services and local specialist services or through the National Association of Diabetes Centres. Consideration should be given to developing such arrangements through a memorandum of understanding reflecting the principles under which IHWs operate:

- assistance with complications screening eg supply visiting diabetes team to:
    - train health workers to perform non-medical assessments and interpret test results
    - assist in developing treatment and referral protocols
    - assist with the clinical management of patients with problems/complications
- advice on the clinical care, education, and organisation of services for people with diabetes
- freecall telephone or fax hotline to specialist services for advice on diabetes problems

Information systems

There is evidence that diabetes care which is supported by registers, reminder and recall systems, and checklists is more effective.

The introduction and use of computerised patient monitoring and recall systems in primary health care services should be facilitated. These local registers, controlled by the IHSs, could be used for recall and for collecting data on the health of the community. Systems have already been developed for this purpose and could be adapted to meet local needs.

Improve access of local communities to health services

National Diabetic Services Scheme (NDSS)

Local communities to hold and distribute blood and urine testing strips, insulin syringes, and injection pen needles to their members with diabetes who access this Commonwealth government subsidised scheme. This would be self funding as a handling charge for items supplied is covered under the scheme.

Pharmaceutical Benefits Scheme items

Explore ways of ensuring access to PBS items for all Indigenous communities.

Develop the infrastructure to implement the recommendations and strategies for Indigenous Australians

A partnership approach is fundamental for the successful implementation of a diabetes strategy for Aboriginal and Torres Strait Islander peoples. This will require effective cooperative effort between all levels of government, community organisations, medical and scientific communities, people with diabetes and other affected people, all working together to control and minimise the social and personal impact. Partnership is based on the commitment to consultation and joint decision making in all aspects of the response. There are no shortcuts to a comprehensive policy framework that involves the affected communities and ensures high quality professional participation. The partnership role of community organisations should not be passive, involving mere consultation after decisions have been made. Rather there should be community involvement at every level of decision making and policy formulation. In the past, too many strategies, programs, policies and services had been established without community input or control. The roles and responsibilities of all players should be clearly defined.

Organisational framework

A national approach to diabetes must encompass the Commonwealth, States/Territories and the community sector. The Aboriginal Health Framework Agreements is the mechanism that has been developed to carry this approach forward at a Commonwealth and State/Territory level. At a local and regional level Aboriginal and Torres Strait Islander primary health care services are the key institutional structure for implementation.

Aboriginal and Torres Strait Islander communities require direct and meaningful input into the *National Diabetes Strategy and Implementation Plan* and therefore require representation on the National Diabetes Advisory Committee (see Section 3). It is proposed that an Indigenous Australians' Reference Group is established and that this group is chaired by NACCHO. The chairperson of this Reference Group would become a member of the National Diabetes Advisory Committee. It is proposed that the secretariat for this Reference Group is provided by the OATSIHS. The Reference Group would link with the State and Territory Indigenous Health Forums, which involve all stakeholders and provide advice and input on policy and planning processes.

National Aboriginal Coordinator for diabetes and lifestyle diseases

This position should be established and funded for an initial 2-3 years to facilitate appropriate implementation of agreed diabetes strategies in Indigenous communities.

Recommendations

45. Establish and fund a position for a National Aboriginal Coordinator for Diabetes and Lifestyle Diseases to work closely with the National Diabetes Strategy Secretariat and Workings Groups, and Indigenous communities and organisations to implement the recommendations of the *National Diabetes Strategy and Implementation Plan* for Indigenous Australians

46. Strengthen the capacity of Indigenous health services and Aboriginal health workers to provide effective diabetes care and prevention services and monitor the outcomes. This should include:
    - examining the clinical utility and cost effectiveness of providing Indigenous health services with a DCA 2000 analyser and cartridges to perform near patient HbA_{1c} measurement
    - the provision of equipment for:
        - testing for microalbuminuria (Micral strips, DCA 2000 analyser)
        - screening for foot problems
    - the development and implementation of local plans for:
        - screening and treatment of diabetic retinopathy and access to equipment required for screening, and local or regional laser therapy
        - screening of people with diabetes for foot problems
        - screening pregnant women for undiagnosed diabetes and GDM
    - training Aboriginal health workers in diabetes prevention and care and providing them with appropriate resource materials

47. Conduct periodic general health checks to identify a range of disorders, including diabetes and associated health problems (eg overweight, hypertension, microalbuminuria and hyperlipidaemia) every 1-2 years from age 18

48. Improve access to medications and supplies provided under the Pharmaceutical Benefits Scheme and the National Diabetic Services Scheme for rural and remote Indigenous communities

49. Reduce structural and environmental impediments in the food distribution system to increase access to healthy and affordable food. Addressing problems in food distribution should be undertaken in collaboration with the National Public Health Nutrition Strategy

50. Increase levels of physical activity through the provision of recreational facilities, sports and other activities that are community based. Planning and implementation of initiatives to address this recommendation should be linked with the Active Australia campaign

51. Establish principles regarding the choice of treatment of end stage renal disease for Indigenous peoples and improve the provision of and access to dialysis and transplantation

People from non-English Speaking Backgrounds

Key points

- Australia is one of the most multi-cultural nations in the world
- The overseas born population has increased from 20% of the total Australian population in 1976 to 23% in 1996 (approximately 4.2 million people)
- Australia's migrants come from over 230 countries and speak over 190 languages. Approximately 15% of Australians speak a language other than English at home
- There are ethnic differences in the prevalence of type 2 diabetes with higher rates observed in Pacific Islanders, Asian Indians, Chinese, some Arab populations and Southern Europeans
- The age and sex standardised rate of self reported diabetes in the overseas born population is 3.0%. compared to 2.1% in the Australian born population
- The incidence of GDM is increased amongst women born on the Indian subcontinent, Africa, Vietnam, Mediterranean nations, Egypt and other Arabic countries and other Asian nations, compared with women born in Australia and New Zealand. These groups will therefore also have a higher risk of later developing type 2 diabetes
- There are a lack of data evaluating the effectiveness of diabetes care for people from non-English-speaking backgrounds
- People from non-English speaking backgrounds experience disadvantage in terms of access to the range of diabetes services available, access to appropriate education and information for effective self management, and access to ongoing community support

Background

Australia is essentially a nation of immigrants and is reputed to be one of the most multi-cultural nations in the world. This cultural and linguistic diversity brings many benefits but presents certain barriers to the delivery of effective health care.

While Australian governments have supported immigration for most of this century, the size and composition of the migrant intake have been influenced by many factors. These include economic and political conditions here and in the countries of origin and changes in Australian government policies (ABS, 1997). Despite the constantly changing diversity, Australia has been able to maintain a relatively high degree of social cohesion and harmony (Multicultural Affairs Unit Department of Premier and Cabinet Victoria, 1997).

Australia has an Indigenous heritage spanning over more than 40,000 years. The building of the culturally diverse nation as it is today, began in 1788, with European settlement by the convicts and the soldiers who commanded them, and were by and large of British origin. The gold rush era of the 1850s and 1860s saw an influx of peoples from a variety of cultural backgrounds. However, the fear that diverse groups would not be able to coexist in the one country, led to the move towards restriction of settlers to people from Britain (ABS, 1997).

The White Australia Policy, which was not completely abandoned until 1973, conserved the high proportion of Anglo-Celtic immigrants. Until this time the United Kingdom and Ireland had been the largest source of settlers, with 78% of settlers in 1925 being British nationals, falling to 44% in 1974 (ABS, 1997).

In 1947 Australia began to accept large numbers of displaced persons from Europe, particularly Eastern Europe, Italy and the Netherlands (ABS, 1997). Large numbers of people from Greece and Germany accompanied an increase in the numbers of settlers from Italy and the Netherlands in the 1950s. The number of Southern European immigrants remained high throughout the 1960s. By 1970 the number of immigrants from Italy and Greece was tapering off, although the levels of immigrants from Yugoslavia remained relatively high into the early 1970s (ABS, 1997). Since the 1970s, Asian immigration has increased. Table 10 shows the changes in birthplace groups from 1976.

Table 10: Overseas-born population: top 12 birthplace groups

Countries	1976 %	Countries	1986 %	Countries	1996 %
UK & Ireland	41.1	UK & Ireland	34.7	UK & Ireland	28.7
Italy	10.3	Italy	8.0	New Zealand	7.1
Greece	5.7	New Zealand	6.4	Italy	6.1
Yugoslavia	5.3	Yugoslavia	4.7	Former Yugoslav republics	4.4
Germany	4.0	Greece	4.3	Vietnam	3.6
Netherlands	3.4	Germany	3.6	Greece	3.4
New Zealand	3.2	Netherlands	3.0	Germany	2.8
Poland	2.1	Vietnam	2.6	China	2.5
Malta	2.1	Poland	2.1	Hong Kong & Macau	2.3
USSR	1.9	Malta	1.8	Netherlands	2.3
India	1.4	Lebanon	1.8	Malaysia	2.3
Lebanon	1.2	India	1.5	Philippines	2.2
Other	18.3	Other	25.6	Other	32.2
Total	100.0	Total	100.0	Total	100.0
MESC(a)	46.5	MESC(a)	44.1	MESC(a)	39.5
NESC(b)	53.5	NESC(b)	55.9	NESC(b)	60.5

(a) Main English speaking countries
(b) Non-English speaking countries

Source: Migration, Australia (Cat. No. 3412.0)

The overseas born population has increased from 20% of the total Australian population in 1976 to 23% in 1996, or around 4.2 million people. Australia now has a migrant population coming from over 230 countries and speaking over 190 languages. Approximately 15% of Australians speak a language other than English at home (Multicultural Affairs Unit Department of Premier and Cabinet Victoria, 1997). The waves of immigration are reflected in the age structure of the individual groups of the overseas born population, as the policy was to select migrants from a narrow age band. Migrants from Southern European groups thus have a higher median age than groups from Asian birthplace (ABS, 1997).

The most popular state for new arrivals is NSW. Migrants from non-English speaking countries are overwhelmingly concentrated in cities, and outside the large cities, they tend to reside in well-watered coastal areas, mining communities and inland irrigated agricultural enclaves (DA & FECCA, 1997). Within cities the proportion and make-up of the non-English speaking migrants vary between the local government areas, with some groups constituting a significant proportion or a majority of the population. This does not remain static. On arrival and for the first decade or two of their residence in Australia, internal migration of people born overseas is very high. After this settling-in period their mobility patterns more closely resemble those of the Australian-born population (ABS, 1997).

Diabetes related issues

In general, migrants on arrival have better health than people born in Australia, this superior health status is a result of explicit health criteria governing selection for immigration. However, rates of illness and disability increase with the duration of residence While the reasons for this are unclear, it is suggested that this may be the result of the material circumstances encountered by migrants in their everyday lives (Schofield, 1995).

Ethnic differences in the prevalence of diabetes have been reported world-wide. Epidemiological studies demonstrate the susceptibility to type 2 diabetes of various ethnic groups such as Micronesian, Polynesian and certain Melanesian Pacific Islanders (Zimmet et al, 1990), migrant Asian Indians and Chinese (Dowse et al, 1990; King et al, 1993), some Arab populations (King et al, 1993) and some European communities, especially Southern European (King et al, 1993). There is also evidence of an increased incidence of GDM amongst women from some ethnic groups. Beischer et al, (1991) demonstrated a higher incidence of GDM in women born on the Indian subcontinent, Africa, Vietnam, Mediterranean nations, Egypt and other Arabic countries or other Asian nations, compared with women born in Australia and New Zealand. Comparable results were found by Moses et al (1994) in a study of the Illawarra region of NSW. These groups will therefore also have a higher risk of later developing type 2 diabetes.

Many of the ethnic groups with high prevalence rates are represented in Australia. The ABS (1997) reported that the age and sex standardised rate of diabetes in the overseas born population was 3.0%, which is higher than that of the Australian born population (2.1%). People born in Southern Europe have high crude diabetes prevalence rates of 7.8%, although this group also has a high median age. The National Health Survey conducted in 1989-1990 demonstrated that risk factors for diabetes (physical inactivity, obesity) are reported by a significantly higher proportion of adults from specific ethnic groups (Welborn et al, 1995). Screening of those at risk in these communities appears to be suboptimal. A study in the Arabic-speaking population in the Central Sydney Area Health Service highlighted that females in particular were unlikely to be screened for diabetes (Rissel et al, 1997).

High prevalence rates are found in migrant groups which may have experienced a greater degree of westernisation. As well as possessing a high genetic risk of diabetes, it is likely that many ethnic groups migrating to Australia will also face an increased risk of developing diabetes due to exposure to environmental factors associated with adopting a westernised/industrialised lifestyle (McCarty et al, 1996). Moreover, these people are at greater risk of developing and experiencing adverse effects of diabetes complications as many will be disadvantaged in accessing health facilities, particularly those who do not speak fluent English.

While there is a strong indication that ethnic groups are experiencing high rates of diabetes, data on the actual numbers of Australian residents affected and the associated socio-economic costs are lacking (McCarty et al, 1996). Migrants from non-English speaking backgrounds (NESB) represent a significant proportion of the diabetic population. A study of ambulatory diabetes care showed that an interpreter was required for 12.9% of patients (Flack et al, 1997). However, research often excludes NESB people because it is considered too difficult or expensive to include them.

There is anecdotal evidence to suggest that non-English speaking people with diabetes do not receive the same standard of health care and education as their English speaking counterparts and as a result, experience poorer health outcomes. A study by de Blieck et al, (1993), found that non-English speaking people utilised diabetes ambulatory health care resources less than English speaking patients, their self-care practices were less than recommended, and when commencing insulin, they had a greater utilisation of inpatient services. It is also reported that poor control is common and in some ethnic groups particularly marked (DA and FECCA, 1997).

Qualitative research conducted by FECCA for Diabetes Australia identified unaddressed needs among people with diabetes from non-English-speaking backgrounds including access to services; availability of information in community languages; patient-centred care; culturally sensitive health care providers; suboptimal surveillance and monitoring (DA and FECCA, 1997). Also a survey conducted of health services confirmed a shared sense among health care providers of the inadequacy of current resources for people from non-English-speaking backgrounds (DA and FECCA, 1997).

Beyond these efforts, other epidemiological data to describe the prevalence and toll of diabetes among NESB communities now resident in Australia are scant. Data are urgently required to evaluate the effectiveness of health services in addressing the health needs of NESB people.

The migrant population is characterised by great diversity in socio-economic status, linguistic and cultural backgrounds between and within different population groups. It is this diversity which has enriched the social fabric of the nation, but in the face of a health care system which is orientated towards the homogeneous majority, they are consequently disadvantaged.

Common features of migrants from non-English speaking countries which impact on their health status include (DA and FECCA, 1997):

- lack of English skills
- limited literacy in any language
- cultural and religious mores and beliefs that differ from the Australian ‘norm’
- employment at the ‘lower’ skill levels in the labour market
- higher representation among the long-term unemployed

The result is that non-English speaking migrants suffer from a lack of access to services which will maximise their health status. Improving access to appropriate and adequate diabetes care and education is impeded by:

- the diversity of languages spoken which creates difficulty and expense in translating health education material
- lack of a central clearing house for diabetes literature in community languages
- the difficulty people with limited English skills and unfamiliarity with the health system have in participating in their health care
- the difficulty in determining the most appropriate messages and how to present them
- the diversity of cultural, health beliefs and attitudes of different population groups There is no single method of correctly approaching health problems in NESB groups
- increased social problems due to loss of family and social networks, and socio-economic disadvantage
- many NESB people entering Australia as refugees being wary of authority due to past physical or emotional trauma.

These may include food habits and beliefs which may be contrary to recommendations for diabetes eg. religious obligations such as fasts. Social customs such as being compelled to take food or drink offered, may also create obstacles to good diabetes control.

The recommendations for care of diabetes do not differ for NESB people from those of their English speaking counterparts, however there is the need to improve access to the health care system for this group. This will require a greater degree of coordination of effort than is currently the case.

There has been a variety of initiatives and recommendations for improving health care and diabetes care in the NESB population. In 1979, the Federation of Ethnic Communities' Councils of Australia (FECCA) was established. This is a voluntary non-party political community-based organisation which promotes multiculturalism as the social policy that best ensures fair opportunities for all Australians. The Federation seeks to represent the interests and concerns of ethnic Australians, and monitors a wide range of issues. It works to ensure that programs devised by governments are fair and responsive to the interests of the whole Australian community, including those from diverse ethnic backgrounds.

The Public Health Association of Australia (1991) adopted a policy which affirmed the principles of equity in regard to multiculturalism and health. DA and FECCA (1997) produced a report which identified that NESB people experience disadvantage in terms of access to the range of diabetes services available, access to appropriate education and information for effective self management, and access to ongoing community support. They recommended that relevant diabetes organisations develop and implement:

- an access and equity strategy
- a clearing house for diabetes-related materials and resources, including those that are language and culture specific
- training for health professionals and community health workers be supported

- a national and coordinated response to targeting populations in the Australian community who are at high risk of developing type 2 diabetes and its complications

Other initiatives have included a number of GP and Divisional projects, diabetes clinics for different language groups, group education and support groups and the production of literature by DA and literature and programs by some state organisations.

The success of future initiatives will depend upon consultation and coordination of effort. Therefore there is a need for a National NESB Diabetes Coordinator to work with NESB communities and their health care providers to implement the recommendations of the *National Diabetes Strategy and Implementation Plan* and to seek ways of empowering NESB people to obtain appropriate care.

Recommendations

52. Establish and fund a position for a National NESB Diabetes Coordinator to work closely with the National Diabetes Strategy Secretariat and Working Groups, and NESB communities and organisations to implement the recommendations of the *National Diabetes Strategy and Implementation Plan* for people from non-English speaking backgrounds
53. Disseminate information about the current recommendations for diabetes clinical care and self care in community languages eg:
    - translate into the major community languages the ‘best practice’ consumer diabetes guidelines developed under the *National Diabetes Strategy and Implementation Plan*
    - advertise diabetes clinical care and self care recommendations through community language newspapers nationally
54. Diabetes Australia to print the National Diabetic Services Scheme forms into the major community languages
55. Establish and maintain a clearing house and resource directory of teaching materials and other resources for the care of non-English speaking people with diabetes. Diabetes Australia would be an appropriate organisation to operate this service

People living in rural and remote Australia

Key points

- Australia’s population is distributed over vast distances with 32% living in rural and remote areas
- People living in rural and remote regions have worse health and higher death rates than urban people
- Diabetes, cerebrovascular disease and ischemic heart disease are some of the strongest differentials for the increased death rate in people living in rural and remote areas
- The majority of Australia’s Indigenous population live in remote or rural areas, and older people, and those with chronic illnesses, are often over-represented in these areas
- People in remote and rural areas are often disadvantaged with respect to availability and access to adequate and appropriate quality health care
- There is both a shortage and an uneven distribution of health care providers in rural and remote Australia due to problems with the recruitment, retention and continuing education of the rural health workforce
- The principles of clinical management of diabetes are not different to urban people. The challenge is to overcome barriers to ensure the provision of high quality multidisciplinary integrated care to all people with diabetes in remote and rural areas
- Models of health service delivery which are effective in metropolitan areas are not always the best approach for rural and remote Australia

Background

The population of Australia is mainly concentrated in the capital cities and large urban centres in two widely separated coastal strips, neither of which extends more than about 300 km inland (ABS, 1997). The remainder of the population, around 32% (The Office of Rural Health, 1995), live in rural and remote areas between these strips. In this context, rural is defined as anywhere outside a capital city or major urban area. Four categories of rural/remoteness (rural major, rural other, remote major and remote other) are identified in terms of population density and proximity to an urban area or capital city (Harris, 1992). Rural areas are characterised by vast distances between settlements, small sparsely distributed populations, isolation, harsh environments, a wide range of settings and conditions, and substantial social and cultural diversity among populations.

People living in remote and rural areas have a different illness profile than those living in metropolitan communities. Although comprehensive rural health statistics are lacking, there have been reviews of studies of health differentials between rural and urban Australians (Clarke, 1990; Humphries, 1990). Rural Australians have significantly more ill-health than urban people and higher death rates than metropolitan residents; 15% higher for men and 9% higher for women (Mathers, 1994). Non-metropolitan residents have higher rates of death for all major causes except for cancers and mental disorders. Some of the strongest differentials for selected causes of death include diabetes - 46% higher for women (but not higher for men), cerebrovascular disease - 24% higher for men and 27% higher for women and ischaemic heart disease - 11% higher for men and 17% higher for women (Mathers, 1994).

There is evidence of substantial geographical variations in patterns of utilisation of services indicating inequities in health care for rural people. Craft et al (1997) found that in the surgical management of breast cancer, rural women tended to undergo mastectomy rather than breast-conserving surgery, which may reflect the relative lack of access to postoperative radiotherapy. In an evaluation of the utilisation rates of coronary artery bypass graft procedures, Rushworth et al (1994) reported that rural residents had fewer of these procedures than residents in areas in which the procedure was available. However, there was no evidence that the burden of ischaemic heart disease was less in rural areas.

The majority of Australia’s Indigenous population live in remote or rural areas, and older people, and those with chronic illnesses, are often over-represented in rural areas (Mathers, 1994a). For many groups with special needs, disadvantage is compounded by remote and rural location. Isolated marginal populations have different epidemiological profiles and social and structural problems which are often overlooked when attempting to direct scarce health resources to the most common and prevalent public health problems (Fitzpatrick and Manderson, 1995).

General issues

People in remote and rural areas are often disadvantaged with respect to availability and access to adequate and appropriate quality health care. Barriers they face include:

- distance including unavailability of year-round transport in some remote areas
- shortage of health professionals and inadequate training
- poor economic infrastructure
- ongoing logistic and communication problems
- fewer or less comprehensive hospital services and other local health services which are inadequate to meet the needs of the population
- difficulties with intersectoral coordination
- financial pressures and decreasing services
- unemployment
- lifestyle and cultural attitudes towards health

(Fitzpatrick and Manderson, 1995).

There is both a shortage and an uneven distribution of health care providers in rural and remote Australia. There are approximately 97 medical specialist/100,000 persons in capital cities, 80/100,000 in other urban areas, 28/100,000 in rural regions and 26/100,000 in remote regions, with a similar pattern evident for general practitioners and allied health professionals (Harris M, 1992). There are also serious problems with the recruitment, retention and continuing education of the rural health workforce (Office of Rural Health, 1995).

Significant barriers, which restrict performance of duties, were reported by 53% of all rural health practitioners (Harris R, 1992). These include:

- lack of resources
- lack of professional support
- geographic isolation
- lack of skills
- work-related stress

Retaining staff is difficult due to these barriers, and many staff relocate for reasons associated with family education or work opportunity, or professional or career advancement (Harris R, 1992). A Nursing Retention and Recruitment Taskforce identified professional isolation and lack of access to education were particular issues for nurses working in remote and rural areas (Kennerson and Chiarella, 1996). In a survey of rural GPs, Dickinson et al (1995) found that they were relatively young and providing a broad range of services to their patients. Many had not planned for rural practice and required further training after their arrival.

A number of recent initiatives have been established to address these problems. The Commonwealth, State and Territory governments have adopted the National Rural Health Strategy issued by the Australian Health Minister's Conference in March 1994 as part of the effort to improve delivery of high quality health services to people in remote and rural Australia (Office of Rural Health, 1995). The General Practice Strategy is one of the Commonwealth strategies designed to redress the uneven distribution of GPs in Australia. The Rural Incentives Program provides grants for re-locating GPs, training grants to improve skills of rural and remote GPs and grants to encourage GPs to practise in remote locations (Office of Rural Health, 1995). Training posts for specialist medical practitioners have been established in rural and remote areas to increase specialist services available in country areas.

GPs provide most of the primary health care in rural and remote areas, with curative services predominating and preventive health given a low priority (Dunne et al, 1994). The pattern of mortality and morbidity suggest that health promotion and preventive measures have an important role in rural areas. Humphreys et al, (1993) examined the sources of health-related information which were most valuable to rural residents, and concluded that GPs and pharmacists were overwhelmingly the most important source of preventive health information for rural inhabitants. Therefore health promotion efforts in rural regions will need to ensure integration with curative health service provision, and rural GPs need to take a pivotal role in preventive health service delivery (Dunne et al, 1994).

Even where there is adequate resourcing of health services in remote and rural regions, health problems are not necessarily resolved, because the services are poorly aimed, there is lack of community control over the allocation of funds or the identification of priority in services, inappropriate and/or unacceptable programs, or the lack of staff to meet community needs (Fitzpatrick and Manderson, 1995).

Models of health service delivery which are effective in metropolitan areas are not always the best approach for rural and remote Australia (PHAA, 1991). Different structures are required for effective health services in remote and rural areas because of the distinct pattern of morbidity and mortality in rural areas and the barriers faced by rural people (PHAA, 1991).

Health care should be provided in a way that is appropriate to the social and cultural context in which it operates. There should be local community participation in the assessment of health needs, in the planning, management and evaluation of local services.

Diabetes specific issues

The principles of clinical management of diabetes are not different for people from remote or rural regions of Australia. However the barriers they face in accessing adequate and appropriate quality health care require different structures and models of health service delivery. While the majority of diabetes care for people living in remote and rural areas is carried out by GPs, the role of diabetes educators, dietitians, podiatrists and Aboriginal health workers in providing and organising services for people with diabetes in rural and remote areas is essential to the provision of comprehensive diabetes care.

Recognising the barriers to service provision, the challenge is to overcome these and provide high quality multidisciplinary integrated diabetes care to all people with diabetes in remote and rural areas. With this in mind a workshop for non-medical rural clinicians from rural and remote NSW (NSW Health, 1996) identified some of the barriers specific to diabetes service provision in rural areas, and potential solutions, including:

- a lack of understanding among non-diabetes health professionals about many aspects of the clinical management of diabetes
- inadequate or unavailable mechanisms for clinical follow-up
- inadequate or unsatisfactory interaction with GPs
- low profile of local diabetes services
- inadequate access to allied health workers
- absence of dedicated diabetes budgets at a regional health service level

Suggested methods to overcome these barriers included:

- the option to attend Diabetes Centres for periodic training attachments or reciprocal placements
- outreach training/continuing education
- visiting outreach specialist services
- undergraduate and post graduate health professional students to rotate through rural health services
- a 24 hour freecall hotline to obtain specialist advice

Telemedicine is a potential method of delivering services to remote or rural areas where health care is inadequate or not available (LaMay, 1997). Potential applications for telemedicine include clinical assessment, diagnosis and treatment, professional supervision, and a wide range of educational purposes (Yellowlees & McCoy, 1993). The educational and supervisory assistance that can be given via a telemedicine network can improve the skills of isolated workers, making long term retention in their local communities more likely (Yellowlees & McCoy, 1993). A telemedicine program for eye disease, including assessing diabetic retinopathy, is currently being trialed in western NSW. Should telemedicine prove economically viable, an Australia-wide network could improve rural health and increase health workers retention in remote communities.

Streamed care

WHO (1991; 1995) describes three options for diabetes care ranging from minimal to optimal depending on the available level of local services. Where optimal care, ie freely available specialist diabetes teams and centres are unavailable, greater reliance on primary and generalist care provided by health professionals with additional diabetes specific training and skills is necessary. ‘Streamed care’ is a proposed model for overcoming deficiencies in service delivery and is particularly suited where resources are scarce, such as rural and remote regions. The concept is predicated on overcoming deficits in the availability of specialist services by defining three streams of care and designating a local diabetes team, or individual health professional, to provide an advanced level of diabetes care and to coordinate care between the streams. The model requires a notional categorisation of diabetes care into:

- *routine or basic care* which can be provided by primary care physicians and non-medical health workers
- *semi-specialised care* such as complications assessment and the management of minor problems which can be performed by primary care health workers with training and support from specialist services
- *specialist care* such as the management of significant complications, management of young people with type 1 diabetes and pregnant women with pre-existing diabetes which require specialist services

The implementation of streamed care involves the following steps:

- defining the tasks in terms of categories of diabetes care
- matching the tasks and available health care providers
- providing training to local health care providers
- developing referral criteria and avenues of referral
- formal arrangements with specialist support services

Recommendation

56. Regional health services to develop local strategies to implement the *National Diabetes Strategy and Implementation Plan* including:
    - coordination of regional activities to prevent fragmented service delivery
    - ensuring access of people with diabetes living in rural and remote areas to support services similar to those available to their urban counterparts
    - collection of local diabetes information
    - provision of training programs for local health professionals
    - development of partnerships between local clinicians and major specialist centres

Children and adolescents

Key points

- Approximately 14 per 100,000 children under 15 years of age develop type 1 diabetes each year
- In NSW the incidence of type 1 diabetes has increased over the past 5 years from 17.1 to 21.6 per 100,000
- Up to the age of 20 years approximately 1 in 1500 people has type 1 diabetes
- Beta cell destruction is more aggressive in this age group compared to adults
- Almost all children and adolescents with type 1 diabetes will develop some evidence of diabetes complications as adults
- Type 2 diabetes is emerging as a problem among adolescents in Indigenous Australians and in other high risk populations
- Psychosocial and physiological differences at various stages of growth and development present special challenges in caring for children and adolescents with type 1 diabetes
- Children and adolescents should have access to care by a specialist interdisciplinary team
- Schooling can also present additional problems for children and adolescents with diabetes
- The transition from a paediatric to an adult service for the adolescent with diabetes is often difficult, the effect is not well understood and frequently underestimated, and needs to be carefully managed

Background

The vast majority of people who develop diabetes in childhood and adolescence have type 1 diabetes. Although Australia lacks a national register, State-based surveys (Glatthaar et al, 1988; Verge et al, 1994) indicate an incidence of diabetes of about 14 per 100,000 per annum in the under 15 year old age group. Data from the NSW Register show that the incidence of type 1 diabetes in NSW has increased over the past 5 years from 17.1 to 21.6 per 100,000 (Craig et al, 1997). Up to the age of 20 years approximately 1 in 1500 people has type 1 diabetes.

The course of beta cell destruction is more aggressive in this age compared to adults and children rapidly lose all insulin secretory capacity and become totally dependent on insulin. This, together with erratic eating patterns, variable exercise, the tendency to 4-6 viral illnesses each year, hormonal changes associated with growth spurts and pubertal development, all contribute to difficulties in optimising diabetes control. The occurrence of severe hypoglycaemia in children and adolescents is approximately twice as common as adults (DCCT, 1994; Davies et al, 1997; Porter et al, 1997; Porter et al, 1996).

The morbidity of diabetes in children and adolescents includes diabetic ketoacidosis, severe hypoglycaemia, cognitive deficits and EEG abnormalities in those diagnosed under the age of

5 years (Rovet et al, 1987; Ryan et al, 1985; Porter et al, 1996), poor growth and pubertal delay. Mortality is also 2-4 times higher than in non diabetic children. In addition to the early onset of microvascular complications, virtually all children and adolescents will have some evidence of diabetes complications in adulthood. Duration of diabetes is an important factor in the development of microvascular complications and nearly 100% of people with type 1 diabetes will have retinopathy after 15 years of diabetes (Mitchell, 1980). Recent evidence indicates that the prepubertal years can no longer be regarded as offering protection against the development of these complications (Donaghue et al, 1997; Donaghue et al, 1997).

Type 2 diabetes is also emerging as a problem among adolescence in Indigenous Australians and in other high risk populations. There are no data on the extent of the problem but the increase in adverse factors which predispose to the development of type 2 diabetes, such as increasing weight, suggests that type 2 diabetes will become an increasing problem among children and adolescents from at risk populations.

The child and adolescent depend on their parents, the health care system, consumer organisations (JDFA and DA), and the Government to be their advocates. A number of international groups have acknowledged the special needs of children and adolescents including the St Vincent Declaration, the philosophy statement of the International Diabetes Federation, the International Society for Paediatric and Adolescent Diabetes Declaration of Kos, and the Cancun Declaration of the Association of Latin American Diabetes Associations.

The psychosocial and physiological differences at the various stages of growth and development mean that the problems of looking after children and adolescents often differ from those faced by adults with type 1 diabetes. Distinct and separate problems confront the families and the diabetes care team when caring for the toddler age group (under 2 years of age), the preschool child, the child at school and the early and advanced adolescent.

Children and adolescents should have access to care by an interdisciplinary team trained in childhood diabetes, consisting of a paediatric endocrinologist or physician trained in the care of children and adolescents with diabetes, diabetes educator, dietitian and psychologist/social worker. This is particularly relevant to the young child where age of onset is a predictor of subsequent re-hospitalisation. Experiences at diagnosis set the scene for living with diabetes and it is important to have a ‘good start’.

Diabetes in a child or adolescent generally causes acute and prolonged distress. Part of the assessment at diagnosis should be a developmental, behavioural and psychosocial history of the child and family. Early counselling for pre-existing problems and those created by the crisis of diabetes should be initiated from the time of diagnosis by a psychologist or social worker.

The period of schooling can also be a time which may present additional problems for children and adolescents with diabetes. Children with chronic illness are more at risk of school absenteeism and dysfunction than their healthy peers and school personnel must be sufficiently informed to enable them to provide a classroom environment which facilitates the child’s full integration. Most diabetes centres caring for children and some diabetes associations provide school visits by diabetes educators to inform the staff. There are at least 26 separate educational authorities in Australia. While many State authorities have well developed policy and procedure manuals for the management of childhood diabetes, there is a

lack of uniformity and in some cases no procedures are in place. A national approach would address this problem.
The transition from a paediatric to an adult service for the adolescent with diabetes is often difficult and the effect is not well understood and frequently underestimated. If this transition is not carefully managed there may be lack of follow-up with a prolonged period of poor glycaemic control resulting in suboptimal health, an acceleration of microvascular complications and no access to emergency advice. Transfer to an adult service should be carefully planned well in advance of the time of transfer.

Issues in relation to the priority programs

Section 5 details the Priority Programs for improving health outcomes in all people with diabetes. In addition the following particular points are relevant to children and adolescents.

Improving quality of care in people with diabetes

Specific guidelines and protocols on the care, monitoring and complications screening and treatment for children and adolescents with type 1 diabetes should be developed. The guidelines produced by APEG and NSW Health could be used as the basis for these national guidelines which should address the special needs of young children and include recommendations on transition from paediatric to adult services and protocols for management of children attending school.

Systems should be developed to assist adolescents to effectively transfer their care from paediatric to adult services.

Blood sampling for pathology (eg HbA_{1c} measurement) should be collected by finger prick and pathology services should routinely provide this facility.

Research efforts should be directed to developing non-invasive blood glucose monitoring technology and to improving monitoring to detect and prevent severe hypoglycaemia.

Information

Data are urgently required to quantify the impact of diabetes on children and adolescents. The establishment of the national insulin treated diabetes register and the existing State-based APEG registers should be used to facilitate this process. Standardised national data sets should ensure the collection of data relevant to children and adolescents. Regular collection (every 5 years) and national pooling of glycaemic control and complications data should be performed.

Linkage to other data collection sources detailed in the Information Section (Section 3) will be required to ensure collection of mortality and hospitalisation data.

Best practice

Routine diabetes care of children and adolescents with type 1 diabetes should be provided by a specialist team with expertise in the management of children with type 1 diabetes. There are few diabetes educators, dietitians and social workers/psychologists with specific training in this field. The relatively small numbers of patients in the community and the distribution of these specialist services poses access problems for some, especially in remote areas. Specialist outreach services to some areas has been an attempt to address this problem. Data are required on the percentage of children and adolescents who have access to specialist services in order to identify future needs.

Strategies should be developed to improve health professional knowledge about childhood and adolescent diabetes by continuing education programs conducted by specialist paediatric/ adolescent diabetes services in conjunction with health professional organisations and universities. A system for networking and sharing of resources should be developed and should be coordinated by the National Association of Diabetes Centres.

Coordination

The proposed restructuring of the management of the *National Diabetes Strategy and Implementation Plan* includes the establishment of a Childhood and Adolescent Reference Group which should ensure that attention to issues relevant to this group are maintained.

A needs assessment of children and adolescents with diabetes in Australia should be developed in order to identify and prioritise issues which need to be addressed.

Research

Programs for the prevention and cure of type 1 diabetes are detailed in Section 4. Other research priorities relating to diabetes care, monitoring, complications prevention and reduction, and impact of diabetes on quality of life issues need to be defined and should constitute one aspect of the national needs assessment.

Recommendations

57. Conduct a national assessment of the needs of children and adolescents with diabetes
58. Develop specific guidelines and protocols on the clinical care, monitoring, and complication screening and treatment for children and adolescents with type 1 diabetes. This should include recommendations for transition from paediatric to adult services and protocols for diabetes management in children attending school
59. Conduct regular collection and national pooling of glycaemic control and complications data on children and adolescents with diabetes every 5 years using standardised data sets
60. Ensure that diabetes care for children and adolescents with type 1 diabetes is provided by a specialist team with expertise in the management of children with type 1 diabetes
61. Focus research efforts on:
    - the prevention and cure of type 1 diabetes
    - complications prevention and reduction
    - reducing the impact of diabetes on quality of life
    - developing non-invasive blood glucose monitoring technology
    - improving monitoring to detect and prevent severe hypoglycaemia

The elderly

Key points

- The definition of elderly is arbitrary but generally refers to people aged 65 years or more
- Life expectancy of Australians aged 65 years is 15 years for males and 19 years for females
- In 1995 11.9% of the Australian population was aged 65 years or older and is projected to increase to 17.5% by 2021. The proportion of people aged 85 or more in the population aged 65 years and over will increase from 8.8% in 1995 to approximately 15% in 2021
- People aged 65 years and older account for 30% of total admissions and 48% of in-patient days
- The 1995 National Health Survey estimated that 2.4% of Australians have self reported diabetes and this prevalence increased to 8.9% for those aged 75 years and over
- Elderly people will increasingly represent a greater proportion of the total diabetic population because of their increasing numbers and higher prevalence of diabetes
- The prevalence of diabetes complications increases with age with cardiovascular disease being a major problem
- Diagnosing diabetes in the elderly can be difficult and is often delayed because of a lack the classic symptoms
- The elderly commonly have multiple co-existing chronic conditions which require multiple medications and which may hinder management, exacerbate the impact of diabetes and the level of disability experienced
- The provision of care for people with diabetes in residential or nursing homes is often inadequate and staff do not have the necessary training to manage the complex problems of elderly people with diabetes
- Hypoglycaemia is a serious hazard for the elderly who are less able to recognise and react to impending hypoglycaemia. The risk of severe or fatal hypoglycaemia associated with the use of oral agents or insulin increases exponentially with age
- Hyperglycaemia may be left untreated increasing the risk of acute and longer term diabetes complications. As yet there are no data from a randomised trial in the elderly which establishes the optimal blood glucose level that maximally reduces the risk of complications while minimising the risks of therapy

Background

The definition of elderly is arbitrary and there are real differences between chronological and physiological age. In general, people aged 65 years or more are included in the ‘elderly’ category. The current life expectancy of Australians aged 65 years is 15 years for males and 19 years for females. Therefore health maintenance strategies including disease prevention and treatment are important issues not only for maximising quality of life but also for the health budget.

The elderly population can span an age range of 30 years or more, and as a consequence, there is much diversity in the elderly population, with many elderly people remaining active and financially independent. However some older people are disadvantaged by poverty, isolation and cultural factors which result in restricted access to services. Ageing is not viewed positively in Australia and is seen as a time of mental and physical decline. The lower workforce participation and the low level of personal savings contribute to the resulting loss of independence and productivity. These factors contribute to negative attitudes towards the elderly as a financial and practical burden on society which can result in discrimination (Healthy Ageing Taskforce, 1997).

The Australian population is ageing. In 1995 11.9% of the Australian population was aged 65 years or older and is projected to increase to 17.5% by 2021 (ABS, 1997). The projections also show significant growth in the number of people aged 85 years or more, with this age group having an increasing share in the population aged 65 years and over, rising from 8.8% in 1995 to approximately 15% in 2021 (ABS, 1997).

From these changing demographics, expenditure for health care services for elderly people will increase as a proportion of the total health care budget (Haas et al, 1995). The elderly are major consumers of social services including health and hospital services (Andrews & Carr, 1990). In both the private and public sectors combined, the population aged 65 years and older accounted for a high proportion of admitted patient activity, accounting for 30% of total admissions and 48% of in-patient days. Their average length of stay was 7.3 days, compared with 4.5 days for all patients (AIHW, 1997). A substantial proportion of all services provided under the Medicare Benefits Schedule are medical and diagnostic services for people aged 65 years and over (Haas et al, 1995). There is a need to ensure effective and efficient planning and allocation of adequate services for the elderly to avoid the need for future generations to compete for resources (Healthy Ageing Task Force, 1997).

The prevalence of diabetes is not evenly distributed throughout the population, with prevalence rates increasing steadily with age (ABS, 1997; McCarty et al, 1996). The 1995 National Health Survey showed that 2.4% of Australians have self reported diabetes and this prevalence increased to 8.9% for those aged 75 years and over. The increased prevalence of diabetes in the elderly results from an increasing number of people with diabetes reaching old age as a result of better management, and the increasing number of non-diabetic people reaching old age and developing diabetes as a result of long exposure to risk factors (Muggeo, 1997).

The prevalence of diabetes complications such as macrovascular disease and renal impairment also increases with age. Cardiovascular disease is a major problem for all people with diabetes and is compounded by the natural atherosclerotic ageing process (Verhoeven, 1997). Age is the biggest risk factor for stroke in the person with diabetes (Bell, 1994).

Issues relating to diabetes

The treatment of diabetes in the elderly does not differ in principle from the treatment of the younger person with diabetes, however the specific problems of the elderly such as multiple pathology, polypharmacy, social isolation and depressed cognitive function must be taken into account. Health care providers should be aware that consultation, evaluation of medical history and physical examination of elderly patients are more time consuming and require more skill and patience (Muggeo, 1997). The elderly person may require multiple health providers because of multiple pathology which requires a coordination of effort.

The Australian Pensioners' and Superannuants' Federation (APSF, 1991) in a survey of consumer satisfaction found that older people with chronic illness who fared well were those who had access to multidisciplinary clinics, well coordinated care between hospitals and local services and access to allied health services. The treatment model for diabetes of attributing an equal role to the consumer, emphasis on education, self management and access to multidisciplinary clinics was found to lead to more satisfaction with the health system for elderly people (APSF, 1991).

Diagnosis of diabetes can be difficult and is often delayed in the elderly as many of the classic symptoms such as tiredness, weight loss and visual disturbances are accepted as part of the normal ageing process. Polyuria may not occur due to a high renal threshold for glucose or is attributed to other conditions such as urinary tract infections, prostatism or prolapse (Tattersall, 1997). Symptoms which do occur may be vague. When elderly people are screened with an oral glucose tolerance test, approximately 50% with diabetes are unaware they have diabetes (Meneilly & Tessier, 1995). Levetan et al (1998), found that one third of hyperglycaemic hospitalised patients had no prior history of diabetes, and concluded that failure to consider the possibility of diabetes represents a missed window of opportunity for making an earlier diagnosis of diabetes.

Harris et al (1992) showed that the clinical diagnosis of type 2 diabetes is delayed by at least 4 - 7 years which is of concern since earlier diagnosis and intervention delay the development of complications. Sunder et al (1997) found a significant number of previously undiagnosed diabetic complications in hospitalised patients by adopting a proactive approach to screening for complications. Given the high use of hospital services by the elderly, this is a potential intervention point for increasing the diagnosis of diabetes and its complications in the elderly.

The elderly commonly have multiple co-existing, often chronic conditions, which require multiple medications and which may hinder management, exacerbate the impact of diabetes and the level of disability experienced (Sinclair & Barnett, 1993). Self management may be hindered by impaired cognition, poor vision, poor hearing, decreased dexterity and mobility. Maintaining a good diet can be difficult for older people for a range of reasons including the difficulty in changing lifetime habits, the condition of their mouth and teeth, transport difficulties in accessing foot outlets, lack of interest in cooking and socio-economic state. There may be an inability to perform regular activity due to the effects of other medical problems such as arthritis. An inability to adequately self-care may compound problems associated with increasing dependency such as anxiety and depression. In the elderly, the impact of diabetes on the physical, emotional, cognitive, and social function is most pronounced (O'Connor & Jacobsen, 1990; Stewart et al, 1989).

Attending specialised services can be difficult for the elderly since they may be less mobile due to functional disability and transport problems and are therefore less likely to receive specialist care when required.

Diabetes and its complications can accentuate the 'normal' age-related deterioration in function, resulting in impaired physical and social function (O'Connor & Jacobsen, 1990). Examining the sensori-motor function of elderly people with diabetes, Lord et al, (1993), found evidence that older people with diabetes have problems with stability and related sensori-motor factors which place them at an increased risk of falls.

Patients in residential or nursing homes are possibly the most vulnerable section of the aged population (Benbow et al, 1997). In America, nursing home care for people with diabetes cost $US1.83 billion in 1992 (American Diabetes Association, 1992). Benbow et al (1997) found that despite their high morbidity and greater use of health resources, the provision of care for residents with diabetes in residential or nursing homes in north west England was inadequate. There is little organised care for this group and the staff express feelings of isolation and bewilderment at the complex problems of elderly people with diabetes (Tattersall & Page, 1998). It is essential that those providing care for elderly people with diabetes have access to appropriate education, including not only the staff of nursing homes, but relatives and carers in the community. Suggestions to improve service delivery to nursing home patients have included diabetes specialist nurses with particular responsibility for elderly patients who can provide education and continuing support for carers (Benbow et al, 1997), and establishing channels of communication between residential and nursing homes with local diabetes services whereby staff in homes could attend regular updates and also contact diabetes teams for advice (Tattersall & Page, 1998).

In Australia, care of people resident in facilities other than a registered nursing home is often provided by non-nursing staff. Currently there are uncertainties about the legality and legal liabilities of these ‘personal care assistants’ in performing diabetes related duties such as administering insulin. In addition there are quality of care concerns. Diabetes Australia has investigated this issue but currently the situation remains unresolved predominantly because of significant legislative differences between the various States and Territories.

Hypoglycaemia is a serious hazard for the elderly person with diabetes as they are less able to recognise and react to impending hypoglycaemia (Verhoeven, 1997). A number of studies have found that the risk of severe or fatal hypoglycaemia associated with the use of oral agents or insulin increases exponentially with age (Meneilly & Tessier, 1995). A protracted state of hypoglycaemia poses the risk of irreversible brain damage, profoundly altering cognitive function seriously affecting quality of life (Tiengo, 1997). It can provoke serious cardiovascular events, cause impaired balance with the risk of falls and fractured limbs, and be misdiagnosed as a dementia related illness. Factors which combine to increase the risk of severe hypoglycaemia in the elderly include reduced release of counterregulatory hormones and a lack knowledge about hypoglycaemia, its prevention and corrective action (Meneilly & Tessier, 1995).

Hyperglycaemia may also be left untreated increasing the risk of acute and longer term diabetes complications. As yet there are no data from a randomised trial in the elderly which establishes the optimal blood glucose level that maximally reduces the risk of complications while minimising the risks of therapy. It is anticipated that the UKPDS will help address this issue (Turner et al, 1996). Often failure to improve diabetes control is justified by the myth that elderly people have a very short life expectancy. However, the average 80 year old woman in western society has a life expectancy exceeding 9 years but can expect to spend half of this time with a major disability (Manton & Stallard, 1991). Reducing the contribution of diabetes complications to this risk of disability has the potential for achieving significant health gain and reducing health care expenditure on the elderly.

The pharmacological treatment of diabetes in the elderly requires careful consideration of the risk of drug interactions if the person is taking multiple medications. There is also the possibility of reduced renal and hepatic function in the elderly, resulting in a long half-life for drug effects.

The growth rate of the elderly population and the higher prevalence of diabetes in this population, mean that elderly people will increasingly represent a greater proportion of the total diabetic population. Access to high quality care will require coordination, training and support for health care providers. The GP has a vital role in the coordination of care in the elderly person with diabetes.

There is a general lack of specialised services for the aged, and programs are not always tailored to their special needs. In order to address this problem, it may be more appropriate to have a geriatrician join the diabetes team rather than setting up diabetic clinics for elderly people (Sinclair & Barnett, 1993).

Many issues relating to the care of elderly people with diabetes must be addressed in order to effectively deal with the increasing burden of diabetes in this age group. The recommendations of the *National Diabetes Strategy and Implementation Plan* are intended for all people with diabetes and for those predisposed to the development of diabetes. It is important to ensure the elderly have access to these programs. The following is an additional specific recommendation for the elderly.

Recommendation

62. Implement strategies to improve the quality of care of elderly people with diabetes admitted to hospital and who reside in aged care facilities and hostels

Section 7 Economic considerations

Economic considerations

Key points

- Diabetes total annual cost is estimated at $A1 billion (in 1995 dollars), or $A2,774 per year for each person in Australia with diagnosed diabetes. This figure includes $A553 million in direct costs and $A418 million in indirect costs
- Direct cost figures significantly underestimate the cost burden of diabetes because it is a recognised comorbidity and contributing factor to other conditions which utilise health resources, especially cardiovascular disease
- Indirect costs due to lost productivity and premature mortality make a significant contribution to the economic impact of diabetes
- Intangible costs relating to the impact of diabetes on the individual's quality of life are rarely considered because of the difficulty in assigning costs to quality of life factors
- The 4% of the population with diabetes accounts for 12% of the total health care expenditure
- Type 2 diabetes accounts for 70% of the total diabetes expenditure
- The cost of health care for diabetes is dependent on diabetes control as assessed by HbA_{1c}. Direct costs for adults with diabetes increase by 36% with an HbA_{1c} of 10% compared with an HbA_{1c} of 6%. Decreasing HbA_{1c} from 10% to 9% saves approximately $A1,800 for uncomplicated diabetes and $A6,300 for diabetic people with hypertension and heart disease
- Poor glycaemic control is making a significant contribution to the excessive health care costs associated with diabetes in Australia
- Introducing interventions to increase screening to detect and treat vision threatening retinopathy would decrease annual expenditure on diabetic eye disease by $A15 to $A31 million
- The annual cost of treatment of end stage renal disease in Australia is $A23.5 million. Treatment of people with type 1 diabetes with albuminuria with an ACE inhibitor is highly cost-effective
- Introduction of a foot care program to reduce amputations and improve treatment of foot ulcers would recover implementation costs within 2-3 years
- The cost of opportunistic screening for type 2 diabetes is $535 for each newly diagnosed case of type 2 diabetes and IGT

Background

Measurement of disease costs is important in defining the impact of the disease on the community and in providing an economic justification for disease control and action and an input into evaluating the potential cost-effectiveness of interventions for the purpose of priority setting (Mathers, 1998a). This is particularly relevant for diabetes, which is associated with excessive costs to society and to the individual, for which proven interventions are available which can reduce this economic burden. The cost components of the economic impact of diabetes include:

- direct costs
- indirect costs
- intangible costs

Direct costs

Direct costs are the health sector costs of providing health services for people with diabetes and include inpatient and non-inpatient treatment, out-of-hospital medical services, allied health services, pharmaceuticals, ambulance, aids/appliances, community and public health and administrative costs.

Although data are available to allow the calculation of direct costs, there is no mechanism for identifying and tracking individuals with diabetes throughout the health system in Australia and therefore only estimates of direct costs can be made by apportioning total expenditure in the health sector to diabetes based on prevalence estimates. This is inherently problematic but particularly so for diabetes which is a recognised comorbidity and contributing factor in a number of other conditions which utilise health resources, especially cardiovascular disease. It is generally agreed that direct cost figures significantly underestimate the cost burden of diabetes.

Indirect costs

Indirect costs measure costs due to illness, disability and premature mortality and the impact these have on the individual, his/her family and on society because the person is too ill or has died prematurely and has not fulfilled their productive potential.

There is controversy about assigning a monetary value to indirect costs attributable to lost productivity. Because methodologies are controversial and contentious, the AIHW has elected not to include indirect costs in its Disease Costs and Impact Study (Mathers, 1998a). However, diabetes does result in real indirect costs, for example from sick days off work, and therefore some allowance for indirect costs is warranted. More controversial is the calculation of lost productivity resulting from premature death. The human capital approach values lost work at market earnings and imputes a value for unpaid work such as housework. Opponents of this methodology argue that this grossly overestimates the actual costs of premature mortality which in reality relate only to the costs of replacing that worker and/or the cost of training someone else and are dependent on prevailing employment opportunities.

Intangible costs

Intangible costs are more subjective and relate to the impact of diabetes on the individual's quality of life resulting from personal suffering. These are rarely considered because of the difficulty in assigning costs to quality of life factors which may lead to a reduction in quality of life for people with diabetes and their carers.

Intangible costs are usually expressed in terms of quality of life measures. The most popular is the Quality Adjusted Life Year (QALY) which is calculated by multiplying the preference value for that state with the time the person is likely to spend in that state (Greenlaugh, 1997). The Global Burden of Disease Study (Murray & Lopez, 1996) has recently proposed an internationally standardised form of QALY, the Disability-Adjusted Life Year (DALY) to express years of life lost to premature death and years lived with a disability of specified severity and duration. One DALY is one lost year of healthy life. Further research is required to evaluate the utility of this measure.

Apart from the cost of illness, the benefits, which accrue from interventions, require consideration. In general these include the economic benefits which result from prevention of illness that is expensive to treat and that avoids admission to hospital and results in a return to work; clinical benefits of postponement of death or disability, relief of pain etc; and improved quality of life through increased independence, improved well being, release from sick role etc.

A number of measures are used to compare costs and outcomes of interventions. Cost-benefit analysis describes both costs and benefits in monetary terms. On the other hand cost effectiveness analyses are usually expressed in terms of cost of the disease per QALY. Interventions costing less than $A30,000 per QALY are considered highly cost-effective interventions (Laupacis et al, 1992). Where there is no agreement on the value of the benefit, cost consequences, for example number of limbs saved, can be used.

The estimated cost of diabetes in Australia

The Rise and Rise of Diabetes in Australia (McCarty et al, 1996) noted that diabetes is extremely costly, both on an individual level and for the whole Australian society. Although there are inadequate data to precisely estimate the total cost of diabetes in Australia, this report estimated the total annual cost to be close to $A1 billion (in 1995 dollars), or $A2,774 per year for each person in Australia with diagnosed diabetes. This figure included $A553 million in direct costs and $A418 million in indirect costs. The direct costs are considered an underestimate because hospital in-patient data do not include the cost of all admissions and procedures where diabetes may be a contributing factor, estimate of testing equipment and materials is thought to be conservative and public health, community health and ambulance costs have not been included. The indirect costs were based on estimates of Years Potential Life Lost to age 75, which is an ‘estimate highly dependent upon the assumptions used’.

The *Disease Costs and Impact Study* (DCIS) (Mathers & Penm, 1998b) determined the annual direct cost of diabetes to be $A312 million. In this study the direct costs are calculated by apportioning estimates of recurrent health expenditure (published by AIHW) to categories of disease using Australian data on disease prevalence and health service utilisation. However, as noted by the authors, this approach needs to be interpreted with caution for a specific disease where a bottom up approach (such as used in *The Rise and Rise of Diabetes*) would give more accurate estimates rather than the DCIS which used a top-down approach. The DCIS costs are also subject to the problems of underestimates for the same reasons as outlined above.

International information on estimated diabetes costs

A number of international studies have examined the cost of diabetes and confirm the over utilisation of health services by people with diabetes. Some of these studies appear to offer a more accurate picture of the economic burden of diabetes because of databases which allow accurate identification of people with diabetes and the health costs they incur. The findings of these studies are remarkably similar and accord with the report of Rubin et al (1994) that the estimated 4% of the population which has diabetes accounts for 12% of the total health care expenditure.

Most studies examining the costs of diabetes have not dissected the cost attributable to the two main types of diabetes however it is estimated that type 2 diabetes accounts for 70% of the total expenditure (Alberti, 1997). It should be noted however that the DCIS estimated that 2 diabetes accounted for 57% of total diabetes expenditure (Mathers & Penm, 1998b).

The South Glamorgan study (Currie et al, 1997) examined the utilisation of hospital resources and reported that the 1.4% of people with identified diabetes were responsible for 5.5% of admissions and 6.4% of outpatient attendances, and because of the increased length of stay occupied 9.4% of bed days. Apart from macrovascular disease, other conditions where diabetes had less obvious clinical effects were significant in increasing case severity as measured by longer lengths of stay or increased probability of hospital admission. The crude relative risks for admission for diabetes related complications ranged from 10.4 for eye complications to 15.6 for peripheral vascular disease. Furthermore, the study reported that 7% of admissions were for people with diabetes but 45% of these were never classified during the routine coding process with either a primary or secondary diagnosis of diabetes. In addition, people with diabetes occupied 10.7% of bed days and their length of stay was 10.7 days compared with 6.7 days for non-diabetic people. The proportion of total cost of care was 8.7%, increasing with age being greatest for 60-74 year age group which accounted for 38% of diabetes admissions, 40% of total expenditure and 33% of bed day use. This translates into an excess cost of acute hospital care of approximately $A4,000 per person at 1994/5 prices, amounting to 86% of the expenditure on people with diabetes or equivalent to 6400 admissions and 73,000 bed days.

Selby and colleagues (Selby et al, 1997) examined the costs of medical care during 1994 in 85,209 members registered with diabetes in a managed care organisation with age and sex matched non-diabetic members. Excess expenditure in individuals with diabetes was approximately $A5,400 per person which was 2.4 times the cost of care for non-diabetic individuals. The largest proportion of costs was for hospitalisation (38.5%) and 38% of total costs were spent on treating long term complications, predominantly coronary heart disease and end stage renal disease. Consistent with previous reports, 3.6% of members accounted for 11.9% of the total health care costs.

The cost of health care for diabetes has been shown to be dependent on diabetes control as assessed by HbA_{1c} (Gilmer et al, 1997). Direct costs of care for adult diabetic members of a health maintenance organisation over a 3 year period increased by 5%, 11%, 21% and 36% respectively for each 1% increase in HbA_{1c} from 6% to 10%. Decreasing HbA_{1c} from 10% to 9% saved approximately $A1,800 for uncomplicated diabetes and $A6,300 for diabetic people with hypertension and heart disease. These data suggest that considerable economic benefits result from reducing HbA_{1c} to below 8% wherever possible and research has demonstrated that improved glycaemic control results in fewer diabetes complications.

In addition to any intervention effect, benefits will also accrue from indirect cost savings. These costs were systematically studied for people with diabetes aged 20-65 in the Swedish town of Vetlanda (Olsson et al, 1994) compared with the general population workforce. This study examined sick days and premature retirement due to permanent disablement. Insulin treated men had 31.1 sick days compared with 17.8 for the non-diabetic population and insulin treated women 26.1 compared with 19.9. Sick days were similar in non-insulin treated and non-diabetic people.

Permanent disability was three times higher for men over age 40 and twice as high for women over age 50. Because there are more non-insulin treated than insulin treated people in the community, the number of permanently disabled non-insulin treated people was twice as high as expected. The annual excess costs of lost production due to short term illness and permanent disability in diabetic patients was $A10,800 per patient aged 20-64, mostly due to permanent disability which accounted for 92% of this cost in people aged 40-64.

Cost effectiveness of interventions

Improving glycaemic control to prevent complications

Available data suggest that considerable economic benefits result from reducing HbA_{1c} due mainly to improved glycaemic control resulting in fewer diabetes complications. However, additional costs are incurred in improving glycaemic control and therefore is it cost effective? The DCCT Research Group assessed the lifetime benefits and costs of intensive therapy as practised in the DCCT (DCCT Research Group, 1996) for people with diabetes who met eligibility criteria for the DCCT and estimated that approximately 17% of people with type 1 diabetes fulfilled these criteria - 120,000 people in the USA of whom 37% of these would be in the primary prevention group and 63% in the secondary prevention cohort. Reducing HbA_{1c} to the level achieved in the DCCT intensively treated group (HbA_{1c} 7.2%) would produce for each individual 7.7 years of additional sight, 5.8 additional years free of ESRD, 5.6 additional years free of LEA, an additional 15.3 years of life free from significant microvascular or neurological complication and an additional 5.1 years of life. The lifetime additional costs of intensive therapy was approximately $A52,000. After allowances for discounting, the cost of intensive treatment was $A 44,000 per year of life gained and $A 31,000 per QALY, costs which are considered cost effective.

The DCCT findings also have been extrapolated to develop a model to simulate people with newly diagnosed type 2 diabetes (Eastman et al, 1997) to compare treatments which achieved an HbA_{1c} of 10% or 7.2%, respectively. The predicted cost-effectiveness of comprehensive treatment is approximately $A24,600/QALY gained using DCCT intensive treatment costs. The model showed the cost/QALY gained is the lowest for minorities and for those with the highest HbA_{1c} and that intervention was least cost effective in the treatment of diabetes beginning late in life.

These costs relate to intensive therapy as delivered in the DCCT and it is generally believed that similar improvements in diabetes control can be achieved far more cheaply. In fact it has been estimated that the increased treatment costs of improving diabetes control can produce positive net benefit after 5-7 years (Gilmer et al, 1997). However the main obstacle to the multifactorial intervention programs to prevent complications which could potentially lead to cost savings is the large initial investment.

Extrapolation of these data to Australia is difficult because of a lack of large population studies which have assessed glycaemic control in people with diabetes. One study of 1,114 people with type 2 diabetes showed that 34% of non Indigenous Australians and 53.1% of Indigenous Australians consulting an urban diabetes service had an HbA_{1c} of more than 2% above the upper limit of normal and would qualify for programs to improve diabetes control

(Colagiuri S et al, 1997). If international data for children and adolescents with type 1 diabetes are applicable to Australians, 64% with diabetes diagnosed for more than 2 years have an HbA_{1c} above 8% (Mortensen & Hougaard, 1997). Despite the lack of local data it seems likely that a significant percentage of Australians would benefit from programs to improve control and that poor glycaemic control is making a significant contribution to the excessive health care costs associated with diabetes.

Detection and treatment of diabetic retinopathy

There are no reliable data on the current proportion of blindness in Australia caused by diabetic retinopathy but detailed estimates have been reported in the NHMRC guidelines on the Management of Diabetic Retinopathy (NHMRC, 1997). Furthermore, available data are likely to seriously underestimate the extent of the problem. Both the MVIP and the BMES indicate that less than one third of eligible persons are receiving a blind or blind-age pension. Commonwealth data indicate that in 1994 8,300 people were receiving a blind pension and 13,300 were receiving an age-blind pension, i.e. 21,600 Australians. Using US data adjusted for Australian Blindness criteria, ABS census data and estimates of diagnosed diabetes, it is estimated that up to 14,000 Australians have moderate visual impairment (corrected VA 6/24-6/60) and up to 7,200 are legally blind (corrected VA < 6/60) from diabetic retinopathy. This suggests a three-fold increase in the number of blind Australians compared with the estimated 2,000 who currently receive blind pensions for diabetic retinopathy.

The cost of providing pensions to the current 21,600 Australians receiving blind pensions is estimated at $A339 million in 1994 - $A20,200 per year for people under age 65 and $A 13,100 per year for people over age 65. For persons blind from diabetic retinopathy, the 1996 annual cost could be between $A13 and $A40 million, depending on the estimates of the proportion of pension recipients who are blind from diabetic retinopathy.

Screening costs can be estimated using Medicare rebates for examination by ophthalmologists (the most expensive scenario) for the estimated 350,000 people with diagnosed diabetes in 1996. Screening every 2 years and with follow up every 3-12 months of the 35% with retinopathy, the annual Medicare cost of screening is around $A19 million with full compliance.

Vision threatening retinopathy-requiring treatment is estimated to be present in 44,000 Australians (11% of known diabetes cases - 19,000 with PDR and 25,000 with macular oedema without PDR). Each year 6,900 are estimated to require laser treatment for PDR and another 7,500 for macular oedema. A conservative estimate of the Medicare cost of such laser treatment is around $A25 million plus fluorescein angiography costs of $A1.5 million and vitrectomy costs of $A0.5 million - i.e. total $A27 million. Therefore the total estimated combined screening and treatment cost is $A46 million per annum.

Modelling studies performed by the University of Melbourne Ophthalmology Department (NHMRC, 1997) indicate that the overall health care expenditure (including disability) incurred by the Commonwealth Government due to diabetic retinopathy and its associated consequences at 30% compliance was $A193 million each year. These studies confirm a substantial saving to government from screening and treatment programs for diabetic retinopathy. Introducing interventions to increase compliance to 80% would decrease expenditure to $A178 million, a saving of $A15 million. If the higher blindness costs are used the savings would amount to $A31 million.

With the low cost blindness disability estimates, the Commonwealth Government would incur increased costs of approximately $A5 million for 7 to 10 years following which significant savings would be generated thereafter. For high cost blindness disability estimates, savings would result from the first year of the program. Although the extra savings from yearly compared to second yearly eye examination are small, compliance with screening may be facilitated by including screening as part of the annual review.

In addition to cost savings, detection and treatment of diabetic eye disease is also highly cost-effective when benefits are expressed as QALYs. The cost of providing currently recommended screening and treatment of diabetic retinopathy is estimated (on US data) at $A 2,700 per person-year of sight saved (Javitt & Aiello, 1996). The cost per QALY associated with detecting and treating diabetic retinopathy is approximately $A3,000/QALY for people with type 1 diabetes, $A4,500/QALY for people with insulin treated type 2 diabetes and $A 5,400/QALY for people with non-insulin treated type 2 diabetes (Javitt & Aiello, 1996). These are considered highly cost-effective interventions (Laupacis et al, 1992).

End stage renal disease prevention

The financial burden of diabetic renal disease is considerable with the estimated direct cost of ESRD treatment in Australia being $A50,000 per patient per year. In 1994, 227 new people with diabetes entered treatment programs for ESRD with 824 entering these programs over the past 5 years (301 with type 1 diabetes and 523 with type 2 diabetes). Taking into account 5 year survival rates of patients receiving treatment for ESRD, an estated 470 people with diabetes are receiving treatment for ESRD each year in Australia at a cost of $A23.5 million. In addition many people with diabetes and ESRD are ineligible or cannot access treatment programs. Also 7% of all transplantation in 1994 were performed in people with diabetes. People with ESRD consume more than 10 times the health resources of the average person.

There is significant potential for reducing this burden by adopting simple evidence based practices. Screening and treatment programs for microalbuminuria and macroalbuminuria (with and without renal insufficiency) have been shown to be cost-effective since screening is inexpensive, ACEI treatment is affordable and the potential benefits in reducing the cost of expensive ESRD and achieving increased life expectancy and years free of ESRD are high. Modelling has estimated that reducing the decline in renal function by 50% in people with Stage 4 disease can delay the onset of ESRD by approximately 15 years and the need for ESRD treatment programs by 40% and concluded that costs and savings would balance if the annual rate of increase of albuminuria was decreased from 20% to 18% (Borch-Johnsen et al, 1993). Another modelling study reported that ACEI treatment of people with type 1 diabetes with microalbuminuria achieves a highly cost:effectiveness ratio of $A12,100 per year of life saved using a conservative estimate of beneficial effect of treatment (Siegel et al, 1992). This figure compares favourably with the cost effectiveness of treating hypertension in the general population. Furthermore these analyses do not take into account the expected reduction in coronary artery disease from the use of ACEI in people with diabetes and microalbuminuria.

Neither of the previous two studies had long term outcomes data on the effect of ACEI treatment in delaying in progression to ESRD or death. Treatment of diabetic nephropathy with an ACEI in type 1 diabetes with overt diabetic nephropathy results in a 50% reduction in the risk of both progressive renal insufficiency and the combined endpoints of death, dialysis and transplantation compared with placebo treatment. Treatment with ACEI compared with blood pressure control using another agent, would result in direct life timesavings of $A 50,000 per person with type 1 diabetes and $A15,200 per person with type 2 diabetes. Initiation of this therapy in people with type 1 and type 2 with nephropathy in 1995 in the US would have realised a total direct cost saving of $US189 million a year for 1999 and $US475 million in 2004 (Rodby et al, 1996).

These studies confirm that implementation of a program to detect and treat diabetic nephropathy in any of its clinical stages is highly cost effective and would result in substantial savings to the health system and reduce individual suffering. The implementation of such a program does not require expensive initial funding and could be commenced immediately.

Diabetic foot disease management

Diabetic foot problems are a major cost to the health care system. The direct cost of an amputation in the UK in 1996 was $A27,600 for a major amputation and $A6,900 for a minor amputation (Connor, 1997) and are estimated to be similar in Australia. Applying these costs to the 2,800 amputations which are performed each year in Australia gives a total direct cost of approximately $A48 million each year. A 50% reduction of LEA would result in an annual saving of $A24 million whereas a further increase, which has been the trend over the past decade, will result in an escalation of the cost to the health system.

The average cost of hospitalisation for treatment of a diabetic foot ulcer was $A12,474 in 1994. By comparison outpatient treatment by a specialist foot care team reduces this cost by 85% (Hoskins, 1994). Population studies shown that 1.5% of the diabetic population has a foot ulcer at any one time. If 10% of these people have ulcers treated by traditional hospital treatment, the cost to the health system will be approximately $A7.5 million a year. If the number of people hospitalised because of diabetic foot ulcers could be reduced to 2.5% by ambulatory specialist foot care treatment, the direct treatment costs would be reduced to $A 2.7 million a year, an annual saving of $A4.8 million. This, combined with the annual savings achieved through reducing LEAs, would fund the recommendation to establish specialist diabetic foot clinics in each health area/region throughout Australia, with the costs being recovered within 1-2 years.

These estimates are consistent with the findings of Reiber who performed a modelling exercise of 100,000 males with type 2 diabetes. Based on US costs, the total five-year direct costs of foot care without a foot care program were calculated to be $A31 million and with a program $A23 million with the break even time from implementation being 2-3 years. (Reiber, 1996). This study concluded that prophylactic footcare is highly effective in reducing ulcers and amputations, saves money in direct costs (not to mention indirect costs and improvements in quality of life) and that the expenditure required to implement the program is recouped in a short period of time. Furthermore, the study by Bakker and Dooren demonstrated that a specialist foot clinic which achieved a 43% reduction in amputations, resulted in a saving of $A 65,000 per annum. (Bakker & Dooren, 1994).

Cardiovascular disease

The economic assessment of the impact of CVD in diabetes is difficult because of the numerous interrelated and confounding factors. The age and sex-adjusted risk of admission to hospital with acute myocardial infarction and chronic ischaemic heart disease for people with diabetes is 8.3 and 7.2 times greater than in non-diabetic people (Jacobs et al, 1991). The proportional costs of CVD complications to the total hospitalisation costs was 74% (Jacobs et al, 1991). Huse et al (1989), estimated that 47% of the total direct and indirect costs of diabetes were due to CVD.

The economic impact of CVD and diabetes does not take into account the burden relating to undiagnosed or unrecognised diabetes, the prevalencde of which is close to that of diagnosed diabetes and would result in a doubling of the cost estimates relating to diagnosed diabetes.
Cost effective interventions are available to reduce the impact of CVD in diabetes and include primary prevention programs (Baxter et al, 1997) and secondary prevention strategies.

Early detection of type 2 diabetes

A comprehensive cost-benefit analysis of screening programs is limited by lack of data on the precise prevalence of undiagnosed diabetes and the clinical impact of an early diagnosis on morbidity, mortality and quality of life. Data from the Australian Screening Study provides an indication of the numbers of individuals which would be involved at the various stages of an opportunistic screening program (Welborn et al, 1997).
Using these data it is possible to calculate the cost of diagnosing each new case of type 2 diabetes and IGT. Based on the presence of risk factors and/or symptoms, 23,200 people were assessed as requiring a laboratory glucose estimation at a cost of $26.10 each ($9.55 for the glucose estimation and $16.55 patient episode initiation fee). These people also needed to return to their general practitioner to obtain the result of the test (standard consultation fee $21). On the basis of the glucose measurement, 6,550 people went on to have an oral glucose tolerance test at a cost of $34.25 each ($17.70 for the glucose tolerance test and $16.55 patient episode initiation fee) and needed to return to their general practitioner to obtain the result of the test (standard consultation fee $21). The total cost is $1,454,608 i.e $535 for each newly diagnosed case of type 2 diabetes and IGT.

A recent theoretical cost analysis of opportunistic screening for diabetes obtained quite different results (Easton & Segal, 1998). This study concluded that the cost of opportunistic screening of people with two risk factors (being obese and Italian-born) was $183 for each new case of type 2 diabetes and IGT. Obviously this discrepancy relates to significant difference in the assumptions used in the model.

Despite these costing differences, the cost of screening is relatively small compared to the potential for cost benefits from minimising the development of diabetes related complications.

Type 2 diabetes prevention program

The prevention of type 2 diabetes and its prediabetic stages including IGT and the Metabolic Syndrome has considerable potential to improve the health status of the Australian population by reducing morbidity and premature mortality and improving quality of life. However, a lack of data make quantifying this potential difficult.

The cost-effectiveness of a number of intervention strategies aimed at reducing weight and improving physical fitness was analysed by Segal et al (Segal et al, 1996). Interventions included workplace group programs, intensive diet and behavioural modification for the seriously obese and for women with previous gestational diabetes, advice provided by general practitioners, bariatric surgery for the severely obese and mass media campaign. Benefits were analysed in terms of diabetes years prevented and life years gained. The study concluded that cost-effective options for prevention of type 2 diabetes are available and can achieve a substantial improvement in health status at little cost or potential future net savings. The actual cost-effectiveness estimates are particularly sensitive to the success rates used in the model and to a lesser extent to the program costs and discount rates (Segal et al, 1996).

Gestational diabetes

There are few published studies which have examined the economic impact of GDM. The components which contribute to healthcare costs associated with GDM include:

- screening and diagnosing GDM
- treatment of women with GDM
- immediate and long term consequences of a diagnosis of GDM for both the mother and infant
- longer term follow up and interventions to prevent the development of type 2 diabetes

Currently, approximately 50% of pregnant women are tested for GDM (Moses & Colagiuri, 1997; Wein et al, 1998), mostly using a two step procedure involving a screening test followed by an oral glucose tolerance test if the screening test is positive. Screening for GDM is relatively inexpensive and has been calculated to cost approximately $10 per person (Moses et al, 1997). However this cost is dependent on where the testing is performed, being more expensive if performed in a private pathology laboratory because of the additional cost of the patient episode initiation fee (see Early Detection of Type 2 Diabetes - Section 5).

Treatment costs of women with GDM are also dependent on how and where care is provided. Moses et al (1997) calculated a cost of care which included self monitoring of blood glucose, diabetes and dietary education, and medical consultation to be in the order of $380 for each woman not requiring insulin and $470 each for women requiring insulin treatment.

The major potential public health benefit of diagnosing GDM derives from identifying a cohort of women who are at increased risk of the future development of diabetes. It has been suggested that each women with a previous GDM pregnancy should be assessed annually for the development of type 2 diabetes (NZSSD, 1995). The cost of ongoing annual surveillance of these women by the protocol of the Australian Diabetes Screening Survey (Welborn et al, 1997) would incur an annual cost of $102 for each woman.

Gregory et al (1993) have estimated savings of $US32 million over 10 years with interventions which prevent 10% of US women with previous GDM developing type 2 diabetes and savings of $US140 million if 25% were prevented from developing type 2 diabetes, targets which are realistic and feasible given the results of recently reported intervention studies (Pan et al, 1997).

Clearly more data are required for a more detailed and comprehensive analysis of the costs associated with GDM. Such analyses would also help inform discussion and recommendations about screening and intervention programs for GDM.

Summary

Although methods and models for precisely determining the costs associated with diabetes and its complications need to be further developed and refined, it is increasingly possible to quantitate the financial burden it imposes. It is apparent that the cost of diabetes is high and will rise dramatically over the next decade unless measures are taken to reduce complications in all people with diabetes and prevent or delay the onset of diabetes in as far as this is possible. It is also clear that health systems all over the world are struggling to meet increasing demands and that resources are not always readily available to implement new initiatives. However, there is sufficient evidence to demonstrate that an initial investment in additional programs to reduce the health burden of diabetes can, in many instances, be recouped in a relatively short timeframe, and will result in real savings to the health system.

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Appendix 1 The consultation process

The consultation process

The consultation process for the development of the *National Diabetes Strategy and Implementation Plan* took place over a period of six months and involved one local, one state, and two national surveys, 14 workshops, over 60 meetings with key organisations and individuals, circulation of draft material for comment, and informal and opportunistic consultation with consumers, clinicians and public health practitioners. Many people have contributed in addition to the significant occasions of consultation listed. The support and advice of Dr John Carter and Ms Jeannette Baldwin during the development of the Strategy is particularly acknowledged.

Surveys

Survey of parents of children with diabetes

Conducted by Mr Stephen Higgs, Vice President of JDFA, this informal survey sought parents' perspectives on what are the key issues and vital concerns in dealing with diabetes

NAP Survey July 1997

This involved surveying approximately 250 stakeholder organisations and individuals regarding the strengths and limitations of the NAP and seeking suggestions for improvements in emphasis and direction for the National Diabetes Strategy

People from Non-English speaking backgrounds September/October 1997

Through the Centre for Culture, Ethnicity and Health in Melbourne, people with diabetes from three language groups (Russian, Greek, Chinese) were surveyed regarding access to diabetes services and recommended standards of care

NADC Survey October 1997

Forty five Diabetes Centres were surveyed to determine i) the approximate number of occasions of service currently provided to people with different types and stages of diabetes and different treatment modes within current staffing constraints and ii) obtain consensus on what would constitute 'best practice' in this area

Group consultations

Workshops and meetings convened to consult about the development of the National Diabetes Strategy

- Commonwealth, State and Territories Health Departments Workshop, 11-12 September 1997, Canberra
- OATSIHS Workshop Commonwealth Health Department, Canberra, 10 October 1997
- Indicators Meeting Diabetes Centre Prince of Wales Hospital, Sydney with Drs Stan Bennett and Kuldeep Bhatia (AIHW) and Ms Angela Reddy (DH&FS) , 10 October 1997
- NACCHO Workshop Canberra, 8 December 1997
- Expert Clinicians convened by the National Diabetes Strategy Secretariat, Sydney 31 January 1998

Other workshops and meetings at which the National Diabetes Strategy Development Team was represented for consultation purposes

- Aboriginal Health Workers Seminar, June 1997, Darwin
- Active Australia Workshop October 1997, Canberra
- MACOD Meetings, May and August 1997, Sydney
- MESAG Meetings, June and December 1997, Sydney
- National Diabetes Indicators Meeting (DH&FS), August 1997, Sydney
- National Divisions Diabetes Program Workshop August 1997, Sydney
- Retinopathy Guidelines Committee Meeting, August 1997, Melbourne
- ADEA Tasmanian State Branch Meeting, September 1997, Hawley Beach, Tasmania
- NSW Health Department Diabetic Retinopathy Meeting, 17 September, 1997, Sydney
- Greek and Spanish Diabetes Support Groups, Sydney

Individual Consultations

Dr Ian Anderson - Medical Adviser, OATSIHS, DH&FS

Ms Jeannette Baldwin - National Diabetes Strategy, Diabetes Australia

Ms Karen Barfoot - Chief Executive Officer, JDFA, Sydney

Ms Gail Batman - Medicare Rebates DH&FS

Dr Stan Bennett - Australian Institute of Health and Welfare, Canberra

Mr Kuldeep Bhatia - Australian Institute of Health and Welfare, Canberra

Dr Knut Borch-Johnsen - Steno Diabetes Center, Denmark

Dr Robert Brazenor - Pharmaceutical Benefits Scheme, DH&FS Canberra

A/Professor Lesley Campbell - St Vincent’s Hospital, Sydney

Dr John Carter - Chairman, MACOD

Mr Laurie Clay - Durri Medical Service, Kempsey, NSW

Dr Peter Colman - President, Australian Diabetes Society

Dr John Daniels - Redfern Aboriginal Medical Service, Sydney

Dr Margaret Dorsch - Diabetes and Injury Unit, DH&FS, Canberra

Ms Fidelma Doran - Population Health Strategies, DH&FS, Canberra

Dr Michael Fett - NH&MRC Strategic Development, DH&FS, Canberra

Ms Susan Garner - NH&MRC Strategic Development, DH&FS, Canberra

Ms Penny Graham - Population Health Strategies, DH&FS, Canberra

Professor Mark Harris – Director, Integration SERU, Sydney

Professor Anne Harding - Director, NATSEM, Canberra

Mr Stephen Higgs -Vice President, JDFA, Sydney

Dr Wendy Hoy - Renal Physician, Menzies School of Health Research, Darwin

Mr Roger Hughes - Public Health Division, DH&FS, Canberra

Ms Rebecca James - Adviser to the Federal Minister for Health, Melbourne

Ms Jenny Jefferson - General Practice Branch, DH&FS, Canberra

Dr George Jerums - Austin Hospital, Melbourne

Ms Anne Kemp - Chief Executive Officer, DA-NT, Darwin

Mr Steve Larkin - Chief Executive Officer, NACCHO, Canberra

Ms Tricia Marshall – President, Australian Diabetes Educators Association

Mr Michael Moffatt - State Health Financing, DH&FS, Canberra

Mr Charles McCaskell- Knight, Healthcare Agreements, DH&FS

Ms Naomi Meyers - NACCHO and Redfern Aboriginal Medical Centre, Sydney

Professor Paul Mitchell - Department of Ophthalmology, Westmead Hospital, Sydney

Ms Bronwyn Nicholas - Acting Director, GP Divisions and Grants Program, DH&FS

Professor Dan O’Leary - School of Optometry, University of NSW, Sydney

Dr David Owens - Welsh Retinopathy Project, Cardiff, Wales

Dr Andrew Parkes - Medical Director, Health Insurance Commission, Canberra

Ms Angela Reddy - Benchmarking and Health Services Outcomes, DH&FS, Canberra

Ms Leonie Segal - Health Economist, Monash University, Melbourne

Dr Tim Smythe - Director of Policy, NSW Health Department

Mr Brooke Thorpe – CEO, Diabetes Australia, Canberra

Dr Tarun Weeramanthri - Chronic Diseases Network, Northern Territory Health Services

Professor Judith Whitworth - Chief Health Officer, DH&FS, Canberra

Dr Andrew Wilson - Chief Health Officer, NSW Health Department, Sydney

Professor Dennis Yue - Diabetes Centre, Royal Prince Alfred Hospital, Sydney

Additional advice or information was supplied by

Mr Bernie Ayers - Diabetes Australia National Office, Canberra

Ms Mary-Ann Bonney - Diabetes Network, Integration SERU, UNSW

Ms Kim Brown - Far West Health Services Planning, Broken Hill

Ms Bella Brushin - Centre for Culture Ethnicity and Health, Melbourne

Dr Geoff Byrne - President, Australian Paediatric Endocrine Group

Mr Joe Chakman - Executive Director, Optometrists Association of Australia

Mr Michael Choueifate - FECCA National Office, Canberra

Dr Jeff Flack – Chairperson, NDOQRIN Committee

Ms Dulcie Flowers - Redfern Medical Centre, Sydney

Dr Michael Frommer - NSW Health Department

Dr Bill Jeffries - Secretary, Australian Diabetes in Pregnancy Society

Professor David Lyle - University Department of Rural Health, Broken Hill

Dr Colin Mathers - Australian Institute of Health and Welfare, Canberra

Ms Jayne Mc Greal - Diabetes Centre, Prince of Wales Hospital Sydney

Dr Justin O Day - Ophthalmologist, Melbourne

Ms Alison Petchell - The Australian Podiatry Council

Dr Pat Phillips - The Queen Elizabeth Hospital, South Australia

Ms Linda Primrose - Diabetes Service, Devonport, Tasmania

Professor Martin Silink - The New Childrens Hospital, Sydney

Mr Colin Sindall - National Nutrition Strategy, Deakin University, Victoria

Ms Jeannine Streatfield - OATSIHS, DH&FS, Canberra

Professor Hugh Taylor - Department of Ophthalmology, Melbourne University

A/Professor Bernie Tuch - Prince of Wales Hospital, Sydney

Draft material

Draft material was circulated to the MACOD and MESAG, various sections of the Commonwealth Department of Health and Family Services, the Australian Diabetes Society and the Australian Diabetes Educators Association and other expert clinicians

Specific segments of the document were also circulated to individuals and organisations with expertise in particular areas and aspects of diabetes prevention and care.

Appendix 2 Providers and organisations

Providers and organisations

Medical clinicians most commonly involved in diabetes care

General practitioners

There are 17,711 recognised general practitioners throughout Australia (DH&FS, 1997). The infrastructure provided by Divisions of General Practice (DGP) is increasing the capacity of GPs to enhance and monitor the effectiveness of the care they provide. In 1996, there were 118 Divisions throughout Australia (Young & Liauw, 1996) with 78% of GPs being members of their local Division; 48% were members of the RACGP, and 44% were members of the AMA (Ward & Donnelly 1997). Although it is strongly recommended that type 1 diabetes and GDM are managed under specialist supervision, GPs are the most common entry point into the health system and are the major providers for type 2 diabetes. It is estimated that approximately 80% of all care of diabetes takes place outside specialist services making GPs pivotal to optimising the outcomes of diabetes care.

Endocrinologists/diabetologists

There are approximately 300 endocrinologists practising in Australia either in publicly funded hospital positions, private practice, or a combination of both. A small number of these are trained in paediatric endocrinology. Endocrinologists are concentrated in urban areas with very few practising in the rural sector. All major teaching hospitals in Australia have departments of endocrinology and the medical directors of Diabetes Centres are almost invariably endocrinologists.

Consultant general physicians

Consultant physicians are the major providers of specialist diabetes care in rural Australia as there are very few endocrinologists practising outside of metropolitan areas. ASCPIGM, the professional body for consultant general physicians, oversees the postgraduate training program for consultant general physicians and is an important point of contact for the dissemination of diabetes guidelines and information**.**

Non-medical Clinicians

Diabetes nurse educators

There are approximately 1,000 diabetes educators registered as members of the ADEA (ADEA Secretariat, 1997) with a small number trained in paediatric diabetes care. The majority of diabetes educators are nurses whose practice in the field of diabetes is a specialised extension of their primary role as a nurse. This role includes the provision of diabetes education, clinical care, staff training, health promotion and counselling services. Diabetes educators practice in the full range of health care settings from remote and isolated community care to metropolitan tertiary referral institutions. Depending on the practice context, some diabetes nurse educators may be involved predominantly in teaching self care principles and skills to people with diabetes while others function almost exclusively in a clinical capacity. Diabetes educators have traditionally operated in an unofficial ‘advanced practice’ role with considerable clinical and management responsibilities, particularly in the area of outpatient insulin initiation.

Dietitians

Approximately 2,000 dietitians are registered with the DAA (DAA, 1997). Although the majority of these do not work in dedicated diabetes positions, most dietitians in clinical practice provide at least some of their services to people with diabetes. Diet is the cornerstone of management for all types of diabetes, thus making the input of dietitians into patient education and dietary counselling, staff training, and service planning and evaluation an essential component of diabetes care. Most diabetes services either have a dietitian as part of the team or have referral access to dietitians. However, there is considerable anecdotal evidence supported by examples of long waiting lists, that there are insufficient dietitians available to fill the need for diabetes dietary services.

Podiatrists

There are an estimated 1,660 registered podiatrists in the six States of Australia with the majority practising in the private sector and some working on a sessional basis or similar arrangements in publicly funded health facilities. The involvement of podiatrists experienced in diabetes care is crucial to the prevention and management of foot problems, particularly wound healing and the prevention of foot ulcers and amputation. There is considerable variation per 1,000 population in the number of employed and full time equivalent podiatrists in different States, the lowest being 6.3 (Qld) and the highest 13.2 (Vic) podiatrists per 1,000 people (APodC, 1994). The APodC is the umbrella organisation that links the state-based Podiatry Associations.

Community nurses

Community nurses have an important role in the care of people with diabetes, particularly those with type 2 diabetes and the elderly. In many rural and remote areas they function as diabetes educators although their positions are not designated as such. All community nurses are frequently in contact with people with diabetes and, as primary carers, are often in a position to intervene early in the course of adverse changes in diabetes health status. Community nurses are an important target group for the dissemination and implementation of ‘best practice’ guidelines for diabetes education and management.

Aboriginal health workers

Aboriginal health workers are employed in ACCHs funded through the OATSIHS, and through State funded health services. There is no agreed definition and role delineation for Aboriginal health workers and, except in the Northern Territory, they are not registered by the State/Territory. Consequently, it is difficult to estimate precise numbers but best estimates indicate there may be in the vicinity of 1,000 Aboriginal health workers throughout Australia. In recent times there have been increasing efforts to formalise and standardise training to improve the knowledge and skills base of Aboriginal health workers, making an enhanced clinical role for Aboriginal health workers likely in the future.

Optometrists

There are currently approximately 2,500 optometrists practising in Australia. This is equivalent to one full time optometrist per 9,000 people. The distribution of optometrists throughout the country is similar to the distribution of the population. Many optometrists provide visiting outreach services to remote areas, an activity that is subsidised by the Commonwealth under Section 129A of the Health Insurance Act. Thus optometric services are available to most Australians (OAA, 1998).

Psychologists/Social workers

The inclusion of a psychologist and/or social worker in the diabetes team is desirable to assist with the psychological adjustment necessitated by a diagnosis of diabetes, particularly in children and young adults, and the continuing need for personal motivation and behaviour modification to meet the demands of a diabetes regimen. However, there are few psychologists or social workers employed directly in diabetes care.

Pharmacists

There are approximately 10,500 pharmacists practising in Australia. A small number are employed in publicly funded health facilities with the majority operating in private sector pharmacies which number in the vicinity of 5,000 (PSA, 1997). In addition to their role of dispensing and advising on medications, pharmacists are a useful source of general health information for the public, and for disease specific information for people with health risks and health problems. The potential to increase the role of the pharmacist in health promotion and consumer awareness programs should not be overlooked.

Pharmaceutical companies

Approximately 12 of the pharmaceutical companies operating in Australia market medications, equipment, reagents or other products for diabetes. Many dedicate substantial funding and energy to supporting diabetes care through research, educational, and service development grants, assistance with professional training, and the development of patient and provider educational material. Their potential as a vehicle for supporting the co-ordinated dissemination of uniform guidelines and protocols for diabetes prevention and care is frequently underestimated.

Diabetes specific services

Diabetes services are delivered in a wide variety of settings and may be provided by privately or publicly funded individual health professionals as indicated above. The predominant model for interdisciplinary diabetes care involves ambulatory services usually delivered by hospital based specialist centres. Other types of services include those offered by the DA State Associations, and supplies services such as the NDSS.

Diabetes Centres

Diabetes Centres are discrete units comprising an interdisciplinary team of health professionals dedicated to the provision of clinical and educational services for diabetes. Their role includes patient education and clinical care, health professional support and training, and a quality improvement, research and an evaluation function. Diabetes Centres are found in most major metropolitan teaching hospitals and usually have close liaison with local general practitioners and community health staff under formal or informal shared care arrangements. Diabetes Centres are increasingly referred to as Diabetes Ambulatory Care Centres. Services provided by Diabetes Centres are conducted on an outpatient basis and include individual and group patient education, outpatient insulin stabilisation, complication screening, foot assessment and treatment clinics, and health professional training. Inservice training for hospital staff and the management and education of inpatients with diabetes are also important functions of Diabetes Centres.

National Diabetic Services Scheme

NDSS is a service through which people with diabetes can obtain blood and urine testing reagents, insulin syringes and needles at subsidised prices. It is funded by the Commonwealth through the Pharmaceutical Benefits Branch of the DH&FS and the supplies are distributed by DA through its State Associations.

Diabetes Organisations

A number of diabetes organisations have evolved which share many common goals, although each has a specific area of interest and influence.

The Australian Diabetes Educators Association

ADEA is the professional organisation for diabetes educators and comprises around 1,000 specialist diabetes nurses, dietitians, podiatrists, psychologists, and non-medical academic and research health professionals with an interest in diabetes. Its role is to provide its members with professional support, accredit diabetes specialist nurses and allied health workers, set professional standards and standards for patient care, and advise DA on non-medical aspects of diabetes care and educational material for people with diabetes.

The Australian Diabetes Society

ADS is the professional organisation for medical practitioners and researchers involved in diabetes care. It has approximately 450 members across Australia and is predominantly composed of endocrinologists working in diabetes clinical care and research, and scientists involved in basic diabetes research. ADS membership also includes general physicians, general practitioners, academics and non-medical health professionals with an interest in diabetes. As the initiator of the *National Action Plan for Diabetes to the Year 2000 and Beyond*, ADS has played a major role in raising the profile of diabetes in Australia in recent years. ADS constitutes the medical and scientific section of DA.

The Australian Diabetes in Pregnancy Society

ADIPS advances clinical and scientific knowledge of diabetes in pregnancy and its effect on babies by supporting clinical research, providing a forum for researchers to discuss and organise research, disseminating scientific knowledge and providing comment on issues concerning diabetes in pregnancy. ADIPS is currently formulating expert guidelines for the management of gestational diabetes and educational pamphlets for consumers. ADIPS has approximately 100 members from various medical, nursing and paramedical disciplines.

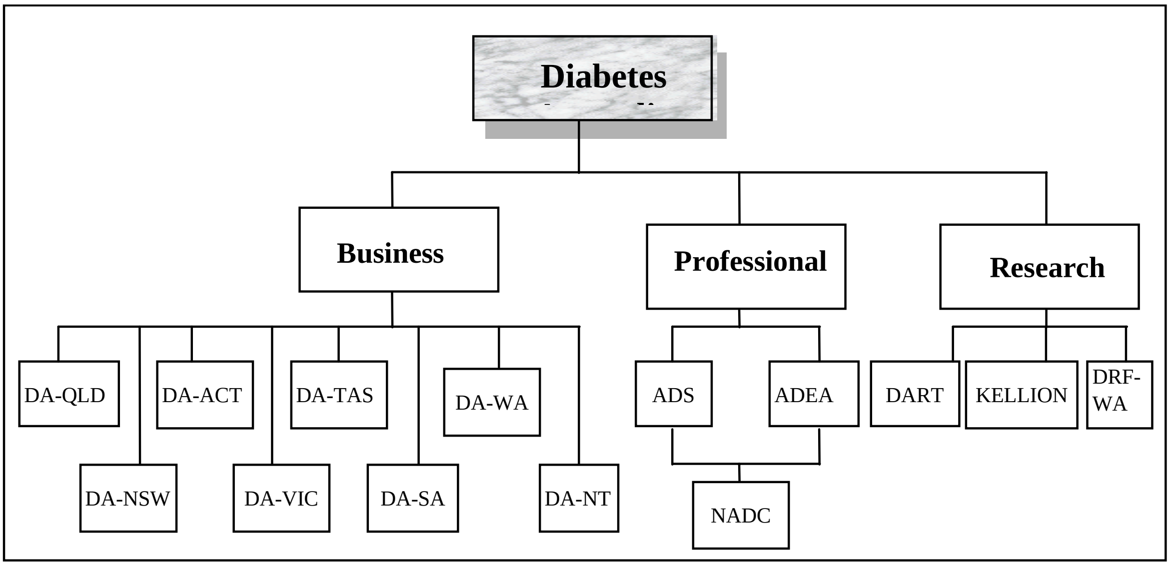
The Australian Paediatric Endocrine Group

APEG is the professional organisation for medical practitioners, primarily paediatric endocrinologists and paediatricians and non medical health professionals involved in the clinical care of children and adolescents with diabetes and endocrine disorders. APEG is actively involved in setting standards of care for children and adolescents with diabetes and its members have a wide range of diabetes related research interests.

Diabetes Australia

Diabetes Australia is a not-for-profit, non-government organisation**.** It is a federation of 12 diabetes organisations (Figure A1) including State and Territory Associations, a professional medical, scientific and educational arm comprising ADS and ADEA, and a research arm comprising the DA Research Trust (DART), the Kellion Foundation and the Diabetes Research Foundation of Western Australia (DRF-WA). DA offers practical assistance to people with diabetes and their carers. Funds are invested in research, health education and support services, advocacy, product provision and public awareness. State and Territory Associations offer a range of services including the supply of products, education and health care materials and support groups. Since 1987, specialised self management products have been supplied to people with diabetes at subsidised prices through the NDSS, which is administered by DA under contract to the Commonwealth Government.

Figure A1: Member Organisations of Diabetes Australia



Juvenile Diabetes Foundation Australia

JDFA is a not-for-profit, non-government organisation specialising in the needs of people with type 1 diabetes, particularly children and adolescents. The major functions of JDFA are advocacy for the rights and needs of people with type 1 diabetes and raising funds to support research. JDFA raises considerable funds for research aimed at preventing and curing type 1 diabetes and is a member organisation of JDF International, the largest private supporter of diabetes research worldwide. JDFA recently entered into a Memorandum of Understanding with the NHMRC to provide $5 million for diabetes research over the next 5 years. JDFA also provides support and advice to people and families with type 1 diabetes both centrally and through a network of local ’chapters’. The community education activities of JDFA concentrate on promoting awareness of the serious nature of type 1 diabetes.

The National Association of Diabetes Centres

The NADC is the umbrella organisation for specialist diabetes services and is jointly administered by the professional associations for diabetes, ADEA and ADS. The NADC provides a forum for peer support and peer review for diabetes services as well as a collective identity to promote networks and lobbying to improve diabetes services and resources. The national body of the NADC is concerned with policy, membership, accreditation, and national programs. The State Sections deal with local implementation issues and service networks, and the provision of specialist support to non-diabetes health professionals. Through its network of 50 interdisciplinary Diabetes Centres and Services across Australia, the NADC provides an ideal mechanism for conducting national programs for data collection, health professional training, specialist outreach services, and clinical research.

Appendix 3

Indicative costing for Priority Recommendations

Priority Recommendation

Implement a National Program to Improve the Quality of Diabetes Care (*Recommendation 40*)

Implementation steps	Responsibility	Completion time	Cost	Funded by
Appoint a National Diabetes Quality of Care Advisory Group	National Diabetes Task Force	3 month	$7,500 (annual cost of supporting Advisory Group	NDS
Develop national guidelines for quality care of people with diabetes	Quality of Care Advisory Group	12 months	$ 30,000	NDS
Dissemination strategy for the guidelines	National Diabetes Task Force and Quality of Care Advisory Group	18 months	$ 10,000	NDS
Program Implementation [full implementation after guidelines developed]	National Diabetes Task Force and Quality of Care Advisory Group	?	?	?

Priority Recommendation

Implement a National Diabetes Visual Impairment Prevention Program (*Recommendation 41*)

Implementation steps	**Responsibility**	**Completion time**	**Cost**	**Funded by**
Appoint a National Diabetic Retinopathy Advisory Group	National Diabetes Task Force	1 month	$7,500 (annual cost of supporting Advisory Group	NDS
Finalise strategic action plan for a State Pilot project	Retinopathy Advisory Group	3 months		NDS
Call for tenders and award contract for the State Pilot project	National Diabetes Task Force and Retinopathy Advisory Group	6 months		
Conduct State Pilot Project	Successful tenderer	18 months	1.5 million	NDS and relevant State or Territory
Evaluation and report	Successful tenderer	24 months	Included in above	

Priority Recommendation

Implement a National Diabetes End Stage Renal Disease Prevention Program (*Recommendation 42*)

Implementation steps	Responsibility	Completion time	Cost	Funded by
Appoint a National Diabetic Renal Disease Advisory Group	National Diabetes Task Force	3 months	$7,500 (annual cost of supporting Advisory Group	NDS
Develop national guidelines for the management of diabetic renal disease	Renal Disease Advisory Group	12 months	$ 30,000	NDS
Dissemination strategy for the guidelines	National Diabetes Task Force and Renal Disease Advisory Group	18 months	$ 10,000	NDS
Program Implementation [full implementation after guidelines developed]	National Diabetes Task Force and Renal Disease Advisory Group	?	?	?

Priority Recommendation

Implement a National Diabetic Foot Disease Management Program

(*Recommendation 43*)

Implementation steps	Responsibility	Completion time	Cost	Funded by
Appoint a National Diabetic Foot Disease Advisory Group	National Diabetes Task Force	3 months	$7,500 (annual cost of supporting the Advisory Group	NDS
Develop national guidelines for the management of diabetic foot disease	Foot Disease Advisory Group	12 months	$ 30,000	NDS
Dissemination strategy for the guidelines	National Diabetes Task Force and Foot Disease Advisory Group	18 months	$ 10,000	NDS
Program Implementation [full implementation after guidelines developed]	National Diabetes Task Force and Foot Disease Advisory Group	?	?	?

Priority Recommendation

Implement a National Diabetes Cardiovascular Disease Prevention Program (*Recommendation 44*)

Implementation steps	**Responsibility**	**Completion time**	**Cost**	**Funded by**
Appoint a National Diabetes Cardiovascular Advisory Group	National Diabetes Task Force	3 months	$7,500 (annual cost of supporting Advisory Group	NDS
Develop national guidelines for the prevention and management of cardiovascular disease in people with diabetes	Diabetes Cardiovascular Advisory Group	12 months	$ 30,000	NDS
Dissemination strategy for the guidelines	National Diabetes Task Force and Cardiovascular Advisory Group	18 months	$ 10,000	NDS
Program Implementation [full implementation after guidelines developed]	National Diabetes Task Force and Cardiovascular Advisory Group	?	?	?

Priority Recommendation

Implement a National Program for the Early Detection of Type 2 Diabetes (*Recommendation 22*)

Implementation steps	Responsibility	Completion time	Cost	Funded by
Appoint a National Diabetes Early Detection Advisory Group	National Diabetes Task Force	3 months	$7,500 (annual cost of supporting Advisory Group	NDS
Develop national guidelines for the early detection of diabetes	Diabetes Early Detection Advisory Group	12 months	$ 30,000	NDS
Dissemination strategy for the guidelines	National Diabetes Task Force and Diabetes Early Detection Advisory Group	18 months	$ 10,000	NDS
Program Implementation Link to type 2 diabetes prevention program	National Diabetes Task Force and Diabetes Early Detection Advisory Group	?	?	?

Best practice priorities

Priority Recommendation

Implement a National Type 2 Diabetes Prevention Program

(*Recommendation 23*)

Implementation steps	Responsibility	Completion time	Cost	Funded by
Appoint a National Diabetes Prevention Advisory Group	National Diabetes Task Force	3 months	$7,500 (annual cost of supporting Advisory Group	
Develop a diabetes prevention strategy	National Diabetes Prevention Advisory Group	6 months		NDS
National Diabetes Awareness Campaign				NDS
• feasibility	Consultants	Completed	$ 37,000	NDS
• market research	Consultants	In progress	$ 145,000	NDS
• awareness campaign [format and extent will depend on outcome of market research ? Initially conduct as pilot project in one State/Territory]	National Diabetes Prevention Advisory Group	Dependent on completion of market research	$ 750,000	NDS
• evaluation	Consultants National Diabetes Prevention Advisory Group	3 months after first campaign	$ 30,000	NDS
Link with national program for the early detection of type 2 diabetes including educational campaign and material for GPs	National Type 2 Diabetes Prevention and Early Detection Advisory Groups	Concurrent with development of prevention strategy	$ 100,000	NDS

Best practice priorities

Priority Recommendation

Develop best practice evidence based guidelines for diabetes prevention and care for health professionals and consumers in collaboration with the NHMRC (*Recommendations 6 and 10*)

Implementation steps	Responsibility	Completion time	Cost	Funded by
Appoint a National Diabetes Consumer Advisory Group	National Diabetes Task Force	3 months	$7,500 (annual cost of supporting Advisory Group	NDS
Develop national consumer guidelines for diabetes care	Diabetes Consumer Advisory Group and NHMRC	12 months	$ 30,000	NDS
Dissemination strategy for the guidelines	National Diabetes Task Force and Diabetes Consumer Advisory Group	18 months	$ 10,000	NDS

Best practice priorities

Priority Recommendation

Optimise the quality and accessibility of diabetes prevention and care for Indigenous Australians (*Recommendation 46-51*)

Implementation steps	Responsibility	Completion time	Cost	Funded by
Strengthen the capacity of Indigenous health services and Aboriginal health workers to provide effective diabetes care and prevention services and monitor the outcomes. This should include:	Indigenous Australians Reference Group to the National Diabetes Advisory Committee			
• examining the clinical utility and cost effectiveness of providing indigenous health services with a DCA 2000 analyser and cartridges to perform near patient HbA_{1c}	OATSIHS, NACCHO, National Diabetes Task Force	12 months	$ 250,000 (50 DCA 2000, ~ 200 cartridges)	
• the provision of equipment for - testing for microalbuminuria (Micral strips, DCA 2000 analyser cartridges) - screening for foot problems	OATSIHS, NACCHO, National Diabetes Task Force	12 months	$ 5,000 Micral strips or $ 70,000 (200 cartridges) $ 3,000 (mono-filaments)	? NDS Medicare cashout ? NDS
• the development and implementation of local plans for: - screening and treatment of diabetic retinopathy and access to equipment required for screening, and local or regional laser therapy - screening of people with diabetes for foot problems - screening pregnant women for undiagnosed diabetes and GDM	Local community	12 months		
• training Aboriginal health workers in diabetes prevention and care and provide appropriate resource materials	OATSIHS, NACCHO, NADC National Diabetes Task Force	12 months	$ 500,000 (travel, workshops & kits)	NDS

Priority Recommendation

Optimise the quality and accessibility of diabetes prevention and care for people of non-English speaking backgrounds (*Recommendations 53-55*)

Implementation steps	Responsibility	Completion time	Cost	Funded by
Appoint a National Reference Group of non-English speaking background Australians	National Diabetes Advisory Committee	3 month		
Translate and distribute national consumer guidelines for diabetes care into major community languages	Reference Group and Diabetes Consumer Advisory Group	12 months	$ 30,000	NDS
Translate NDSS forms into major community languages	Reference Group and DA	12 months	$ 20,000	NDS
Establish and maintain a clearing house and resource directory for teaching materials	Reference Group and DA	18 months	$ 20,000	NDS

Priority Recommendation

Implement a national initiative for the detection and management of Gestational Diabetes and ongoing monitoring of women who have had gestational diabetes (*Recommendations 24 & 27*)

Implementation steps	**Responsibility**	**Completion time**	**Cost**	**Funded by**
Establish a National GDM Advisory Group	National Diabetes Task Force	3 months	$ 7,500 (annual cost of supporting Advisory Group)	NDS
Develop a National Consensus Position on testing for GDM, recommended standards of care and a protocol for the ongoing clinical management of women following a GDM pregnancy	National GDM Advisory Group	15 months	$30,000	NDS
Develop a dissemination strategy and disseminate the guidelines	National GDM Advisory Group	18 months	$10,000	NDS
Call for tenders for a State wide pilot project of a recall system for targeting women with a previous GDM pregnancy for monitoring for development of glucose intolerance	National Diabetes Task Force	3 months		
Conduct the State wide pilot project	Successful tenderer	18 months	$150,000 to $200,000	NDS
Project evaluation	Successful tenderer	24 months		

Best practice priorities

Priority Recommendation

Conduct a national assessment of the needs of children and adolescents with diabetes (*Recommendation 57)*

Implementation steps	Responsibility	Completion time	Cost	Funded by
Appoint a National Committee to conduct the needs assessment	National Diabetes Task Force	3 months		
Conduct a national needs assessment and report back to National Diabetes Task Force	Appointed Committee	9 months	$ 50,000	NDS

Best practice priorities

Priority Recommendation

Hold a National Diabetes Summit to obtain wide endorsement of the *National Diabetes Strategy and Implementation Plan* and develop a consensus position on roles and responsibilities for its implementation (*Recommendation 15)*

Implementation Steps	Responsibility	Completion time	Cost	Funded by
Hold a National Diabetes Summit	National Diabetes Task Force	3 months	$ 75,000	NDS

Coordination priorities

Priority Recommendation

Form a National Diabetes Task Force to oversee the implementation of the *National Diabetes Strategy and Implementation Plan* (*Recommendation 16)*

Implementation steps	**Responsibility**	**Completion time**	**Cost**	**Funded by**
Form a National Diabetes Task Force	Minister, MACOD & Commonwealth DH&FS	1 month		
Convene the Diabetes Advisory Committee and the Commonwealth /State /Territory Diabetes Forum	National Diabetes Task Force	2 months		
Convene the Reference Groups	National Diabetes Task Force	3 months		

Coordination priorities

Priority Recommendation

Coordinate implementation of *the National Diabetes Strategy and Implementation Plan* (*Recommendations 18,19,45,52,39)*

Implementation steps	Responsibility	Completion time	Cost	Funded by
Convene the Advisory Working Parties	National Diabetes Task Force, Diabetes Advisory Committee and the Commonwealth /State /Territory Diabetes Forum	3 months		
Appoint a Medical Director	National Diabetes Task Force	6 months	$ 100,000 per year	NDS
Appoint a National Aboriginal Coordinator for Diabetes and Lifestyle	National Diabetes Task Force and NACCHO	3 months	$ 75,000 per year (salary & travel)	NDS
Appoint a National Coordinator for non-English speaking background communities	National Diabetes Task Force and NESB Reference Group	3 months	$ 75,000 per year (salary & travel)	NDS
Establish a national network for lifestyle related non-communicable diseases	DH&FS NHPA NPHP	6 months		

Information priorities

Priority Recommendation

Conduct a National Diabetes Prevalence Study linked to the National Biomedical Risk Factor Survey (*Recommendation 3)*

Implementation steps	Responsibility	Completion time	Cost	Funded by
Appoint a committee to investigate the feasibility and to oversee the prevalence study	National Diabetes Task Force	1 month	$ 7,500 (annual cost of supporting committee)	NDS
Conduct a feasibility study	National Diabetes Task Force Overseeing Committee	In progress	$ 100,000	NDS
Subject to a favourable report on the feasibility study, call for tenders to conduct a prevalence study	National Diabetes Task Force	9 months		
Conduct prevalence study	Successful tenderer	24 months	$ 1.5 – 2 million	NDS Other interested parties

Information priorities

Priority Recommendation

Establish and maintain systems for the collection and management of information to evaluate the effect of implementing the *National Diabetes Strategy and Implementation Plan* (*Recommendations 2 and 4)*

Implementation steps	Responsibility	Completion time	Cost	Funded by
Establish a National Diabetes Information Advisory Group	National Diabetes Task Force	3 months	$ 7,500 (annual cost of supporting Advisory Group)	NDS
Develop a set of Data Standards for diabetes for incorporation into the National Health Data Dictionary	National Diabetes Information Advisory Group	6 months		
Develop mechanisms to promote record linkage and comprehensive diabetes data collection on diabetes mortality and end stage complications eg cardiovascular disease, amputation, blindness and end stage renal disease	National Diabetes Information Advisory Group	12 months		
Explore ways of nationally co-ordinating and pooling diabetes data collection initiatives currently being undertaken and planned for the future	National Diabetes Information Advisory Group and National Diabetes Task Force	12 months		
Establish a diabetes data information clearing house to facilitate access to diabetes data information for consumers, providers and planners	National Diabetes Information Advisory Group and National Diabetes Task Force	12 months	$ 100,000	NDS

Priority Recommendations

Explore mechanisms to link funding with performance indicators relevant to access, process and outcomes of diabetes care and develop and implement mechanisms to reward and reinforce effective practice (*Recommendations 36 and 37)*

Establish a Working Party to explore opportunities to enhance funding for implementation of the recommendations of the *National Diabetes Strategy and Implementation Plan* (*Recommendation 35)*

Implementation steps	Responsibility	Completion time	Cost	Funded by
Establish a Working Party to explore these opportunities with relevant sections of the DH&FS	National Diabetes Task Force	3 months	$7,500 (annual cost of supporting Advisory Group	NDS
Prepare a report for the National Diabetes Task Force	Working Party	12 months		

Research priorities

Priority Recommendations

Convene a National Diabetes Research Working Party with equal representation of the various research disciplines, and consumer representation to work with the NHMRC Strategic Research Committee to develop a prioritised research agenda for diabetes which covers all aspects of diabetes across the continuum of care (*Recommendations 32 and 33)*

Increase NHMRC research funding for diabetes to reflect its status as a National Health Priority Area (*Recommendation 31)*

Implementation steps	**Responsibility**	**Completion time**	**Cost**	**Funded by**
Convene a National Diabetes Research Working Party	National Diabetes Task Force	3 months	$7,500 (annual cost of supporting Advisory Group	NDS
Commission the NHMRC Strategic Research Committee to work with the National Diabetes Research Working Party to prepare a prioritised research agenda for diabetes	National Diabetes Task Force	3 months		
Prepare a prioritised research agenda for diabetes	NHMRC Strategic Research Committee & National Diabetes Research Working Party	6 months	$ 50,000	NDS
Liaise with NHMRC	National Diabetes Task Force	12 months	?	?

Appendix 4 Implementation indicators

Section 3: Information

	Recommendations	Indicator	Timeframe
1	Establish the National Diabetes Register for people with insulin treated diabetes and consider expanding it into a comprehensive National Diabetes Register.	• National Diabetes Register operational • Feasibility report on expansion into a comprehensive register	• 6 months • 1 year
2	Establish a National Diabetes Information Advisory Group with representation of the NDR, NHPC, NDOQRIN, AIHW and ABS to:	• Diabetes Information Advisory Group established	• 3 months
	• develop a set of Data Standards for diabetes for incorporation into the National Health Data Dictionary	• National data standards for diabetes developed • Incorporation into National Health Data Dictionary	• 6 months • 1 year
	• develop mechanisms to promote record linkage to ensure that accurate and comprehensive diabetes data are collected on diabetes mortality and end stage complications ie cardiovascular disease, amputation, blindness and end stage renal disease	• Report on record linkage opportunities	• 1 year
	• explore ways of nationally co-ordinating and pooling diabetes data collection initiatives currently being undertaken and planned for the future	• Report on mechanisms for national coordinating and pooling diabetes data	• 1 year
	• establish a diabetes data information clearing house to facilitate access to diabetes data information for consumers, providers and planners	• Diabetes data information clearing house established	• 1 year
3	Conduct a National Diabetes Prevalence Study linked to the National Biomedical Risk Factor Survey	• Feasibility study performed • Survey completed	• 9 months • 2 years
4	Monitor quality of care processes and outcomes through:		
	• collection of annual cross sectional clinical outcomes information using the NDOQRIN minimum dataset through Divisions of General Practice, the NADC and the National Diabetes Register	• National data collection by NADC and DGP	• 1 year
	• the Health Insurance Commission utilising Medicare item numbers for HbA1c, lipids, microalbuminuria, and retinal screening	• HIC Report on diabetes related data	• 1 year
5	Develop models for utilising diabetes data to provide information about the cost of diabetes and cost effectiveness of specific interventions	• Costing model for diabetes developed	• 1 year

Section 3: Consumer, provider, and public awareness

	Recommendations	Indicator	Timeframe
6	The National Diabetes Task Force to oversee in collaboration with DA, JDFA, the National Diabetes Advisory Committee Consumer Reference Group, and NHMRC, the development of: • evidence based diabetes guidelines for consumers, or the adaptation of the NSW Health Department Consumer Guidelines, for national application • a dissemination strategy which takes account of existing mechanisms and networks such as the NDSS distribution, local pharmacies, and diabetes educational literature and product information prepared by pharmaceutical companies	• NHMRC Evidence based diabetes consumer guidelines • A consumer guidelines dissemination strategy	• 1 year • 18 months
7	DA to establish a formal mechanism for consumer advocacy, and the handling of complaints, which includes appointing appropriately trained consumer advocates and complaints officers to the National Office and each State and Territory Association	• Adoption of documented formal consumer advocacy and complaints mechanisms by DA	• 1 year
8	The National Diabetes Task Force to approach undergraduate medical, nursing, and allied health schools across Australia, and the RACGP Training Program, to include core standardised information on diabetes which: • clearly differentiates between type 1 diabetes and type 2 diabetes • emphasises the serious consequences of undetected or poorly controlled diabetes • highlights risk factors, symptoms and diagnostic criteria, and management principles for type 1 diabetes, type 2 diabetes and GDM	• Development of standardised diabetes information • Negotiations with Undergraduate schools and RACGP about adoption into teaching and training programs	• 1 year • 2 years
9	Introduce cultural sensitivity training into undergraduate medical, nursing, dietetics, podiatry, and social work courses, and continuing education programs for GPs	• Cultural sensitivity package developed • Package distributed to relevant organisations	• 1 year • 2 years
10	Identify effective methods of raising consumer awareness of diabetes and evaluate the role of consumers in influencing providers to implement evidence based diabetes clinical practice	• Evaluation report	• 18 months
11	Conduct a National Community Awareness Program on Diabetes linked to the programs for the prevention and early detection of type 2 diabetes	• A National Community Awareness Program conducted	• 1 year

Section 3: Best practice

	Recommendations	Indicator	Timeframe
12	Develop, in collaboration with the NHMRC, best practice evidence based clinical management guidelines for each of the prevention and care programs detailed in the *National Diabetes Strategy and Implementation Plan*. for implementation through a structured dissemination process which includes undergraduate and relevant postgraduate training program for medical, nursing and allied health workers throughout Australia.	• Working Parties established to formulate guidelines in conjunction with NHMRC • Guidelines developed	• 6 months • 1 year
13	Develop and implement incentives for providers to apply the recommended standards of diabetes care	• Strategies document and implementation plan	• 1 year
14	Provide incentives for consumers to access recommended standards of care eg discounted self care supplies for demonstrating participation in annual complications screening	• Strategies document and implementation plan	• 1 year

Section 3: Coordination

	Recommendations	Indicator	Timeframe
15	Hold a National Diabetes Summit to obtain wide endorsement of the *National Diabetes Strategy and Implementation Plan* and develop a consensus position on roles and responsibilities for its implementation	• National Diabetes Summit held	• 3 months
16	Form a National Diabetes Task Force to oversee the implementation of the *National Diabetes Strategy and Implementation Plan*	• National Diabetes Taskforce formed	• 1 month
17	Establish the following Reference Groups to represent key stakeholders on the National Diabetes Advisory Committee – Indigenous Australians, non-English Speaking Background Australians, Consumer, Childhood and Adolescent, Medical and Scientific, Education, and General Practice	• Reference Groups established	• 3 months
18	Establish National Advisory Working Parties to address each of the programs detailed in the *National Diabetes Strategy and Implementation Plan*	• Working Parties established	• 3 months
19	Appoint a *National Diabetes Strategy and Implementation Plan* Medical Director	• A national Medical Director appointed	• 6 months

Section 4: Type 1 diabetes

	Recommendations	Indicator	Timeframe
20	Establish a national infrastructure to support and conduct studies aimed at preventing type 1 diabetes	• A National Advisory Group on Prevention of Type 1 Diabetes appointed • A strategic plan developed	• 6 months • 1 year
21	Establish a national infrastructure to support and conduct studies aimed at curing type 1 diabetes	• An Australian Pancreas Transplant Advisory Group appointed • A strategic plan developed	• 6 months • 1 year

Section 4: Type 2 diabetes

	Recommendations	Indicator	Timeframe
22	Implement a National Program for the Early Detection of Type 2 Diabetes linked to the Type 2 Diabetes Prevention Program and the Program to Improve the Quality of Diabetes Care	• A National Diabetes early Detection Advisory Group appointed • National guidelines developed • Dissemination and evaluation strategies developed	• 3 months • 1 year • 1 year
23	Implement a National Type 2 Diabetes Prevention Program linked to the National Early Detection of Type 2 Diabetes.	• A National Diabetes Prevention Advisory Group appointed • National guidelines developed • Dissemination and evaluation strategies developed	• 3 months • 1 year • 1 year

Section 4: Gestational diabetes

	Recommendations	Indicator	Timeframe
24	Establish a National GDM Advisory Committee to develop a National Consensus Position on testing for GDM, and develop and disseminate recommended standards of care and a protocol for the ongoing clinical management of women following a GDM pregnancy	• A national GDM Advisory Group appointed • National guidelines developed • Dissemination and evaluation strategies developed	• 3 months • 15 months • 18 months
25	Develop a national standardised midwives minimum data set to collect data on GDM	• A national standardised midwives minimum dataset produced	• 1 year
26	Expand the National Diabetes Register to include women with a GDM pregnancy	• GDM included in National Diabetes Register	• 2 years
27	Develop a recall system for targeting women with a GDM pregnancy for ongoing lifestyle advice and monitoring for the future development of glucose intolerance	• A GDM recall system developed • Statewide recall system piloted and evaluated	• 3 months • 2 years

Section 4: Pregnancy in women with pre-existing diabetes

	Recommendations	Indicator	Timeframe
28	Develop national guidelines on the management of pregnant women with pre-existing diabetes	• National guidelines developed	• 1 year
29	Ensure that diabetic women of child bearing age have access to pre-pregnancy counselling and optimised diabetes control prior to conception	• Consumer and provider awareness campaign	• 1 year
30	Monitor the outcomes of pregnancies in women with pre-existing diabetes through the National Diabetes Register	• Information on pregnancy in women with pre-existing insulin treated diabetes collected through National Diabetes Register	• 1 year

Section 4: Research

	Recommendations	Indicator	Timeframe
31	Increase NHMRC research funding for diabetes to reflect its status as a National Health Priority Area	• NHMRC funding for diabetes similar to that of other National Health Priority Areas	• 2 years
32	Convene a National Diabetes Research Working Party with equal representation of the various research disciplines, and consumer representation	• A National Diabetes Research Working Party established	• 3 months
33	Commission the NHMRC Strategic Research Committee to work with the National Diabetes Research Working Party to develop a prioritised research agenda for diabetes which covers all aspects of the continuum of care	• A prioritised research agenda for diabetes	• 6 months
34	Use the agreed research agenda to direct diabetes research funding from government and non government sources and evaluate and review the research agenda every 5 years	• NHMRC funding linked to prioritised research agenda	• 2 years

Section 4: Health system

	Recommendations	Indicator	Timeframe
35	Establish a Working Party to explore opportunities to enhance funding for implementation of the recommendations of the *National Diabetes Strategy and Implementation Plan*	• Working Party established	• 6 months
36	Explore mechanisms to link funding with performance indicators relevant to access, process and outcomes of diabetes care eg, contracts with State, Territory, and regional health services should include a requirement to provide services which offer the recommended processes of diabetes care and meet agreed diabetes outcome indicators	• Strategic Report on mechanisms to link funding to performance indicators	• 1 year
37	Develop and implement mechanisms to reward and reinforce effective practice through financial incentives and professional and organisational accreditation programs	• Strategic Report on mechanisms to reward effective practice	• 1 year
38	Explore mechanisms to provide incentives to increase consumer participation in best practice	• Strategic Report on consumer incentives	• 1 year
39	Establish a national network of lifestyle related non communicable diseases and prevention programs	• National lifestyle related non communicable disease network established	• 1 year

Section 5: Priority programs

	Recommendations	Indicator	Timeframe
40	Implement a National Program to Improve the Quality of Diabetes Care	• A National Diabetes Quality of Care Advisory Group established • National guidelines developed • Strategic plan developed	• 3 months • 1 year • 1 year
41	Implement a National Diabetes Visual Impairment Prevention Program	• A National Diabetic Retinopathy Advisory Group established • A Strategic Plan developed • Strategic plan piloted and evaluated in one State	• 3 months • 6 months • 3 years
42	Implement a National Diabetes End Stage Renal Disease Prevention Program	• A National Advisory Committee on Diabetic Renal Disease established • National guidelines developed • Strategic plan developed	• 3 months • 1 year • 1 year
43	Implement a National Diabetic Foot Disease Management Program	• A National Diabetic Foot Disease Advisory Group established • National guidelines developed • Strategic plan developed	• 3 months • 1 year • 1 year
44	Implement a national Diabetes Cardiovascular Disease Prevention Program	• A National Diabetes Cardiovascular Advisory Group established • National guidelines developed • Strategic plan developed	• 3 months • 1 year • 1 year
	Implement a National Program for the Early Detection of Type 2 Diabetes linked to the National Type 2 Diabetes Prevention Program and the Program to Improve the Quality of Diabetes Care	• (See Recommendation 22)	
	Implement a National Type 2 Diabetes Prevention Program linked to the National Early Detection of Type 2 Diabetes Program.	• (See Recommendation 23)	

Section 6: Indigenous Australians

	Recommendations	Indicator	Timeframe
45	• Establish and fund a position for a National Aboriginal Co-ordinator for diabetes and Lifestyle Diseases to work closely with the National Diabetes Strategy Secretariat and Working Groups, and Indigenous communities and organisations to implement the recommendations of the *National Diabetes Strategy and Implementation Plan* for Indigenous Australians.	• A National Coordinator appointed	• 3 months
46	Strengthen the capacity of Indigenous health services and Aboriginal health workers to provide effective diabetes care and prevention services and monitor the outcomes. This should include:		
	• examining the clinical utility and cost effectiveness of providing Indigenous health services with a DCA 2000 analyser and cartridges to perform near patient HbA_{1c} measurement	• Pilot and evaluate a use of DCA 2000 analysers in IHSs	• 1 year
	• the provision of equipment for - testing for microalbuminuria (Micral strips, DCA 2000 analyser) - screening for foot problems	• A Strategic Report on provision and funding of equipment	• 1 year
	• the development and implementation of local plans for: - screening and treatment of diabetic retinopathy and access to equipment required for screening, and local or regional laser therapy - screening of people with diabetes for foot problems - screening pregnant women for undiagnosed diabetes and GDM	• Local plans developed	• 1 year
	• training Aboriginal health workers in diabetes prevention and care and providing them with appropriate resource materials	• Training programs and resource materials for AHWs	• 1 year
47	Conduct periodic general health checks to identify a range of disorders, including diabetes and associated health problems (eg overweight, hypertension, microalbuminuria and hyperlipidaemia) every 1-2 years from age 18	• Local protocols and screening programs	• 1 year
48	Improve access to medications and supplies provided under the Pharmaceutical Benefits Scheme and the NDSS for rural and remote Indigenous communities	• Improved NDSS and PBS access	• 1 year
49	Reduce structural and environmental impediments in the food distribution system to increase access to healthy and affordable food. Addressing problems in food distribution should be undertaken in collaboration with the National Public Health Nutrition Strategy	• Strategic plans developed	• 2 years

Section 6: Indigenous Australians (cont)

50	Increase levels of physical activity through the provision of recreational facilities, sports and other activities that are community based. Planning and implementation of initiatives to address this recommendation should be linked with the Active Australia campaign	• Strategic plans developed	• 2 years
51	Establish principles regarding the choice of treatment of end stage renal disease for Indigenous peoples and improve the provision and access to dialysis and transplantation	• Protocol and guidelines developed	• 1 year

Section 6: People from Non-English Speaking Backgrounds

	Recommendations	Indicator	Timeframe
52	Establish and fund a position for a National NESB Diabetes Coordinator to work closely with the National Diabetes Strategy Secretariat and Working Groups, and NESB communities to implement the recommendations of the *National Diabetes Strategy and Implementation Plan* for people from non-English speaking backgrounds.	• A National Coordinator appointed	• 3 months
53	Disseminate information about the current recommendations for diabetes clinical care and self care in community languages eg: • translate into the major community languages the ‘best practice’ consumer diabetes guidelines developed under the *National Diabetes Strategy and Implementation Plan* • advertise diabetes clinical care and self care recommendations through community language newspapers nationally	• Consumer guidelines in major community languages • Community advertisements	• 2 years • 1 year
54	Diabetes Australia to print the National Diabetic Services Scheme forms in the major community languages	• NDSS forms printed in major community languages	• 1 year
55	Establish and maintain a clearing house and resource directory of teaching materials and other resources for the care of non-English speaking people with diabetes. Diabetes Australia would be an appropriate organisation to operate this service	• A clearing house established	• 18 months

Section 6: People Living in Rural and Remote Australia

	Recommendations	Indicator	Timeframe
56	Regional Health Services to develop local strategies to implement the *National Diabetes Strategy and Implementation Plan* including: • coordination of regional activities to prevent fragmented service delivery • ensuring access of people with diabetes living in rural and remote areas to support services similar to those available to their urban counterparts • collection of local diabetes information • provision of training programs for local health professionals • development of partnerships between local clinicians and major specialist centres	• Regional Strategic Plan developed	• 1 year

Section 6: Children and adolescents

	Recommendations	Indicator	Timeframe
57	Conduct a national assessment of the needs of children and adolescents with diabetes	• A national needs assessment conducted	• 9 months
58	Develop specific guidelines and protocols on the clinical care, monitoring, and complication screening and treatment for children and adolescents with type 1 diabetes. This should include recommendations for transition from paediatric to adult services and protocols for diabetes management in children attending school	• Guidelines developed	• 1 year
59	Conduct regular collection and national pooling of glycaemic control and complications data on children and adolescents with diabetes every 5 years using standardised data sets	• Collection of national data on children and adolescents	• 1 year
60	Ensure that diabetes care for children and adolescents with type 1 diabetes is provided by a specialist team with expertise in the management of children with type 1 diabetes	• Strategic Plan for the provision of specialist diabetes care for children with type 1 diabetes	• 1 year
61	Focus research efforts on: • the prevention and cure of type 1 diabetes • prevention and reduction of complications of diabetes • reducing the impact of diabetes on quality of life • developing non-invasive blood glucose monitoring technology • improving monitoring to detect and prevent severe hypoglycaemia	• Strategic Plan for addressing research priorities	• 1 year

Section 6: The elderly

	Recommendations	Indicator	Timeframe
62	Implement strategies to improve the quality of care of elderly people with diabetes admitted to hospital and who reside in aged care facilities or hostels	• Strategic Plan developed	• 1 year

Appendix 5 Glossary of terms

Glossary of terms

Australian Health Ministers' Advisory Council (AHMAC)	A group comprising heads of Commonwealth, State and Territory government health departments which provides advice to Australian Health Ministers
Best Practice	In the health sector this means the highest standards of performance in delivering safe, high quality care, as determined on the basis of available evidence and by comparison among health care providers.
Certification	A process usually carried out by a professional body that certifies a practitioner as qualified to practice in certain ways. It is usually based on the training and experience of the practitioner and his or her satisfactory performance at examinations set by the professional body.
Clinical Guidelines	Systematically developed statements to assist providers and users of health services to make decisions about appropriate health care for specific circumstances.
Clinical Protocols	Practice guides designed to assist health practitioners make optimal decisions about health care interventions for specific circumstances. Protocols may take the form of algorithms, which set out, in sequential form, particular treatment choices for particular circumstances.
Clinician	A practising health professional who provides clinical services
Consumer	A person who uses the health care system. For the purpose of this document the term 'consumer', should be taken to mean a person with diabetes who uses the health care system.
Co-ordinated Care	A system of co-ordination of care of patients between different health programs or sectors of the health system usually with the assistance of designated care coordinators or managers.
Diabetes Centre	A Diabetes Centre has been defined by ADS and ADEA as a 'discrete unit comprising an interdisciplinary team of health professionals dedicated to the provision of clinical and educational services for people with diabetes'.
Equity	Equity is concerned with creating equal opportunities for access to health and health care, which means improving opportunities especially of the most disadvantaged. It seeks to reduce or eliminate those differences that arise from factors which are avoidable and unfair.
Evidence based	Based on a systematic review of the results of peer reviewed publications classified according to the rigour of the research methods used.
Goal	A goal is a general statement of intent and aspiration. A goal describes outcomes which might reasonably be achieved in the light of current knowledge and resources. Goals apply to the broad population. Priority populations can be identified when it is clear that different strategies are required for the priority group than for the population as a whole.
Health Intervention	A health intervention is a program, service or activity which is carried out to improve or maintain health, health behaviours or other factors associated with health.
Health Outcome	A health outcome is a change in the health of individuals, groups of individuals or populations, as a result of a variety of factors such as health services, health promotion programs, ageing, the environment, lifestyle factors or programs unrelated to health.
Healthcare	Agreements between the Commonwealth Government and State and Territory

Agreements	Governments, under which the Commonwealth provides financial assistance to the States and Territories to help them to provide universal hospital coverage for eligible Australians.
Indicator	A health indicator is unit of information that reflects, directly or indirectly, the performance of an intervention or health service
Outreach Service	Outreach service has been defined by the NSW and ACT Section of the NADC as one where the Specialist Diabetes Centre staff visits a rural or remote location to provide clinical and educational services with sufficient frequency to influence the health status of the target population. An outreach service may also entail the provision of training and support to local health professionals by the specialist service
Peer Review	Review of the work practices of a person or tem of people, by a person or team with equivalent standing and qualifications
Provider	An individual health practitioner or an institution which provides health services
Quality of Care	The term quality of care includes efficiency, effectiveness, accessibility, patient satisfaction, appropriateness of care and patient safety
Smart Card	Also known as "patient smart card". A portable electronic record of a patient's medical history, which may be protected by a personal identification number (PIN) or password.
Strategy	A strategy outlines a broad approach. Strategies cover a wide range of desired actions and changes including structural, medical, educational, organisational, economic and technological.
Target	A target is specific and measurable. In most cases, a health gain target states the amount of change in health gain that could reasonably be expected for a given population within a given time frame. Health gain includes mortality, quality of life, disability, disease states and other significant health states such as risk factors. Targets focus on populations, rather than individuals.