



Australian Health Ministers' Conference

**National Service
Improvement
Framework for
Diabetes**

DIABETES

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PREAMBLE: National Service Improvement Frameworks

BACKGROUND

In October 2002, the Australian Health Ministers' Advisory Council agreed to the development of National Service Improvement Frameworks for the national health priority chronic conditions of diabetes, asthma, cardiovascular disease, and arthritis and musculoskeletal conditions, under the auspices of the National Health Priority Action Council. The Council's purpose is to drive health service improvements to achieve better health outcomes for all Australians with these conditions, especially disadvantaged groups.

The frameworks are joint initiatives of the Australian and state and territory governments, and form an integral component of the broader National Chronic Disease Strategy. The frameworks draw upon the expertise of a range of stakeholder groups including leading clinicians, national, state and territory policy makers, consumers and members of non-government and other health organisations.

Each disease specific framework complements the Strategy and forms part of a national approach for improving health services for chronic disease prevention and care. The Strategy is an umbrella strategy supporting a consistent and effective approach for all non-communicable chronic diseases.

Aims of the National Service Improvement Frameworks

The frameworks aim to encourage the delivery of more person centred, equitable, timely, effective, affordable and cohesive health care for all Australians. In particular, in reference to the national health priority area chronic conditions, the frameworks are intended to:

- prevent and limit the progression of these chronic conditions
- slow the onset of the complications that can cause severe disabilities and be life threatening
- reduce preventable hospital admissions
- address inequity by reducing variations in care that appear
 - across different clinicians and health services
 - across people from metropolitan, regional, rural and remote areas
 - in the care and services provided to disadvantaged groups, in particular Aboriginal and Torres Strait Islander peoples.

Principles Guiding the National Service Improvement Frameworks

In identifying the health service needs of the Australian community, the NSIFs:

- adopt a population health approach
- prioritise health promotion and illness prevention

- achieve person centred care and optimise self-management
- provide the most effective care
- facilitate coordinated and integrated multidisciplinary care across services, settings and sectors
- achieve significant and sustainable change
- ensure that progress is monitored
- locate people, families and communities affected by chronic disease at the centre of care
- span both the continuum of care and the life course for the condition and embrace, where necessary, prevention, diagnosis, treatment, rehabilitation, living with the condition, and palliation
- span different clinical and community settings
- acknowledge that many chronic diseases share risk factors (e.g. nutrition, obesity and physical activity)
- support and encourage the application of evidence-based practice
- focus on the need for disadvantaged, special population groups and Aboriginal and Torres Strait Islander people, in particular, to have access to appropriate health services—these groups include: people with mental disorders; the frail elderly; people with disabilities; people who are socioeconomically disadvantaged; people in regional, rural and remote communities; people from culturally and linguistically diverse communities
- acknowledge carers and families affected by chronic disease as being part of the broader experience of these conditions.

Key Deliverables of the National Service Improvement Frameworks

The NSIFs identify ‘critical intervention points’, namely, points along the continuum of care where opportunities exist to make significant health gains and improve services.

These points are identified through an analysis of the:

- needs of the well community for information about and opportunities to engage in preventive activity for a specific chronic disease
- preventive actions
- needs of people with a specific chronic disease
- optimal system or service responses to these needs
- gaps between the optimal system or service responses and what currently happens; opportunities for gains in health outcomes and improvement at the system level for each of the gaps.

Implementation of the National Service Improvement Frameworks

The NSIFs will serve as high level guides to inform:

- consumers
- health care workers
- planners and designers
- policy makers, funders and providers
- professionals and managers.

The frameworks recognise that the provision of high quality health services is complex, as health care is a responsibility shared between the Australian, state and territory governments, and public, private and non-government organisations, and consumers themselves. States and territories have their distinctive arrangements and programs to deliver care to their communities, including a range of local service plans, service frameworks and strategies. As such, the frameworks do not prescribe what health services should look like at the local level, but rather seek to support and complement the broad range of national, state, territory and local initiatives already established or in progress to facilitate the delivery of optimal services (including the national tobacco, alcohol, nutrition and physical activity strategies).

Neither are the frameworks intended to replace existing clinical practice guidelines and pathways, and processes of accreditation, clinical audit and benchmarking approaches. On the contrary, they are provided to further encourage the adoption of activities, practices and processes that will translate evidence into practice. They state what needs to happen to achieve optimal care, but are not implementation plans or guides as to how to achieve this change. Separate implementation plans will be need to be developed in consultation with relevant stakeholders.

CHAPTER 1: National Service Improvement Framework for Diabetes

CONTEXT FOR THE FRAMEWORK

Prevalence of Diabetes

Diabetes is a chronic and potentially disabling medical condition affecting millions of people worldwide. In Australia, diabetes rates among the top six leading causes of death, accounting for 2.5% of all deaths in 2002.^{1*} The AusDiab study showed that 7.5% of the population has the disease (approximately 940 000), with prevalence estimates ranging from 0.3% in the 25–34 year age group to 23.6% in people over 75 years of age.²

There is good evidence of a dramatic increase in the prevalence of diabetes in Australia.² As the Australian population ages, diabetes (along with other chronic conditions such as arthritis, asthma, and heart disease) will affect more lives than ever before. In fact, the number of people with diabetes is expected to double by 2010, making primary prevention of diabetes a national priority.² Obesity is linked strongly to Type 2 diabetes and is also a risk factor for other chronic conditions such as hypertension, cardiovascular disease and arthritis. Furthermore, obesity is increasing rapidly in prevalence, particularly in children and young people.

In people with established diabetes, secondary prevention of the long term, debilitating complications of diabetes, including heart, eye, kidney disease and nerve damage, is also necessary to reduce mortality and optimise the quality of life of people with the disease.

Diabetes in Aboriginal and Torres Strait Islander People

In Aboriginal and Torres Strait Islander peoples, the reported prevalence of diabetes is two to four times higher than in the non-Indigenous population. After adjusting for age, Aboriginal and Torres Strait Islander peoples are almost four times more likely than their non-Indigenous counterparts^{3,4} to develop diabetes. Pacific Islanders, people of Chinese descent and those from the Indian Subcontinent are also more likely than other Australians to have diabetes, in particular Type 2 diabetes.⁵

All health services, whether private or government, or providing primary, secondary or tertiary care, rehabilitation, or counselling, have a responsibility to ensure they provide effective and appropriate services to Aboriginal and Torres Strait Islander people. These services should be provided in accordance with the Australian Health Ministers' Advisory Council's Aboriginal and Torres Strait Islander Cultural Respect Framework. In addition, addressing the needs of Aboriginal and Torres Strait Islander people should be incorporated at all levels of health policy development and implementation.

The life expectancy of Aboriginal and Torres Strait Islander people is 17 years less than that of other Australians. Aboriginal and Torres Strait Islander people have higher

* This is generally considered to be an underestimate due to methods of reporting

rates of disease in almost every disease category and in every age group. Factors which contribute to continued poor health in Aboriginal and Torres Strait Islander peoples include socioeconomic disadvantage; social, political and environmental factors, specific health risk factors and lack of access to health care. Aboriginal and Torres Strait Islander people use public hospital services more and private health care services less than other Australians. Barriers to health care access include affordability, distance, access to transport, availability of health professionals and cultural appropriateness and acceptability of services.

Aboriginal and Torres Strait Islander people access all parts of the health system and all types of services across the continuum of care. It is therefore important that all aspects of these services and all policies which affect these services consider any barriers (e.g. physical, economic, cultural or other) which may limit equitable access for Aboriginal and Torres Strait Islander people. Health service providers should consider the development of effective data systems that enable monitoring and improvement of both accessibility and effectiveness of health care provided to Aboriginal and Torres Strait Islander Australians.

Diabetes in Australia—National Action

In recent years, the significant personal, social and economic costs of diabetes have been well recognised, and Australian, state and territory governments have been working together to identify ways to prevent and manage the disease.

In 1996, diabetes became the fifth National Health Priority Action (NHPA) area. The NHPA initiative provides a focal point for national attention and effort on health conditions that cause the greatest burden and where the greatest health gains can be achieved. Subsequently, a set of priority indicators covering prevention, screening and early intervention, treatment and management of the condition was developed.⁶

Following the inclusion of diabetes in the NHPA initiative, the Australian, State and Territory Governments agreed to the National Diabetes Strategy 2000–2004.⁷ The strategy covers diabetes prevention and management, helping governments and service providers to identify key areas for action to improve the health of Australians with, or at risk of, diabetes. Specifically, it aims to:

- ensure appropriate attention is given to primary prevention, including risk reduction, effective high quality management of diabetes and research
- establish an effective partnership between governments, health care professionals, non-government organisations, consumers and carers
- build on experience and successes to date.

Furthermore, as part of the 2001–02 Australian Government Budget, the Government announced funding of \$43.4 million over four years to ensure a national approach to improving the prevention, earlier diagnosis, and management of people with diabetes. This resulted in the establishment of the National Integrated Diabetes Program (NIDP), consisting of four components that:

- provide incentives for general practice to achieve earlier diagnosis and best practice management of people with diabetes
- provide infrastructure and support for Divisions of General Practice to work with general practitioners and other health professionals to remove barriers to better care for people with diabetes
- engage consumers with diabetes to enable appropriate self-care and support partnerships with health professionals
- support changes in the practices of health professionals.

Research into Prevention of Type 1 Diabetes

Research is currently underway to investigate ways to prevent Type 1 diabetes. One example is the project jointly managed by the National Health and Medical Research Council (NHMRC) and the Juvenile Diabetes Research Foundation which has seen the formation of the Diabetes Vaccine Development Centre. At present, this Centre is assessing studies directed toward candidate vaccines. The Australian Government has recently committed \$30 million over four years for the establishment of an islet cell transplantation program in Australia to find a cure for Type 1 diabetes. The aim of the program will be to refine the clinical procedure of islet cell transplantations and to carry out supporting research into the transplant therapy, associated health outcomes, and the effectiveness of this procedure. There are also various programs aimed at reducing the complications of Type 1 diabetes including education campaigns and diet counselling.

Prevention and Management of Type 2 Diabetes

Many of the Australian, state and territory programs are intended to help prevent the growing prevalence of Type 2 diabetes, and to build awareness of the complications associated with all types of diabetes. Some of the specific prevention initiatives in Australia which address lifestyle risk factors include: Acting on Australia's Weight, Eat Well Australia, and the Active Australia campaign.

A consortium led by Diabetes Australia is well advanced in the preparation of national evidence-based guidelines for Type 2 diabetes. The NHMRC have endorsed six of these, targeting:

- primary prevention
- case detection and diagnosis
- management of lipid abnormalities
- diagnosis and management of hypertension
- identification and management of foot disease
- prevention and detection of macrovascular disease.

Further, guidelines for management of Type 1 diabetes in children and adolescents have been prepared by the Australasian Paediatric Endocrine Group (APEG), guidelines for blood glucose control are progressing, and guidelines for retinopathy are under review. Work to develop guidelines for patient education is yet to commence.

Cost of Diabetes

Diabetes is a burden both financially and socially for individuals with diabetes, their families and carers, and the community as a whole.

In 1993–94, the direct health system cost of diabetes was estimated to be \$372 million.⁸ Type 1 diabetes was estimated to account for 42% of the cost despite only 10–15% of people having this type of diabetes. When the complications of diabetes were taken into account, the total direct health system costs were estimated to be around \$681 million in 1993–94.⁸ The cost of diabetes in 1995 was estimated to be \$561 million by McCarty et al 1996⁹, producing a similar figure for the direct costs. The authors qualified their estimate, however, indicating that it was likely to be an underestimate of the true direct costs of diabetes.

A more recent study is Diabco\$ Australia¹⁰ which assessed the direct, indirect and intangible costs of Type 2 diabetes in Australia. The burden of diagnosed Type 2 diabetes was estimated to be \$3 billion a year. The cost per person was 2.8 times higher if both microvascular and macrovascular complications were present. The main components of direct health costs were hospitalisation due to complications (32%) and the use of medicines to treat complications (26%).

Diabco\$ Australia used the EQ-5D validated tool to measure quality of life. This tool is designed for use in health economic studies and looks at five aspects of quality of life: mobility, self-care, usual activity, pain/discomfort and anxiety/depression. The self-reported negative impact of diabetes on quality of life was found to be significant, particularly when complications were present. Furthermore, 30% of people with diabetes in the study reported problems with anxiety/depression.¹⁰

Self-management of Diabetes

Diabetes is a chronic, life-long condition that affects every part of a person's life. Adherence to medical treatment and self-management of diabetes are demanding but necessary disciplines to avoid the short and long term complications of the disease.

Supporting people with diabetes to effectively self-manage and live successfully with diabetes, particularly through diabetes education, is essential to creating person centred diabetes services.

Current Services

Australia compares well to the rest of the world in the range of services available to enhance the capacity of people with diabetes to manage their condition and enhance their quality of life. For example:

- diabetes information and education is widely available from a range of sources, including health professionals, the media, pharmacies and such organisations as Diabetes Australia and the Juvenile Diabetes Foundation
- the National Diabetes Service Scheme (NDSS) facilitates access to products and services by providing blood and urine testing strips, syringes and needles for special injecting systems at subsidised prices
- clinical practice guidelines to support the provision of high quality, evidence-based care to people with diabetes pervade general practice and secondary care settings.

However, there is still capacity for improvement in service. Deficiencies in care and support relate primarily to detection and diagnosis of diabetes (especially Type 2 diabetes); lack of coordination between services provided in community, general practice and hospital settings; the inability to provide ongoing and proactive education and support for self-management and lifestyle change; failure to provide evidence-based, best practice care; and undetected and poorly managed psychosocial issues.

THE NATIONAL SERVICE FRAMEWORK FOR DIABETES

Overview

The Diabetes NSIF outlines what all Australians with, or at risk of, diabetes can expect to receive from the Australian health care system, irrespective of where they live, their cultural and linguistic background, and their socioeconomic position. To do this, it draws on scientific evidence and the unique experiences of people with diabetes to identify where critical improvements can be made to health service arrangements at state, territory and national levels.

Components of the Framework

The framework, depicted in Figure 1, acknowledges that communities comprise people who differ in their level of health service need from well people, who want simply to reduce their risk of developing diabetes, to the severely ill, who require care and support to manage the disease in its advanced stages (the horizontal axis).

FIGURE 1: NATIONAL SERVICE IMPROVEMENT FRAMEWORK
Diabetes

Organising matrix for service improvement

		Condition of Diabetes			
		Well Community (including those at increased risk)		People with the condition (and their families and carers)	
	Reduce the Risk	Find the condition early	Best care and support in the early stages	Best long term care and support	Best care and support for acute episodes
AIM— People will be able to:					
WHAT ARE THE OPTIMAL PERSON OR PATIENT CENTRED SERVICES FOR THE CONDITIONS?					
People's needs	↓ The needs of people who have or are at risk of the condition →				
Optimal Services					
WHAT IS HAPPENING NOW?					
Current practice in meeting people's needs and providing optimal services	↓ Gaps in current care →				
WHAT ARE THE PRIORITIES FOR IMPROVING CARE?					
Critical intervention points where practical and significant health gains and service improvements can be made	↓ Where do the gaps between the optimal services and current practice matter? →				
WHAT ACTIONS ARE NEEDED FOR CHANGE TO OCCUR?					
Actions linked to critical intervention points	↓ Local, jurisdictional and national level →				

Making Change from the needs of individuals

To Systems Change

According to the framework, optimal health services for people with different service needs can be derived by using empirical evidence and consensus to answer the following series of questions (the vertical axis):

1. What are appropriate person centred services for people with or at risk of developing diabetes?

In particular, what are the needs of people, families and communities affected by this disease?

2. What is happening now?

Specifically, how effective are current services in meeting these needs? Based on the evidence, what is best practice care?

3. What is required for the necessary changes to occur?

If health services are not meeting the needs of the community, what system level changes are required to improve service provision? Do models of good and innovative practice exist?

4. What are the priorities for improving care?

What are the aspects of care, or critical intervention points, in which Australia might invest most usefully to reduce death and distress from diabetes? The identification of priorities is based on consideration of whether an aspect of care is:

- important in terms of death, suffering or health care costs
- considered suboptimal, given what is known about optimal services and current care
- is able to be improved significantly.

5. What are the national priority actions for change?

What actions could be taken by national and state/territory governments, in collaboration with professional colleges, non-government organisations, consumer groups and other key stakeholders, as a basis for establishing the optimal services identified in the framework.

Answers to these questions, posed for people at each stage of the diabetes continuum, are presented in the subsequent chapters of this document.

Considerations in Interpreting the Framework

Interpretation and analysis of the Diabetes NSIF is limited by a paucity of data relating to:

- the costs, benefits and feasibility of different models of service provision in Australia
- the extent of variation in approaches to diagnosing diabetes in the community
- the care provided to people with diabetes between or after periods of acute treatment by community nurses, family or other care providers
- factors affecting relations between socioeconomic variables and the prevalence of diabetes.

The five stages identified on the horizontal axis of the framework should not be interpreted as discrete elements. Rather, in an effective health system a person's movement through the system will be seamless, and there will be integration and communication between the services provided at each point in the system. This level of integration may be achieved through the implementation of integrated diabetes services.

Table 1 is presented as a guide to the content of this document.

Table 1: Chapter Guide to the Diabetes NSIF

<p>Chapter 3 <i>Reduce the Risk</i></p>	<p>Chapter 4 <i>Find the conditions early</i></p>	<p>Chapter 5 <i>Early stages</i></p>	<p>Chapter 6 <i>Long-term care and support</i></p>	<p>Chapter 7 <i>Acute episodes</i></p>
<p>Reduce the risk of diabetes</p> <p>INFORMATION TO SUPPORT PARTICIPATION Systems support consistent, evidence-based information about how to reduce the risk of developing overweight, obesity and diabetes</p> <p>ACCESS TO INTERVENTIONS TO REDUCE RISK Systems support access to activities and programs that may reduce risk: Engage in healthy lifestyle behaviours (eat a healthy nutritious diet, engage in regular physical activity and avoid overweight/obesity and smoking)</p> <p>SUPPORT FOR RISK REDUCTION INTERVENTIONS The environment supports risk reduction activities</p>	<p>INFORMATION TO SUPPORT PARTICIPATION Systems support early, accurate diagnosis of the conditions.</p> <p>ACCESS TO INFORMATION Systems support access to the information about the importance of self management and prevention of complications</p>	<p>INFORMATION TO SUPPORT PARTICIPATION Systems support consistent, evidence-based information about the conditions to promote self management shared participation in care decisions</p> <p>LIFESTYLE CHANGE Systems support healthy lifestyle behaviours</p> <p>SELF-MANAGEMENT SUPPORT AND PARTNERSHIPS IN DECISION MAKING Systems support self-management (education; written individualised management plan; planned review, and ongoing support to prevent avoidable acute episodes)</p> <p>EARLY DETECTION AND FOLLOW UP OF COMPLICATIONS</p>	<p>INFORMATION TO SUPPORT PARTICIPATION Systems support consistent, evidence-based information about the conditions to promote shared participation in care decisions</p> <p>ENSURE SMOOTH TRANSACTION FROM HOSPITAL TO COMMUNITY BASED CARE Systems support timely access to services (multi-disciplinary teams, flexible service delivery, partnerships to build service capacity). Systems support continuity of care during transition.</p> <p>PREVENT HOSPITAL ADMISSION AND IMPROVE HOSPITAL TREATMENT Planned review and ongoing support to prevent acute episodes reoccurring</p> <p>SUPPORT FOR HIGH QUALITY SERVICES Systems support high quality care (workforce development; evidence-based practice and decision support systems)</p>	<p>INFORMATION TO SUPPORT PARTICIPATION Systems support consistent, evidence-based information about detecting acute episodes to promote shared participation in care decisions</p> <p>ACCESS TO CARE AND SUPPORT Systems support timely access to services</p> <p>SELF-MANAGEMENT SUPPORT Systems support self-management (education; written individualised management plan; planned review, and ongoing support to prevent avoidable acute episodes)</p> <p>SUPPORT FOR HIGH QUALITY SERVICES Systems support high quality care (continuity of care; detection of and response to adverse events)</p>

CRITICAL INTERVENTION POINTS FOR DIABETES MANAGEMENT

The critical intervention points and their derivation, relevant optimal services and rationale are described in detail in the subsequent chapters. The critical intervention points are ordered according to their position along the continuum of care.

Particular attention will be required to achieve improvements for Aboriginal and Torres Strait Islander peoples, and disadvantaged groups, across all critical intervention points and national priority actions. The development and implementation of strategies and services will need to take place within guidelines established in the Australian Health Ministers' Advisory Council's Aboriginal and Torres Strait Islander Cultural Respect Framework.

List of Critical Intervention Points for Diabetes

Reduce risk (See Chapter 2, pages 15–23)

1. Provide access to culturally appropriate information on food, nutrition and physical activity to assist in mitigating the risks of overweight, obesity and Type 2 diabetes, especially in high risk groups and in those people with impaired glucose metabolism.
2. Establish national, state, territory and local plans to prevent obesity and Type 2 diabetes by promoting healthy eating and physical activity including healthy weight in collaboration with other national health priorities and policies.

Diagnose diabetes early (see Chapter 3, pages 25–28)

3. Develop and disseminate information about diabetes risk factors and symptoms to the community, primary care providers and other relevant health care workers.
4. Improve systems so that all people at risk of diabetes are referred appropriately and assessed promptly and effectively, particularly those at high risk.

Best care and support during the early stages (see Chapter 4, pages 29–42)

5. Develop and implement national clinical practice guidelines covering the diagnosis and management of diabetes and its complications with the aim of preventing the onset and slowing the progression of diabetic complications.
6. Establish national, state, territory and local plans to reduce rates of smoking using evidence-based public health strategies and government actions.
7. Develop and implement systems to prevent and limit the progression of the complications of diabetes for all Australians, particularly those living in regional, rural and remote areas and Aboriginal and Torres Strait Islander peoples.
8. Put in place processes to assess the extent to which clinical practice guidelines are adopted and to encourage strongly their implementation.
9. Continue and, where necessary, strengthen and/or establish systems to improve the coordination of care for people with diabetes, including defined referral pathways and designated coordinators of care.
10. Develop and implement strategies to encourage multidisciplinary care, emphasising the central role of the person with diabetes in diabetes care, and their capacity for self-management.
11. Inform people diagnosed with diabetes, regardless of their point of contact with the health system, of available sources of information, education and support for health, psychosocial and financial issues.
12. Develop measures to support absolute risk estimation as a tool in assessing people known to have diabetes but without overt cardiovascular disease.
13. Improve access to treatment services for all Australians, particularly those living in regional, rural and remote areas and Aboriginal and Torres Strait Islander peoples.

-
14. Work towards improving supportive care for people with diabetes by implementing psychosocial clinical practice guidelines.
-

Best long term care and support (see Chapter 5, pages 43–55)

15. Continue and, where necessary, strengthen and/or establish systems to improve the coordination of care for people with diabetes, including defined referral pathways and designated coordinators of care.

 16. Develop comprehensive programs for the early detection and management of diabetic retinopathy and nephropathy.

 17. Develop and implement strategies to ensure that all people with diabetes have adequate access to appropriate foot care and/or podiatry services.

 18. Develop and implement strategies to reduce preventable hospital admissions in people with diabetes.

 19. Provide information through accreditation of services, credentialing of practitioners or other strategies to help people with diabetes assess the quality of care being provided.

 20. Work towards improving supportive care for people with diabetes by developing and implementing psychosocial clinical practice guidelines.

 21. Provide adolescents with diabetes with a seamless transition from paediatric to adult care, with services appropriate both for chronological age and developmental attainment.

 22. Develop and implement strategies to encourage multidisciplinary care.

 23. Develop and implement strategies to ensure widespread implementation of clinical practice diabetes guidelines.

 24. Develop and implement strategies and policies to encourage the safe and quality use of medicines.
-

Best care and support for acute episodes (see Chapter 6, pages 57–62)

25. Develop a community wide awareness program about the short and long term complications of diabetes.

 26. Provide information to people with diabetes, their families and carers to assist them to identify and respond to impending deterioration in diabetes management.

 27. Manage diabetic ketoacidosis in children and adolescents according to a national written guideline in facilities appropriate for their age.

 28. Provide appropriate information for people with diabetes about follow-up, practical issues, support services and self-care.
-

NATIONAL PRIORITY ACTIONS FOR CHANGE

There are nine priority actions which underpin the critical intervention points. If these actions were undertaken by Australian, state and territory governments, the basis for many of the changes identified in the framework would be in place.

1. Provide improved support for comprehensive health promotion efforts aimed at encouraging and monitoring the uptake of healthy behaviours (in the key areas of nutrition, smoking, and physical activity) in people with and without diabetes, and facilitating health promoting environments through integrated efforts at national, state, territory and local levels.
2. Establish integrated and networked diabetes services to improve continuity of care from ‘reducing risk’ to ‘care at the end of life’.
3. Investigate arrangements which provide improved support for multidisciplinary care in hospitals and the community.

4. Develop agreed diabetes plans at national, state, territory and local levels, as appropriate, to monitor all aspects of diabetes management for the purpose of quality improvement, including performance indicators.
5. Provide evidence-based consumer information about the environmental, behavioural and genetic risks of diabetes.
6. Continue and, where necessary, strengthen and/or establish national approaches to assist primary care workers (especially general practitioners) to offer high quality and appropriate assessment of risk, early detection of diabetes, referral to treatment, coordination of treatment and supportive care.
7. Support the enhancement of the capacity of people with diabetes to understand and manage their diabetes through national, state, territory and local approaches.
8. Implement and evaluate culturally appropriate programs to improve diabetes prevention and management with special emphasis on the needs of disadvantaged groups, Aboriginal and Torres Strait Islander peoples, and those from culturally and linguistically diverse backgrounds.
9. Review the evidence, gaps in research and opportunities for action within a specific timeframe, at least every three years.

CHAPTER 2: Reduce the Risk of Diabetes

OVERVIEW

There are several types of diabetes, with different causal mechanisms. 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. Type 2 diabetes is the commonest form of diabetes, affecting 85–90% of all people with diabetes, and is characterised by insulin resistance and relative insulin deficiency. Whereas Type 2 diabetes has traditionally been considered a disease of late onset (over 40 years of age), it is now occurring increasingly in younger people.

Other forms of diabetes include gestational diabetes mellitus (GDM), which affects approximately 4% of pregnant women, and the less common Maturity Onset Diabetes of the Young (MODY), medication induced diabetes and stress hyperglycaemia.

Studies to find ways to prevent the onset of Type 1 have generally been unsuccessful although several recent studies suggest antigen based prevention therapy may be feasible.^{11,12} On the other hand, research over the last decade has provided strong evidence to suggest that people can prevent or reduce the risk of developing Type 2 diabetes by making healthy lifestyle choices in relation to weight, nutrition and physical activity.¹³⁻¹⁵ Pharmaceutical interventions have also proven to be effective in delaying or preventing Type 2 diabetes.¹⁵⁻¹⁷

The number of people, including children, who are either overweight or obese, is increasing rapidly. With an ageing and increasingly overweight and physically inactive population, and a cultural mix encompassing several groups known to be at high risk of diabetes, the possibility of an epidemic of diabetes in young and middle-aged Australians is a matter of importance both for health services and economic and public policy.¹⁸

The best possible way to reduce the risk of diabetes is to focus on prevention. Providing the general public and health professionals with appropriate information and a supportive environment has the potential to reduce Type 2 diabetes.

PEOPLE'S NEEDS

To reduce the risk of their developing diabetes, people want and need to:

- understand the risk of developing diabetes, by having access to highly credible, nationally consistent, evidence-based information about risk factors for diabetes
- know how to reduce the risk of diabetes
- live in an environment that supports healthy lifestyles
- be able to access information and support to develop skills and knowledge to adopt healthy lifestyles
- be able to access risk prevention programs such as physical activity groups and weight loss programs, that are affordable and appropriate
- understand how family history affects the risk of their developing diabetes.

OPTIMAL SERVICES

Nationally consistent, evidence-based information about the risk factors for diabetes and opportunities for risk reduction will be available.

Information will be available to the community, health professionals and the media, which will:

- indicate the amount of risk reduction that might occur if the recommended behaviours are adopted; this will enable people to make informed choices
- acknowledge the source of the information and the approach used to assess the evidence so that people can be certain of the quality of the information
- be appropriate for different groups within the community, particularly disadvantaged groups, including those from lower socioeconomic, culturally and linguistically diverse, and Aboriginal and Torres Strait Islander backgrounds.

Programs and strategies will be implemented to ensure that people's environments support and encourage risk reduction.

Governments and other significant social structures will have coordinated plans to reduce the prevalence of diabetes through the application of legislation, financial incentives and disincentives, and policy. These plans will target:

- improved nutrition
- increased rates of healthy physical activity
- reduced rates of smoking
- improved access to interventions aimed at facilitating the adoption and maintenance of healthy lifestyles
- improved access to adequate maternal and child health care and nutrition, particularly in Indigenous populations, to address low birth weight and subsequent risk of diabetes.

People will be encouraged to engage actively in behaviours to reduce their risk of developing diabetes

- Regular community education initiatives including, where appropriate, media information campaigns, will promote the value of specific risk reduction behaviours.
- Health professionals will have the knowledge and skills necessary to assist people to identify whether they and/or members of their family are at-risk and to encourage the uptake of healthy lifestyle behaviours.
- Overweight or obese individuals will have access to appropriate lifestyle improvement programs.

People with special needs and from culturally and linguistically diverse backgrounds will have access to appropriate, tailored information and risk reduction programs

Specific information and risk reduction programs will be available to people from lower socioeconomic, culturally and linguistically diverse, and Aboriginal and Torres Strait Islander backgrounds.

RATIONALE FOR OPTIMAL SERVICES

Access to evidence and information about risk reduction

Optimal Services: People in the community will have access to consistent and evidence-based information about opportunities for risk reduction. The information will be provided in an integrated manner so that people can readily understand how to take action to reduce the risk of their developing diabetes. The information will be appropriate for different groups within the community, particularly people from lower socioeconomic, culturally and linguistically diverse, and Aboriginal and Torres Strait Islander backgrounds. People will feel confident that they will receive accurate information about new opportunities for risk reduction in diabetes. Data will be available to support improvement of current programs and future interventions.

Modifiable risk factors

Modifiable risk factors for Type 2 diabetes include the following:

Overweight and obesity

Obesity, as measured by the Body Mass Index (BMI) (weight in kilograms divided by height in metres, squared) and waist circumference (measurement taken halfway between the rib cage and pelvis), has been linked to the risk of developing Type 2 diabetes in both men and women. Absolute weight gain throughout adulthood is also a significant independent risk factor for diabetes, and abdominal obesity is particularly adverse.²

There is evidence that the prevalence of obesity is increasing in Australia. The Australian Bureau of Statistics National Health Surveys conducted between 1989–90 and 2001 show a rapid rise in the prevalence of obesity among both men (an 80% increase) and women (a 71% increase) during the 13-year period. Analyses of these surveys also show a smaller increase in the prevalence of overweight but not obesity (14% in both men and women). In 2001, on the basis of self-reported height and weight, an estimated 16% of men and 17% of women aged 18 years and over were obese—a total of 2.4 million obese Australian adults. A further 4.9 million Australian adults (42% of men and 25% of women aged 18 years and over) were estimated to be overweight but not obese.¹⁹ Previous comparisons of measured and self-reported height and weight have shown that people tend to overestimate their height and underestimate their weight.²⁰

Obesity is also on the rise among children and adolescents. For children and adolescents aged seven to 15 years, obesity increased from 1.4% of boys and 1.2% of girls in 1985, to 4.7% of boys and 5.5% of girls in 1995.²¹ Children and adolescents who are overweight have a greater likelihood of becoming overweight adults.²² As dietary habits are typically established early and are fairly resistant to change, effective targeting of obesity in children and young people is likely to require a 'life-course' approach, whereby interventions aim to encourage families to adopt healthy lifestyle behaviours, and engender a philosophy of *'healthy babies, healthy children, healthy adults'*.

Certain population groups appear at greater risk of becoming overweight and obese than others.²³ This information is useful for targeting those subgroups in the community most at risk of developing Type 2 diabetes. For example:

- men are more likely than women to be overweight and to have excess abdominal fat (although the prevalence of obesity does not differ between men and women)
- older population groups (e.g. 45–65 year olds) are more likely than younger groups (e.g. 20–24 year olds) to be obese
- adults living outside major cities are more likely to be overweight than their urban counterparts.²³

The NHMRC, in conjunction with the Population Health Division of the Australian Government Department of Health and Ageing, has developed clinical practice guidelines

for general practitioners on the management of overweight and obesity in children, adolescents and adults.^{24,25} The guidelines provide comprehensive advice that will help doctors identify the best and safest way for people with diabetes to maintain a healthier body weight and ensure that consistent and evidence-based information is given. The guidelines are also useful to other health professionals.

The National Obesity Taskforce submitted its report and a national action agenda for children, young people and their families to Australian Health Ministers in November 2003. *Healthy Weight 2008—Australia's Future—The National Action Agenda for Children and Young People and their Families*²⁶ recommends actions across a range of settings such as child care, schools, primary care, maternal and infant health care, neighbourhoods, workplaces, food supply, family and community services, media and marketing. The focus is on children and young people (i.e. 0–18 years) and their families.²⁶ A key requirement of the proposed framework is support for young people and their families, both in the home and in the wider community, and implementing a cross-sectoral, multi-settings approach which addresses the underlying environmental and lifestyle causes of overweight.²⁶

Physical activity

Research has shown that the risk of Type 2 diabetes and associated insulin resistance can be reduced significantly by substantive weight loss in those who are severely obese (BMI > 35 kg m²). Further, randomised control trials (RCTs) exploring the impact of lifestyle interventions, notably diet and physical activity, on prevention of Type 2 diabetes in high risk groups have noted up to a 58% reduction in the incidence of the disease. Little is known, however, about the type of physical activity that is most protective.

While people who are physically active appear to have a reduced risk of developing impaired glucose tolerance (IGT) and Type 2 diabetes, only 58% of Australian adults aged 18–75 years report spending sufficient time (i.e. at least 150 minutes of walking, moderate and/or vigorous activity per week) being physically active for health benefit.¹⁶

Nutrition

There appears to be an association between increased consumption of plant foods and lower incidence of obesity (a risk factor for diabetes) and Type 2 diabetes. At this stage it is not clear if the protective effect for diabetes is the result of a lower body weight.

For people with diabetes, the consumption of vegetables is likely to be of particular value due to their fibre content, low energy density and relative beneficial effect on blood sugar.²⁷ The joint WHO-FAO consultation on carbohydrates concluded that foods rich in slowly digested or resistant starch, or high in soluble fibre, might be protective against diabetes.²⁸

Evidence suggests that people with a high intake of dietary fat, in particular saturated fat, are at increased risk of insulin resistance and Type 2 diabetes. *The Australian Dietary Guidelines for Adults* recommend that at risk individuals should consume a diet with approximately 30% energy as fat, with no more than 10% energy as saturated fat.²⁷

Foods eaten or prepared away from home play a large role in the diet of many Australians. This is potentially an issue as often the servings are large with a high energy content. McCrory et al 2000²⁹ found that consumption of restaurant food was associated positively with body fatness. This was independent of physical activity levels, alcohol intake, smoking status and education level. The authors also found that restaurant meals tended to be high in fat and low in fibre. Take-away foods are chosen for a range of reasons such as type of food, ease of access, incentives (buy one, get one free), consistency between outlets, and fast and courteous service. The take-away food industry invests in large marketing campaigns to entice consumers to buy its product. To achieve healthier food consumption patterns, increased collaboration and commitment to promoting healthier options is vital.³⁰

Psychosocial stress

Psychosocial stress has been cited as a possible risk factor for Type 2 diabetes. For example, there is some evidence to suggest that exposure to stressful life events may increase the risk of diabetes.³¹ It is likely, however, that this association is mediated by other factors.

For example, evidence from one US study found that individuals with minimal emotional support were at greater risk of diabetes when exposed to one undesirable stressful life event than individuals with higher levels of emotional support.³²

Depression has also been cited as a risk factor for diabetes³³, and it is associated with adverse diabetes outcomes.^{34,35}

Smoking

Smoking has been shown to increase insulin resistance and diminish insulin secretion, both of which are linked with the onset of Type 2 diabetes.³⁶ At this point there is not adequate evidence that smoking is an independent risk factor for the presence of undiagnosed diabetes, or for the future development of Type 2 diabetes.³⁷

Socioeconomic factors

Characteristics of the social environment—including the socioeconomic status of individuals (income and employment), social isolation or exclusion, and access to local services and facilities (especially transport)—are linked closely with population health. In particular, people with lower incomes, lower levels of education and lower status occupations have worse health than those with higher incomes, education levels or occupations.³⁸ Health is also poorer among individuals residing in communities characterised by low levels of social support and cohesion.³⁹ For these reasons the planning of urban environments provides an important opportunity to reduce health risks and maximise health gains for urban communities.

Differences in smoking, obesity, vulnerability to illness, blood pressure, low-density lipoprotein cholesterol, and high-density lipoprotein cholesterol do not account wholly for the observed relationship between socioeconomic position and health outcomes. In the Whitehall study of British civil servants, psychosocial characteristics—such as low control of daily activities and an effort-reward imbalance in the workplace, and other factors such as heart rate variability and disturbances of the autonomic nervous system—were identified as possible mediators of a link between coronary heart disease and social position. In the Whitehall II study, an effort-reward imbalance was also associated with Type 2 diabetes.⁴⁰

Non-modifiable risk factors

Non-modifiable risk factors for Type 2 diabetes include family history, age, and gestational diabetes (a form of diabetes that may develop during pregnancy).

Family history of Type 2 diabetes is a risk factor for undiagnosed Type 2 diabetes in other family members. The lifetime risk of developing Type 2 diabetes is estimated to be 40% if one parent has the disease.³⁷ Further, people have about twice the chance of having undiagnosed Type 2 diabetes when they have a family history of the condition.³⁷

Although family history and age are non-modifiable risk factors for Type 2 diabetes, knowledge about these might motivate an individual at risk to make some positive lifestyle changes.

Provision of information about risk and risk reduction

The presence of risk factors is often not enough to motivate people to engage in activities that will prevent the onset of Type 2 diabetes. Rather, people must *perceive* that they are at risk for Type 2 diabetes, and *believe* that this risk can be reduced before they will initiate and sustain appropriate diet and physical activity behaviours and prophylactic medication.

Paradoxically, research has shown that the individuals most at risk of developing diabetes (i.e. presence of multiple risk factors and/or a family history of diabetes) do not necessarily perceive they are at risk of developing Type 2 diabetes.⁴¹ This finding has serious implications for the prevention of diabetes in high risk groups.

Availability of information

Diabetes information and education is available from a wide range of sources—diabetes centres, diabetes educators, medical practitioners, pharmacies and practice nurses. Information regarding risk factors for Type 2 diabetes and how to prevent the condition is available currently from Diabetes Australia in English and translated into some of the main community languages. This information is unlikely, however, to meet the needs of all people from culturally and linguistically diverse backgrounds, particularly those from new and emerging communities. Recognising this, Diabetes Australia commissioned a report from the Australian Institute of Health and Welfare (AIHW) to identify communities at high risk that may need information in their own language.

The material provided through Diabetes Australia is based on information that has been approved by the NHMRC, the Australian Diabetes Society (ADS), and the Australian Diabetes Educators Association (ADEA).

In addition to material provided by Diabetes Australia, some of the State and Territory Departments of Health have developed culturally appropriate resources relevant for the prevention of diabetes, especially for Aboriginal and Torres Strait Islander people. Information is also available through the pharmaceutical industry and reputable websites, such as *HealthInsite*.

The development and dissemination of resource material from many sources makes it important to ensure reliability and consistency in the information provided to avoid confusion. Having nationally consistent education materials would help to avoid this problem.

A recent project commissioned by Diabetes Australia under the NDSS Strategic Development Grant agreement⁴² identified and analysed what was needed in the areas of information and education for people with diabetes. A number of initiatives likely to support the prevention of diabetes were proposed, some of which are provided by Diabetes Australia. They include:

- establishing a free call help line
- establishing a national clearing house that acts as a central repository for information and education materials
- utilising community radio
- providing lifestyle education.

Availability of data

There is no nationally coordinated system in place to monitor dietary intake, physical activity levels and body mass index. Availability of baseline data is necessary to improve current programs and plan for future interventions.

Environments to reduce diabetes risk

Optimal Services: People will be provided with an environment that encourages risk reduction. People will be confident that their environment supports risk reduction. They will know that their governments have a coordinated plan to reduce the most important diabetes risks through application of legislation, financial incentives and policy. To increase rates of physical activity, the plan will include: policies for the establishment of public spaces for physical activity; policies in schools to encourage physical activity; reduction in financial disincentives to participate in formal physical activity programs. To increase healthy diet, the plan will include policies in schools and workplaces to encourage healthy eating choices and strategies to ensure that all people have access to good quality fruit and vegetables at an affordable price, irrespective of where they live.

Diabetes risk can be reduced by ensuring that the environment limits exposure to risks, through the application of legislation, financial incentives and disincentives, and policy approaches. Many strategies targeting risk factors for diabetes have been implemented and evaluated, including:

Environmental strategies to increase rates of physical activity

- *Policies for the establishment of public spaces for physical activity (e.g. walk and bike ways).* Interventions to alter environments by removing barriers and providing more opportunities for physical activity can be effective.⁴³ It is recognised that more could be done to improve access to public spaces for physical activity in Australia.⁴⁴
- *Policies in schools to encourage physical activity.* There is inconsistent evidence about the impact of school based programs in encouraging physical activity.⁴⁵
- *Reduction in financial disincentives to participate in formal physical activity programs.* Several studies have identified financial cost as a barrier to participation in physical activity.⁴⁶⁻⁴⁹

Environmental strategies to increase healthy diet

- *Policies in schools and workplaces to encourage healthy eating choices.* There is some evidence that school based programs can improve diet among school children⁵⁰ and good evidence that worksite interventions are effective in increasing the fruit and vegetable consumption of workers.^{51,52}
- *Eat Well Australia: an agenda for action for public health nutrition* provides direction for improvements in diet in Australia. This document outlines the need to equip educators such as teachers and health professionals with the knowledge, skills, framework and tools to encourage healthy changes in diet.

Strategies to ensure that all people have access to good quality fruit and vegetables of an affordable price

- Access to food is related to supply, price and quality. Several factors impact on these characteristics including seasonal and unusual weather patterns and transport practices and costs, particularly in relation to rural and remote areas.⁵³ The Strategic Inter-Governmental Nutrition Alliance has proposed—to address quality, price, access and isolation issues—that produce grading and pricing systems should be improved, and that the public should be educated about this. Also, to retain the quality of produce, standards for transport should be developed and promoted, and the training of staff involved in handling and marketing improved.⁵³
- Price reductions are an effective strategy to increase the purchase of healthy foods in community based settings such as work sites and schools.⁵⁴ In Australia, lower income adults are more likely than their higher income counterparts to report that price is a barrier to increasing their fruit and vegetable consumption.⁵⁵ Socioeconomic differences in fruit and vegetable consumption are apparent in Australian adults.⁵⁵

There is an opportunity to reduce the risk of diabetes by providing environments that foster a healthy diet and increased levels of physical activity.

Encouraging and supporting risk reduction

Optimal services: People will be encouraged to reduce their risk of diabetes. There will be regular media and community information programs promoting the value of risk reduction behaviours. Health professionals will assist individuals to identify their own risks of diabetes and will have the knowledge and skills to assist individuals to reduce their risk accordingly. Individuals who are overweight or obese will have access to weight reduction programs.

In addition to the provision of information and safe environments, people and communities can be actively encouraged to take positive steps to reduce their risk of diabetes. Over the 40 years, several strategies have been implemented and trialled, including the following.

Mass media campaigns

Mass media campaigns can play a significant role in forming and influencing people's attitudes and behaviour.⁵⁶⁻⁵⁸ The *Life. Be in it* Campaign was launched at a national level in 1977 to promote an active lifestyle for all Australians; since then there have been a number of campaigns aimed at influencing such lifestyle choices as physical activity, fruit and vegetable consumption and smoking.

To achieve sustained change, campaigns may need to be renewed to allow for policy changes and to keep the message on people's agenda. Whereas evidence for the effectiveness of mass media campaigns alone in changing health behaviour is inconclusive, there is evidence for their effectiveness when coupled with other community education and environmental changes (such as social norms, supportive physical environments and access to behaviour change programs such as smoking cessation, physical activity groups).⁵⁹

Health professionals

General practitioners and allied health professionals have a significant role in encouraging healthy lifestyle choices. Eighty percent of Australians visit a general practitioner at least once a year.⁶⁰ Attempts by general practitioners to positively influence lifestyle choices of their patients are generally most effective when:

- strategies are tailored to reflect the unique needs of the person
- single rather than multiple risk factors are targeted
- preventive attempts reflect an understanding of behaviour theory.

The SNAP Framework⁶¹ has been developed to guide the implementation of integrated approaches to modifying a limited set of behavioural risk factors in general practice, and focuses on smoking, nutrition, alcohol and physical activity (SNAP; available on the Royal Australian College of General Practitioners' Web site). The SNAP Framework aims to improve health outcomes in the community by supporting and enhancing the role that general practice plays in increasing levels of good nutrition and physical activity and decreasing smoking prevalence and alcohol misuse. In terms of preventing diabetes, good nutrition and physical activity are key areas but smoking and alcohol consumption are not. Nevertheless, the SNAP framework is a useful model as it represents a system wide approach to behavioural risk factor identification and management, and it acknowledges the importance of socioeconomic factors in behavioural risk factor modification. The initiative targets consumer awareness of the links between behavioural risk factors and chronic disease and highlights the role of the general practitioner as an agent for supporting behavioural change.

The *Lifestyle Prescription Initiative*, introduced as part of the *Focus on Prevention* package in the Australian Government's 2003–04 Budget, is built upon and consistent with the SNAP Framework. The initiative aims to make it easier for general practitioners and their practices to encourage people to make healthy lifestyle choices, by providing a framework for:

- discussion of lifestyle health issues
- advice in the form of a written script
- referral to other providers to support healthy lifestyle choices.

The *Lifestyle Prescription Initiative* will support and encourage general practitioners to incorporate lifestyle risk reduction into their usual processes of care. Lifestyle prescriptions are tools for general practitioners to use when giving people healthy lifestyle

advice, whether this is about quitting smoking, eating a healthier diet, reducing alcohol consumption, increasing physical activity, managing body weight or a combination of these.

Other opportunities to reduce risk

In addition to media campaigns and the work of health professionals, local council initiatives and walking/fitness groups, exercise physiologists, personal trainers and others working in the fitness and weight loss industries present significant opportunities to further reduce the risk of Type 2 diabetes through provision of appropriate information and strategies targeting high risk groups.

Reducing Risk in Special Needs Communities

Optimal services: People with special needs, including people from lower socioeconomic groups, Aboriginal and Torres Strait Islander peoples and people from culturally and linguistically diverse communities will have access to appropriate information, programs and environments to help them reduce their risk of diabetes.

People from lower socioeconomic groups have higher rates of diabetes. Lower socioeconomic status is associated with higher rates of smoking, lower rates of physical activity, lower rates of fruit and vegetable consumption^{55,62} and higher rates of obesity.⁶³

Aboriginal and Torres Strait Islander peoples also have a higher incidence of Type 2 diabetes, and are twice as likely as other people to smoke.⁶⁴

There is also evidence to suggest that some culturally and linguistically diverse communities have higher rates of Type 2 diabetes than others. Pacific Islanders, people of Chinese descent and those from the Indian Subcontinent are also more likely than other Australians to have diabetes, in particular Type 2 diabetes.⁵ Relatively little is known about how to develop information and programs for different communities.

Information resources should be developed to cater for the specific needs of intended target groups, including the format in which information is presented. The state and territory diabetes organisations provide information about risk in languages other than English. Translated print materials are available nationally to major non-English speaking background groups through a number of sources.

The difficulties faced by Aboriginal and Torres Strait Islander peoples include affordability, distance and appropriateness of information and services. It is recognised that there is poor access to culturally appropriate services for Aboriginal and Torres Strait Islander peoples and that much more needs to be done to address this.

Better understanding of, and improved programs for, risk reduction in special communities is a priority. While these programs may be resource intensive, they represent an opportunity to significantly impact on communities where risk may be much higher than the Australian norm.

There is an opportunity to reduce risk of diabetes through programs that meet the special needs of people from lower socioeconomic groups, Aboriginal and Torres Strait Islander peoples and people from culturally and linguistically diverse backgrounds.

CHAPTER 3: Diagnose Diabetes Early

OVERVIEW

Type 1 diabetes is most frequently diagnosed in childhood and adolescence with approximately three-quarters of patients diagnosed before the age of 30. Young people with diabetes generally become ill rapidly and are diagnosed with diabetes very quickly. Most frequently, a diagnosis is made on the basis of such symptoms as excessive thirst, frequent drinking, excessive hunger, frequent urination, weight loss and sometimes vomiting.

For some young people, however, Type 1 diabetes has a 'catastrophic' onset⁶⁵, and is diagnosed after an emergency presentation for treatment of diabetic ketoacidosis (DKA); a condition caused by relative deficiency of insulin and acutely high levels of blood glucose. If left untreated, DKA can lead to coma and death in a matter of days.

Type 2 diabetes, on the other hand, is most frequently diagnosed in people over 40 years of age, although prevalence rates in younger age groups are increasing. Many people with Type 2 diabetes are unaware that they have the disease, either because they have no symptoms, or because such symptoms as tiredness and lethargy are easily attributed to the stresses and strains of everyday life. Not uncommonly, an abnormal urine or blood glucose test performed as part of a health screening or routine medical examination may be the first indication that a person has Type 2 diabetes. Alternatively, one or more of the long term complications of the disease, for example heart and kidney disease and/or visual impairment, may be the first sign.

Raising awareness of the risk factors for and signs and symptoms of diabetes among the general public and health professionals will assist early diagnosis of Type 1 and Type 2 diabetes. Ensuring that Type 1 diabetes is diagnosed early has the potential to prevent some of the deaths resulting from DKA, especially in young children. Early diagnosis of Type 2 diabetes may prevent and/or slow the progression of the debilitating long term complications of the disease.

Gestational diabetes is a temporary form of diabetes that occurs during pregnancy, when certain hormones stop insulin from working properly. It is usually detected during a routine screening test at 28 weeks. Gestational diabetes is generally managed with healthy eating and physical activity, although insulin injections may be required in some cases. Women who have had gestational diabetes may prevent the development of Type 2 diabetes in later life through healthy eating and physical activity, and through ongoing monitoring for early detection.

PEOPLE'S NEEDS

To ensure diabetes is diagnosed early, people want and need:

- to be made aware of the risk factors for and early signs and symptoms of diabetes
- access to services having the knowledge and skills to diagnose and treat diabetes early
- to be aware of the manifestations of diabetes, especially the potentially asymptomatic nature of Type 2 diabetes

- to be aware as soon after diagnosis as possible of opportunities to prevent and/or slow the development of the long term complications of diabetes through early diagnosis and treatment of diabetes.

OPTIMAL SERVICES

People will have access to high quality and appropriate early detection and case detection services

- People with risk factors for and/or signs and symptoms of diabetes will know where to go as a first step to have their symptoms investigated.
- Diagnostic tests will be performed according to best practice evidence. People will have ready access to information about the recommended approaches to diagnosis and screening.
- High risk groups, especially Aboriginal and Torres Strait Islander peoples and people from culturally and linguistically diverse backgrounds, will have access to diagnostic services appropriate to their needs.
- Particular attention will be given to the diagnosis and management of diabetes in special needs groups, especially people with mental illness.

People will have access to information about the manifestations of the disease and the importance of early diagnosis

- Accurate, consistent, evidence-based information about the early symptoms and signs of Type 1, Type 2 and gestational diabetes will be available in a variety of formats.
- Information will stress the importance of early diagnosis for improving long term health outcomes.
- Appropriate, tailored information will be available for people from disadvantaged groups, Aboriginal and Torres Strait Islander peoples and people from culturally and linguistically diverse communities.

RATIONALE FOR OPTIMAL SERVICES

Access to appropriate early detection and case detection services

Optimal services: People at high risk of diabetes or gestational diabetes will have access to services which will detect and treat their disease and advise them of future risks.

Detecting Type 1 diabetes early

Current consensus is that screening of any population for Type 1 diabetes should not occur outside the context of defined clinical studies.⁶⁶ Individuals who screen positive for genetic or immunological markers should have access to appropriate counselling and to organisations/centres participating in intervention and other defined studies.

Detecting Type 2 diabetes

In 2003, the World Health Organization (WHO) and the International Diabetes Federation convened a consensus meeting on diabetes screening. The report of the meeting⁶⁷ identified the following compelling reasons for detecting this disease:

- there is a long, latent, asymptomatic period in which the condition can be detected
- a substantial proportion of people with Type 2 diabetes are undiagnosed
- a substantial proportion of newly diagnosed cases of Type 2 diabetes already have evidence of the microvascular complications of diabetes
- the prevalence of Type 2 diabetes is rising worldwide
- the immediate effects and long term complications of Type 2 diabetes are serious
- the evidence supporting the efficacy of intensive blood glucose, blood pressure and blood lipid control in Type 2 diabetes, and accumulating evidence that treatment of hypertension and dyslipidaemia can prevent cardiovascular disease in people with Type 2 diabetes
- increasing pressure from professional organisations and lay groups to institute screening for Type 2 diabetes if only to further highlight the increasing prevalence and public health importance of the condition.

Early detection mainly occurs opportunistically, when individuals perceived to be at high risk of developing diabetes attend for health care (usually primary health care) for other reasons.

Research is needed to establish whether individuals will or will not benefit from the early detection of Type 2 diabetes through universal screening. However, there is direct evidence that the incidence of diabetes can be reduced in people at high risk of future development of Type 2 diabetes identified as a result of activities targeting diabetes detection.⁶⁷

Testing for Gestational Diabetes Mellitus

Women with GDM have an increased risk of adverse outcomes in pregnancy and increased risk of developing Type 2 diabetes later in life. The Australasian Diabetes in Pregnancy Society recommends that testing for GDM should be considered for all pregnant women. However, if resources are limited, testing may be reserved for those at highest risk.⁶⁸ Risk factors include:

- the presence of glucose in the urine (glycosuria)
- age over 30 years
- obesity
- family history of diabetes
- past history of GDM or glucose intolerance
- previous adverse pregnancy outcome
- belonging to an ethnic group with a high risk of GDM.

It is important that women with diagnosed GDM be counselled with regard to their increased risk of developing Type 2 diabetes later in life. They should be advised about the importance of eating a healthy diet, being physically active and staying within the healthy weight range to prevent or delay the progression to Type 2 diabetes. They should also be encouraged to present to their health care provider for regular testing to detect possible progression to Type 2 diabetes.

Case Detection

It is recommended that the following high risk groups be tested for undiagnosed Type 2 diabetes^{37,69}:

- people with impaired glucose tolerance or impaired fasting glucose
- Aboriginal and Torres Strait Islander peoples aged 35 years and over (or younger in areas where there is a high prevalence)
- certain high risk non-English speaking background groups aged 35 years and over (specifically Pacific Islander people, people from the Indian Subcontinent or of Chinese origin)

- people aged 45 and over who have either obesity (BMI \geq 30) and/or hypertension
- all people with clinical cardiovascular disease (myocardial infarction, angina or stroke)
- women with polycystic ovary syndrome who are obese.

Individuals presenting with the following risk factors are also considered to be at high risk of having undiagnosed Type 2 diabetes⁷⁰:

- women with previous gestational diabetes mellitus
- people aged 55 years and over
- people aged 45 years and over who have a first degree relative with Type 2 diabetes.

The WHO's criteria values for diagnosis of diabetes mellitus and other categories of hyperglycaemia are reproduced in Table 4 of the Appendix.

Aboriginal and Torres Strait Islander Peoples

In a study of the delivery of primary health care to Aboriginal and Torres Strait Islander peoples⁷¹, a number of barriers affecting access to quality health care and early diagnosis through mainstream systems were identified. They included:

- lack of provision and access to health services in rural, remote and outer urban areas
- poor linkages between the different parts of the health system
- lack of a population health focus
- a limited number and uneven distribution of health professionals with appropriate skills to address Aboriginal and Torres Strait Islander people's health issues
- poverty in the Aboriginal and Torres Strait Islander populations, which makes it harder to access private health care
- cultural and social factors such as cultural misunderstandings, poor communication and experiences of discrimination.

A national approach with the capacity to improve the responsiveness of the whole health system to the needs of Aboriginal and Torres Strait Islander people was introduced in the mid-1990s. One of the key strategies was to develop partnerships between the Australian, state and territory governments and the Aboriginal and Torres Strait Islander communities. In addition, there were substantial increases in government expenditure, which allowed for increases in health services and programs, including mainstream programs. It is important that appropriate resources are allocated to build on current achievements and to address the barriers mentioned above.⁷¹

People from cultural and linguistically diverse backgrounds

A recent review⁷² confirmed that cultural diversity has a negative impact on access to services and information. Cultural barriers affecting adherence to self-management recommendations included:

- language barriers and literacy rates
- culturally specific beliefs and attitudes
- lack of access to appropriate culturally specific care
- attitudes of health professionals
- lack of acculturation
- effects of stigmatisation
- financial barriers.

Successful models of health care for people from culturally diverse non-English speaking backgrounds produce successful outcomes when their culturally specific needs are addressed.

CHAPTER 4: Best Care and Support in the Early Stages

OVERVIEW

Unlike other chronic diseases, diabetes places extraordinary responsibility on people with the disease for daily management of a rigorous treatment regimen. At the same time, people with diabetes face the ever present possibility of developing one or more of the short or long term complications of their illness, as well as a reduced life expectancy. Some people will already have complications when diagnosed. Not surprisingly, when diabetes is diagnosed people and their families may experience considerable stress, anxiety and confusion about the implications of the disease and may need some time to overcome this.⁷³

During the early stages of diabetes, people need high quality information about the disease and their treatment options; timely access to evidence-based interventions and multidisciplinary health care teams; and information, support and resources to manage self-care tasks, and the psychological, social and financial impact of the disease. Ideally, care and support during the early stages of diabetes will aim to empower people to take responsibility for their self-management and to engage actively in their care and perform the lifestyle behaviours necessary to reduce their chance of developing the short and long term complications of diabetes. The importance of the link between people with diabetes, self-management and the care provided by their general practitioners and other relevant health care professionals cannot be understated.^{73,74}

People need to be confident that they are receiving effective and reliable care from providers across the health care system. People with diabetes should be supported to make the lifestyle changes that will prevent the progression of their disease.

Access to affordable and effective monitoring equipment and medications is essential. The NDSS is a key government program which provides subsidised access to syringes, needles, blood glucose test strips and insulin pump consumables.

PEOPLE'S NEEDS

To ensure the best care and support during the early stages of diabetes, people want and need:

- information about their condition, treatment options and the support and resources necessary to assist lifestyle modification and active participation in self-management of their day to day health care needs; this will include information about supportive care services and entitlement to financial assistance for costs associated with treatment; and self-testing and administration of medication
- timely access to high quality, evidence-based and person centred care from a diabetes team comprising doctor(s), diabetes nurse educator(s) and dietitian(s) with experience in managing diabetes; podiatrists, social workers, psychologists and other relevant allied health professionals should also be accessible, as required

- opportunities to prevent the long term complications of diabetes through early detection and follow up
- access to reliable information on medicines.

OPTIMAL SERVICES

People will receive information about their condition and have access to education, support and resources to help them participate actively in their care and improve their lifestyle behaviours and health status

- People with diabetes and their families and carers will receive high quality information about their condition, treatment options, medicines and opportunities to slow disease progression.
- Information will be tailored to the cultural, language and literacy needs of people with diabetes, their families and carers.
- People will have access to the education and training they require to help them self-manage their daily health care needs and make the lifestyle changes necessary to improve long term outcomes.
- People who smoke will have access to cessation programs that are affordable and appropriate to their needs.
- People will have access to affordable equipment (test strips, needles, and syringes) through the NDSS to aid self-management of their diabetes.

People with diabetes will be confident that their treatment is consistent with the best available evidence

- There will be agreed national clinical practice guidelines describing the diagnosis and management of diabetes and its complications.
- Services will have local protocols for the treatment and support of people with diabetes based on agreed national clinical practice guidelines or, in the absence of such guidelines, based on the best available evidence.
- Audit systems will collect information about the care of people with diabetes. These will enable evaluation of the extent to which care is consistent with guidelines, evidence and/or local protocols. Information from the audit will be provided to treatment teams and used to develop quality improvement programs.
- People with diabetes will have access to information about the guidelines and/or protocols used by their service providers.
- Health professionals will have access to up to date information and continuing information about diabetes care.
- There will be appropriate and high quality use of medicines.

Systems will be in place to ensure the prevention, early detection and follow-up of diabetes complications

- Services need to have as a primary focus the prevention of complications in people with diabetes.

- People with diabetes will receive regular assessment for the long term complications of diabetes. In particular, people will be assessed for
 - *Disease in the small blood vessels (microvascular disease) and large arteries (macrovascular disease)*. Assessment will include palpation of peripheral pulses and auscultation for carotid bruits, and a resting electrocardiogram (ECG) every two years in asymptomatic people over 50 years of age with at least one cardiovascular risk factor, annual assessment of fasting lipid profile.
 - *Diabetic eye disease (retinopathy)* every two years or annually for people at high risk of diabetes complications. Assessments will be conducted by a general practitioner, optometrist, ophthalmologist or physician and will involve dilated fundus examination, combined with a visual acuity assessment.
 - *Kidney disease (diabetic nephropathy)*. This should involve annual testing for the presence of microalbuminuria commencing at the time of diagnosis for people with Type 2 diabetes and no more than five years after diagnosis for people with Type 1 diabetes; and measurement of serum creatinine and glomerular filtration rate where appropriate.
 - *Nerve damage (diabetic neuropathy)*, which typically manifests as aching pain and burning in the legs and feet, but may also be present in cases of double vision, drooping eyelids and weakness and atrophy of the thigh muscles. People with reduced protective sensation or reduced foot pulses on examination should be assessed at least annually by a podiatrist.
- People will be educated about the importance of daily foot care for preventing injuries to the skin and joints in the foot.
- Diagnosis of diabetic retinopathy will be improved by providing practitioners with regular and appropriate education and more frequent practice.
- Strategies will be in place to support and encourage involvement of chronic disease workers, including Aboriginal health workers, in community based screening for the complications of diabetes. Links will be established and fostered between Aboriginal and Torres Strait Islander communities and the nearest accessible screening services.
- People who develop long term complications of diabetes will receive timely, appropriate and effective investigation and treatment to reduce their risk of disability and premature death.

Children and adolescents with diabetes will have access to patient-focused services that encourage partnerships in decision making, support them in managing their own diabetes and help them to adopt and maintain a healthy lifestyle by:

- identifying people with diabetes as the critical managers of their own disease (when appropriate)
- improving interactions between people with diabetes and health care providers to enhance adherence to treatment protocols
- monitoring physical and emotional status and making appropriate management decisions on the basis of self-monitoring
- managing the effects of diabetes on the person's ability to function in important roles and on emotions, self esteem and relationships with others
- ensuring the availability of appropriate services and protocols to support a smooth transition from paediatric to adult care.

RATIONALE FOR THE COMPONENTS OF OPTIMAL SERVICES

People will receive information about their condition and have access to education, support and resources to assist self-management

Optimal services: People will have access to appropriate self-management strategies, including education programs, to assist them in developing the knowledge, skills and confidence to attend to their daily care and support needs. Programs and services will be available in the community to help people adopt and maintain a healthy lifestyle. Health professionals and other care providers will be aware of the services available in their community.

Self-management

Diabetes is a condition that can affect almost every aspect of a person's life. Self-management is the cornerstone of diabetes care, and describes the health activities undertaken by individuals with diabetes to manage their condition, including daily management, physical activity, improved nutrition, interaction with health care and support services, behaviour and role adaptation, and management of the psychosocial aspects of living with a chronic illness. When people with diabetes are able to be involved actively in their self-care, achievable outcomes include improved health status (e.g. reduced blood glucose levels with no increase in severe hypoglycaemic attacks), a marked improvement in quality of life, reduced depression and anxiety, a significant increase in satisfaction with treatment, and reduced utilisation of health services.^{69,75} There are many barriers and difficulties in achieving the recommended standards of self-care.

Effective self-management of diabetes is best supported by an evidence-based and collaborative approach to care in which health professionals work in partnership with people with diabetes to encourage and support them to take control of and assume increased responsibility for their health. The principles of self-management need to be embedded in the health system to further encourage innovation within the broader paradigm of the person centred approach.⁷⁶

A range of behaviours are targeted by a broad range of evidence-based self-management interventions, including healthy eating, Tai Chi, weight loss, exercise groups, financial advice, parenting and carers training, and Men's Shed support programs. These interventions are provided by a range of public and private sector agencies and non-government organisations (NGOs). The NGOs, in particular, need a level of support in terms of communicating the evidence for self-management and quality control infrastructure.⁷⁶

Self-management is a major focus of the Australian Government's Sharing Health Care Initiative, which aims to improve the quality of life of people with chronic conditions. The initiative comprises demonstration projects testing a range of chronic condition self-management models, including Indigenous specific projects, and education and training of health professionals and people with chronic conditions. To support the demonstration projects, guidelines on self-management have been developed for general practitioners and other health professionals, and education and training support are being provided in the form of a postgraduate education module and training programs on chronic conditions for health professionals and other care providers. As part of the initiative, work is underway to develop self-management education programs that are culturally appropriate and designed for delivery in Indigenous communities. A national evaluation of the Sharing Health Care Initiative is underway.

Diabetes self-management education

Diabetes self-management education aims to inform and teach people with diabetes, their families and carers about how to manage their lifestyle and medication and improve their long term health and quality of life. Education needs to be adapted to each individual's age, maturity, stage of diabetes, lifestyle, level of literacy and culture. Topics may include:

- pathophysiology of diabetes, i.e. the functional changes associated with a particular type of diabetes
- using medications for therapeutic effectiveness
- physical activity
- nutritional principles
- psychosocial adaptation—adjusting to work, family and social roles, and changing from children/adolescent services to adult services
- monitoring blood glucose results, and possibly ketones
- managing high and low blood glucose levels
- managing special events such as sick days and travel
- minimising risks of diabetes complications
- alcohol and other drugs, including tobacco
- health education across the lifespan, e.g. pre-pregnancy planning.

In Australia, diabetes education is provided by a range of health professionals such as general practitioners, endocrinologists/diabetologists, diabetes educators, dietitians, podiatrists, pharmacists and optometrists.

The ADEA has developed standards and processes that enable educators to be recognised as certified or credentialed providers of diabetes education. Most credentialed diabetes educators are nurses or dietitians, although some are physicians and podiatrists.

The Royal Australian College of General Practitioners *Guidelines for Diabetes Management in General Practice* and the ADS's *Guidelines for the Management of Type 2 Diabetes* both suggest that all people newly diagnosed with diabetes should be referred to allied health professionals such as diabetes educators, dietitians, podiatrists and optometrists. Despite this, the AIHW found that in 2000–0177 only 27.9% of people newly diagnosed with Type 2 diabetes were referred on to other professionals by their general practitioner. Of these, only 4.0% were referred to a diabetes educator and 5.1% were referred to a dietitian. There are several possible explanations for these figures, including general practitioners not being aware of the guidelines or disagreeing with them, or services not being available in their local areas. Research into barriers to compliance with the guidelines could assist in improving referral rates.

Access to education services is an ongoing issue for people with diabetes. Colagiuri and Goodall 2004⁴² suggested that '...diabetes education and information should be structured to meet needs as they change in tandem with changes to the stage of life cycle and the physical and psychological impact, and changes to self care requirements associated with different stages of the diabetes disease process.'

Diabetes education resources

Education resources are generally developed to meet the needs of defined target groups or populations, rather than the needs of particular individuals.

Studies show that people with diabetes view other people with diabetes, diabetes specialists, diabetes centres and diabetes specific organisations such as Diabetes Australia

as credible sources of information on diabetes and the associated complications. Other sources include general practitioners, friends and family, pharmacists and the Internet.^{42,78}

Material from such a vast range of sources is likely to differ in quality and consistency. The report *Information & Education For People With Diabetes: A Best Practice Strategy*⁴² was released in 2004 and provides a practical evidence-based strategy to deal with this.

Psychosocial support

The National Survey of Mental Health and Wellbeing, conducted in 1997, revealed that overall about 2.4 million Australian adults experienced some form of mental illness in the previous year, and that almost 6% of Australians experienced depressive disorders in the course of one year.⁷⁹

Depression and anxiety disorders are more prevalent in people with diabetes mellitus^{80,82} than the population generally. The prevalence of major depressive disorder in people with diabetes diagnosed by structured clinical interview ranged from 8.5% to 27.3% in four controlled studies, and 11.0% to 19.9% in five uncontrolled studies. It has also been suggested that depression might have a more severe course in people with diabetes mellitus than in the general population, as studies have shown that people with diabetes are eight times more likely than the general population to have a relapse of depression. Diabetic complications were consistently significantly associated with depression in people with diabetes.⁸³

Depression is a significant problem for people with diabetes and can affect quality of life, motivation to adhere to treatment and, in extreme cases, contribute to death from unsatisfactory management of blood glucose levels. Norris et al.⁸⁴ systematically reviewed the effectiveness of self-management training in adults with diabetes. They noted that studies had shown a positive effect of self-management training on anxiety levels, as well as on metabolic variables.

There is a strong consensus that general practitioners and other healthcare workers should receive further training in recognising the clinical signs of depression. A further high priority for people identified as depressed is increasing access to treatment for depression by psychologists and psychiatrists.

The Better Outcomes in Mental Health Care Program aims to improve the quality of and community access to primary mental health services by supporting general practitioners when they are providing services to people with mental health problems.

The program has five integrated components:

1. Education and training for general practitioners—to familiarise them with the program and increase their mental health skills and knowledge.
2. The 3 Step Mental Health Process—which rewards best practice primary mental health care through assessment, care planning and review.
3. Focused Psychological Strategies—which provides general practitioners with remuneration through the Medicare Benefits Schedule for the provision of evidence-based psychological therapy.
4. Access to Allied Psychological Services—to enable general practitioners registered with the program to access focused psychological strategies from allied health professionals to support their patients with mental health problems.
5. Access to psychiatrist support—which supports psychiatrists to work collaboratively with general practitioners through case conferencing and provides them with access to patient management advice from psychiatrists through the general practitioner Psych Support service.

The Better Outcomes in Mental Health Care Program has established an approach to effectively support general practitioners to provide more comprehensive care to patients with high prevalence mental health disorders. The highly successful program has resulted in increased general practitioner knowledge of and skills in managing mental health problems—around 20% of all general practitioners have undertaken education and training to increase their mental health skills and knowledge in order to participate in the program. The program has provided remuneration to general practitioners for best practice management of mental health problems, which has resulted in general practitioners spending more time with patients experiencing mental health problems.

The Australian Government has reaffirmed its commitment to primary mental health care through the continuation and expansion of the Better Outcomes in Mental Health Care Program to 2008-09. Expansion of the program will give priority to the successful Access to Allied Psychological Services component and to ensuring the quality of the program is maintained. Increased access in rural and remote areas will also be a focus of the program.

Patient support or peer support groups will also be important tools for addressing low level depression and anxiety in people with diabetes.

Access to an environment that supports a healthy lifestyle

Maintaining a healthy diet, being physically active and not smoking are key elements of diabetes management. A supportive environment is imperative to ensure adherence to positive lifestyle behaviours.

Smoking is a well documented risk factor for ill health in general and is a major contributor to diabetes related microvascular and macrovascular complications. Individuals who smoke should be encouraged to stop.

The National Tobacco Strategy⁸⁵ provides a strong evidentiary basis for a number of strategies framed around six themes:

1. financial disincentives for smoking
2. limitations on tobacco advertising
3. labelling of tobacco products
4. sales to minors
5. school based programs
6. promoting cessation of tobacco use.

Environments to support healthy eating and physical activity have been addressed previously in Section 3.3.2 Environments to reduce diabetes risk.

Access to equipment

The NDSS is an initiative of the Australian Government administered by Diabetes Australia. Its aim is to enhance the capacity of people with diabetes to understand and manage their life with diabetes and to ensure they have timely, reliable and affordable access to the supplies and services they require to effectively self-manage their condition. It provides blood and urine testing strips, syringes, needles and insulin pump consumables at subsidised prices to people who register for benefits. Needles and syringes are effectively free to NDSS registrants throughout Australia, due to the support of the relevant state and territory governments who have agreed to meet the registrant co-payment costs incurred.

Those eligible to register for the NDSS are people residing in Australia who have been diagnosed with diabetes by a medical practitioner and hold a current Australian Medicare card or Department of Veteran Affairs file number.

The NDSS distributes products through a network of more than 1100 outlets throughout Australia, a majority being community pharmacies. Purchases can also be made by mail, telephone, facsimile or e-mail, which allows people in rural and remote locations or people who have mobility or communication difficulties to gain access to the products and services they need. The total number of NDSS registrants is in excess of 650 000.

Diabetes Australia has recently conducted a survey of the usage of the NDSS. A number of issues were identified, including lower than expected awareness of the scheme, even among registrants, and there was a perception that general practitioners did not provide enough information about the NDSS to people diagnosed with diabetes. The survey also revealed that people with diabetes accessed products from other sources such as doctors/pharmacists, health clinics and family members. Some of those surveyed appeared to be confused about their type of diabetes and some even advised that they no longer had diabetes. Diabetes Australia is currently reviewing the survey results and will develop a strategy to address the identified issues.

Access to reliable information on medicines

Access to reliable, up-to-date information is crucial when it comes to health matters. In 1993, the NHMRC published guidelines for health professionals on providing information to consumers; the guidelines were reviewed and updated in 2004.⁸⁶ Consumer Medicine Information (CMI) is available for many prescription and pharmacist only medicines, and can be obtained from a range of sources. It is produced by the pharmaceutical company that makes the particular medicine and is designed to provide consumers with standardised information such as dosage, contraindications, and possible adverse effects and risks relevant to the particular medicine.

To ensure widespread distribution of this information, consumers should be encouraged to ask for the CMI when medication is prescribed for them, or when it is dispensed. At present the information is only available in English. While research suggests that people may find it better to receive the information in English than not at all, there is an opportunity to develop strategies which address this.

The National Strategy for Quality Use of Medicines recognises that access to information about medicines play an important role in maintaining health, preventing illness and curing disease.⁸⁷ The National Prescribing Service is a source of independent, balanced, evidence-based information about medicines. It is available to health professionals and consumers through a number of avenues, including the Internet.

People obtain health information from a range of sources, which raises the issue of the quality of the information. Health care professionals play a key role in guiding consumers to quality information.

People will be confident that their treatment is consistent with the best available evidence

Optimal Services: People with diabetes will be confident that they are being treated according to the best available evidence and agreed national clinical practice guidelines. People with diabetes will have access to information about the guidelines and/or the protocols used by their service providers.

A suite of evidence-based clinical guidelines for diabetes care is currently available on the Diabetes Australia and NHMRC websites. The guidelines have been produced by multiple systematic searches of the international literature, reviewing the literature and grading the relevant articles, and synthesising the information into guideline recommendations. The guidelines address: primary prevention, case detection and diagnosis, blood pressure control, macrovascular disease, diabetic foot problems, lipid control, diabetic renal disease, blood glucose control, and patient education.

People will receive regular assessment for the long term complications of diabetes

Optimal Services: People with diabetes will receive regular assessment to prevent or delay the onset of long term microvascular and macrovascular complications based on latest evidence and consistent with agreed national clinical practice guidelines.

Preventing macrovascular complications

Attempts to reduce the onset and progression of the macrovascular complications of diabetes, including myocardial infarction, stroke and peripheral vascular disease, most frequently target four modifiable risk factors.

Blood glucose control

The United Kingdom Prospective Diabetes Study (UKPDS) is, to date, the largest and longest prospective randomised trial in people with Type 2 diabetes. Data derived from the UKPDS show that, on its own, intensive blood glucose control (i.e. maintenance of blood glucose levels as near to normal as possible) with sulfonylurea or insulin has only a moderate tendency to significantly reduce macrovascular complications.⁸⁸

The failure of the UKPDS to demonstrate a benefit for macrovascular complications of intensive control using a sulfonylurea or insulin may reflect the study design or the limitations of the medications themselves. Although sulfonylurea and insulin initially reduce glycosylated haemoglobin (HbA1c) levels, neither prevents a subsequent inexorable rise in blood glucose over time. Newer medications such as thiazolidinediones ('glitazones') target insulin resistance and may reduce HbA1c levels for a longer duration.

Hypertension

Fifty per cent of people with Type 2 diabetes have hypertension (blood pressure > 140/90 mmHg).⁸⁹ Hypertension is less common in Type 1 diabetes but remains an important modifiable risk factor.⁹⁰

As blood pressure levels increase in people with diabetes there is a parallel increase in cardiovascular disease, diabetic retinopathy and nephropathy.⁸⁹ Randomised trial evidence demonstrates clear benefits for people with diabetes from lowering blood pressure. For example, the UKPDS showed that 'tight' blood pressure control with angiotensin-converting enzyme (ACE) inhibitors or β -blockers significantly reduced diabetes related events and diabetes related deaths.⁹⁰ In fact, the benefit of treating hypertension exceeded the benefit of treating hyperglycaemia.

Achieving lower blood pressure targets reduces macrovascular complications. The Hypertension Optimal Treatment Study found that the optimal diastolic blood pressure was 82.6 mmHg. Trials have been unable to define an optimal lower limit of blood pressure, as lower pressure is associated with lower risk even within the normal range.⁸⁹ The recommended blood pressure target for individuals with diabetes is now \leq 130/80 mmHg.

Dyslipidaemia

Colagiuri and Best 2002⁹¹ reviewed recent population studies of lipid-lowering therapy and cardiovascular disease outcomes that included people with diabetes and performed a separate subgroup analysis. Lipid lowering with statins and fibrates was found to be effective in improving cardiovascular disease outcomes in people with diabetes, and their effectiveness is similar to that in the population without diabetes. This effect is well established in secondary prevention and is accumulating for primary prevention.

People with diabetes require aggressive management of dyslipidaemia as part of an overall management strategy to reduce the risk of cardiovascular disease. Access to appropriate and timely medication is important and the PBS restrictions are reviewed on an ongoing basis.

Smoking

Research has shown that tobacco smoking is associated with both microvascular and macrovascular complications of diabetes.^{92,93} Smoking cessation reduces the risk of diseases such as cardiovascular disease and stroke⁹⁴, thus it would be reasonable to suggest that stopping smoking has the potential to reduce these complications.

A review summarising the efficacy and cost effectiveness of smoking cessation approaches found that whilst the general cessation literature was extensive there was limited information relating to diabetes and cessation.⁹⁵ However, the authors felt that there was no reason to believe that cessation would be more or less successful in this population. Given that smoking is an aggravating factor for diabetes complications, people with diabetes who smoke should be counselled and provided with appropriate support to quit.

In 2004, 17.4% of Australians (approximately three million) aged 14 years and over smoked daily and 3.2% (approximately 530 000) smoked less than daily.⁹⁶ As smoking is well documented as a risk factor for ill health generally, and is a major contributor to diabetes related macrovascular and microvascular complications, individuals who smoke should be encouraged to stop.

Recent data shows that 45% of all Aboriginal and Torres Strait Islander peoples aged 14 years and over reported being daily smokers, compared to 17.4% of other Australians.⁹⁷ It is imperative to harness Australia's knowledge and skills in tobacco control to identify and implement specific measures which will address this gap.

Multifactorial and absolute risk approaches

Other trials have confirmed the benefit for people with diabetes of adopting a multifactorial approach to the prevention of macrovascular complications. This approach involves combining behaviour modification with pharmacological therapy targeting hyperglycaemia, hypertension, dyslipidaemia and microalbuminuria, plus low dose aspirin. It simultaneously targets blood glucose, blood pressure, lipid levels and the propensity for thrombosis in diabetes.

For example, a recent study found that a multifactorial approach reduced cardiovascular events, as well as diabetic nephropathy and retinopathy in high risk people with diabetes.⁹⁸ There was no way of knowing, however, which component of the package of interventions yielded the greatest benefit.

The same study also highlighted the limitations of current therapies. For example, blood glucose targets were achieved in only 15% of people with diabetes, and smoking cessation advice was ineffective in both groups. In contrast, lipid and blood pressure targets were achieved by more than half of the intensive multifactorial treatment group. Even greater benefits may be possible if newer treatments could achieve these targets more often.

Data from the UKPDS has been used to develop a *Risk Engine* to predict absolute risk of coronary heart disease using blood glucose, systolic blood pressure and lipid levels, as well as age, sex, ethnicity, smoking status and length of diagnosis of diabetes.⁹⁹ Absolute risk assessment has the potential to assist in setting thresholds for the prescribing of lipids and blood pressure medications, particularly when it is tailored to the needs of specific sub-groups including Aboriginal and Torres Strait Islander populations and those from culturally and linguistically diverse backgrounds.

Preventing microvascular complications

The mechanisms of microvascular disease are complex and include the effects of hyperglycaemia, tissue glycosylation and oxidation. Hypertension is another factor which exacerbates microvascular disease. Data from trials over the past 10 years show that controlling hyperglycemia and hypertension reduces microvascular complications in both Type 1 and Type 2 diabetes. Microvascular complications seldom occur in isolation; they include the following.

Diabetic nephropathy

Diabetic nephropathy is caused by damage to the small blood vessels in the kidney, which filters waste material from the blood. Diabetes is currently equal with glomerulonephritis as the most common reason for entering renal replacement therapy in Australia, rising from 6 to 26% over the past 20 years.¹⁰⁰

Between 20% and 30% of people with diabetes have evidence of overt diabetic nephropathy, defined as persistent clinically detectable proteinuria (i.e. high levels of protein in the urine in association with hypertension and reduced glomerular filtration rate¹⁰¹). Prevalence rates of nephropathy are especially high in Aboriginal and Torres Strait Islander peoples, New Zealand Māori and South Pacific Islanders, placing these groups at particularly high risk of end-stage renal disease (ESRD).

The earliest sign of renal disease in people with diabetes is the presence of increases in urinary albumin excretion, termed microalbuminuria (urinary albumin excretion rate, 30–300 mg/24 h or 20–200 µg/min; or albumin–creatinine ratio > 2.5 mg/mmol in men and > 3.5 mg/mmol in women). Recent survey results indicate that only 50% of people with Type 2 diabetes are having the right tests done to detect early kidney damage¹⁰², and only slightly over one-quarter of people with significant complications known to accelerate kidney disease progression (e.g. hypertension) are being treated effectively.¹⁰³

Of the anti-hypertensive medications, ACE inhibitors and angiotensin II receptor antagonists have shown the most positive effects on diabetic nephropathy. In Type 1 diabetes, ACE inhibitors reduce the progression of microalbuminuria to macroalbuminuria, and the decline in glomerular filtration rate in those with macroalbuminuria.^{104,105} ACE inhibitors also reduce micro-vascular complications in Type 2 diabetes and hypertension. More recently, trials have shown that angio-tensin II receptor antagonists reduce the rate of progression of microalbuminuria to macroalbuminuria and the rate of decline in glomerular filtration rate in overt nephropathy in this patient group.¹⁰⁶⁻¹⁰⁸

Although the weight of trial data supports the use of ACE inhibitors in both types of diabetes, and angiotensin II receptor antagonists in Type 2 diabetes, large trials comparing these anti-hypertensives have not been conducted. Small trials suggest that the combination of an ACE inhibitor and angiotensin II receptor antagonist may have an additional renoprotective effect.¹⁰⁹

There are limited data on diabetic kidney complications among Aboriginal and Torres Strait Islander peoples although data from the ANZDATA Registry indicate that the yearly incidence of ESRD associated with diabetes is considerably higher among these population groups. During 2000, 46% of Aboriginal and Torres Strait Islander people had diabetic nephropathy, compared to approximately 14% in other Australians.¹¹⁰ Due to poorer access to dialysis and transplant programs the problem of ESRD in Aboriginal and Torres Strait Islander people is likely to be underestimated.^{110,111}

Peripheral neuropathy

Peripheral neuropathy is caused by damage to the nerve fibres of the peripheral nerves and typically manifests as aching pain and burning, especially in the legs and feet. With longer duration of disease, people with diabetes may develop painless peripheral neuropathy as the involved neurons are destroyed and sensation is lost. This diminished sensory perception often leads to unperceived injuries to the skin and joints, causing calluses, ulceration and in some cases gangrene which can lead to the need for amputation.¹¹² In fact, foot ulcers and amputations are a major cause of morbidity for people with diabetes, with more than half of all lower-limb amputations in this group being preventable.

Controlling hyperglycaemia and hypertension and identifying patients with peripheral neuropathy or peripheral vascular disease are the mainstays of preventing foot complications. Annual screening for these conditions is recommended. People with reduced protective sensation or reduced foot pulses on examination should be assessed by a podiatrist, and all patients should be educated about daily foot care (inspection, washing

and careful drying, moisturiser for dry skin and cracked heels, nail-care and use of practical footwear). Particular care should be taken with new footwear.

Retinopathy

Diabetic retinopathy is the leading cause of blindness in the adult population.¹¹³ In Type 1 diabetes, almost all people develop signs of retinopathy in the first 20 years. In Type 2 diabetes, up to a third of people have retinopathy at diagnosis¹¹⁴, increasing to two-thirds within 20 years.

There is limited data on the prevalence of diabetic retinopathy in Aboriginal and Torres Strait Islander peoples, although there is some evidence to suggest the rates for these population groups are higher than in those for the general population.¹¹⁵

In the earliest stages of diabetic retinopathy, the characteristic abnormality is increased vascular permeability. Without treatment, microvascular occlusions occur, resulting in retinal ischaemia and, eventually, the growth of new vessels—termed proliferative retinopathy. Macular oedema, caused by increased vascular permeability around the macula, may occur at any stage.

The longer the duration of diabetes, the greater the risk of diabetic retinopathy. The most important treatable risk factors are hyperglycaemia and hypertension, although the benefit of good glycaemic control appears to be greatest in the early stages of the disease.¹¹⁶

Once retinopathy is established, it may be treated with laser photocoagulation, which usually prevents further progression and loss of vision but generally does not restore vision. For proliferative and severe non-proliferative retinopathy, pan-retinal laser photocoagulation is used. Clinically significant macular oedema is treated with focal laser photocoagulation therapy.

The NHMRC guidelines for the management of diabetic retinopathy (1997)¹¹⁷ are currently being updated.

Foot care

Foot problems are the most common cause of hospitalisation for people with diabetes. At the Royal Melbourne Hospital it is estimated that approximately 25% of inpatients have diabetes and of these 20% have active foot problems.^{118,119} The costs of treatment, the preventable nature of many presentations, and the importance and effectiveness of education make foot care in diabetes a service improvement priority.

In 1998, the National Diabetes Strategy and Implementation Plan⁴² identified foot care as a major issue for diabetes management. The aims of the program included a 50% reduction in lower limb amputation by 2005 and an 80% level of screening for diabetes related foot disease risk factors each year.

The NHMRC's *Evidence Based Guideline for Detection and Prevention of Diabetes Foot Problems*¹²⁰ has been drafted in early 2005. Key recommendations include routine assessment for foot problems in people with diabetes. This should occur at a minimum once a year for those without established problems, and quarterly or half-yearly for those with 'at-risk' feet but without a current active problem. Also, people with diabetes should receive specific education relating to foot care.

For optimum outcomes a multidisciplinary team approach should be used in the treatment and management of diabetes related foot complications. People with diabetes therefore need timely access to physicians, podiatrists, specialist nurses, orthotists, surgeons and other relevant health professionals according to their individual requirement.

Detection and assessment

Diabetes complications screening is now established practice in many diabetes centres, and is linked with improved risk factor profiles for people with diabetes.¹²¹⁻¹²³ Complications screening is encouraged in general practice through the NIDP in the form of a 'cycle of care' linked to a Health Insurance Commission payment. The uptake of these payments has been higher¹²⁴ in general practitioner divisions with larger practices, high socioeconomic need and information technology support.

Evidence suggests that screening rates may differ for the different complications of diabetes. For example, the Australian Diabetes Obesity and Lifestyle Study¹²⁵, found that retinopathy screening is performed more frequently than foot screening, and concluded that 'foot screening appears to be poor, with less than one-half of the population reporting a regular examination for foot complications'.

In the case of retinopathy screening, it is also the case that there is wide variation in screening methods performed by different screeners for detecting the various retinal lesions. The sensitivity of retinopathy screening is substantially enhanced if the pupils are dilated, without significant discomfort or side effects, but with an increased examination time.

Jackson et al.¹²⁶ found that, prior to completing an upskilling program, only 24% of general practitioners met the NHMRC diabetic retinopathy screening criterion. This figure rose to 94% following the program. This finding shows the benefits of brief training interventions for improving the quality of general practitioner screening. It suggests also that Australian general practitioners are capable of a much more significant role in community screening for diabetic retinopathy, to allow early identification of treatable disease. This is in line with the NHMRC guideline which states that people with diabetes should request a yearly or two-yearly eye examination to screen for diabetic retinopathy.

Screening and treatment programs for microalbuminuria and macroalbuminuria (with and without kidney insufficiency) have been shown to be cost effective, since screening is inexpensive, treatment is affordable, and the potential cost savings of reducing the number of people requiring renal replacement therapy are high.¹² A recent review of available level I and level II evidence confirmed that the progression of chronic kidney disease (CKD) can be slowed by adequate blood pressure control, administration of statins, cessation of smoking, correction of uraemic anaemia with erythropoietin, glycaemic control, and early referral to a renal unit providing multidisciplinary patient education.¹²⁷ Not only does the early diagnosis of and appropriate therapeutic intervention provide the greatest opportunity for the preservation of kidney function, but many of the known complications of CKD, such as hypertension, osteodystrophy, anaemia, sleep apnoea, cardiovascular disease, hyperparathyroidism and malnutrition, are often already evident at mild levels of CKD.¹²⁷

Children and adolescents with diabetes will have access to patient-focused services that encourage partnerships in decision making, support them in managing their own diabetes and help them to adopt and maintain a healthy lifestyle.

Optimal Services: Children and adolescents with diabetes will have services that cater to their specific needs. Particular attention will be given to needs resulting from transferring to adult services.

Different issues arise for people with diabetes at different ages, and children and adolescents with newly diagnosed diabetes need expert care that reflects an understanding of their unique needs.

Systematic reviews show no advantage of inpatient versus ambulatory care for stabilisation of diabetes.¹²⁸⁻¹³⁴ Care of children and adolescents by a multidisciplinary team has been shown to result in fewer days in hospital, higher levels of diabetes self-care, decreased admission rates, better glycaemic control and delayed onset of complications.¹³⁵⁻¹⁴⁰

In children newly diagnosed with diabetes the frequency of DKA is 16–80%, depending on geographic location.¹⁴¹ It is the leading cause of morbidity and the most common cause of death in children and adolescents. The commonest cause of death is cerebral oedema, and the risk factors for this condition are poorly understood¹⁴², but include newly diagnosed diabetes, younger age, dehydration and severe acidosis.

Specialist medical and nursing staff should be involved in the management of DKA in children and young people.¹⁴³ Clinical units treating these children should have clear written guidelines and access to laboratories which can provide frequent and accurate biochemical variables.¹⁴⁴

After an initial period of stabilisation the child should be regularly reviewed in relation to growth, blood pressure, the onset of puberty and nutrition.^{143,145,146}

For a given level of HbA1c, adolescents experience more severe hypoglycaemia than adults.¹⁴⁷ The physiological changes of growth and puberty demand intensive management if possible for children and adolescents with Type 1 diabetes. Suboptimal control has long term effects on risk of vascular complications which cannot be reversed by improved control in adult life.¹⁴⁸

Psychosocial morbidity is increased in children with diabetes^{149,150}, as it is in other chronic conditions.¹⁵¹ Treatment regimes are often difficult to accept and create difficulties for many children in relation to independence and autonomy. Psychological difficulties are associated with poor control of diabetes.¹⁵²⁻¹⁵⁶ Coping skills training is one of many rigorous interventions found to confer some benefits in mental wellbeing and glycaemic control.^{157,158}

Adolescents have specific needs related to the physical, emotional, psychological sociocultural stages of adolescence.^{144,159} They are less likely to adhere to prescribed care and have poor glycaemic control.¹⁶⁰ The Society for Adolescent Medicine has outlined some principles for a successful transition to adult care.¹⁶¹ These principles are reiterated in the NHMRC Clinical Practice guidelines: Type 1 diabetes in children and adolescents 2005.

The formal transition to adult care should occur at a time of relative stability in an adolescent's health and should synchronise with other important transitions such as leaving school or entering the workforce.¹⁶²

Ideally the transfer should be staged into a preparation and then a formal transition stage. The latter formal stage should be facilitated by the adult diabetes service and involve letters of referral and a documentation of past history. Clear directions for accessing emergency services should be given (as outlined in the NHMRC clinical guidelines referred to above).

CHAPTER 5: Best Long Term Care and Support

OVERVIEW

In the absence of a cure for diabetes, people with the condition rely for their survival on frequent interactions with a range of health professionals, including general practitioners, diabetes specialists, diabetes educators, podiatrists, psychologists and other allied health and community care workers, for the duration of their illness. People with diabetes will also often require care for other health problems (i.e. co-morbidities). The provision of ongoing and multidisciplinary care presents a significant challenge to the current system of health service delivery that has evolved to focus predominantly on people with temporary or acute health needs and acute episodes of care, often provided by a single health professional.

The WHO has outlined a number of generic principles for the effective management of chronic health conditions based on a review of innovative best practice and affordable models of care. These principles are: comprehensive, evidence-based care coordinated across care providers and settings; education and support for people to manage their own conditions and to enhance concordance with effective, accessible interventions; enhanced flow of knowledge and information between people with diabetes and care providers, and across care providers; partnerships between health services and resources in the community; and monitoring and evaluating the quality of services and health outcomes.¹⁶³

PEOPLE'S NEEDS

To ensure the best care and support in the long term, people with diabetes need:

- access to seamless and coordinated health care
- information and support to enable them, when appropriate, to take lead responsibility in decision making, participate fully in self-management of their diabetes, and prevent short and long term diabetes complications
- strategies to prevent crisis situations and unplanned and unnecessary admission to hospital
- continuity in the use of medicines between episodes of care
- optimal management during intercurrent illness, surgery or other episodes of acute care
- health service infrastructure and systems to assist clinical decision making, improve the quality of care and ensure continuity of care
- access to health professionals to assist with psychosocial issues, when required
- access to high quality palliative care at the end of life
- access to acceptable, accountable and appropriate care, irrespective of linguistic or cultural background.

OPTIMAL SERVICES

Systems will be in place to ensure a smooth and effective transition between acute care services, general practice and other primary and community care services

- Systems will foster effective communication, liaison and coordination between people with diabetes and service providers in acute, primary and community care settings including, when necessary, palliative and residential care services.
- People will have a care plan for self-management, treatment and support which includes identification of a health professional responsible for coordinating their care within and across the different care sectors. The care coordinator, or 'health system navigator' might be a general practitioner, diabetes educator or other health professional.
- There will be continuity in the use of medicines between episodes of care through effective provision of medicines information and the development of medication action plans.
- Appropriate models of care in the community which are effective and sustainable in improving continuity of care and health outcomes will be developed and evaluated.
- Specialised services will ensure a smooth transition from paediatric to adult care for young people with diabetes.
- Services will ensure that care for older and frail people with diabetes occurs within the context of a 'whole-of-health' approach that acknowledges the likelihood of co-morbidities in these groups.
- Incentive and payment systems for diabetes care will support and encourage a multidisciplinary approach to care that is coordinated and people focused.

Quality information about self-management and prevention of diabetes complications will be available

- People will have access to high quality and reliable information about all aspects of their disease, including its treatment, self-management, prevention of complications and relevant health services (including allied health).
- Information will be readily available in a range of languages and formats.
- Strategies for effective dissemination of diabetes related information to people from Aboriginal and Torres Strait Islander communities and culturally and linguistically diverse backgrounds will be trialled and developed.

Systems will be in place to prevent and/or improve management of acute hospital admissions

- People with diabetes will have access to services that enable them to avoid unnecessary hospitalisations for stabilisation of diabetes.
- Systems will be in place to ensure appropriate management of diabetes during periods of intercurrent illness, surgery or periods of acute care for treatment of co-morbidities.

Appropriate infrastructure and systems will be in place to assist clinical decision making, improve the quality of care and ensure continuity of care

- Providers of health services to people with diabetes will be aware of, have access to, and be supported in the implementation of best practice clinical management diabetes guidelines.

- Systems will be in place to optimise early detection and management of the complications of diabetes, including patient registers and recall arrangements.
- General practitioners and other health care workers will be responsible for ensuring all of the people they see with diabetes are assessed for the presence of diabetes complications, either by performing examinations themselves or referring appropriately.
- People undergoing screening for diabetes complications will have access to services that can reliably diagnose these conditions.
- Systems will be in place to ensure that there is continuity in the use of medicines.

People will have access to acceptable, accountable and appropriate care

- Diabetes care will be appropriate and acceptable, irrespective of people's cultural and linguistic backgrounds and where they live.
- Systems will be in place to monitor the quality of care provided to people with diabetes.
- People will have access to information about the services provided by different health care providers and quality of services provided by different care providers.

RATIONALE FOR OPTIMAL SERVICES

People with diabetes will have access to seamless and coordinated health care

Optimal Service: People with diabetes will experience their patient journey as seamless and continuous, as if provided by one organised service. They will move between the community, general practice and acute care settings as if the three were part of one service. People with diabetes will participate in all decision making in respect of their care, and be informed about and supported in the daily management of their condition. In addition, they will be able to access appropriate health services by working in partnership with a care coordinator or health systems navigator who knows about all aspects of diabetes including the management, treatment and support services needed for people with this disease.

Models of care

Various models of service delivery have evolved in an attempt to provide more continuous and seamless care and improve health and quality of life outcomes for people with diabetes. Some examples include the following.

Patient-centred care

It has long been acknowledged that providers of health care do not deal with diseases alone, but with people who are ill or concerned about their health.¹⁶⁴ It is also understood that people's attitudes and beliefs in respect of their diagnosis and their ability to cope will impact markedly on how well they achieve their treatment and quality of life targets. Patient-centred care accepts these arguments and seeks to integrate the patient's perspective in each consultation.¹⁶⁵

In a summary of the evidence, Kinmonth¹⁶⁵ reported several positive effects of a patient-centred approach to care, namely increased satisfaction with care, reduced levels of anxiety, and improved adherence to treatment, symptom resolution, and physiological and functional status. The studies reviewed tended to focus on secondary care and integrated the concerns of people with diabetes by direct coaching.

In their own study, Kinmonth¹⁶⁵ designed an RCT to assess the effect of training of general practitioners and practice nurses in patient centred care on lifestyle and physiological status of people with Type 2 diabetes. Despite better communication from general

practitioners and greater treatment satisfaction and wellbeing, several clinical parameters were worse (BMI and triglycerides) and patient knowledge scores were lower at one year. The authors cautioned that professionals committed to a patient-centred approach to consulting should not lose the focus on disease management.

Similarly, in Australia, patient-centred approaches have been linked with increased patient satisfaction, engagement and task orientation, increased practitioner satisfaction, and reduced levels of anxiety and improved quality of life for people with chronic health problems.¹⁶⁶ These data justify continuing implementation of these approaches.

Diabetes shared care

The provision of continuous and seamless care for people with diabetes requires integration and ongoing communication between services provided in the primary (e.g. general practitioner) and secondary (e.g. hospital) health care sectors. Diabetes 'shared care' exemplifies a model of care designed to facilitate this integration. Broadly speaking, shared care is characterised by the joint participation of hospital specialists and general practitioners in the 'planned delivery of care and an enhanced system of exchange of information over and above routine discharge and referral letters'.¹⁶⁷

Early reports of diabetes shared care in Australia have shown that, with adequate support from and communication with hospital based diabetes services, general practitioners can provide appropriate care and effectively implement specialist recommendations.¹⁶⁸⁻¹⁷³ In particular, a group at Royal Prince Alfred Hospital, Sydney, have consistently identified satisfactory outcomes in reports of their model of shared care.

Overseas data also confirm the benefits of shared care. For example, Renders et al.¹⁷⁴ reported that a system of shared care in the Netherlands between a diabetes service and general practitioners proved better than one that focused on improving skills and knowledge of general practitioners (general practitioner care only) in terms of HbA1c improvement. Systolic blood pressure (BP) improvement, however, was greater in the general practitioner care only group.

More recently Smith et al.⁹⁸ undertook a RCT of a structured shared care program in Irish people with Type 2 diabetes and found '...significant improvements in diabetes care delivery and in psychosocial outcomes ...with improved information exchange'.

Care in General Practice

A systematic review of reports on the quality of clinical care in general practice in the United Kingdom, Australia and New Zealand between 1995 and 1999 showed that, in general, processes of care for people with chronic conditions did not reach national guideline standards. For example, in the case of diabetes (14% of the reports reviewed), only 47% of people with diabetes were screened for signs of retinopathy (through examination of the fundi) in the previous year.^{175,176} The report highlighted the difficulties of assessing quality of care in general practice, and recommended that attention be paid to systematic ways of improving it.

There is good evidence that structured general practitioner care, incorporating such elements as recall systems, goal setting and care planning, practice nurse involvement in education and clinical checklists, results in better quality of care.¹⁷⁷ For example, an RCT of structured personal care in Danish people with Type 2 diabetes yielded statistically significant benefits for the intervention group. In particular, the study concluded that individualised goal setting with educational and surveillance support (including prompting of doctors, clinical guidelines, feedback, and continuing medical education) may reduce diabetic complications but without weight gain.¹⁷⁸ Importantly, these findings were achieved in a group of motivated, volunteering general practitioners who were already providing acceptable basic patient care.

General practitioner mini-clinics and educational outreach

Service provision through general practice based diabetes ‘mini-clinics’ (i.e. special clinics outside routine consultations, usually staffed by practice nurses) has been shown to be effective in Australia in terms of improved processes of care for people with diabetes⁴¹ and improved glycaemic control.^{179,180}

New et al. reported on 2 RCTs of nurse led intervention to treat and control hypertension and hyperlipidemia in diabetes in hospital¹⁸¹ and primary care¹⁸² settings in the United Kingdom. In the hospital setting, the intervention was found to be a successful adjunct to hospital based care in terms of achieving BP and lipid targets. In contrast, in the primary care setting, educational outreach performed by specialist nurses to improve target adherence (after one year) to people with diabetes in primary care was not effective. In the latter case, a lack of additional resources was cited as the greatest impediment to success.

Integrated Care specific to Aboriginal and Torres Strait Islander peoples

Diabetes care in Aboriginal and Torres Strait Islander communities has often concentrated on enhancing existing approaches to diabetes within the primary health care sector.¹⁸³ In rural Victoria, the establishment of an integrated diabetes care service within an Aboriginal Health Service was associated with substantial improvements in glycaemic control, blood pressure and lipid control.¹⁸⁴

The Enhanced Primary Care (EPC) items

The provision of seamless and continuous care for people with ongoing health problems, including people with diabetes, will require a reconfiguration of existing health care systems and a supportive infrastructure that encourages a partnership, multidisciplinary approach to the management of chronic disease.¹⁶⁶

In late 1999, the Australian Government introduced Enhanced Primary Care (EPC) items to the Medicare Benefits Schedule. These items provide Medicare rebates for annual health assessments for older Australians, and care planning and case conferencing services for patients of any age with chronic conditions and multidisciplinary care needs. These items and, in particular, the care planning items (with their emphasis on improved coordination of care), are highly relevant to people with diabetes.

Since July 2004, patients who have received an EPC multidisciplinary care planning service from their general practitioner (or whose general practitioner has contributed to a multidisciplinary care plan prepared for the patient by an aged care facility), have also been able to access up to five rebates a year for allied health services. Health professionals whose fees may be subject to a rebate under the allied health and dental items (and whose services are of potential benefit to patients with diabetes) include credentialed diabetes educators employed in private practice, dietitians, podiatrists, Aboriginal and Torres Strait Islander health workers and psychologists.

Medicare Item 710 (a health check for Aboriginal and Torres Strait Islander people aged 15 to 54 years inclusive) was added to the EPC suite of items in May 2004 and is designed to improve the early detection and diagnosis of common and preventable conditions. A mandatory element of the examination included in this service is urinalysis for proteinuria. Blood sugar and lipid testing is specifically listed under ‘investigations as required’ for this service. The development of a simple strategy for good health (including treatment and services) is a mandatory part of item 710.

In July 2005, new items were added to the Medicare Benefits Schedule to further assist general practitioners to manage the health care of people with chronic medical conditions, including people requiring multidisciplinary care. The new Chronic Disease Management items significantly increase care planning options for general practitioners, as well as expanding patient eligibility and increasing the assistance that practice nurses can provide. They also provide for greater flexibility in who can provide review services.

The EPC and the more recent Chronic Disease Management MBS items provide important tools for establishing a systematic, organised and multidisciplinary approach to diabetes care in general practice.¹⁸⁵

People will have access to information and support to facilitate effective self-management and prevention of diabetes complications

Optimal Services: People with diabetes and their families will receive adequate information appropriate to their needs to enable them to take lead responsibility in decisions and participate fully in decision making in respect of their health. This information will include information about their condition (i.e. treatment options, the short and long term complications of diabetes and how these might be prevented), and available diabetes services in the community, general practice and acute care settings. Information will be suitable for the educational and cultural/linguistic background of different individuals.

Provision of information

Most people with diabetes would like access to information about their disease and its treatment. A good understanding of treatment choices and what may happen with the progression of disease improves peoples' satisfaction with care and psychosocial wellbeing. (e.g. see Peel et al. 2004 *Diagnosis of Type 2 diabetes: A qualitative analysis of patients' emotional reactions and information provision. Patient education and counselling*^{53, 269-275}).

Written information

There is some research about how best to provide written information for people with diabetes. For example, in respect of treatment decisions, information should include evidence-based statements about the benefits and harms associated with treatment options and the quality and consistency of the empirical studies underlying these statements. Information should also be presented in a balanced way using concise, jargon free language.¹⁸⁶

Patient held records and treatment plans

Bridgford and Davis^{187,188} reported on their experience with the development and use of a comprehensive patient held record card as part of the Fremantle Diabetes Study. They concluded that use of a comprehensive patient held record was supported by most people with diabetes and health professionals.

In contrast, in a recent RCT of the impact of the New Zealand Diabetes Passport, Simmons et al.¹⁸⁹ found that, in isolation, dissemination of the Passport did not increase diabetes knowledge or self-empowerment although a modest reduction of HbA1c was obtained. They concluded that linking the use of the Passport to other behavioural and educational interventions may render it more useful.

Support for self-management

Information alone, however, may be insufficient to encourage the long term behavioural change required to manage diabetes effectively and improve health outcomes.

- Firstly, the extent to which people's environments support and encourage active participation in health related activity is likely to be significant (see Environments to reduce diabetes risk section, pp 21-22).
- Secondly, psychosocial factors, such as people's beliefs about themselves and their health, are likely to play a role. For example, in people with diabetes, self-efficacy (i.e. belief about one's ability to manage diabetes successfully) is especially

significant, with people who perceive themselves as capable typically reporting the most effective self-management of their condition¹⁹⁰ and better glucose control.¹⁹¹ It is imperative, therefore, that supportive mechanisms are in place to encourage an active sense of competence and responsibility for self-management in people with diabetes. An emphasis on the generic skills of action planning, goal setting and problem solving will assist greatly this process.¹⁹²

Systems will be in place to prevent crisis situations and unplanned and unnecessary admission to hospital

Optimal Services: People with diabetes will have access to services in the community that enable them to avoid acute hospital admissions for stabilisation of their diabetes. When admissions are necessary for management of intercurrent illness or surgery, they are planned between general practitioners, specialists and hospital staff through better use of patient data, care planning, and improved admission and discharge planning.

Outpatient stabilisation

Assessments of outpatient stabilisation of diabetes for adults¹⁹³⁻¹⁹⁶ and children¹⁹⁷ have concluded that ambulatory insulin commencement does not compromise metabolic or psychological outcomes, and has similar psychosocial outcomes for the family as inpatient stabilisation programs.

In 2004, the ADEA launched the *National Standards for the Development and Quality Assessment of Services Initiating Insulin Therapy in the Ambulatory Setting*. The Standards specify the level of care that all health professionals initiating insulin therapy in ambulatory settings should strive to achieve.

Diabetes centres

Limited evidence suggests that diabetes centres may reduce the need for hospitalisation for stabilisation of diabetes. A recent US study¹⁹⁸ reported no reduction over four years in hospitalisation or emergency room use between individuals with Type 2 diabetes managed in a diabetes centre (individuals with more severe diabetes) compared with those managed in a general medical clinic.

A matched case-control study¹⁹⁹ from the UK did find less admissions for diabetes related and unrelated conditions for those seen in a hospital clinic compared with those reviewed in general practice. This is potentially explained by the effectiveness of access to specialist services by hospital clinics in reducing admissions. Similarly, a prospective Italian study²⁰⁰ found that process and outcome results were significantly improved for people attending a diabetes clinic, especially if followed by the same physician.

Appropriate infrastructure and systems will be in place to assist clinical decision making, improve the quality of care and ensure continuity of care

Optimal Services: People with diabetes will be confident that they are being treated according to the best available evidence. There will be agreed national clinical practice guidelines covering the diagnosis and management of diabetes and its complications, as well as the provision of patient information, support and counselling. Services will have local protocols for the treatment and support of people with diabetes based on guidelines where they exist and best available evidence in the absence of agreed national guidelines. Services will have systems for distributing clinical guidelines and supporting their implementation. There will also be strategies for collecting information about an individual's care which enable an evaluation of the extent to which care is consistent with the evidence and their protocols. Information from the audit will be provided to treatment

teams and used to develop quality improvement programs. People with diabetes will have access to information about the guidelines and/or the protocols used by their service providers.

Clinical practice guidelines

Clinical practice guidelines for the prevention of complications of diabetes are summaries of evidence and are often a first step in encouraging evidence-based practice and improving the quality of health care. A summary of the guidelines available currently is provided in Section 5.3.2.

Experience has shown that developing, publishing and printing guidelines is not enough to ensure their implementation. To maximise the uptake of guidelines in clinical practice it is vital to develop and apply a structured and multifaceted implementation process that targets those expected to use the guidelines. In addition, it is important to promote the guidelines to those who can inform and influence clinician and consumer behaviour and to incorporate them into health policy as well as health practice. A combination of strategies is most effective. Possible strategies include, but are not limited to:

- academic detailing
- continuing professional development activities, especially if respected clinical opinion leaders are involved
- decision support systems/electronic information systems
- consumer education/awareness/demand
- audit and feedback.

Other strategies known to increase compliance with clinical management guidelines are: wide consultation during development, involving potential users early, presenting the guidelines in easy to access, user friendly summaries for clinicians and consumers, making guidelines available through a range of media and technologies, providing training for clinicians in the application of the guidelines by respected colleagues, and ensuring that policy supports and encourages the use of guidelines.

To be effective, clinical management guidelines need to change behaviour at the point of care. Overseas data suggest that diabetes guidelines, per se, have very little impact on general practitioner behaviours, including complications screening.^{201,202} This outcome has been attributed to a lack of appropriate organisational and technological (e.g. computerised tracking systems) supports.

In Australia, the data are mixed. For example, Faruqi²⁰³ assessed general practitioner use of the NSW Clinical Management Diabetes Guidelines. Whereas some reported using the guidelines, many were unaware of their existence. The authors recommended that implementation of guidelines not only include general practitioner education 'but also systems to reduce barriers to implementation and to support better quality of GP care.'

A subsequent paper²⁰⁴ reporting the outcomes of a general practitioner self-report survey (43% response rate) found variable adherence to NSW Clinical Management Diabetes Guideline recommendations, ranging from 60% (measuring weight) to 100% (measuring lipids). Group practice general practitioners were statistically more likely to undertake foot and BP checks and microalbumin assessments. Similarly, a Victorian general practitioner self-report survey, assessing adherence to NHMRC guidelines for diabetic retinopathy (59% response rate) found that only 37% had received a copy of the guidelines, and that of those who had, 18% had not read them and 65% had read them only partially.²⁰⁵ Nevertheless nearly all general practitioners did report referring people with diabetes to an ophthalmologist or optometrist at least every two years.

The Australian data suggest that while clinical practice guidelines may have some positive effect on the behaviours of general practitioners that read them, effort is required to ensure

they are distributed broadly to all providers of health care to people with diabetes (e.g. diabetes educators, nurses and other health professionals) and that programs are conducted to facilitate their implementation on a sustained basis.

Registers and recall

Harris et al.²⁰⁶ reported on the quality of care provided by general practitioners using and not using Division based diabetes registers across five Divisions in South Western Sydney. General practitioners who participated in diabetes registers were more likely to provide patient care that approximated evidence-based guidelines than those who did not.

McDermott et al. 2001²⁰⁷ found that implementation of a well supported, paper based recall and reminder system managed locally by health care workers can achieve significant improvements in diabetes care and reduced hospitalisation within remote Indigenous communities.

Ariyaratne et al.²⁰⁸ reported on patterns of use of diabetes registers by general practitioners in an urban Division in Sydney, to assess the impact of the Australian Government's Practice Incentives Program (PIP). They found that most practices used some form of register, but only half of the general practitioners with practice registers were claiming PIP payments, with other factors being identified as motivators for use. For those not using registers, time was the most frequently cited deterrent.

Information technology

Advances in information technology are likely to afford many advantages for the management of diabetes, both for people with diabetes and providers of health services. Some examples of the possibilities in this area follow.

- *Data linkage:* By linking general practitioner division diabetes registers to the West Australian Health Services Research Linked Database, Brameld et al.²⁰⁹ demonstrated that 'linked hospital morbidity data can be used to monitor health outcomes on a general practice population of people with diabetes'.
- *Electronic reminders:* Frank et al.²¹⁰ reported the use of opportunistic electronic reminders and their potential to improve patient care in general practice in Australia. Whilst not successful in increasing diabetes screening they were helpful in some areas of general practitioner behaviour (e.g. immunisation, recording allergies and weight).
- *Computer based consultations:* Recording of diabetes related information is higher in computer based consultations than paper based consultations, especially when the information is easily recorded during the consultation (Mitchell et al.²¹¹).
- *Telemedicine:* Rutten et al.²¹² reported that telemedicine support improves general practitioner care in Type 2 diabetes, through standardisation of information transfer between general practitioners, diabetologists and laboratories and may provide an effective infrastructure for shared diabetes care.
- *Electronic Held Record:* HealthConnect is an overarching national change management strategy to improve the safety and quality in health care by establishing and maintaining a range of standardised electronic health information products and services for providers and consumers of health care. A component of this strategy, electronic health records, will allow consumer health information to be collected electronically, stored safely and exchanged between authorised health care providers with strict privacy safeguards. Implementation of HealthConnect has begun in Tasmania, South Australia and the Katherine region of the Northern Territory, while discussion and other projects are taking place in the remaining States and the ACT. This information network aims to empower consumers

by providing them with greater control over who has access to their health information. Consumers will be able to access and read their own personal health information and therefore be better informed.

- *Electronic decision support software:* Automatic provision of evidence-based recommendations at the point-of-care, through computer based decision support software, has been shown to improve clinical practice significantly.²¹³

Quality use of medicines

Diabetes is a condition that often requires multi-dose and multi-medicine therapy. Poor compliance with and errors in management plans, and errors with medication plans, are major contributors to re-hospitalisation rates in people with chronic disease.^{214,215} Improving the understanding of treatments, and ensuring continuity of care, in particular continuity in medication management between settings, will contribute to improved health outcomes including a reduction in adverse medicine events and reduced hospitalisations.

There is a significant body of evidence to suggest that there is poor continuity in the use of medicines between episodes of care, and that this results in excess morbidity for the person with chronic disease.²¹⁶⁻²²⁵

Medication action plans

The Australian Pharmaceutical Advisory Council released national guidelines on achieving continuity in the quality use of medicines in 1998²²⁶; the guidelines are currently being revised. In addition to providing a set of principles on which to guide the collection of information about consumers' medication regimens, the guidelines also stress the importance of developing individualised Medication Action Plans (MAPs) as part of an overall care plan with the person's treatment team. The development of culturally specific MAPs will support access to quality health information for people, and assist in raising the confidence of people to deal effectively with their condition.²²⁷

Medication reviews

A medication review is a critical review of all prescribed, over the counter and complementary medications undertaken to optimise therapy and minimise medication related problems. The review may take place in the surgery, the home or a health care setting such as a residential aged care facility.

General practitioners and pharmacists work together to review a consumer's medicines and develop a management plan, which is discussed and agreed with the consumer. The general practitioner and the accredited pharmacist are both remunerated for participation in medication reviews.

Provision of medicines information

People are often not aware of what medicines they are taking²¹⁸, and general practitioners are not consistently made aware of changes to treatment plans.²²⁰⁻²²² A lack of medication information provided to out of hospital professionals is associated with an increased likelihood of a person suffering an adverse event related to their medication.^{216,217}

There are a variety of methods of informing people about their medications, including CMI (as described in Section 5.3.1). The use of both oral and written information has been recommended²²⁸, as has the use of medication records. One review has concluded that information provided in an educational context is more effective than information provided through leaflets or booklets. Several trials have assessed the provision of information as part of a multifactorial intervention, and the successes of these support the notion that information is best provided as part of an overarching multidisciplinary care plan.

This plan will include the input of community based health professionals caring for a person with diabetes and will reduce the likelihood of errors in the transfer of medication information between service providers. Two recent trials of the use of medication liaison services as part of a multidisciplinary care model have been effective in reducing problems associated with medications.^{216,217}

People will receive high quality, multidisciplinary care in the management of major diabetic complications

Optimal Services: People with diabetes will receive high quality multidisciplinary care for the long term complications of diabetes.

People with long standing diabetes are prone to a number of microvascular and macrovascular complications which can have a compounding effect on their long term care. Multidisciplinary care is necessary to diagnose and initiate treatment for these disorders.

Diabetic Nephropathy

Diabetes is now one of the two most common reasons for entering renal replacement therapy in Australia²²⁹, rising from 6% to 26% of all cases over the past 20 years. The five-year survival of people with diabetes on renal replacement therapy is significantly worse than for people without diabetes, and is worse for Type 2 diabetes compared to Type 1 diabetes.²²⁹ Only 20% of people with Type 2 diabetes with nephropathy will progress to renal replacement therapy within 20 years, as most will die from vascular disease before end-stage kidney disease develops.²³⁰ Factors associated with the development of diabetic nephropathy include poor glycaemic control, hypertension, long duration of diabetes, abnormal lipid profile, and smoking.²³¹

There is convincing evidence that the onset and course of diabetic nephropathy can be ameliorated through screening for kidney disease in the diabetic population, and by adhering to optimal targets for glycaemic control and blood pressure. In addition, a review of education and information issues among people with diabetes highlighted access to holistic information, such as the effects on the kidneys, as an area for improvement.²³²

Issues relating to care and support during treatment, pre-dialysis, dialysis, and transplantation are similar for people with and without diabetes with kidney disease, and are addressed in the National Service Improvement Framework for Heart, Stroke and Vascular Disease. It is important to note, however, that patient survival on renal replacement therapy is lower for people with diabetes than for people without diabetes. Therefore, the potential gain resulting from service improvements may be even greater for patients with diabetic nephropathy.

Limb Ischaemia and Amputation

The management of gangrene or ulcers in people with diabetes is more difficult than in people without the condition. Eighty-five percent of diabetes related lower-extremity amputations are preceded by a foot ulcer. A multidisciplinary approach to the treatment of people with limb ischaemia and diabetes, which includes prevention, patient education, and comprehensive treatment of foot ulcers, can reduce the amputation rate by between 43% and 85%.²³³

People with diabetes are 10 times more likely to need an amputation than people with non diabetic arterial disease²³⁴, and 40% to 45% of all amputations occur in people with diabetes. People with diabetes generally undergo major amputations at an earlier age than those without diabetes.^{235,236}

Amputation is a marker not just of disease but also of disease management. The decision to operate is determined by many factors, which vary between centres and patients. A high amputation rate might result from high disease prevalence, late presentation, and inadequate resources, but could also reflect a particular approach by local surgeons. In many cases, major amputation is not a mutilating admission of failure but the most appropriate way of ensuring an early return to a relatively independent existence. Conversely, a low rate of amputation might reflect better care, but might also conceal the effects of an inappropriately conservative approach—namely, protracted incapacity, suffering, and death with ulcers unhealed.

Diabetic Neuropathies

In diabetes the metabolic abnormalities damage peripheral sensation, innervation of the small muscles of the foot, and fine vasomotor control of the blood flow in the foot. In sensory neuropathy, loss of protective sensation leads to lack of awareness of incipient or actual ulceration. Motor neuropathy affects the muscles required for normal foot movement, altering the distribution of forces during walking and causing reactive thickening of skin (callus) at sites of abnormal load. Ulcers can form beneath the callus, leading to breakdown of skin.²³⁷

Diabetic autonomic neuropathy

Autonomic neuropathy is a group of symptoms caused by damage to nerves supplying the internal body structures that regulate functions such as blood pressure, heart rate, bowel and bladder emptying, and digestion.²³⁸ Diabetes is the most common cause of autonomic neuropathy in developed countries.²³⁹ The autonomic neuropathy typically presents late in the course of diabetes and is often accompanied by other features of neuropathy. Diabetic autonomic neuropathy can:

- Affect the heart if the cardiac vagus nerve is affected. There is an increase in overall mortality and sudden death in patients with diabetic autonomic neuropathy.
- Cause symptoms of bladder dysfunction are present in up to 50% of patients with diabetes, and there is physiological evidence of bladder dysfunction in 43–87% of those with insulin-dependent diabetes.^{240,241}
- Cause erectile failure is present in 30–75% of diabetic men with diabetes²⁴² and can be the earliest symptom of diabetic autonomic neuropathy.
- Autonomic dysfunction occurs throughout the gastrointestinal tract. Delayed stomach emptying of solids or liquids is present in up to 50% of individuals with diabetes, causing nausea, vomiting, bloating, belching and loss of appetite. Constipation is the most frequently reported gastrointestinal autonomic symptom, found in up to 60% of patients with diabetes.²⁴³
- Diabetic autonomic neuropathy initially results in a loss of the ability to sweat. Paradoxically this can result in excessive sweating in the head and trunk as a compensatory process.²⁴⁴

People will have access to acceptable, accountable and appropriate care

Optimal Services: People with diabetes will receive care that is acceptable, accountable and appropriate for their health needs. This is especially the case for Aboriginal and Torres Strait Islander peoples with diabetes, and people with diabetes from culturally and linguistically diverse backgrounds.

Acceptability of care

At the heart of patient-centred care is the provision of services that are perceived as acceptable and appropriate by people with diabetes. There should be methods in place to ensure that people with diabetes can provide feedback on those aspects of care they do and do not find acceptable.

Glycaemic control is the most common outcome measured in diabetes care, which is not surprising given that near normal blood glucose levels delay the onset and progression of diabetes complications. Nevertheless, the complexity and demanding nature of the treatment regimen required to normalise blood glucose (e.g. more frequent insulin injections and blood glucose monitoring), may impact negatively on people's quality of life. It is imperative, therefore, that evaluations of the effects of diabetes treatment include the acceptability of the treatment to the patient.

Given the cultural diversity of the Australian population, particular attention should be paid to ensuring that services meet the needs of and are acceptable to Aboriginal and Torres Strait Islander peoples and people from culturally and linguistically diverse backgrounds. It is currently acknowledged that the best practice model for the delivery of comprehensive and culturally appropriate primary health care to Aboriginal and Torres Strait Islander communities is provision of Aboriginal Community Controlled Health Services, as well as mainstream services.²⁴⁵

Audit and benchmarking

Audit and benchmarking are tools for assessing the appropriateness and improving the quality of diabetes care.

For example, information generated by the population health monitoring tool CARDIAB has encouraged the 'development of standard minimum clinical datasets, and enabled recording, monitoring and audit of quality of care and health outcomes' for people with diabetes and cardiovascular disease²⁴⁶ in the primary care sector. It has also stimulated improved service delivery in the general practitioner and secondary care environments.²⁴⁷ Specifically, 'GPs have been able to audit their clinical performance and monitor quality of care and health outcomes in diabetes and cardiovascular disease'.

To date there have been four cross-sectional, self-report national audit and benchmarking exercises undertaken in specialist diabetes services (including diabetes centres and specialist endocrinologists). The surveys provide information on the processes of care and health outcomes for people with diabetes attending these services.

Data from the most recent survey in 2002 shows that, in the preceding 12 months, 80.3% of people with diabetes had attended an ophthalmologist, 35.9% an optometrist, 66.4% a diabetes educator, 52.5% a dietitian and 34.2% a podiatrist.²⁴⁸

Consideration needs to be given to the development and implementation of effective data systems that facilitate monitoring and improvement of both the accessibility and effectiveness of health care provided to Aboriginal and Torres Strait Islander peoples.

CHAPTER 6: Best Care and Support for Acute Episodes

OVERVIEW

While an important goal of diabetes management is prevention of acute medical problems, many people with diabetes experience temporary declines in their health status over the course of their condition.

The disease process that characterises diabetes places all people with the disease at risk of developing hypoglycemia (which occurs when blood glucose levels fall below the normal range) and/or hyperglycemia (which occurs when blood glucose levels rise above the normal range). Episodes of hypo- and hyperglycemia are associated with a range of unpleasant symptoms and are potentially life threatening. It is essential that people with diabetes are able to recognise symptoms of these conditions and, where possible, take appropriate preventive action. Timely access to high quality care and support may also be necessary in the event of hypo- and hyperglycemic episodes.

The long term complications of diabetes also predispose people to a range of events that may require acute hospital care, including acute myocardial infarction and stroke, infections and foot ulceration.²⁴⁹ In each case, people with diabetes need to feel confident that they will receive care of the highest quality, support and information to prevent recurrences and, when necessary, access to high quality palliative care at the end of life.

PEOPLE'S NEEDS

People need:

- optimal management and planned review to prevent avoidable acute medical conditions
- information that will help them to recognise early important changes in their health status and pre-empt the development of acute health problems
- knowledge and skills to self-manage their diabetes during and after acute health problems and confidence to seek advice on management from health professionals
- access to rapid, seamless, high quality care during acute episodes
- timely access to competent and knowledgeable health professionals who are responsive to their needs
- information about the event and how to prevent recurrences.

OPTIMAL SERVICES

Systems will be in place to prevent avoidable acute medical conditions

- Self-management education will provide people with the skills, knowledge and confidence to manage their daily health needs.
- People will be encouraged and supported in their attempts to change lifestyle behaviours to prevent and/or slow the progression of diabetes complications.

Information will be available to help people and their families and carers prevent, identify, and respond to the signs of a pending deterioration in diabetes management

- People will receive information to make them aware of the potential for changes in their health status over time, and enable them to recognise a decline in their health.
- Information and education will outline strategies to prevent a decline in health status, including the agreed treatment regime, self-management, lifestyle, and review strategies.
- People with diabetes will have access to a hot line which can provide information about the management of their diabetes.
- Each person with diabetes will have an action plan specifying appropriate and agreed self-management strategies to manage a decline in health status, including when and how to seek professional advice.

People with diabetes will receive high quality care when they experience an acute medical problem

- In the event of a decline in health status, people with diabetes will have timely access to evidence-based care.
- There will be effective communication between health professionals and other care providers to aid the transition of people with diabetes between services and across health sectors.
- People will be monitored appropriately to assess their response to interventions, including adverse effects.
- People will receive information about the event and opportunities to reduce the risk of recurrent episodes.
- Management of the condition will be reviewed to identify areas for improvement and to prevent repeated episodes. The action plan will be revised to reflect changes in care.
- Children and young people with diabetes who develop DKA will be treated in specialist centres. Special arrangements/protocols will exist to ensure access to appropriate services for children and young people residing in rural and remote communities.

RATIONALE FOR OPTIMAL SERVICES

Systems will be in place to prevent avoidable declines in health status

Optimal Services: People with diabetes will have access to diabetes education to empower them to recognise early a deterioration in their health status and be able to respond appropriately by changing their treatment or seeking medical advice.

Hyperglycaemia

Diabetic ketoacidosis and hyper-osmolar non-ketotic coma are acute hyperglycaemic metabolic complications of diabetes. Mortality rates for these acute complications are 15% and 5% respectively, with higher rates of mortality in the elderly and in those presenting in coma or with hypotension.²⁵⁰ Diabetic ketoacidosis can occur in 20–40% of people with newly diagnosed Type 1 diabetes.²⁵¹

People with diabetes can prevent hyperglycaemia through appropriate education and access to medical care during intercurrent illness. People should be aware of how to manage their diabetes during intercurrent illness, so called 'sick-day management'. Controlled trials on risk reduction are lacking in this field.

People with diabetes should be educated by physicians or diabetes educators with regard to more frequent testing and designated target blood glucose level (BGL), and testing for ketones in the urine or blood. People should always be aware of when and how to contact a health care provider and what additional treatment can be administered prior to contacting a health care professional.

Risk reduction also includes education about precipitating events. Whilst infection can be reduced by vaccines (especially Pneumovax, Fluvax) there is no evidence to show this reduces hyperglycaemic crises. Obtaining prompt medical attention for illnesses will ensure early treatment to minimise metabolic derangement. Medical attention can reinforce the importance of close blood sugar monitoring.

Promoting awareness of early symptoms (polyuria, polydipsia, enuresis) in primary and secondary schools through the use of posters reduces the incidence of DKA by increasing early detection of newly diagnosed Type 1 diabetes.²⁵² Therefore, educating the community and raising diabetes awareness is a proven method of reducing acute complications.

All people with diabetes should see a diabetes educator at least once at diagnosis, to educate them on the importance of blood glucose testing, especially during intercurrent illness when hyperglycaemic crises can develop. This education comes under the banner of 'sick day management'.

A low level of adherence to insulin therapy is associated with hyperglycaemic crises. Stopping insulin because of cost has been shown to be a frequent precipitant of DKA in urban African-Americans.²⁵³ Australian data on access to insulin is lacking, but ensuring easy availability of low cost insulin is likely to reduce acute complications.

Severe hypoglycaemia

Severe hypoglycaemia is defined as an episode that requires assistance from another person, and the clinical features can range from disorientation to unconsciousness or convulsions.

To prevent severe hypoglycaemia, people need to recognise early symptoms and to carry out frequent BGL monitoring. People need to be educated regarding symptoms of hypoglycaemia and treatment. Blood glucose awareness training, where people can estimate then verify their BGL, can improve long term control and reduce the incidence of severe hypoglycaemia.²⁵⁴

People's fears need to be explored regarding hypoglycaemia, as this can be a barrier to improving glycaemic control. After an episode of hypoglycaemia, vigilance for 24 hours is required as recognition of further episodes can be impaired. It is well documented that repeat severe episodes often occur in quick succession.

Acute cardiovascular events and stroke

Patient education can lead to earlier recognition and presentation after an acute myocardial infarct and stroke. Community interventions are beneficial, with a Swedish study showing a 12 month campaign, predominantly in the print media, reduced the time to presentation with chest pain from three hours to two hours and 20 minutes.²⁵⁵

In the event of an acute medical problem, people will receive seamless, high quality health care

Optimal services: People with diabetes who develop acute medical conditions will undergo appropriate assessment and receive treatment according to the best available evidence. The response to interventions to manage the acute event, including adverse effects, will be monitored. The long term management of the condition will be reviewed to identify areas for improvement and to minimise the opportunity for recurrent episodes, including the need for additional self-management education and support for the adoption and maintenance of healthy lifestyle behaviours.

Hyperglycaemia

People experiencing hyperglycaemic crises require hospitalisation. In particular, they need prompt access to an acute hospital, with staff trained in the management of these conditions.

The mainstay of medical treatment involves the use of intravenous fluid, insulin and potassium. There are some major differences between the management of acute complications in children and adults.

After a hyperglycaemic crisis, people with diabetes are at risk of a further episode. Therefore, education prior to discharge about the possible causes, symptoms and early treatment is essential.

Severe hypoglycaemia

Intensive therapy aiming for a normal blood sugar is a goal in diabetes treatment. However, this treatment intensifies the risk of hypoglycaemia.²⁵⁶

Identifying people at greatest risk is the initial step to preventing hypoglycaemia. At greatest risk are people with a history of severe hypoglycaemia and people in whom high levels of blood glucose (i.e. high initial HbA1c) were followed by a quick improvement.²⁵⁶ Medication (especially non-selective beta-blockers), nephropathy, and alcohol use also increase the risk.²⁵⁷

Blood glucose monitoring is useful strategy for detecting people at risk. In a study of 78 people with Type 1 diabetes, those with frequent low levels of blood glucose in the first two to three weeks were most at risk of severe hypoglycaemia over the next six months.²⁵⁸ In contrast, HbA1c was not predictive.

Early treatment of hypoglycaemia is essential to prevent long term neurological consequences. Although most people with diabetes have immediately recognisable hypoglycaemic symptoms, those with longstanding diabetes and recurrent hypoglycaemia can develop hypoglycaemic unawareness. For these people, it is difficult to detect the occurrence of hypoglycaemia as the usual warning signs of early hypoglycaemia do not occur. New devices, such as alarming continuous glucose sensors may improve management for these individuals.

To prevent severe hypoglycaemia, people with diabetes should have fast acting carbohydrates available at all times. When a person is unconscious or unable to ingest carbohydrates, friends and relatives need to be able to recognise and treat the

hypoglycaemic episode. Glucagon should be available (and not out of date) and people should be educated on how to prepare and administer it.

In-patient services for people with diabetes

People with diabetes have an increased risk of atherosclerotic disease. A review of 1886 inpatients revealed those with diabetes and new onset hyperglycaemia had an increased mortality (2.7- and 18-fold, respectively), increased length of stay (5.5 and 9 days, respectively), more intensive care requirements (14% and 29%, respectively, versus 9% for those without diabetes and euglycaemia) compared to those without diabetes and euglycaemia.²⁵⁹ Hyperglycaemia is associated with increased mortality after acute myocardial infarction²⁶⁰, stroke²⁶¹, coronary artery bypass surgery²⁶², and in the surgical intensive care unit.²⁶³

Insulin therapy has been shown to be beneficial in improving the prognosis in some of these conditions. It is still unclear whether the benefit is related to controlling the blood glucose level or whether insulin has direct therapeutic benefits.²⁶⁴ In myocardial infarction and in people with diabetes undergoing coronary artery bypass graft surgery, insulin glucose infusions reduced mortality²⁶⁵, the incidence of atrial fibrillation, length of stay, wound infections and recurrent ischaemia.²⁶⁶

Whilst silent coronary disease is common in people with Type 2 diabetes, the best method of detection is unknown. The Australian national evidence-based guidelines for the management of diabetes recommend resting electrocardiogram (ECG) every two years in asymptomatic patients.²⁶⁷ Abnormalities on resting ECG can predict clinically significant silent ischaemia but a normal ECG does not exclude it. In a study of 952 people with Type 2 diabetes and no known coronary heart disease, ST-T abnormalities on resting ECG was the most important risk factor for silent ischaemia.²⁶⁸

People with diabetes need to be asked regularly about symptoms of vascular disease. In a study of 3627 patients undergoing coronary angiography for possible coronary artery disease, a history of chest pain was the most important clinical predictor of significant disease.²⁶⁹ In the same study, resting ST-T wave changes and Q waves were also predictive of significant disease. Symptoms are also important in cerebrovascular disease with a study of 220 patients showing if symptoms of transient ischaemic attack and amaurosis fugax were present, carotid stenosis >75% was present in 37.7%.²⁷⁰

Similarly, people with diabetes need to be examined regularly for clinical signs to detect significant vascular disease. Carotid bruits in asymptomatic people have been shown to have a sensitivity of 84% and specificity of 40% in a study of 441 people.²⁷¹ Absent peripheral pulses are also predictive of significant peripheral vascular disease. A study of 1044 people with Type 2 diabetes revealed that the absence of two or more peripheral pulses or femoral artery bruits were predictive of future amputation during seven years of follow up.²⁷² Atherosclerosis can occur throughout the body, so detection of disease in one area increases the likelihood of involvement in other parts of the body. In a study of 344 patients with diabetes, absent pedal pulses were associated with a twofold excess of coronary heart disease.²⁷³

Diabetes increases the risk of infections, vascular disease, renal disease and limb amputations.²⁴⁹ These disorders predispose to hospitalisations and, therefore, it is not surprising that approximately one in five of all hospital inpatients have diabetes.²⁷⁴ There is growing evidence that hyperglycaemia may be deleterious in hospital, with possible mechanisms including adverse effects on immune function, platelet function and haemostasis, inflammation, endothelial function, myocardial function, cerebral function and oxidative stress.²⁴⁹

Therefore, it seems prudent to aim for good glycaemic control in inpatients with diabetes. In particular, insulin infusions are advocated for acute myocardial infarction, coronary artery bypass graft surgery and surgical ICU setting in the manner used in the above

randomised intervention studies. Insulin infusion titration scales have recently been published which, in clinical trials, have shown a low hypoglycaemia risk.^{275 276} Each institution should develop a guideline for insulin infusion use.

Managing hyperglycaemia is not always an easy task and requires education of nursing and medical staff to understand the importance of good control and tools to achieve it.

CHAPTER 7: Critical Intervention Points for Diabetes Management

The critical intervention points represent those aspects of care where Australia might most usefully invest to reduce the risk of an early death and improve the quality of life for people with diabetes. The identification of critical intervention points is based on consideration of whether an aspect of care:

- is important in terms of reducing the risk of death, suffering or health care costs
- is currently suboptimal, given what is known about optimal services and about current care
- can be improved.

SELECTION OF CRITICAL INTERVENTION POINTS

The critical intervention points were selected as follows:

- a detailed review of the evidence about people's needs and the value of the optimal services was undertaken
- patterns of care in Australia were assessed to identify where services are currently different from the optimal; this analysis was hindered by the lack of data about many aspects of care and about service provision
- the issues identified through these analyses were compared with priorities identified in a number of recent documents; the proposed critical intervention points were reviewed by the National Service Improvement Framework Expert Panel.

The critical intervention points, listed below, are ordered as they would be along the continuum of care.

List of Critical Intervention Points for Diabetes

Reduce risk (See Chapter 2, pages 15–23)

1. Provide access to culturally appropriate information on food, nutrition and physical activity to assist in mitigating the risks of overweight, obesity and Type 2 diabetes, especially in high risk groups and in those people with impaired glucose metabolism.
2. Establish national, state, territory and local plans to prevent obesity and Type 2 diabetes by promoting healthy eating and physical activity including healthy weight in collaboration with other national health priorities and policies.

Diagnose diabetes early (see Chapter 3, pages 25–28)

3. Develop and disseminate information about diabetes risk factors and symptoms to the community, primary care providers and other relevant health care workers.
4. Improve systems so that all people at risk of diabetes are referred appropriately and assessed promptly and effectively, particularly those at high risk.

Best care and support during the early stages (see Chapter 4, pages 29–42)

5. Develop and implement national clinical practice guidelines covering the diagnosis and management of diabetes and its complications with the aim of preventing the onset and slowing the progression of diabetic complications.
6. Establish national, state, territory and local plans to reduce rates of smoking using evidence-based public health strategies and government actions.
7. Develop and implement systems to prevent and limit the progression of the complications of diabetes for all Australians, particularly those living in regional, rural and remote areas and Aboriginal and Torres Strait Islander peoples.
8. Put in place processes to assess the extent to which clinical practice guidelines are adopted and to encourage strongly their implementation.
9. Continue and, where necessary, strengthen and/or establish systems to improve the coordination of care for people with diabetes, including defined referral pathways and designated coordinators of care.
10. Develop and implement strategies to encourage multidisciplinary care, emphasising the central role of the person with diabetes in diabetes care, and their capacity for self-management.
11. Inform people diagnosed with diabetes, regardless of their point of contact with the health system, of available sources of information, education and support for health, psychosocial and financial issues.
12. Develop measures to support absolute risk estimation as a tool in assessing people known to have diabetes but without overt cardiovascular disease.
13. Improve access to treatment services for all Australians, particularly those living in regional, rural and remote areas and Aboriginal and Torres Strait Islander peoples.
14. Work towards improving supportive care for people with diabetes by implementing psychosocial clinical practice guidelines.

Best long term care and support (see Chapter 5, pages 43–55)

15. Continue and, where necessary, strengthen and/or establish systems to improve the coordination of care for people with diabetes, including defined referral pathways and designated coordinators of care.
16. Develop comprehensive programs for the early detection and management of diabetic retinopathy and nephropathy.
17. Develop and implement strategies to ensure that all people with diabetes have adequate access to appropriate foot care and/or podiatry services.
18. Develop and implement strategies to reduce preventable hospital admissions in people with diabetes.
19. Provide information through accreditation of services, credentialing of practitioners or other strategies to help people with diabetes assess the quality of care being provided.
20. Work towards improving supportive care for people with diabetes by developing and implementing psychosocial clinical practice guidelines.
21. Provide adolescents with diabetes with a seamless transition from paediatric to adult care, with services appropriate both for chronological age and developmental attainment.
22. Develop and implement strategies to encourage multidisciplinary care.
23. Develop and implement strategies to ensure widespread implementation of clinical practice diabetes guidelines.
24. Develop and implement strategies and policies to encourage the safe and quality use of medicines.

Best care and support for acute episodes (see Chapter 6, pages 57–62)

25. Develop a community wide awareness program about the short and long term complications of diabetes.
26. Provide information to people with diabetes, their families and carers to assist them to identify and respond to impending deterioration in diabetes management.
27. Manage diabetic ketoacidosis in children and adolescents according to a national written guideline in facilities appropriate for their age.
28. Provide appropriate information for people with diabetes about follow-up, practical issues, support services and self-care.

CHAPTER 8:

National Priority Actions for Change

OVERVIEW

Significant improvements in diabetes management as outlined in the National Service Improvement Framework will require change at the local, state, territory and national level.

A number of strategies may facilitate improvements in diabetes management in Australia, including: the establishment of state and territory diabetes plans; improvements in primary care management of diabetes; improved access to services; the improvement of care for regional, rural and remote communities; the establishment of accreditation systems; strengthening training and professional development; targeted funding systems; the improvement of data and monitoring systems; strengthened approaches to research; and planning strategies for the future.

The adoption of the National Service Improvement Framework for Diabetes will require a systematic implementation plan developed in consultation with states and territories, professional colleges, non-government organisations, consumer groups and other key stakeholders.

Based on the consultations undertaken so far to develop the National Service Improvement Framework for Diabetes, nine initial priority actions are recommended. These national actions underpin the critical intervention points and would provide the basis for many of the changes identified in the framework.

NATIONAL PRIORITY ACTIONS FOR CHANGE

There are nine priority actions which underpin the critical intervention points. If these actions were undertaken by the Australian and state and territory governments, the basis for many of the changes identified in the framework would be in place.

1. Provide improved support for comprehensive health promotion efforts aimed at encouraging and monitoring the uptake of healthy behaviours (in the key areas of nutrition, smoking, and physical activity) in people with and without diabetes, and facilitating health promoting environments through integrated efforts at national, state, territory and local levels.
2. Establish integrated and networked diabetes services to improve continuity of care from reducing risk to care at the end of life.
3. Investigate arrangements that provide improved support for multidisciplinary care in hospitals and the community.
4. Develop agreed diabetes plans at national, state, territory and local levels, as appropriate, to monitor all aspects of diabetes management for the purpose of quality improvement, including performance indicators.

5. Provide evidence-based consumer information about the environmental, behavioural and genetic risks of diabetes.
6. Continue and, where necessary, strengthen and/or establish national approaches to assist primary care workers (especially general practitioners) to offer high quality and appropriate assessment of risk, early detection of diabetes, referral to treatment, coordination of treatment and supportive care.
7. Support the enhancement of the capacity of people with diabetes to understand and manage their diabetes through national, state, territory and local approaches.
8. Implement and evaluate culturally appropriate programs to improve diabetes prevention and management with special emphasis on the needs of disadvantaged groups, Aboriginal and Torres Strait Islander peoples and those from culturally and linguistically diverse backgrounds.
9. Review the evidence, gaps in research and opportunities for action within a specific timeframe, at least every three years.

NEXT STEP

As a national policy document, the National Service Improvement Framework for Diabetes is intended to guide the implementation process which will be steered by each of the jurisdictions. It is expected that the implementation of the NSIF will be a collaborative effort between the Australian and State/Territory Governments as well as public, private and non-government organisations.

Appendix

Table 4. WHO Criteria Values for Diagnosis of Diabetes Mellitus and Other Categories of Hyperglycemia

	Glucose concentration, mmol/L		
	Venous whole blood	Capillary whole blood	Venous plasma*
Diabetes Mellitus:			
Fasting	≥6.1	≥6.1	≥7.0
<i>Or</i>	≥10.0	≥11.1	≥11.0
2-hr post glucose load <i>or both</i>			
Impaired Glucose Tolerance (IGT):	< 6.1	< 6.1	< 7.0
Fasting (if measured)	≥6.7 and < 10.0	≥7.8 and < 11.1	≥7.8 and < 11.1
<i>And</i>			
2-hr post glucose load			
Impaired Fasting Glycaemia (IFG):	≥5.6 and < 6.1	≥5.6 and < 6.1	≥6.1 and < 7.0
Fasting	< 6.7	< 7.8	< 7.8
<i>And</i> (if measured)			
2-hr post glucose load			

*Corresponding values (mmol/L) for capillary plasma are: for Diabetes Mellitus, fasting ≥7.0, 2-h ≥12.2; for Impaired Glucose tolerance, fasting <7.0 and 2-h ≥8.9 and <12.2; and for Impaired Fasting Glycemia ≥6.1 and <7.0 and if measured, 2-h <8.9.

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Glossary

Term	Definition
Absolute risk	One way of expressing the likelihood that a particular event (e.g. disease) will occur for individuals or groups. It is used to estimate the total number of events to be expected by a specific group or the actual odds for an individual to have an event.
Acculturation	Acculturation is the process whereby individuals from one cultural group adopt the characteristics and values of another culture with which they have come in contact.
Allied health professionals	Health care workers trained specifically to assist and support the work of medical professionals. For example, psychologists, dietitians, social workers and podiatrists.
Amaurosis fugax	Temporary blindness that may result from a transient reduction of the blood supply to the eye.
Ambulatory care	Any non-emergency medical care provided in an out-patient setting.
Artherosclerotic disease	Disease characterised by narrowing of the coronary arteries which impedes the flow of blood, and consequently oxygen and nourishment to the heart. The disease increases the risk of angina and heart attack.
Asymptomatic	Without symptoms or producing no symptoms.
Audit	A methodical examination or review of clinical practice.
Auscultation	Auscultation is the process of listening for sounds produced in the body to identify normal or abnormal sounds and to aid in diagnosis.
Benchmarking	A tool used to measure and compare the quality of services provided in one setting with those in other settings. The goal of benchmarking is to improve the quality of care by adopting the best practices of other services.
Carotid bruits	An abnormal sound in the neck that is heard when using a stethoscope to listen to blood flow in the carotid artery (i.e. the main artery in the neck that brings blood to the head). A bruit indicates a fatty build up in the artery and is a sign of higher stroke risk.
Carotid stenosis	Also known as carotid artery atherosclerosis. The condition occurs as a consequence of a narrowing of the carotid artery.
Case detection	Case detection strategies aim to identify asymptomatic individuals at high risk for the development of a particular condition.
Cerebral oedema	Increased brain water content.
Clinical practice guidelines	Systematically developed reviews of evidence to assist health professionals and people with specific conditions to make decisions in respect of their care.

Term	Definition
Coordinated care	Care is coordinated when people experience the care they receive in the primary, community and secondary care sectors as being provided by the one organised service. Coordinated care relies on effective communication, liaison and integration between services provided in the different sectors.
Diabetes	The name given to a group of medical conditions that are characterised by relative or absolute deficiencies in the secretion and/or action of the hormone insulin and other metabolic problems.
Diabetic ketoacidosis	A potentially life threatening condition caused by the enhanced production of ketones in the liver. Ketones are acidic, and high serum concentrations of these fatty acids may lead to kidney malfunction, thereby causing toxins to accumulate in the body.
Dyslipidaemia	A lipid abnormality characterised by raised levels of both triglycerides and low density lipoprotein (LDL) cholesterol, and a low level of high density lipoprotein (HDL) cholesterol.
Enuresis	Frequent involuntary urination
Evidence-based practice	Clinical decision making based on consideration of the best available evidence derived from systematic and clinically relevant research and clinical experience.
Fundus	The bottom or base of any hollow organ; e.g. the fundus of the bladder; the fundus of the eye.
Gestational diabetes mellitus (GDM)	A type of diabetes that starts during pregnancy, usually between the 24th and 28th weeks. GDM affects about 4% of pregnant women, and usually goes away after childbirth.
Glucagon	Glucagon is a hormone that raises the blood sugar level. It is injected in a similar way to insulin and is recommended to reverse hypoglycaemia in people with Type 1 diabetes and some people with Type 2 diabetes.
Glycaemic Index (GI)	Ranking of carbohydrates based on their immediate effect on blood sugar levels. Carbohydrates that break down quickly during digestion have the highest GIs—the blood sugar response is fast and high. Carbohydrates that break down slowly releasing sugar gradually into the blood stream have low GIs.
Glycosuria	Urinary excretion of carbohydrates.
Glycosylation	Glycosylation is the addition of polysaccharides to molecules such as proteins.
HbA1c	Glycosylated haemoglobin, one of the most frequently used indicators of glucose control. HbA1c reflects the amount of oxygen carrying red blood protein that has glucose tightly bound to it and provides a measure or average blood concentration of glucose during the previous two months.
Hyperglycemia	A condition that occurs when blood glucose levels rise above the normal range, and associated with such unpleasant symptoms as excessive thirst, frequent drinking, frequent urination, weight loss, and weakness.

Term	Definition
Hyperosmolar non-ketotic coma	An acute, severe condition that occurs as a consequence of very high concentrations of sugar in the blood occurring mainly in people with Type 2 diabetes. The condition requires urgent medical attention.
Hypertension	A condition that occurs when blood pressure is sustained above the normal range.
Hypoglycemia	A condition that occurs when blood glucose levels fall below the normal range. Symptoms range from such minor inconveniences as sweating, tremors, headache and fatigue to potentially catastrophic experiences, including disorientation, convulsions, loss of consciousness and death.
Impaired glucose tolerance (IGT)	People with IGT have blood sugar levels higher than normal, although not high enough for them to be diagnosed with diabetes.
Inequity	A difference that is unnecessary and avoidable and considered unfair or unjust.
Insulin resistance	In insulin resistance, tissues have a diminished ability to respond to the action of insulin. To compensate for this resistance, the pancreas secretes more insulin. Thus, insulin resistant people have higher plasma insulin levels.
Intensive blood glucose control	Maintenance of blood glucose levels as near to normal levels as possible.
Intercurrent illness	Illnesses occurring at the same time.
Intervention group	Also known as the 'treatment group', the group of people in a RCT who receive the treatment being evaluated.
Ischaemia	Local anaemia due to obstruction of the blood supply.
Ketonuria	Increased excretion of ketone bodies in urine.
Level I evidence	Evidence that is based on RCTs (or meta-analysis of such trials) of adequate size to ensure a low risk of incorporating false-positive or false-negative results.
Level II evidence	Evidence that is based on RCT's that are too small to provide Level I evidence. These may show either positive trends that are not statistically significant or no trends and are associated with a high risk of false negative results.
Macrovascular disease	Disease characterised by narrowing of the large blood vessels, predominantly the coronary and cerebral arteries.
Macular oedema	The term given to describe water logging of the macular area of the eye, i.e. the light sensitive part of the retina responsible for the sharp, direct vision needed to read and drive.
Microalbuminuria	The earliest sign of renal disease in people with diabetes, indicated by the presence of protein in the urine.
Microvascular disease	Disease characterised by narrowing of the small blood vessels.
Multifactorial risk	An approach that determines an individual's level of risk of experiencing an event by assessing the presence or absence of multiple risk factors.
Nephropathy	Medical term for kidney disease.

Term	Definition
Neuropathy	A condition that involves damage to the nerve fibres of either the peripheral nerves or the autonomic nervous system.
Non-proliferative retinopathy	The first stage of diabetic eye disease. During this stage, dilation and haemorrhaging of the capillaries in the retina cause a range of visual impairments.
Patient held record (PHR)	Patient held records exist in a number of formats. All PHRs are designed to ensure that people have ready access to individualised information about their medical condition, and an ongoing record of their care.
Patient registers	Accurate listings of patients with certain disorders.
Person-centred care	Person-centred care is an approach to care in which people share management of their illness with their health professionals. The three elements defining person-centred care are communication; partnerships; and a focus beyond the specific condition to health promotion, healthy lifestyles and quality of life.
Polydipsia	Frequent drinking due to extreme thirst.
Polyuria	Excessive urination.
Primary prevention	Promoting health in people who have not yet begun to develop disease to help them avoid that disease. An example is counselling young people on dietary practices to help them reduce their risk of subsequently developing heart disease or diabetes.
Proliferative retinopathy	Eye disease in which the abnormal blood vessels originating from the optic nerve bleed and scar.
Quality use of medicines (QUM)	Selecting management options wisely, choosing suitable medicines if a medicine is considered necessary and using medicines safely and effectively.
Randomised Control Trial (RCT)	The RCT is one of the most commonly reported methods for evaluating the effectiveness of treatments. The essential features of an RCT are: the comparison between a treatment and placebo group; participants are allocated randomly to one of the two groups; and there is at least a single and more likely a double blind procedure used to collect the data. If sufficient rigour is used to conduct these processes, then it should be possible to conclude that the observed outcome, if statistically significant, has indeed been caused by the treatment, i.e. there is a high probability that the treatment works.
Retinopathy	Narrowing of the small blood vessels that affect the retina and lens of the eye.
Secondary prevention	Early detection and treatment of people who have begun to develop the disease (possibly with silent symptoms). An example is screening to detect high blood pressure so that people with preclinical symptoms can be treated with appropriate medications or lifestyle change.

Term	Definition
Self-management	Describes the health activities undertaken by individuals with diabetes to manage their condition, including daily management, physical activity, improved nutrition, interaction with health care and support services, behaviour and role adaptation, and management of the psychosocial aspects of living with a chronic illness.
Type 1 diabetes	A form of diabetes that is characterised by a deficiency in insulin secretion. It is currently thought to result from autoimmune processes which selectively target and destroy the cells in the pancreas responsible for the production of insulin.
Type 2 diabetes	A form of diabetes that occurs as a consequence of a deficiency in insulin action.

Frequently Used Abbreviations

ADEA	Australian Diabetes Educators Association
ADS	Australian Diabetes Society
AIHW	Australian Institute of Health and Welfare
AMI	Acute Myocardial Infarction
APEG	Australian Paediatric Endocrine Group
BGL	Blood Glucose Level
BMI	Body Mass Index
BP	Blood Pressure
CDE	Credentialed Diabetes Educator
CDM	Chronic Disease Management
CHD	Coronary Heart Disease
CKD	Chronic Kidney Disease
CMI	Consumer Medicine Information
DKA	Diabetic ketoacidosis
EPC	Enhanced Primary Care
ESRD	End-stage renal disease
GDM	Gestational Diabetes Mellitus
MAP	Medication Action Plan
MBS	Medicare Benefits Schedule
MODY	Maturity Onset Diabetes of the Young
NCDS	National Chronic Disease Strategy
NIDP	National Integrated Diabetes Program
NDSS	National Diabetes Service Scheme
NGO	Non-government Organisation
NHMRC	National Health and Medical Research Council
NHPA	National Health Priority Action
NHPAC	National Health Priority Action Council
NSIF	National Service Improvement Framework
RACGP	Royal Australian College of General Practitioners
RCT	Randomised Control Trial
UKPDS	United Kingdom Prospective Diabetes Study
WHO	World Health Organization

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