

National Health Priority Areas Report

Diabetes mellitus

1998

Commonwealth Department of Health and Aged Care
Australian Institute of Health and Welfare

AIHW Cat. No. PHE 10

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ISBN 0 642 39401 6

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Commonwealth Department of Health and Aged Care and Australian Institute of Health and Welfare (1999) *National Health Priority Areas Report: Diabetes Mellitus 1998*. AIHW Cat. No. PHE 10. HEALTH and AIHW, Canberra.

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Editing, production and desktop publishing by Ampersand Editorial & Design, Canberra.

Cover design by Miller Street Studio, Canberra.

Publications Approval Number 2529.

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Thanks are also due to the following organisations for their assistance in the preparation of this report:

Australian Diabetes Educators' Association
Australian Diabetes in Pregnancy Society
Australian Paediatric Endocrine Group
Juvenile Diabetes Foundation of Australia
Integration SERU, School of Community Medicine, University of New South Wales
National Association of Diabetes Centres

Executive summary

This report on diabetes¹ is one of a series of biennial reports to Australian Health Ministers on each of the five National Health Priority Areas (NHPAs). It is part of a process that involves various levels of government and draws on advice from non-government sources, with the primary goal of reducing the incidence and impact of diabetes in Australia. This report should be read in the context of other activity in the area of diabetes:

- the *National Diabetes Strategy and Implementation Plan* report (Colagiuri et al 1998) produced for the Ministerial Advisory Committee on Diabetes; and
- the *National Diabetes Strategy*, based on the findings of the *National Diabetes Strategy and Implementation Plan* report and this NHPA report, which will be considered by Australian Health Ministers in July 1999.

Overview of diabetes in Australia

Diabetes is characterised by high blood levels of glucose, caused by deficient production of insulin (the hormone that helps metabolise glucose) and/or resistance to its action. Over the course of this chronic disease, a variety of complications can arise, including heart disease, stroke, blindness, kidney problems and lower limb amputations. Diabetes can also lead to pregnancy-related complications, both for the mother and the foetus or newborn baby. It is the seventh leading cause of death in Australia, and contributes significantly to morbidity, disability, poor quality of life and loss of potential years of life.

There are four main categories of diabetes:

- *Type 1 diabetes*, characterised by a complete deficiency of insulin, and estimated to be present in 10 to 15 per cent of people with diabetes in Australia.
- *Type 2 diabetes*, the predominant form of diabetes in Australia and worldwide. It is a common chronic disease among people 40 years and over, and is characterised by a relative insufficiency of insulin and resistance to its action.
- *Gestational diabetes*, which occurs during pregnancy in about 4 to 6 per cent of women not previously known to have diabetes, and greatly increases their risk of developing diabetes later in life.
- *Other types*, including diabetes secondary to other biological and metabolic events, in addition to known genetic abnormalities.

While diabetes is caused by both genetic and environmental factors, lifestyle-related risk factors such as obesity and physical inactivity play a significant role in the development and progression of Type 2 diabetes and gestational diabetes.

Both the incidence and prevalence of diabetes are rising worldwide, including Australia. While there are no national data on diabetes prevalence, it is estimated that 700,000 Australians had diabetes in 1995, about half of whom were not aware that they had the condition. This figure is projected to rise to 770,000 by the year 2000 and to 950,000 by 2010. Unless effective prevention strategies are put into place, the impact of diabetes will continue to rise.

¹ In this report, diabetes mellitus is referred to as diabetes.

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The burden of diabetes is even greater on certain population groups within Australia. Available data suggest that the overall prevalence of diabetes among Indigenous adults is at least two to four times that of non-Indigenous adults. The prevalence of diabetes is also higher among some population groups and among older Australians. Death rates for diabetes in the remote areas of Australia are two to three times higher than in metropolitan areas.

Diabetes and its complications are a sharply increasing component of health care costs, and this increase is likely to continue as the population continues to age. In 1993–94 alone, the direct costs of diabetes and its complications were estimated at \$681 million.

Measuring progress

Under the NHPA initiative, progress towards reducing the health problem is measured by time trends of risk factor prevalence, and morbidity and mortality. A major task in developing this first report on diabetes was to design a set of 20 priority indicators, each with a standard definition, to be used for monitoring and reporting. This report gives a picture of the current status of diabetes, generated using indicators for which data are available. Subsequent NHPA reports on diabetes will also report on progress towards national health targets, as trend data become available.

Summary statistics indicate that the prevalence of diabetes varies considerably among population groups in Australia, and that death rates from diabetes among males are rising. Obesity and physical inactivity, the two major risk factors for diabetes, are common in the general population and even more prevalent in people with diabetes.

Approaches to diabetes control

Diabetes services exist across the continuum of care, and are delivered by a range of organisations and providers with varying roles and responsibilities. Effective coordination is important at both organisational and service levels, to ensure that consumers receive consistent, high quality care.

Prevention of diabetes

The most effective strategy to reduce the impact of diabetes and its complications is to prevent people from developing the disease. Type 1 diabetes cannot be prevented at present, although studies are in progress to understand the causes of the disease. However, there is evidence that Type 2 diabetes can at least be delayed through modification of risk factors. High-risk groups for primary prevention include people with impaired glucose tolerance or gestational diabetes, and those with other risk factors for diabetes, such as obesity and physical inactivity.

Population approaches are expected to have a greater impact than high-risk approaches in reducing the burden of Type 2 diabetes, simply because of the size of their target group, but there are few reliable data to demonstrate the effectiveness of population-based interventions.

A combination of legislative, educational and economic approaches is required to promote physical activity, good nutrition, the reduction of overweight and obesity, and successful management of risk factors across the population. This will have benefits that go considerably beyond diabetes, because the behavioural and physiological risk factors for diabetes often also play a major role in the development of other common conditions such as cardiovascular disease and some cancers. While the health sector should take the lead in preventive actions, it will ensure more lasting effects if it forms long-term partnerships and alliances with other sectors.

Work is in progress at the Commonwealth, State and Territory, and regional levels, to establish such partnerships, improve the infrastructure for primary prevention and coordinate health promotion activity across major health issues.

Early detection of Type 2 diabetes

Early detection of Type 2 diabetes is important because diabetes can remain asymptomatic for many years and significant diabetes-related morbidity can be present before diagnosis. The earlier a person with diabetes is diagnosed, the sooner treatment can be given to control blood glucose levels and delay onset and progression of many diabetes-related complications.

Currently, there is no nationally organised approach to early detection of diabetes, and most cases are diagnosed through opportunistic screening by general practitioners (GPs) and other health professionals.

Management of Type 1 and Type 2 diabetes

Once diagnosed, effective management of Type 1 and Type 2 diabetes is critical to improving health-related quality of life, as it reduces the chance and magnitude of complications and premature mortality. Treatment of diabetes is directed towards achieving strict control of blood glucose levels. There is consensus that this level of control is feasible for the majority of people with diabetes, but only through a collaborative effort involving the person with diabetes, carers and health service providers.

Australia has a strong network of diabetes treatment services that provide routine care for people with diabetes, either through primary care physicians or through interdisciplinary, ambulatory care centres.

Secondary prevention of established complications is important. Since interventions generally achieve the best results if started in the early asymptomatic stages, and complications can progress to an advanced stage before symptoms develop, regular medical screening for diabetes-related complications is essential to identify those people who require treatment.

Special populations

The *National Diabetes Strategy and Implementation Plan* report (Colagiuri et al 1998) highlighted several population groups who require special consideration in diabetes prevention and care services, because of a greater prevalence of diabetes, or difficulties in access to services, or both. These population groups are:

- *Indigenous Australians*, who have limited availability and access to necessary and culturally appropriate health care, and for whom there are a number of additional inter-related factors which contribute to persistent poor health.
- *People from culturally and linguistically diverse backgrounds*, who may experience disadvantages in terms of access to the range of diabetes services available (because of language barriers), appropriate education and information for effective self management and continuing community support.
- *People living in rural and remote areas*, who face disadvantages in accessing adequate and appropriate health care.
- *Children and adolescents*, who have the longest course of the disease and the greatest risk of complications, and among whom optimising diabetes control may be more difficult than among adults.
- *Older Australians*, for whom issues such as multiple pathology, polypharmacy, social isolation and depressed cognitive function complicate the provision of effective preventive and management services.

Opportunities and future directions

Future directions in diabetes will be shaped by the development and implementation of the National Diabetes Strategy. It is important that existing activity at national, jurisdictional and regional levels is examined during the implementation of the National Diabetes Strategy, and that future action recognises past experience and successes and builds on current activity. This action will involve governments at all levels, the private sector, non-government and community organisations, and consumers and carers.

Governments have a number of broad levers at their disposal to foster better programs and practice and to discourage inappropriate practice. Some of these levers could be employed within the following priority areas for diabetes.

Increased commitment to prevention

The primary prevention messages relating to health and lifestyle across the major health issues are virtually the same. National action in these areas will be most effective if there is coordination across different program areas, consistent health messages and adequate funding.

The National Public Health Partnership and preliminary work on a National Primary Prevention Strategy should contribute much to this area. The implementation of the National Diabetes Strategy should forge further links with these strategies rather than duplicating their work with diabetes-specific messages. Currently, there is no funding infrastructure in place to address coordination issues. However, a number of innovative proposals could be further explored which could draw together processes and principles established under existing arrangements.

Increasing rates of early detection

As with prevention, increased awareness of diabetes in the population and among health professionals is necessary before rates of early detection can increase. By raising awareness of diabetes, the Community Awareness of Diabetes Strategy (CADS) currently being developed is expected to increase rates of diagnosis among people with diabetes who do not know they have the condition. This strategy requires both jurisdictional support and Government commitment. In order to convert increased awareness into greater rates of diagnosis, health professionals also need appropriate skills in case finding, testing and follow-up. The development and dissemination of national guidelines on these issues will enable health professionals to detect diabetes at earlier stages.

Improving the capacity of the health system to deliver, manage and monitor services

The infrastructure for diabetes services in Australia is complex. Mechanisms need to be in place to ensure that a coordinated approach to diabetes is undertaken in Australia. The establishment of a National Diabetes Advisory Committee to report to Australian Health Ministers through the Australian Health Ministers' Advisory Council (AHMAC) would facilitate the achievement of this goal. This approach would allow a streamlining of the existing advisory mechanisms, and a focus on a number of key areas. In particular, the promotion of better practice, quality of care and management of complications could be achieved through:

- the effective implementation of existing clinical practice guidelines and development and implementation of guidelines in other areas;
- a national program to encourage the provision of evidence-based, coordinated services to prevent the development or progression of complications;
- establishing efficient recall mechanisms to allow regular monitoring;
- provision of relevant, up-to-date and culturally appropriate information to facilitate self management among people with diabetes;
- ensuring adequate access to diabetes specialists and allied health professionals, especially for those in rural and remote areas;
- increasing health professionals' participation in diabetes care through sustainable continuing education;
- continued funding to increase the number of Aboriginal health workers; and
- specific activities to address diabetes in pregnancy and the continuing care and monitoring of women who develop gestational diabetes.

Improving data development and information systems

Currently, there is little understanding of the incidence and prevalence of diabetes and its complications in Australia and within population subgroups, hindering the development of health planning and resource allocation. This information is needed at regional, State and national levels.

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The main information requirements include the following.

- The development of standard definitions for each aspect of monitoring, to enable consistent information to be collected by the various diabetes health service providers, and outcomes to be evaluated in relation to health service utilisation. Inclusion of agreed diabetes fields into existing national minimum datasets is essential to obtain timely and accurate data. An existing data system for diabetes could be the basis for this.
- Surveys and other data collection techniques are needed to assess and monitor the incidence and prevalence of diabetes in the general population and in special populations with higher prevalence rates.
- A mechanism that promotes data linkage across service settings has the potential to increase efficiency and improve diabetes health outcomes and should be investigated in the short term. National coordination of record linkages is desirable as currently there is duplication of effort across jurisdictions.

Enhancing research into diabetes

Research has increased understanding of diabetes, its risk factors and effective treatments to control the disease and delay the onset of complications. Research needs to be continued to ensure progress is made towards a cure, as well as further improving prevention and management interventions.

Major research issues include reviewing allocation of research funding for diabetes and establishing research priorities within diabetes.

Summary — Important future directions in diabetes

- Coordinating primary prevention strategies across major health issues.
- Establishing processes and mechanisms for the early detection of diabetes.
- Coordinated management of diabetes, including diabetes-related complications.
- Disease management strategies that involve the patient and are culturally appropriate.
- Sustainable continuing education of health professionals, including Aboriginal health workers.
- Standardising recommendations of care for pregnant women with gestational diabetes or diabetes.
- Addressing issues of access to services and information for higher-risk groups.
- Systematic development of diabetes datasets and a national diabetes monitoring system.
- Gaining a better understanding of diabetes, its causes and interventions that may reduce its impact, through research.

Introduction

Background

This report on diabetes² is one of a series of biennial reports to Health Ministers on each of the five National Health Priority Areas (NHPAs) — cancer control, injury prevention and control, diabetes mellitus, cardiovascular health and mental health. This report is being released concurrently with the reports on cardiovascular health and mental health. Reports on cancer control and injury prevention and control were released in mid 1998 (DHFS & AIHW 1998a; 1998b).

Although each report targets a group of discrete diseases or conditions and the recommended strategies for action are often specific in nature, the NHPA initiative recognises the role played by broader population health initiatives in realising improvements in the health status of Australians. Public health strategies and programs that target major risk factors such as smoking may benefit several priority areas, for example diabetes mellitus, cardiovascular health and cancer control.

This report is part of an encompassing NHPA process that involves various levels of government and draws on expert advice from non-government organisations, with the primary goal being to reduce the impact of diabetes on the Australian population.

The National Health Priority Areas initiative

Based on current international comparisons, the health of Australians is among the best in the world and should continue to improve with continued concerted efforts across the nation. The NHPA initiative emphasises collaborative action between Commonwealth and State and Territory Governments, the National Health and Medical Research Council (NHMRC), the Australian Institute of Health and Welfare (AIHW), non-government organisations, appropriate experts, clinicians and consumers. It recognises that specific strategies for reducing the burden of illness should be holistic, encompassing the continuum of care from prevention through treatment and management to rehabilitation, and should be underpinned by evidence based on appropriate research.

By targeting specific areas that impose high social and financial costs on Australian society, collaborative action can achieve significant and cost-effective improvements in the health of Australians. The diseases and conditions targeted through the NHPA process were chosen because they are areas where significant gains in the health of Australians can be achieved.

From National Health Goals and Targets to National Health Priority Areas

The World Health Organization (WHO) published the *Global Strategy for Health for All by the Year 2000* in 1981 (WHO 1981). In response to this charter, the *Health for All Australians* report was developed and represented Australia's 'first national attempt to compile goals and targets for improving health and reducing inequalities in health status among population groups' (Health Targets and Implementation Committee 1988). The 20 goals and 65 targets focused on population groups, major causes of sickness and death, and risk factors.

² In this report, diabetes mellitus is referred to as diabetes.

Introduction

A revised set of targets was published in the *Goals and Targets for Australia's Health in the Year 2000 and Beyond* report (Nutbeam et al 1993). Goals and targets were established in four main areas — reductions in mortality and morbidity, reductions in health risk factors, improvements in health literacy, and the creation of health-supportive environments. However, this framework was not implemented widely.

The *Better Health Outcomes for Australians* (DHS 1994) refined the National Health Goals and Targets program. The focus of goals and targets was shifted to four major areas for action — cancer control, injury prevention and control, cardiovascular health and mental health. As a corollary to this, Australian Health Ministers also adopted a national health policy which committed the Commonwealth and State and Territory Governments to developing health goals and targets in the priority health areas and re-orienting the process towards population health.

In 1995, it was recognised that there were a number of fundamental shortcomings in the National Health Goals and Targets process, principally that there were too many indicators (over 140 across the four health priority areas), there was a lack of emphasis on treatment and ongoing management of the disease/condition, and there was no national reporting requirement. In implementing a goals and targets approach, emphasis was placed on measures of health status and reduction of risk factors. However, no nationally agreed strategies were developed to promote the change required to reach the targets set.

This led to the establishment of the current NHPA initiative. Health Ministers agreed at their meeting in July 1996 that a national report on each priority area be prepared every two years, to give an overview of the impact on the health of Australians in these areas, allowing time for major changes in health indicator status to become apparent. These reports would include a statistical analysis of surveillance data and trends for a set of agreed national indicators. It was also agreed that diabetes mellitus should become the fifth NHPA.

The *First Report on National Health Priority Areas 1996* (AIHW & DHFS 1997), a consolidated report on progress in all the priority areas, was presented to Health Ministers in August 1997.

Development of the report

In developing this report, the National Health Priority Committee (NHPC) appointed a consultant author to work with a Diabetes Overseeing Group to provide expert advice on diabetes prevention and care, and the AIHW to provide statistical analysis of data on diabetes.

This report results from collaboration with over 150 professionals from the fields of prevention and diabetes management and from specialists working with specific populations at risk, notably Indigenous people. These professionals provided valuable input on current progress towards addressing the diabetes problem and in identifying a small number of levers for achieving better health.

The AIHW provided expert services in data provision and analysis. This included the development of national indicators for diabetes, as well as routine monitoring of previously agreed indicators.

Purpose and structure of the report

The *First Report on National Health Priority Areas 1996* (AIHW & DHFS 1997) provided an overview of the impact of diabetes on the Australian community and discussed work in progress on the development of a set of national indicators.

This report builds on the work of the *First Report*, and must also be read in the context of other activity in the area of diabetes. After diabetes mellitus became the fifth NHPA, the Commonwealth Government announced funding of \$7.7 million over three years for activities that would improve awareness and management of diabetes in Australia. Significant projects funded include the Community Awareness of Diabetes Strategy (CADS), the establishment of a National Diabetes Register and a consultancy that led to the production of the *National Diabetes Strategy and Implementation Plan* report (Colagiuri et al 1998) for the Ministerial Advisory Committee on Diabetes.

The *National Diabetes Strategy and Implementation Plan* report provides a comprehensive review of evidence-based practice in diabetes prevention and care and proposes three 'change imperatives' for maximising outcomes — best practice, information and coordination. It has been used as a key source document for this report.

A National Diabetes Strategy, based on the findings of the *National Diabetes Strategy and Implementation Plan* report and this NHPA report, will be considered by Australian Health Ministers in July 1999. This strategy will provide direction and priorities for the provision of research, prevention and care services for people with or at risk of diabetes.

This report provides an overview of the incidence, prevalence and cost of diabetes, and gives baseline data and information on underlying trends in prevention and treatment. It also adds to the information in the previous reports on action in diabetes prevention and care across Australia. The States and Territories provided input focused on six areas — guidelines, service collaboration, client focus, provider focus, information systems, and research and development. The results were collated and used to identify current activity in relation to prevention, early detection and improved management of diabetes.

This report also identifies perceived opportunities for implementation of evidence-based practice across the nation, and proposes a number of levers to progress change. The report does not provide a comprehensive analysis of all diabetes services currently being delivered in States and Territories, but highlights a small number of innovative, evidence-based interventions that are considered to have the potential to achieve significant health gains.

Within the report, approaches to address the disproportionate incidence and impact of diabetes on selected populations, most notably Indigenous Australians, are an important consideration.

Chapter 1 provides an overview of diabetes in Australia, including the current extent and cost of the problem, major risk factors, diabetes-related complications, health service use, long-term trends over time and comparisons of the rate of diabetes in Australia with those of other countries.

Chapter 2 presents the newly developed indicators on diabetes and reports on those for which there were data available in 1998.

Introduction

Chapter 3 provides an overview of the current status of prevention, early detection and management of diabetes in Australia. For each of these areas, information is provided on the size of the problem, best practice, and the cost-effectiveness of intervening.

Chapter 4 presents an overview of diabetes services and infrastructure in Australia, including the roles and inter-relationships of organisations and service providers. It also gives a summary of national and State and Territory activity in prevention, early detection and management of diabetes, focused on the six areas outlined above.

Chapter 5 describes the current status of prevention and management of diabetes among specific population groups — pregnant women who have gestational diabetes or pre-existing diabetes; children and adolescents with Type 1 diabetes; Indigenous Australians; rural and remote residents; people from culturally and linguistically diverse backgrounds; and older Australians. It also outlines additional national and jurisdictional activity to address the needs of the special groups.

The report concludes with a consideration of possible strategies for reducing the impact of diabetes in the Australian context, and a proposal for action which builds on Australia's record in the areas of prevention and management (Chapter 6).

1 Overview

This chapter addresses the broad range of issues related to diabetes³ epidemiology, risk factors and complications. It provides a brief overview of the disease, including its possible causes, and its impact in terms of morbidity, mortality and health care costs. The chapter aims to provide background information critical to the development of strategies for diabetes prevention and management.

1.1 Background

Diabetes is a chronic disease, characterised by hyperglycaemia or high levels of glucose, which is caused by deficient insulin production and/or resistance to its action. It is the seventh leading cause of death in Australia, and contributes significantly to morbidity, disability, poor quality of life and loss of potential years of life. Over the course of the disease, diabetes can lead to a variety of complications including heart disease, stroke, blindness, kidney problems and lower limb amputations (AIHW & DHFS 1997). Diabetes can also lead to pregnancy-related complications, both for the mother and the foetus or newborn baby.

The incidence and prevalence of diabetes are rising worldwide. According to the WHO, there will be an estimated 300 million people with diabetes in the year 2025, a large proportion in countries with limited opportunity for its management and control (King et al 1998). The progressive ageing of the population means that a growing number of people are at increased risk of diabetes. Risk factors such as obesity, inappropriate nutrition and physical inactivity are also increasingly unmasking susceptibilities to the disease, even in non-industrialised communities (Bhatia et al 1984; King et al 1985).

The rise and rise of diabetes has also been observed in Australia (McCarty et al 1996). According to a conservative estimate by the International Diabetes Institute, an estimated 700,000 Australians (about 4 per cent of the total population) had diagnosed or undiagnosed diabetes in 1995 (Amos et al 1997). The number has almost doubled since the early 1980s, and is projected to rise to 770,000 by the year 2000 and to 950,000 by 2010 (see Figure 1.1). Unless effective prevention strategies are put into place, the figure will pass one million over the next 15 to 20 years. The disease is much more prevalent among some Australian communities, in particular the Indigenous population and people of Asian/Pacific Islander descent (McGrath et al 1991; Strong et al 1998a).

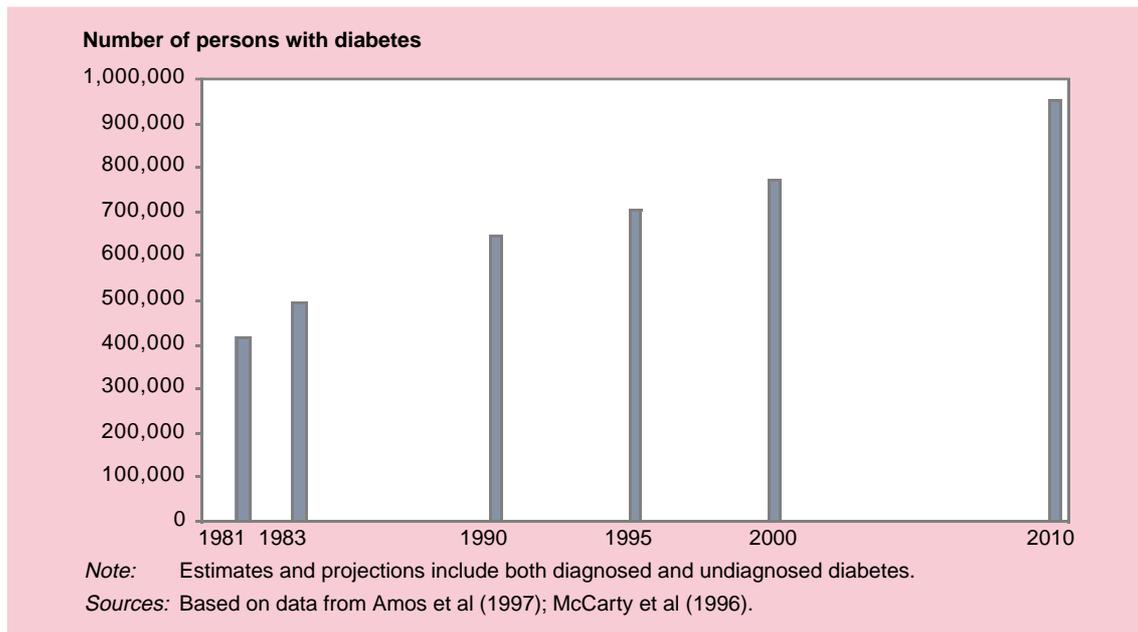
Diabetes and its complications are a sharply increasing component of health care costs, and this is likely to continue to increase as the population ages further. For 1993–94 alone, the direct costs of diabetes and its complications are estimated to be \$681 million (Mathers & Penm 1999). This figure does not include indirect costs, such as lost productivity and premature mortality.

Diabetes and its associated complications compromise the quality of life of many Australians. However, there is now evidence that tight control of glucose, lipids and blood pressure levels is effective in preventing diabetes-associated complications in both Type 1 (DCCT Research Group 1996a) and Type 2 diabetes (UKPDS Group 1998a; 1998b; 1998c). Early detection and effective management are therefore the keys to diabetes control. While improved detection of the disease may add to disease costs in the short term, the total costs are likely to stabilise or fall with earlier diagnosis and prevention of complications.

³ Unless otherwise noted, the term diabetes refers to diabetes under code 250 of the International Classification of Disease, 9th Revision (WHO 1977).

Overview

Figure 1.1: Estimates and projections of diabetes prevalence in Australia, 1981–2010



1.2 Types of diabetes

Because the common feature of diabetes is elevated blood glucose concentration, in the past it was considered to be a single disease. However, it is now clear that diabetes is a heterogeneous metabolic abnormality caused by many different mechanisms. Four major types of diabetes are commonly recognised (Alberti & Zimmet 1998). In addition, impaired glucose tolerance defines a level of blood glucose catabolism that is intermediate between normal and diabetes.

Type 1 diabetes. One of the most common chronic conditions of childhood (although about half of all new cases are among adults), Type 1 diabetes is characterised by a complete deficiency of insulin, the hormone that metabolises glucose. The clinical onset of Type 1 diabetes is usually quite sudden, but may be gradual in adults and in some children. People with Type 1 diabetes require insulin therapy for glycaemic control to survive, the condition is therefore also termed *insulin-dependent diabetes mellitus* or *IDDM*. Usually an autoimmune disease — a condition in which the immune system attacks its own tissues — the development of Type 1 diabetes may also be idiopathic.

Type 2 diabetes. One of the common chronic diseases among people 40 years and over, Type 2 diabetes is characterised by relative insulin insufficiency or resistance to its action. People with this form of diabetes do not usually require insulin to survive, hence it is also known by the term *non-insulin-dependent diabetes mellitus* or *NIDDM*. The pathogenetic mechanisms of Type 2 diabetes are not fully understood. However, it appears to be a two-stage process; resistance to insulin action that often is exacerbated by obesity, followed by inability of the β cells in the pancreas to produce adequate amounts of insulin (Bishop et al 1993).

Some of the characteristics that distinguish Type 1 and Type 2 diabetes are described in Table 1.1.

Table 1.1: Characteristics of Type 1 and Type 2 diabetes

Type 1 diabetes

- Most commonly appears under age 40, but can appear at any age
- Results from the destruction of insulin-producing pancreatic β cells
- Absolute insulin deficiency — insulin required for survival
- Abrupt onset of severe symptoms, but the clinical picture may develop slowly in some cases
- Proneness to ketoacidosis
- Strong association with human leucocyte antigens

Type 2 diabetes

- Appears primarily in adults, but can present at any age
- Can be asymptomatic for many years
- Associated with obesity, but can also develop in non-obese people
- Many people with Type 2 diabetes exhibit insulin resistance, hyperinsulinaemia, hypertension or dyslipidaemia
- Limited dependence on exogenous insulin, and not ketoacidosis prone
- The need to follow a careful diet and exercise regimen
- Complex aetiology and pathophysiology
- High heritability, but no strong association with known genetic markers

Gestational diabetes. About 4–6 per cent of women not previously known to have diabetes develop hyperglycaemia during pregnancy. Women with known diabetes who become pregnant do not fall into this category. In most cases of gestational diabetes, the hyperglycaemia resolves soon after the delivery; however, in some cases, especially among those from high-risk population groups, it may continue, leading to a diagnosis of diabetes. Gestational diabetes carries health risks for the infant, and even when the mother’s blood glucose levels return to normal after the pregnancy, the mother remains at high risk of developing diabetes later in life.

Other types of diabetes. This category is uncommon, and includes diabetes caused by a variety of distinct genetic and pathological mechanisms that are generally clearly defined.

1.3 Disease incidence and prevalence

There are no national estimates of the incidence or prevalence of diabetes in Australia that are based on blood glucose testing. However, the Australian Bureau of Statistics (ABS) has generated national information on self-reported prevalence of diabetes through its National Health Surveys (NHS).

Overview

According to the NHS conducted in 1995, nearly 430,700 persons (2.4 per cent of the total population) reported having had diabetes at some time during their lives. More than 80 per cent of this group of people reported current diabetes. A further 225,000 persons (1.2 per cent of the population) reported high blood glucose levels (ABS 1997a).

These figures are considered to be significant underestimates for two reasons:

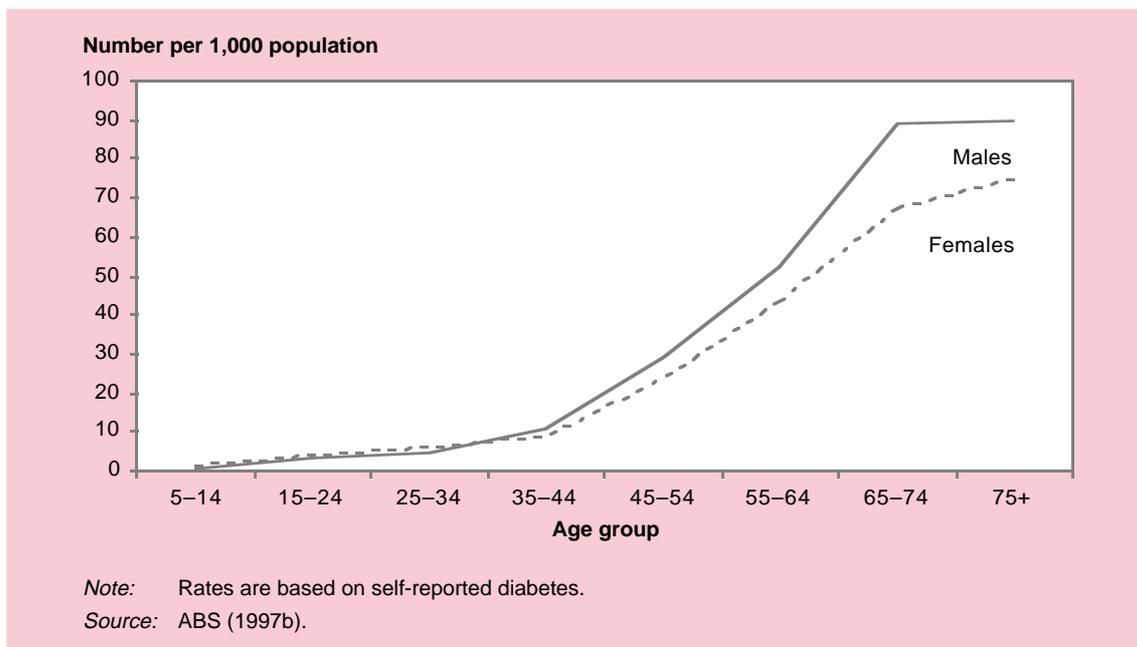
- since the estimate is based on self reporting, the true prevalence of diagnosed diabetes is more likely to be under-reported; and
- a large proportion of diabetes in the community remains undiagnosed.

It has been estimated that for each known case of Type 2 diabetes, there may be at least one person in the population whose diabetes has not been diagnosed. Using this ratio as the correction factor, a revised estimate is that around 4 per cent of the population (nearly 700,000 persons) had diabetes in 1995 (Amos et al 1997). This estimate is supported by several regional studies that also suggest a prevalence rate of between 3 and 5 per cent (McCarty et al 1996).

Age-specific prevalence

The prevalence of diabetes increases with age, from 1 per 1,000 persons among those aged less than 15 years to 89 per 1,000 persons among those aged 75 years and over. The prevalence increases in a similar fashion in both sexes up to the age of 40 years. From then on, the prevalence rate increase is faster in both sexes, but considerably more so among males, being almost one-third higher in the 65–74 year age group (Figure 1.2).

Figure 1.2: Age-specific prevalence of diabetes by sex, Australia, 1995



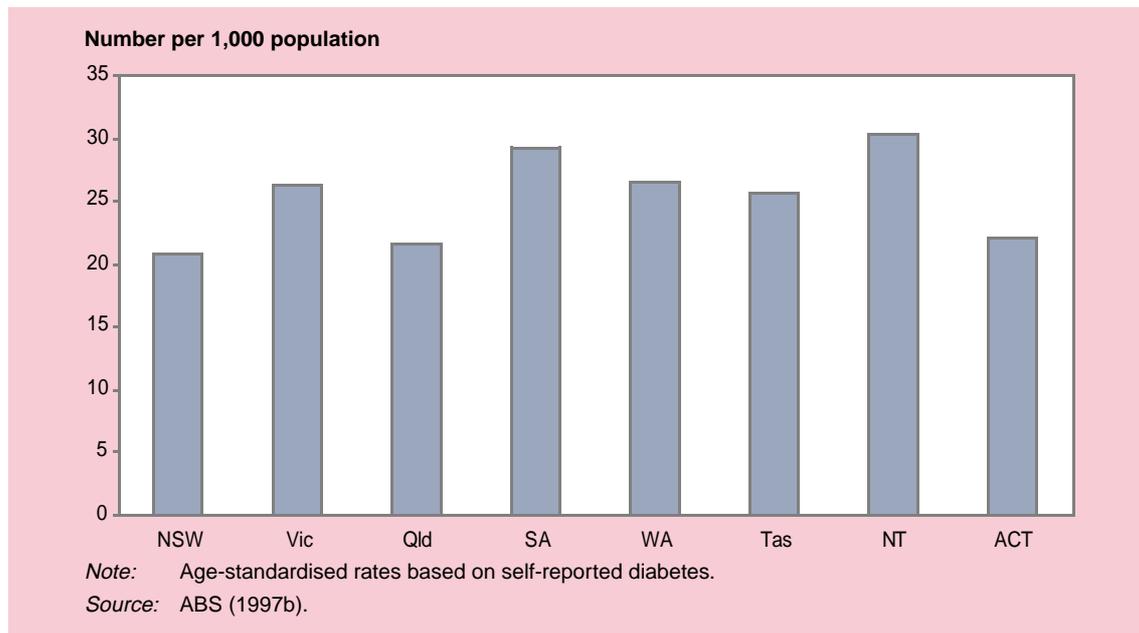
Type 1 diabetes is the dominant form of the disease in age groups to 34 years; in older age groups Type 2 becomes the major form.

Regional variation

There is significant regional variation in the prevalence of diabetes in Australia (Figure 1.3). The age-standardised prevalence for the Northern Territory is around 50 per cent higher than the rate for New South Wales. This probably reflects the Northern Territory's much larger proportion of Indigenous people, among whom Type 2 diabetes is highly prevalent.

Several community studies on diabetes in Australia have revealed regional variations in the prevalence of diabetes (McCarty et al 1996). Substantial variation has also been noted in associated complications and mortality.

Figure 1.3: Regional variation in the prevalence of diabetes, Australia, 1995



Disease prevalence by type of diabetes

There are no national estimates of the relative distribution of the various forms of diabetes, but figures have been derived from self-reported information from the 1995 NHS (ABS 1997b). According to these derived estimates, 12 per cent of all those reporting current diabetes have Type 1 and 88 per cent have Type 2 diabetes (ABS 1997b).

Type 1 diabetes

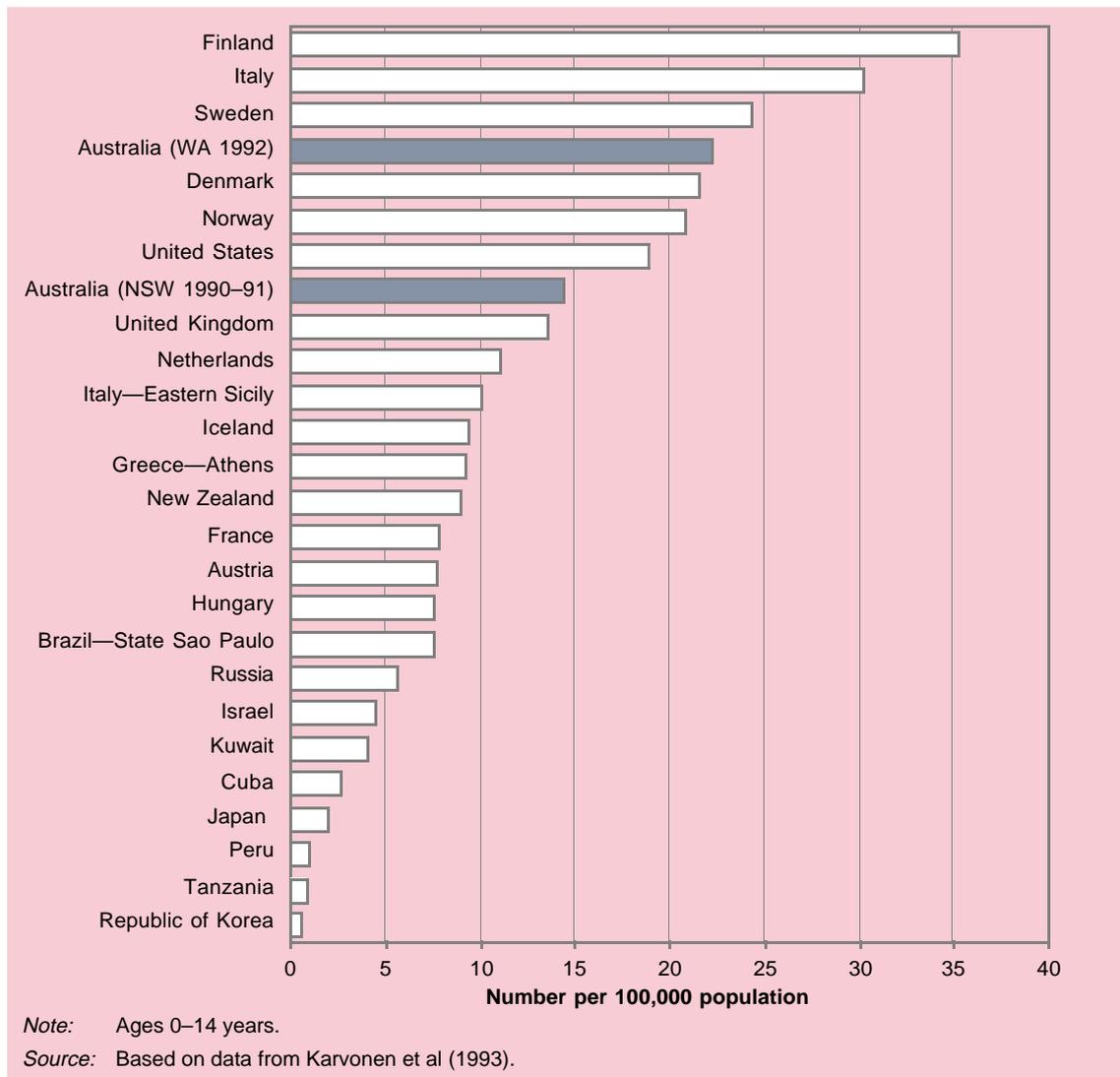
Although the incidence of Type 1 diabetes is significantly lower than that of Type 2 diabetes, the former accounts for a high proportion of existing cases because of its peak onset much earlier in life. Based on the 1995 NHS self-reported information (ABS 1997b), around 42,600 persons — with an estimated prevalence rate of around 218 per 100,000 persons — are estimated to have Type 1 diabetes.

Estimates from regional studies indicate that the incidence of Type 1 diabetes ranges from 12 to 15 per 100,000 persons among those younger than 15 years. The prevalence estimates vary from 59 to 74 per 100,000 among those in the age range 0 to 19 years (McCarty et al 1996).

Overview

Significant inter-population variation exists in the incidence of Type 1 diabetes (Karvonen et al 1993). No information is available on the disease incidence and prevalence among population groups currently resident in Australia. However, the disease is relatively uncommon in source countries of people of non-European descent (Figure 1.4). When present, it is more often of the idiopathic rather than the autoimmune type.

Figure 1.4: Incidence of Type 1 diabetes — international comparisons



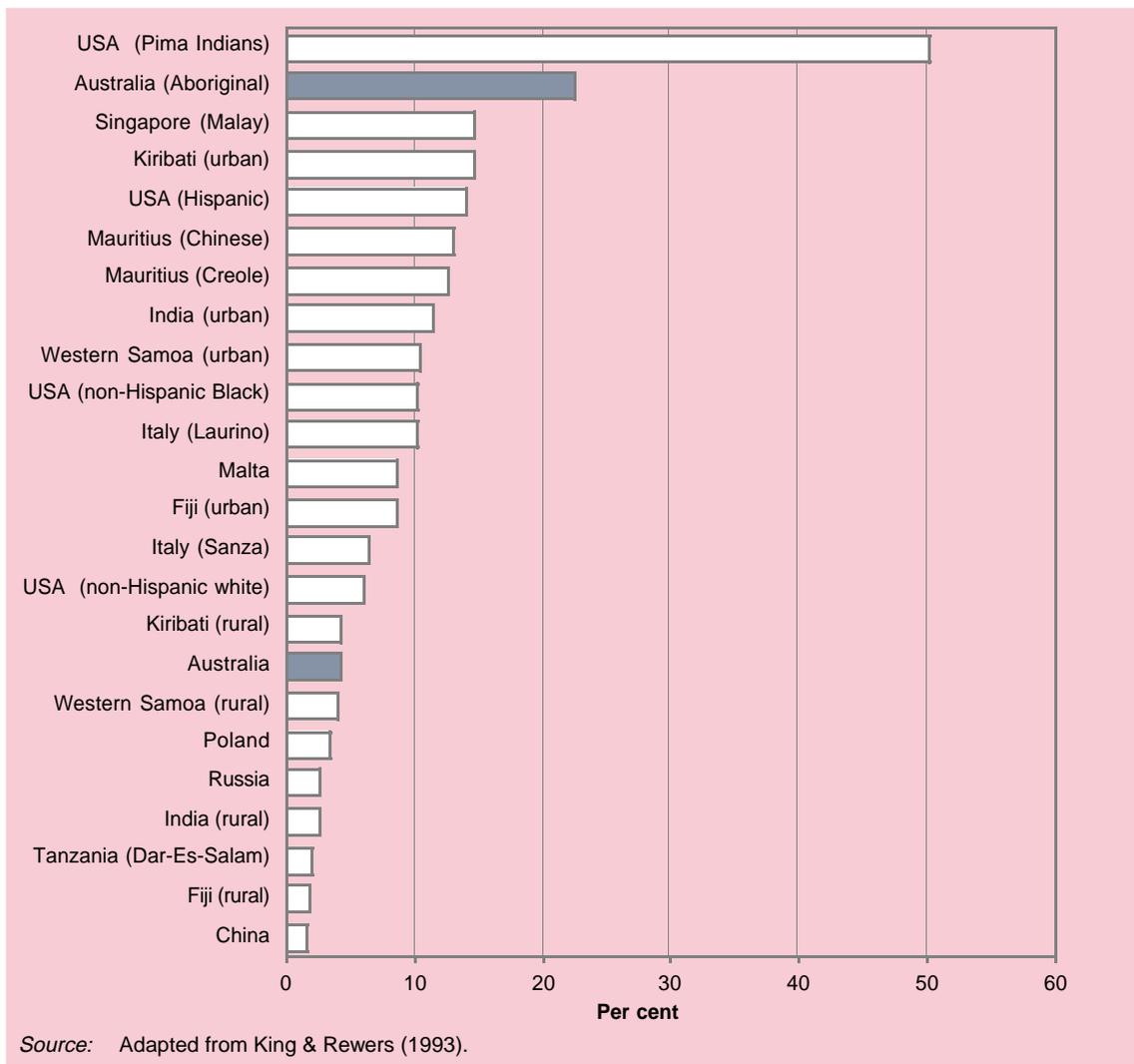
Type 2 diabetes

Type 2 is the predominant form of diabetes in Australia and worldwide. However, the disease may remain undetected for extended periods, leading to underestimation of its incidence and prevalence.

It is estimated from NHS data that around 312,400 persons had Type 2 diabetes in 1995. A large proportion of those who did not know their type of diabetes, as well as those who were on insulin but not classifiable as Type 1, are also assigned to this category. The estimate needs further adjustment to allow for the proportion of undiagnosed cases (one to one) in the population. Accordingly, the prevalence of Type 2 diabetes in Australia is estimated to be around 3,320 per 100,000 persons.

The proportion of Type 2 diabetes is much higher among people from Asia and the Pacific Islands (Figure 1.5). In some population groups, eg the Wanigela people of Papua New Guinea, almost one in two persons in the age group 30 to 54 years is known to have this form of diabetes (Dowse et al 1994). More than 20 per cent of Indigenous Australians in this age group are estimated to have diabetes (McCarty et al 1996).

Figure 1.5: Prevalence of Type 2 diabetes — international comparisons



Gestational diabetes

In Australia, rates of gestational diabetes range from 6 to 9 per cent among women from a European background. Almost one in five Indigenous women may experience gestational diabetes. The prevalence of gestational diabetes among certain ethnic populations (eg from India, Asia, Pacific Islands) is much higher (up to 20 per cent) than in Caucasian women (3–5 per cent) (Beischer et al 1991; Yue et al 1996).

According to the 1995 NHS, some 12 per cent of women (aged 20 years and above) who were told they had diabetes reported having had gestational diabetes. The proportion rose from less than 40 per cent among those aged 20–24 years to more than 50 per cent among those aged 30–39 years.

Overview

An analysis of 1996 New South Wales data on mothers and babies indicates that 3 per cent of mothers developed gestational diabetes during their pregnancy (NSW Health Department 1998). The proportion with gestational diabetes was much higher among mothers from north-east Asia (8 per cent), and south Asia and south-east Asia (both around 7 per cent).

Other types of diabetes

There is limited information available on the prevalence in Australia of various types of diabetes grouped under this category, which currently account for a very small proportion of cases. Most of the reports are based on specific family studies.

1.4 Risk factors

Type 1 diabetes

The condition usually results from an autoimmune process, where the body creates antibodies against components of the pancreatic β cells, which are then destroyed, leaving the individual virtually unable to produce insulin. The process is triggered by environmental factors in genetically predisposed individuals.

Although no modifiable risk factors have been clearly identified, variation in incidence over time, geographical distributions and twin studies all suggest the role of both genetic and environmental factors in the pathogenesis of Type 1 diabetes.

Genetic factors

In families who have a member with Type 1 diabetes, other family members have a higher risk of developing the disease than do people in the general population, suggesting the presence of a genetic component. However, more than 80 per cent of Type 1 diabetes occurs in people with no family history of the disease. Concordance for Type 1 diabetes among identical twins is only about 30–50 per cent (Dorman et al 1995). However, a strong association of this form of diabetes with various human leucocyte antigens has been demonstrated.

Environmental factors

A variety of environmental factors that trigger autoimmune destruction of β cells has been proposed. Children who are breastfed for a shorter time and/or are introduced to cow's milk early are at an increased risk of developing Type 1 diabetes, suggesting a response to cow's milk may lead to increased risk (Dahl-Jorgensen et al 1991; Gerstein 1994). Certain viruses have also been implicated as risk factors, but have not been substantiated in large-scale studies.

Type 2 diabetes

Type 2 diabetes results from a combination of abnormalities of insulin secretion and insulin action. The pancreatic β cells are unable to produce enough insulin to cope with the amount of circulating glucose, and the muscle, fat and liver (on which insulin mainly works) are relatively resistant to its action (insulin resistance).

Conditions associated with insulin resistance are therefore important risk factors for this type of diabetes. Several genetic and environmental factors also contribute to the precipitation of Type 2 diabetes.

Genetic factors

Type 2 diabetes is known to have a strong genetic component, with twin studies showing concordance rates of up to 80 per cent. Although the genes for certain rare forms of Type 2 diabetes have been identified, the genetic basis of the more common form remains unknown. It is likely that multiple genes in various combinations, acting on different metabolic functions, lead to Type 2 diabetes.

Other risk factors

Obesity: The risk of developing Type 2 diabetes rises continuously with increasing obesity, and is approximately five to ten times greater in those classified as obese (body mass index [BMI] 30 and over) than in those with an acceptable weight (BMI under 25) (Perry et al 1995; Shaten et al 1993).

The proportion of overweight adults in Australia is high, and continues to rise. The proportion of overweight or obese females (BMI over 25) increased from almost 27 per cent in 1980 to 46 per cent in 1995 (AIHW 1998a). The proportion of overweight or obese males also increased from almost 48 per cent to more than 68 per cent over the same period. The proportion of obese males (BMI 30 and over) increased dramatically, more than two times, from about 8 to 19 per cent, between 1980 and 1995. The proportion of obese females increased from around 7 to 16 per cent during this period.

Physical inactivity: Several studies indicate that physical activity plays a protective role against the development of diabetes (Helmrich et al 1991; Manson et al 1991, 1992; Perry et al 1995). After other risk factors have been accounted for, people who undertake regular exercise have a 30 to 60 per cent lower risk of developing diabetes than those who do not. The effect appears to be somewhat weaker in females, and in those who are not overweight.

In Australia, the proportion of adults who do not exercise regularly is high. Almost one-third of Australian adults do not participate in any physical activity (AIHW & DHFS 1997). Reported participation in exercise undertaken for sport, recreation or fitness increased slightly between 1989–90 and 1995, from 64 to 67 per cent in males and 64 to 66 per cent in females, but these increases are mainly due to increased participation in physical activity by people aged 35–54 years. The proportion of people undertaking physical activity at low, moderate and high levels remained fairly stable between 1989–90 and 1995 (Armstrong 1998).

Diet: Diet is an important determinant of obesity, and as such is thought to play a crucial role in the development of Type 2 diabetes. Research into the long-term effects of diet is hindered by difficulties in accurately measuring dietary intake. High saturated fat intake is considered to be an important dietary determinant of Type 2 diabetes (Marshall et al 1994), although this has not been confirmed by other studies (de Courten et al 1997).

Age: Increasing age is a major risk factor for Type 2 diabetes. As the population of Australia progressively ages, the burden of Type 2 diabetes is expected to rise.

Overview

Low birth weight: Studies linking low birth weight with disease later in life suggest an increased lifetime risk for Type 2 diabetes (Hales & Barker 1992). The association is independent of gestational age, gender, adult BMI, waist-to-hip ratio, and social class at birth and in adulthood (Rewers & Hamman 1995). The risk also extends to impaired glucose tolerance and insulin resistance (Phillips et al 1994).

Gestational diabetes

The aetiology and risk factors for gestational diabetes are generally similar to those of Type 2 diabetes. Population variation in the prevalence of gestational diabetes also suggests the presence of a genetic component in this condition. The genetic factors may be the same as those that bring about Type 2 diabetes in later years.

Other forms of diabetes

A variety of risk factors and genetic defects are known to contribute to these forms of diabetes. The environmental factors precipitating these forms are not always identifiable, but may include infections and drug or chemical induced factors.

1.5 Diabetes-related complications

Diabetes results in a variety of complications over the course of the disease, often resulting in limitation of activity and disability. Psychosocial effects of this life long problem have also been documented.

Complications of diabetes can be broadly classified as microvascular, macrovascular and those associated with pregnancy (see Table 1.2). The risk of microvascular complications is similar in Type 1 and Type 2 diabetes (after accounting for age and duration of diabetes), but macrovascular complications are more common with Type 2 diabetes. All types of diabetes in pregnancy are associated with obstetric and neonatal complications, although gestational diabetes is not known to be associated with foetal malformations.

Table 1.2: Major diabetes-related complications

Microvascular disease	Intra-uterine problems
<ul style="list-style-type: none">• Nephropathy• Retinopathy*• Neuropathy	<ul style="list-style-type: none">• Foetal malformations• Spontaneous abortions• Stillbirths
Macrovascular complications	<ul style="list-style-type: none">• Macrosomia• Neonatal hypoglycaemia and other metabolic abnormalities• Increased obstetric interventions
<ul style="list-style-type: none">• Coronary heart disease• Stroke• Peripheral vascular disease	

* Other visual disorders such as cataracts and glaucoma are also present more commonly among persons with diabetes.

Note: Risk factors for some of the above listed complications, such as high blood pressure and elevated levels of cholesterol, are also present more commonly among persons with diabetes.

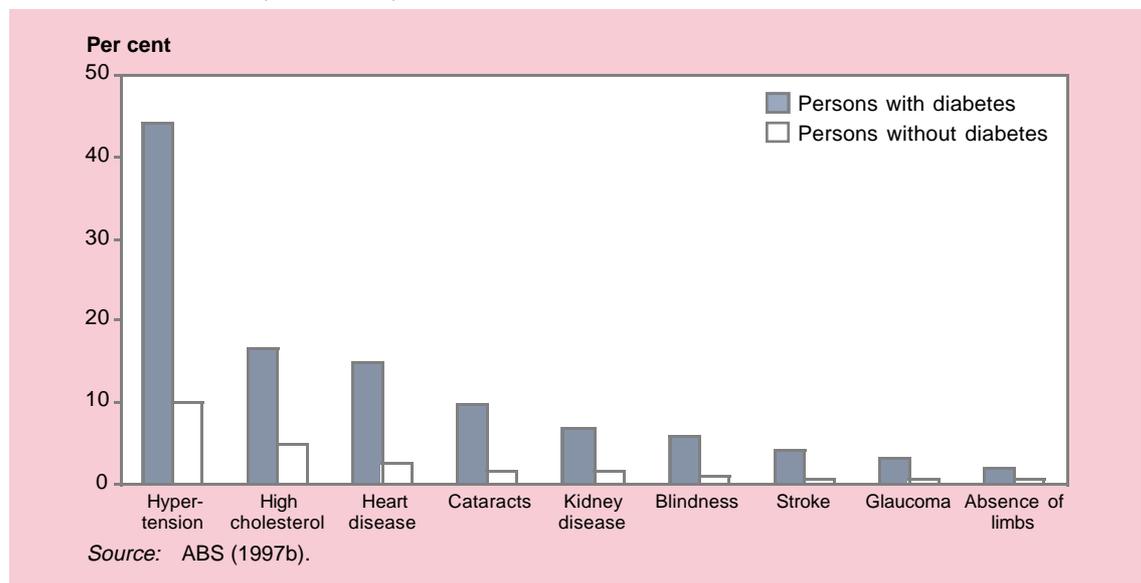
Diabetes-related complications

A range of risk factors is known to contribute or lead to the development of complications among people with diabetes. In addition to age, sex, duration of disease and genetic factors, these include hyperglycaemia, obesity, high blood pressure, high cholesterol, tobacco smoking, lack of self-management skills and poor access to appropriate care.

Tight glucose control can delay the onset and slows the progression of complications in both Type 1 (DCCT Research Group 1993) and Type 2 (UKPDS Group 1998a) diabetes. All of the complications can progress to an advanced stage before the person with diabetes becomes symptomatic, and only regular medical screening can detect the complications at the earlier treatable stages. Similarly, the prevention of foetal malformations requires excellent glucose control from before conception, while other pregnancy-related complications need regular obstetric monitoring and timely intervention.

Australian data on the complications of diabetes are limited. A study in South Australia has estimated that among people with Type 2 diabetes, more than 66 per cent had at least one microvascular complication and 53 per cent at least one macrovascular complication (Phillips et al 1998). The National Diabetes Clinical Data Collection Project, conducted by the National Association of Diabetes Centres (NADC 1998), collects information on some of the complications of diabetes among those attending specialist services. Self-reported information on the complications was also collected during the 1995 NHS (Figure 1.6).

Figure 1.6: Self-reported prevalence of associated conditions and complications of diabetes, Australia, 1995



Microvascular complications

Nephropathy

Kidney disease, or nephropathy, is a major complication of diabetes. It is first diagnosed by the detection of protein in the urine (albuminuria). On average, more than 40 per cent of people with diabetes have elevated levels of urinary albumin and the prevalence is higher in those with diabetes of longer duration (Nelson et al 1995).

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The South Australian survey reveals the presence of albuminuria in more than 34 per cent of people with Type 2 diabetes (Phillips et al 1998). The survey also shows evidence of renal dysfunction among 23 per cent of males and 41 per cent of females with Type 2 diabetes.

During the 1995 NHS, around 7 per cent of people with diabetes reported some form of kidney disease (ABS 1997b). This proportion was more than four times that noted among those without diabetes.

Over time, diabetic nephropathy can progress to end-stage renal disease, requiring dialysis or transplantation for survival. Within 10 years of the development of nephropathy, progression to renal failure occurs in about 10 per cent of people with Type 2 diabetes, and in 50 per cent of those with Type 1 diabetes (Nelson et al 1995).

Diabetes is the second most common reason for entering end-stage renal disease programs, up from fourth over the past decade (Disney 1996). The proportion of people with diabetic nephropathy among Australian patients registered in the Australia and New Zealand Dialysis and Transplant Registry was about 14 per cent in 1992 and 18 per cent in 1996 (Disney et al 1997). Renal failure as a consequence of diabetes is common among Indigenous Australians. In Central Australia, it is estimated that renal disease is the direct cause of death in 22 per cent of Indigenous people with diabetes (Phillips et al 1995).

Retinopathy

Diabetic retinopathy is the most common cause of visual loss in adult Australians under the age of 60. Its prevalence in Australia is estimated to vary from 28 to 51 per cent, with about 12 per cent having vision-threatening retinopathy (Mitchell & Moffitt 1990; Constable et al 1983; Phillips et al 1998). The estimated annual incidence of new retinopathy in Australia is between 6 and 14 per cent. The problem is caused by damage to small blood vessels in the retina and is readily treatable by laser therapy if identified early. Two other eye complications that lead to loss of vision, glaucoma and cataracts, are also more common among those with diabetes.

The onset of retinopathy may be early among people with Type 1 diabetes. Overseas studies indicate that the prevalence of early retinopathy in young people varies from 18 to 64 per cent (Burger et al 1986; Frank et al 1982; Kingsley et al 1988; Klein et al 1984). In New South Wales, the prevalence of early retinopathy among adolescents with diabetes, aged 11 to 20 years, has been estimated at 42 per cent (Fairchild et al 1994).

According to the 1995 NHS, glaucoma and cataracts are respectively five and six times more prevalent among people with diabetes than among those without it (ABS 1997b). Similarly, the rate ratio for blindness is estimated to be around six times greater among those with diabetes. The annual incidence of blindness among people with diabetes attending specialist diabetes services is estimated to be less than 1 per cent (NADC 1998).

Neuropathy, infections and amputations

Neuropathy (damage to the nerves) is a common debilitating complication of diabetes, mainly affecting the feet and legs. Neuropathy can cause pain, but more importantly can lead to foot ulcers, foot infections and gangrene. The prevalence of neuropathy is similar in both Type 1 and Type 2 diabetes, and increases with age, duration of diabetes, and worsening of glucose control (Eastman 1995).

According to a study in Western Australia, 14 per cent of people with diabetes had neuropathy (Knuiman et al 1986). The South Australian study revealed neuropathy among 20 per cent of people with Type 2 diabetes (Phillips et al 1998). Large studies from Europe and the United States report the prevalence of neuropathy between 16 and 32 per cent (Tsfaye et al 1996; Fedele et al 1997; Franklin et al 1994; Walters et al 1992).

The prevalence of neuropathy and various foot problems among people with diabetes attending specialist diabetes services are estimated to be:

- peripheral neuropathy — 28 per cent;
- peripheral vascular disease — 13 per cent;
- current foot ulcers — 2 per cent;
- previous foot ulcers — 6 per cent; and
- amputations in the last 12 months — 1 per cent (NADC 1998).

According to the 1995 NHS, almost 2 per cent of people with diabetes had an amputation, at three times the rate for people without diabetes (ABS 1997b). Several overseas studies indicate that the amputation rate is about 10 times higher among diabetic than among non-diabetic people, and also that 50 per cent of all non-traumatic amputations are carried out in people with diabetes (Reiber 1996).

Macrovascular complications

Cardiovascular disease

The age-adjusted relative risk for cardiovascular disease is two to three times higher for those with diabetes than those without it, and is higher for females than males (in contrast to the general population). The 10-year risk for a cardiovascular event in a 51-year-old person with Type 2 diabetes has been calculated as 16 per cent for males and 15 per cent for females. These rates are more than doubled, to 38 and 36 per cent respectively, if the person smokes, has high cholesterol and high blood pressure (Eastman & Keen 1997).

Coronary heart disease. People with diabetes have higher rates of coronary heart disease than those without diabetes. This is partly because they have higher levels of risk factors such as obesity, high blood pressure and high cholesterol, although this does not fully explain the excess of coronary heart disease in people with diabetes (Tuomilehto et al 1997). Diabetes is considered to be an independent risk factor for coronary heart disease.

During the 1995 NHS, about 15 per cent of people with diabetes reported the presence of coronary heart disease, which is almost six times the rate reported by people without diabetes (ABS 1997b). The South Australian survey indicates the

Overview

presence of coronary heart disease in more than 34 per cent of respondents (Phillips et al 1998). According to the NADC study, around 5 per cent of people with diabetes attending diabetes clinics experienced a heart attack in the 12 months prior to attendance (NADC 1998).

Stroke. Data from the United States show that strokes occur two to six times more frequently in people with diabetes than in the rest of the population. High blood pressure, which is common in people with Type 2 diabetes, seems to be a strong contributing factor. During the 1995 NHS, more than 4 per cent of people with diabetes reported having suffered a stroke, in comparison to less than 0.5 per cent among those without diabetes (ABS 1997b). The NADC study has estimated the incidence of stroke to be more than 2 per cent among people with diabetes (NADC 1998).

Peripheral vascular disease. This disease results in a reduced blood flow to legs and feet. Studies in Sweden and the United States indicate that peripheral vascular disease is about four times as common in people with diabetes as in those without diabetes (Palumbo & Melton 1995), and its prevalence rises with the duration of disease. The incidence of peripheral vascular disease among people with diabetes is estimated to be around 13 per cent (NADC 1998). The South Australian survey indicates the presence of peripheral vascular disease in about 32 per cent of participants (Phillips et al 1998).

Intra-uterine complications

Women with diabetes are at a higher risk of having a large for gestational age baby (Mello et al 1997; McMahan et al 1998), leading to an increased risk of difficult labour and delivery (Casey et al 1997).

It has been suggested that insulin therapy may reduce the incidence of large for gestational age babies born to women with diabetes (Simmons & Robertson 1997; Moses & Griffiths 1995). Compared to those without diabetes, mothers with diabetes experience a significantly higher incidence of pregnancy-induced hypertension and pre-term birth (Mello et al 1997), urinary tract infection, pre-eclampsia and uterine bleeding (McMahan et al 1998; Martinez-Frias et al 1998).

Children born to mothers with diabetes are at a high risk of developing foetal malformations, foetal distress, and neonatal complications including hypoglycaemia, respiratory distress and jaundice (Kamath et al 1998; Martinez-Frias et al 1998; ADA 1993). It has been suggested that Down's syndrome may also occur more often in babies born to mothers with diabetes (Narchi & Kulaylat 1997). The infants of mothers with pre-gestational Type 1 diabetes or gestational diabetes may also develop insulin resistance and impaired glucose tolerance early in life (Plagemann et al 1997).

1.6 Health service use

People with diabetes are approximately twice as likely as those without it to consult health professionals or use hospital services (ABS 1997b). The higher rate of use is related to treatment and metabolic control, as well as to complications associated with the disease.

People with Type 1 diabetes seek medical help much more often than those with Type 2 diabetes. According to the 1995 NHS, the average annual number of medical services used by people with Type 1 diabetes is almost six times higher than for those with Type 2 diabetes, and the ratio for average number of hospital separations is more than eight times.

Visits to the doctor

According to the 1995 NHS, people with diabetes consult a doctor (general practitioner [GP] or any specialist) twice as often as those without diabetes (46 per cent compared with 23 per cent). Among those people with diabetes who visited the doctor in the two weeks before the survey, the proportion was 100 per cent among persons with Type 1 diabetes aged 0–24 years. The proportion decreased to 60 per cent for those aged 25–34 years, and between 30 and 50 per cent for ages above 35 years (Mathers & Penm 1999).

Consultations with other health professionals

People with diabetes consult other health professionals and facilities more often than those without the condition. According to the 1995 NHS, at least one out of fourteen people with diabetes had visited hospital casualty, emergency or outpatients in the last two weeks, almost three times the rate of people without diabetes. Almost 2 per cent of people with diabetes also reported a hospital inpatient episode during that period (ABS 1997b).

Hospital separations

In 1996–97, a total of 267,449 hospital separations listed diabetes as a diagnosis. Diabetes was the principal diagnosis for about 9 per cent of these separations.

Diabetes is not always reported as the principal diagnosis in hospital separations data because the condition considered responsible for the hospitalisation is recorded as the principal diagnosis. The more frequent primary diagnoses of interest, where diabetes was listed as an additional diagnosis, were:

- cardiovascular disease, ICD-9-CM:390–459 (23 per cent),
 - coronary heart disease, ICD-9:410–414 (12 per cent),
 - stroke, ICD-9:430–438 (4 per cent),
 - peripheral vascular disease, ICD-9:441–444 (1 per cent),
 - heart failure, ICD-9:428 (4 per cent);
- eye disease, ICD-9:360–379 (5 per cent),
 - cataracts, excluding congenital forms (4 per cent); and
- kidney disease, ICD-9:580–589 (1 per cent).

Data on hospital separations provide an indication of the use of health care. However, because hospital separation collections in Australia do not have a unique patient identifier, there can be multiple counting of patients depending on the number of inpatient episodes. The above hospital separation figures are therefore only an estimate of the extent of morbidity associated with diabetes requiring hospitalisation, and cannot be used as population-based estimates of diabetes prevalence.

1.7 Mortality

In 1996, diabetes was cited as the underlying cause of 2,991 deaths in Australia, accounting for more than 2 per cent of deaths from all causes, with an age-standardised rate of 16 per 100,000 persons (ABS 1997c). It was the seventh leading cause of death that year.

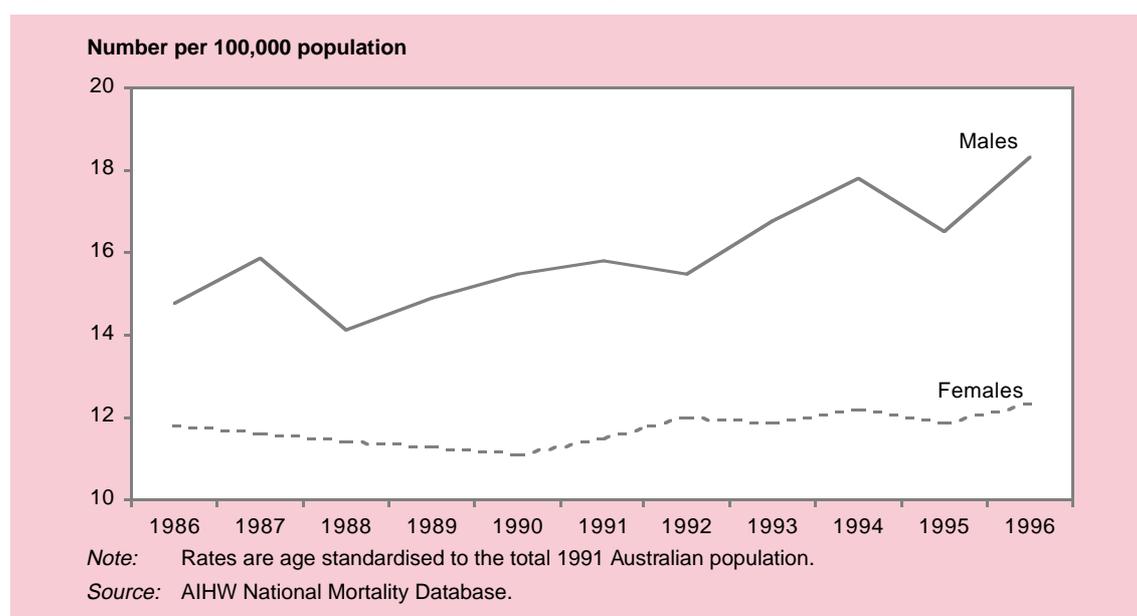
Diabetes contributes to a much larger proportion of deaths than the above figures would suggest. In 1995, diabetes was the underlying cause of death for 2,708 persons. However, there were an additional 8,839 deaths where diabetes was mentioned on the death certificate but was not reported as the underlying cause of death. Diabetes thus could have contributed to almost 7 per cent of total deaths, with an age-standardised rate of 49 per 100,000 population in 1995 (ABS 1997c).

The above statistics do not account for lack of recording of diabetes on death certificates. It is estimated that between 27 and 44 per cent of death certificates for people with diabetes do not even list diabetes as a cause of death (Whittall et al 1990; Riley et al 1995; Phillips et al 1995).

Trends in diabetes mortality

Between 1991 and 1996, death rates for diabetes increased annually by 1.5 per cent and 5.9 per cent among males and females respectively. While some of this change reflects the increasing prevalence of the disease, changing practices in determining the underlying cause of death may have also contributed to this trend. No data are available to separately determine trends in mortality associated with Type 1 and Type 2 diabetes. Age-standardised death rates for diabetes and trends over time since 1986 are plotted in Figure 1.7.

Figure 1.7: Trends in death rates for diabetes, by sex, Australia, 1986–1996



Premature mortality

Premature mortality is more common among people with diabetes than in the general population. Diabetes mortality increases sharply after age 50, and is higher among males than females in each age group in Australia.

In the United States, using data from the 1970s and early 1980s, the death rate ratio for people with Type 1 diabetes in comparison with those without diabetes is estimated to be between 5 and 12, with their life expectancy reduced by about 15 years (Harris 1995). More recent European studies indicate a ratio of between 2 and 4 (Nystrom et al 1992; Modan et al 1991). Similarly, for people with Type 2 diabetes in the United States, the death rate is estimated to be about twice that of the general population (Harris 1995).

People with childhood-onset Type 1 diabetes in Tasmania are reported to have more than four-fold excess mortality, and those with adult-onset Type 1 diabetes a 1.8-fold excess mortality, over the general population (Riley et al 1995). In Western Australia, the death rate for people with diabetes has been estimated to be between 20 to 80 per cent higher than that for the general population (Knuiman et al 1992; McCann et al 1994).

No national estimates of these ratios are currently possible due to the lack of multiple cause-of-death data. However, the ABS has recently introduced multiple coding for death data which should allow an assessment of this risk ratio in Australia.

Causes of death among people with diabetes

Cardiovascular disease is the leading cause of death among people with diabetes, followed by renal disease (Phillips et al 1990). Among Indigenous adults in Central Australia, renal disease and infections were the direct cause of death in around 22 per cent and 21 per cent of people with diabetes, respectively (Phillips et al 1995).

Due to the lack of multiple coding, it has not been possible to generate national cause of death statistics for people with diabetes until now. However, since 1997 ABS has initiated the coding of underlying as well as associated causes of death and this will allow better analysis in the future.

1.8 Special population groups

The *National Diabetes Strategy and Implementation Plan* report (Colagiuri et al 1998) has highlighted several population groups that require special consideration in diabetes prevention and care services. These population groups are:

- Indigenous Australians;
- people from culturally and linguistically diverse backgrounds;
- people living in rural and remote areas;
- children and adolescents; and
- older Australians.

Indigenous Australians

Diabetes, mostly Type 2, is a major cause of morbidity and mortality among Indigenous Australians. Epidemiological investigations suggest that the overall prevalence of diabetes among Indigenous adults is between 10 and 30 per cent, at least two to four times that of the non-Indigenous population (de Courten et al 1998). A recent study of Indigenous children and adolescents has documented a high prevalence of Type 2 diabetes (2.7 per cent), and of risk factors for Type 2 diabetes (Braun et al 1996). Pooled data from south-eastern and central Australian Indigenous people, aged 20–49 years, also show a 12 per cent prevalence of Type 2 diabetes, compared with 1 per cent in a Victorian country town sample of non-Indigenous people in the same age range (Guest & O’Dea 1992).

In the 1994 National Aboriginal and Torres Strait Islander Survey (NATSIS), more than 4 per cent of Indigenous persons reported diabetes as a long-term illness (ABS 1996a). The rate is one-third higher among Indigenous females than males. The survey also indicated that diabetes is more prevalent among Indigenous people living in rural areas. An oversample of Indigenous individuals during the 1995 NHS has also provided similar estimates (ABS 1999).

The high prevalence of diabetes among Indigenous populations is thought to relate to a rapid change from a traditional to a Westernised lifestyle. In addition, obesity is common — 25 per cent of males and 29 per cent of females have a BMI over 30 (ABS 1996a). Furthermore, Indigenous mothers are two to three times more likely to have babies of low birth weight (ABS & AIHW 1997), a risk factor for diabetes as described earlier.

The full impact of diabetes-related complications has not been studied in the Indigenous population. However, in a study from the Northern Territory, the incidence of end-stage renal disease associated with diabetes was found to be more than 26 times higher in the Indigenous population (Hoy et al 1997).

According to Phillips et al (1995), among Indigenous people diagnosed with Type 2 diabetes, the eight-year survival rate is less than 56 per cent in males and 80 per cent in females. The death rate ratios, when compared to non-diabetic Indigenous Australians, were 2.1 for males and 1.7 for females. Renal disease was the direct cause of death in more than 22 per cent of cases, infections accounted for almost 21 per cent of deaths and coronary heart disease for almost 14 per cent of deaths.

An increasing trend in diabetes mortality has been noted among Indigenous Australians. Between 1985 and 1994, diabetes mortality rose sharply, at an annual rate of 9.6 per cent among males and 5.4 per cent among females (Anderson et al 1996). In 1996, the death rates for diabetes among Indigenous males and females were 149 and 216 per 100,000 persons respectively.

People from culturally and linguistically diverse backgrounds

Australia's population now has about 23 per cent overseas-born people. On arrival, the migrants tend to have better health than people born in Australia, although rates of illness and disability increase with duration of residence (AIHW 1998a).

However, certain migrant groups have a high prevalence of and mortality from diabetes (Strong et al 1998a). The 1995 NHS data indicate a higher prevalence of diabetes among people born in southern Europe, other European countries, Asia, and other countries compared with those born in mainly English-speaking countries. In particular, diabetes is highly prevalent among Micronesian, Polynesian and certain Melanesian Pacific Islanders, migrant Asian Indians and Chinese (Dowse et al 1990; King & Rewers 1993). Some Arab populations and people from some European communities, especially those from southern Europe, also have a high prevalence of Type 2 diabetes (King & Rewers 1993).

There is also evidence of an increased incidence of gestational diabetes among women born on the Indian subcontinent, or in Africa, Vietnam, Mediterranean countries, Egypt and other Arab countries or other Asian nations, compared with women born in Australia and New Zealand (Beischer et al 1991; Moses et al 1994).

These patterns are in contrast to the overall health status of persons born overseas (Strong et al 1998a). Two major risk factors for diabetes, physical inactivity and obesity, are significantly higher among adults in some population groups (Welborn et al 1995). People of some population groups are also less likely to be screened for diabetes.

While overseas-born people represent a significant proportion of people with diabetes, language may be a barrier to accessing relevant services (Flack et al 1997). For example, it is known that many people from culturally and linguistically diverse backgrounds use ambulatory care services less often than English-speaking people, and practise less self care than recommended, but use inpatient services more often (de Blied et al 1993). Poor glycaemic control is also common and more marked in some ethnic groups (Diabetes Australia & FECCA 1997).

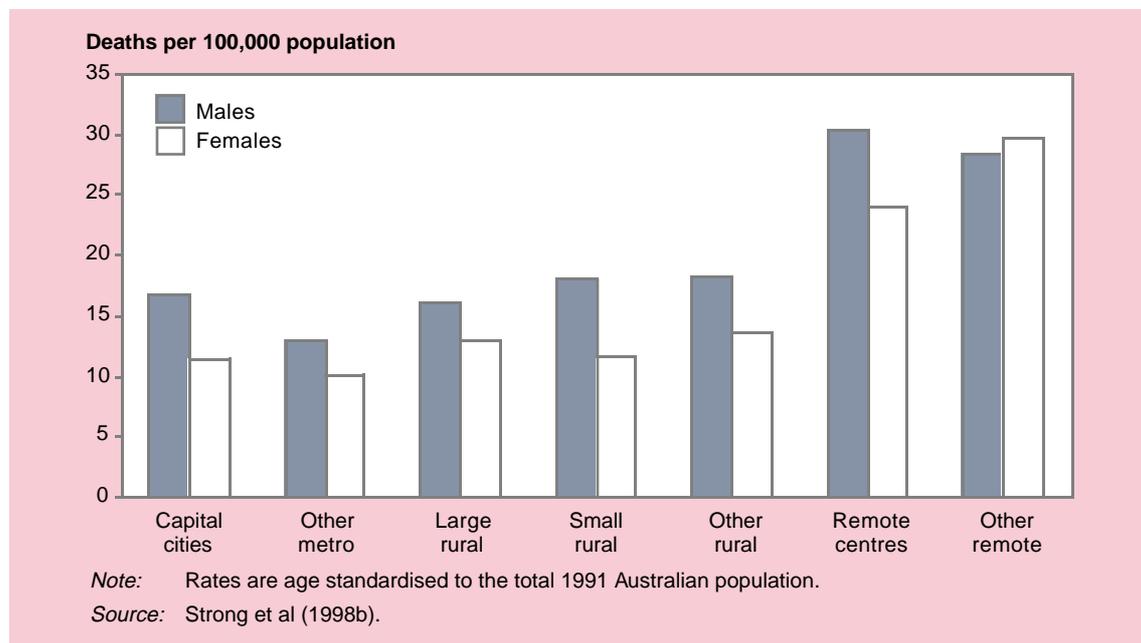
People living in rural and remote areas

The health of populations living in rural and remote areas is worse than those living in urban areas (Trickett et al 1997; Strong et al 1998b). Death rates for all major causes, coronary heart disease, respiratory disease and injury are higher in rural and remote areas. These differences also apply to diabetes.

Mortality from diabetes is significantly higher in remote areas when compared to other areas (see Figure 1.8). During 1992–1996, for example, the death rates for diabetes in the remote areas of Australia were two to three times higher than in metropolitan areas. Slightly higher rates are observed for hospitalisation with diabetes as the principal diagnosis (Strong et al 1998b).

Overview

Figure 1.8: Rural and remote area variation in death rates for diabetes, Australia, 1992–1996



Rural and remote Australians have slightly different patterns of risk factors and health actions compared with their metropolitan counterparts (Trickett et al 1997). For example, more than 53 per cent of males and 43 per cent of females in 'other remote areas' are reported to be overweight compared with 49 per cent of males and 34 per cent of females living in 'metropolitan areas'. High alcohol consumption is also more common in rural and remote areas (Strong et al 1998b).

Hospital separation rates for endocrine, nutritional and metabolic diseases and for diseases and disorders of the kidney and urinary tract are substantially higher in remote areas. The higher rate of problems of the kidneys and urinary tract in remote areas is largely due to renal failure among Indigenous people in remote communities (Trickett et al 1997; Strong et al 1998b).

Children and adolescents

Almost all diabetes among children and adolescents is Type 1, although Type 2 diabetes may be present in a small number of cases.

It is believed that the incidence of diabetes in childhood has increased substantially in developed countries in the last 40 years (Waterson et al 1997). In Australia, the prevalence is estimated to be around 130 per 100,000 (Silink 1994). There are two peaks in the incidence of diabetes among children and adolescents, at 4–6 and 10–14 years.

The frequency of severe hypoglycaemia in children and adolescents is approximately twice that in adults (Colagiuri et al 1998). In particular, among those diagnosed with diabetes before the age of five years, ketoacidosis, severe hypoglycaemia, cognitive disabilities and electroencephalogram abnormalities are common. Virtually all children with diabetes will have evidence of diabetes-related complications in adulthood.

Morbidity among children with diabetes is high. The hospital separation rate for children with the principal diagnosis of diabetes was 44 per 100,000 in 1996–97 (Moon et al 1998). A study in Newcastle has found that among adolescents (aged 11–19 years) with Type 1 diabetes of a median duration of seven years, the prevalence of retinopathy was 42 per cent. Nearly all had mild background retinopathy, a rate comparable to recent reports from other centres (Fairchild et al 1994).

Mortality is also two to four times higher in diabetic children than in their non-diabetic counterparts. Over the period 1979–1996, there were 40 deaths in children under the age of 15 years from diabetes.

The social costs of childhood diabetes are substantial — 39 per cent of children with diabetes missed school in the two weeks prior to the 1995 NHS because of their condition, and 9 per cent of adolescents missed school for the same reason.

Optimising diabetes control among children and adolescents with diabetes may be more difficult than among adults, as children and adolescents have a number of additional challenges including erratic eating patterns, the tendency to get four to six viral illnesses each year and hormonal changes associated with growth spurts and pubertal development. The psychological effects of diabetes and the need for constant monitoring are also higher among children and adolescents.

Older Australians

The prevalence of diabetes increases steadily with age. Increased longevity increases the likelihood of co-existence of multiple chronic conditions. Diabetes, together with ageing, makes older people more vulnerable to diseases such as cardiovascular disease (Colagiuri et al 1998). However, the presence of diabetes in older Australians may be sometimes overlooked, with many of the classic symptoms of diabetes dismissed as part of the ageing process which may lead to unwarranted diabetes-related complications.

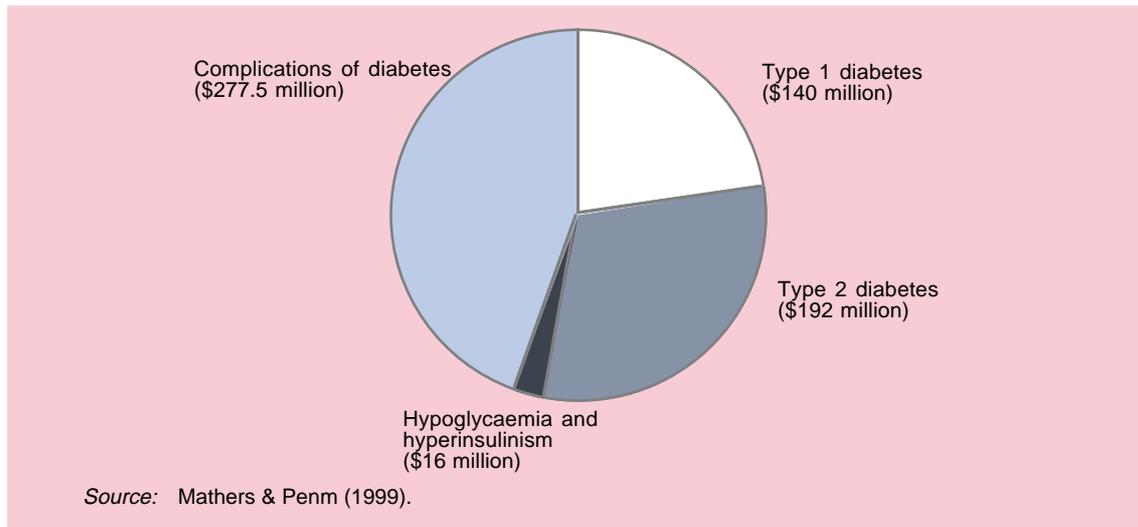
The risk of developing diabetes-related complications such as macrovascular disease and renal failure also increases with age. More than 20 per cent of older people with diabetes have retinopathy and symptoms of macrovascular disease at the time of diagnosis (NHMRC 1997a; Colagiuri et al 1998).

1.9 Health system costs

The 1993–94 health system costs attributable directly to diabetes are estimated to be \$387 million (Mathers & Penm 1999). These include costs incurred for hospitalisation, medical consultation and procedures, pharmaceuticals, allied health services, research and other support. Although only accounting for around 12 per cent of the total cases of diabetes, Type 1 accounts for more than 40 per cent of diabetes costs (Figure 1.9).

Overview

Figure 1.9: Diabetes costs in Australia, 1993–94



The above costs relate to health services for which diabetes is identified as the diagnosis or the underlying problem. However, as described earlier, diabetes also contributes substantially to morbidity and mortality resulting from a variety of conditions. Some of the health system costs for these conditions can be attributed to diabetes. Mathers and Penm (1999) estimate this amount to be around \$294 million.

The total figure for health system costs attributable to diabetes thus amounts to \$681 million. Estimated average annual health system costs attributable to each diagnosed case of diabetes are about \$1,727 for males and \$2,124 for females. Estimated lifetime attributable health system costs in Australia for each diagnosed case of diabetes are about \$25,880 for males and \$37,830 for females (Mathers & Penm 1999).

1.10 Diabetes and other national health priority areas

The burden of diabetes overlaps with and contributes to the burden of disease for other NHPA diseases and conditions. The most prominent connection is between diabetes and cardiovascular diseases, because of their shared risk factors. People with diabetes, in particular those on insulin therapy, are also prone to a variety of mental problems and conditions.

Cardiovascular health

Not only do diabetes and cardiovascular disease share common risk factors, but diabetes is an independent risk factor for cardiovascular disease as well. The presence of a common aetiological factor for risk factors for cardiovascular disease and diabetes has been proposed. However, limited information is available on whether the presence of cardiovascular disease promotes diabetes in some way.

As discussed earlier, diabetes is an important cause of coronary heart disease and stroke. In contrast to people without diabetes, coronary heart disease appears earlier in life and is more often fatal among those with diabetes. People with diabetes may have a worse prognosis after stroke, and the role of elevated blood pressure in stroke may be accentuated by the presence of diabetes. Mortality is also increased among people with diabetes and peripheral vascular disease, in particular if foot ulcerations, infection or gangrene occur.

High blood pressure, high cholesterol and obesity often present along with diabetes, as well as all being independent risk factors for cardiovascular disease. In combination with glucose intolerance and other risk factors such as physical inactivity and smoking, each one of these factors presents a greater cardiovascular risk. In particular, high blood pressure and diabetes often occur together. Evidence is also accumulating that high cholesterol and glucose intolerance may have a common aetiological factor.

Despite these similarities, mortality from cardiovascular disease and diabetes are moving in opposite directions. While the ageing of the population following reductions in mortality from cardiovascular disease may have contributed to these opposite trends, the role of other factors also needs to be understood if common risk factor prevention strategies are to be considered.

Cancer control

Several studies have shown that diabetes is associated with some forms of cancer. It has been identified as a risk factor for pancreatic cancer (Fisher et al 1996; Lee et al 1996) and as a possible risk factor for prostate cancer (Ilic et al 1996). People with diabetes have also been shown to be at a higher risk of developing primary liver cancer and perhaps cancer of the biliary tract (Adami et al 1996). In a 15-year follow-up study of people with Type 2 diabetes in Japan, death rates for cancers of the liver and the pancreas have been shown to be respectively three times and twice the expected rates (Sasaki et al 1996). However, a significant association between pancreatic cancer and diabetes has been discounted in other studies (Gullo et al 1996).

Mental health

There have been several studies of depression and anxiety in individuals with diabetes, including assessment of quality of life and symptom reporting. Some have concluded that depression is related to diabetes itself, others to associated psychosocial factors. Kohen et al (1998) report that the effect of diabetes, especially the depressive effect, is an important factor in determining quality of life independent of the level of physical illness. Depression may affect individuals at different stages of the illness.

A study conducted in south-west Sydney (Flack et al 1995) has found mild to moderate levels of depression and significant anxiety, irrespective of diabetes type or duration of disease among individuals commencing insulin therapy. Amato et al (1996) have found depression in association with diabetes among a group of older patients.

Overview

Peyrot and Rubin (1997) also report higher levels of depression and anxiety among individuals with diabetes than in the general population, especially for those with more diabetes-related complications. This finding is supported by the United Kingdom Prospective Diabetes Study (UKPDS), which concludes that the prevention of complications could prevent deterioration in quality of life for people with diabetes.

Rajala et al (1997), on the other hand, have found that the impact of diabetes on depression is not strong. Depression is present as a comorbidity with several chronic diseases and unfavourable social factors, such as sick leave and retirement, suggesting a psychosocial origin of depression in persons with Type 2 diabetes.

Suicide is not generally one of the adverse outcomes among people with diabetes, but may be under-reported or represented as deaths from hypoglycaemia resulting from intentional insulin overdose (Robinson & Rabins 1989). Depression among people with chronic renal failure, a serious complication of diabetes, has been shown to result in outright termination of treatment, and covert or overt suicide. Data from Europe and the United States suggest that the suicide rate among those on dialysis is 10 to 15 times that in the general population (Haenel et al 1980; Neu & Kjellstrand 1986).

Injury prevention and control

There is some evidence of an increased association between diabetes and injury. Data from Finland indicate a high rate of accidents among people with Type 1 diabetes (DERI Mortality Study Group 1991).

Hypoglycaemia when driving is known to cause accidents as it affects the person's level of consciousness. Visual impairment due to diabetic retinopathy and cataracts can also interfere with driving ability. Diabetic retinopathy affects night vision and cataracts are associated with excessive headlight glare (Frier 1992).

However, the evidence to indicate that drivers with diabetes have a higher rate of road accidents than their non-diabetic counterparts is limited. Recent studies have shown only a minor or no increase in accident rates among drivers with diabetes (Stevens et al 1989; Songer et al 1988). A study in Western Australia has also shown that there is no overall difference in the hospital admission rates from accidents between those with diabetes and the general population (de Klerk & Armstrong 1983).

2 Diabetes — an indicator-based profile

The NHPA initiative takes a ‘goals and targets’ approach to health monitoring, with time series used for predicting and measuring health outcomes. A set of priority indicators, each with a standard definition, is used for monitoring and reporting.

The previous chapter presented a general overview of diabetes in Australia, using data derived from a variety of surveys and studies. However, currently available data do not give a national picture of diabetes or provide a baseline for assessing progress towards the overall NHPA goal of reducing diabetes and its impact on the population. This chapter provides a profile of the current status of diabetes, using a set of defined indicators.

A major task in developing this first report on diabetes was to design a set of indicators for standardised monitoring and reporting. The process used for developing these indicators is described below. For detailed information on each indicator, see Appendix 1.

NHPA indicators differ from other types of health indicators in that they provide indirect information about future achievements based on historical trends, and can be linked to strategies for achieving set targets. These are developed and prioritised using a set of criteria, one of which is that the relevant data are being collected on a regular basis, or there is a commitment to put systems in place to collect that information, so that trends over time can be monitored. It is also considered desirable that the indicators reflect social goals. This requires taking an integrated approach to health monitoring by tying the NHPA indicators to outcomes for social justice and access issues.

The most important feature of NHPA indicators is their wide ownership. Developed with input from a range of stakeholders, these indicators are likely to be influential, valid and reliable measures for monitoring progress towards better health outcomes in Australia.

2.1 Goals for diabetes indicators

The goals that form the basis for diabetes indicators are as follows:

- to reduce diabetes incidence, particularly among populations at increased risk of developing the disease;
- to improve health-related quality of life, and reduce complications, disability and premature mortality attributable to diabetes;
- to achieve maternal and child outcomes for women with gestational diabetes or with pre-existing diabetes, equivalent to those of non-diabetic pregnancies; and
- to improve the capacity of the health system to deliver, manage and monitor services for the prevention of diabetes and the care of people with diabetes.

These goals are statements of intent and aspiration, outcomes that Australia might reasonably hope to achieve in the light of current knowledge of the disease and available technology and resources. The goals aim to achieve the primary objectives of good health and well being for people with diabetes through reducing the burden

Diabetes — an indicators-based profile

of diabetes-related illness, reducing inequality, increasing community participation and creating healthy environments. In general, the above-mentioned goals apply to the population as a whole, but priority populations are identified when different strategies are required for the priority group.

2.2 Indicator development

A health outcomes framework (see Table 2.1) was used to design indicators across the continuum of care for diabetes. The framework was developed by the National Health Information Management Group (NHIMG) Working Party on Health Outcomes Activities and Priorities, and endorsed by the Australian Health Ministers' Advisory Council (AHMAC).

The framework provides the basis for selecting an indicator, giving it meaning beyond the measure it may represent, and helps obtain an integrated view of the problem. It also facilitates systematic identification of indicators, helps set priorities for developing mechanisms for monitoring outcomes and progress towards targets, and enables comparisons across populations.

The NHIMG framework has a simple two-dimensional grid with three major columns covering health care outcomes through prevention, management and maintenance, and three major rows of indicators covering primary outcomes, risk factors and process/ quality. The grid as a whole refers to a specified health condition or problem, and is applied to a specified population or subgroup (AIHW & DHFS 1997).

Table 2.1: NHPA diabetes indicators mapped to NHIMG health outcomes framework

Indicator	Prevention			Management	Maintenance
	<i>Universal</i>	<i>Selective</i>	<i>Indicated</i>		
Primary outcomes	Disease incidence/prevalence: 1.1a; 1.2a	Disease incidence/prevalence: 1.1 (b,c); 1.2 (b,c); 1.3	Diabetes-related complications: 3.1; 3.2; 3.3; 3.4		
Risk	Risk factors: 2.1a; 2.2a	Risk factors: 2.1b; 2.2b	Risk factors: 2.3; 2.4; 2.5	Health status: 6.1 Screening and management: 7.2	
Process and quality		Screening and management: 7.2	Screening and management: 7.1	Diabetes-related complications: 3.1; 3.2; 3.3; 3.4 Hospital separations: 4.1; 4.2; 4.3; 4.4; 4.5 Screening and management: 7.1; 7.2	
System					

Notes: Some indicators map to more than one cell. Mortality indicators (5.1 and 5.2), on the other hand, do not fit within the NHIMG framework of disease prevention, management and maintenance. See Table 2.2 for full titles of the indicators.

2.3 NHPA indicators for diabetes

The indicators given below have been developed following consultation with various stakeholders. More detailed information on each of the indicators is given in Appendix 1.

Table 2.2: Diabetes indicators for NHPA reporting

Indicator	1998 reporting
<i>1 Disease incidence and prevalence</i>	
1.1 Prevalence rates for Type 1 and Type 2 diabetes in: a) general population; b) Indigenous population; and c) among people from culturally and linguistically diverse background	✓
1.2 Incidence rates for Type 1 and Type 2 diabetes in: a) general population; b) Indigenous population; and c) among people from culturally and linguistically diverse background	X
1.3 Gestational diabetes among women aged 20–44 years, by parity	X
<i>2 Risk factors for diabetes and associated complications</i>	
2.1 Prevalence rates for obesity and being overweight (as measured by BMI) in: a) general population; and b) among persons with Type 2 diabetes	✓
2.2 Rates for non-participation in regular, sustained, moderate aerobic exercise in: a) general population; and b) among persons with Type 2 diabetes	✓
2.3 Prevalence rates for high blood pressure among persons with Type 2 diabetes: a) ≥ 140 mmHg systolic and/or 90 mmHg diastolic and aged < 60 years; b) ≥ 160 mmHg systolic and/or 90 mmHg diastolic and aged ≥ 60 years; and/or c) those on medication for high blood pressure	✓
2.4 Prevalence rates for high levels of lipoproteins among persons with Type 1 and Type 2 diabetes: a) total cholesterol above 5.5 mmol/L; and b) high density lipoproteins below 1.0 mmol/L	✓
2.5 Prevalence rates for fasting hypertriglyceridaemia among persons with Type 1 and Type 2 diabetes	✓
<i>3 Diabetes complications</i>	
3.1 Proportion of persons with end-stage renal disease with diabetic nephropathy as a causal factor	✓
3.2 Incidence rate for eye disease among clinically diagnosed persons with diabetes	✓
3.3 Prevalence rate for foot problems among persons with clinically diagnosed diabetes	✓
3.4 Incidence rates for coronary heart disease and stroke in: a) general population; and b) among clinically diagnosed persons with diabetes	✓

continued

Diabetes — an indicators-based profile

Table 2.2: Diabetes indicators for NHPA reporting (continued)

Indicator	1998 reporting
<i>4 Hospital separations for diabetes complications</i>	
4.1 Hospital separation rate for end-stage renal disease with diabetes as an additional diagnosis	✓
4.2 Hospital separation rates for coronary heart disease or stroke with diabetes as an additional diagnosis	✓
4.3 Hospital separation rates for conditions other than end-stage renal disease and coronary heart disease/stroke among: a) persons for whom diabetes was reported as the principal diagnosis or an additional diagnosis; and b) persons without diabetes as a reported diagnosis.	✓
<i>5 Mortality</i>	
5.1 Death rates for diabetes in: a) general population; b) Indigenous population; and c) among people from culturally and linguistically diverse backgrounds	✓
5.2 Death rates for coronary heart disease and stroke among persons with diabetes in: a) general population; b) Indigenous population; and c) among people from culturally and linguistically diverse background	✗
<i>6 Health status</i>	
6.1 Self-assessed health status of persons with and without diabetes	✓
<i>7 Screening and management</i>	
7.1 Proportion of persons with diabetes tested for glycosylated haemoglobin level at least every six months	✗
7.2 Proportion of pregnant women being tested for gestational diabetes	✗

2.4 Indicator-based summary statistics

This section provides a short summary of the impact of diabetes on the health of Australians and emerging trends using available data on NHPA indicators. The indicators summarised below cover six different aspects: prevalence of diabetes, its risk factors, associated complications, hospitalisation, mortality and health status.

The information included here is largely statistical in nature, put together to generate a profile of events and trends across the continuum of care.

Disease prevalence

Indicator 1.1: Diabetes prevalence

- Prevalence of diabetes varies considerably among population groups in Australia. The estimates, based on self reports, range from around 1,880 per 100,000 persons in the general population to over 8,700 per 100,000 persons in the Indigenous population.

Risk factors

Indicator 2.1: Overweight and/or obesity

- Obesity is common in the general population, with about 13 per cent of males and 14 per cent of females with BMI scores of more than 30. The relative proportions are much higher among persons with diabetes, with almost 32 per cent of males and 43 per cent of females with diabetes rated as obese.

Indicator 2.2: Lack of physical activity

- A large proportion of the general population and persons with diabetes undertake low levels of exercise, or are sedentary. According to the 1995 NHS (ABS 1997a), more than 66 per cent of the adult population and almost 75 per cent of people with diabetes do not participate in regular, sustained, moderate exercise.

Indicator 2.3: High blood pressure

- Based on the NADC survey, the prevalence rates for high blood pressure are estimated as 266 per 1,000 males and 347 per 1,000 females with Type 2 diabetes and under the age of 60 years. Given a slightly higher cut-off point, the prevalence rates for high blood pressure among persons with diabetes and over the age of 60 years are similar to those noted for persons under the age of 60 years.
- The average blood pressure levels in Australia have shown a downward trend for several years, and the trend is continuing. This has positive implications for reduction in the prevalence of diabetes and diabetes-related outcomes in Australia.

Indicator 2.4: High levels of lipoproteins

- According to the NADC survey of patients attending specialist diabetes services, almost 25 per cent of people with Type 1 diabetes, and more than one-third of people with Type 2 diabetes, have high levels of cholesterol. Population-based studies indicate that the proportion may be much higher than that observed under controlled, clinic conditions.

Indicator 2.5: Fasting hypertriglyceridaemia

- According to the 1998 NADC survey of patients attending specialist diabetes services, less than 2 per cent of people with Type 1 diabetes but more than 8 per cent of those with Type 2 diabetes have high levels of triglycerides. No population-based information is available to provide a comparative picture of hypertriglyceridaemia outside the clinic setting.

Diabetes-related complications

Indicator 3.1: End-stage renal disease

- The proportional contribution of diabetic nephropathy to the incidence of end-stage renal disease is on the rise. Not only did the number of new diabetic end-stage renal disease registrants with the Australia and New Zealand Dialysis and Transplantation Registry (ANZDATA) more than double between 1991 and 1996, but the relative contribution of diabetic nephropathy to overall end-stage renal disease also increased by more than 70 per cent during this period.

Indicator 3.2: Eye diseases

- No information on the national incidence of diabetic retinopathy, or the blindness it causes, is available. The NADC data suggest an annual incidence rate of 8 per 1,000 persons for blindness among those attending specialist diabetes services.

Indicator 3.3: Foot problems

- According to the 1998 NADC survey, the prevalence rate for foot ulcers is 25 per 1,000 persons. More than twice as many are reported to have had foot ulcers previously. The incidence of amputations has been estimated as 10 per 1,000 persons with diabetes attending diabetes clinics.

Indicator 3.4: Coronary heart disease and stroke

- According to the 1998 NADC survey, the rate of incidence for heart attack, used as a proxy for coronary heart disease, is 46 per 1,000 persons attending diabetes clinics. This rate is more than 19 times higher than that noted in the general population. The incidence rate for stroke among persons attending the diabetes clinics has been estimated at 24 per 1,000 persons.

Hospitalisation associated with diabetes

Indicator 4.1: Hospitalisation for end-stage renal disease

- In 1996–97, there were a total of 20,344 hospital separations where both renal failure and diabetes were listed as co-diagnoses. The separation rate is estimated to be 1.0 per 1,000 persons, accounting for approximately 8 per cent of all separations with renal failure as a listed diagnosis.

Indicator 4.2: Hospitalisation for coronary heart disease and stroke

- There has been a marked rise in the proportion of separations with diabetes as a co-diagnosis with coronary heart disease or stroke. This may be partly because of an increasing propensity to list diabetes as an additional diagnosis or comorbidity. No such increase has been noted for coronary heart disease or stroke separations as a whole.

Indicator 4.3: Hospitalisation for other conditions

- Diabetes is a co-diagnosis for about 6 per cent of hospital separations where coronary heart disease, stroke and renal disease are not the listed diagnoses. The proportion may be an underestimate since diabetes is not coded consistently.

Mortality

Indicator 5.1: Death rates

- Death rates for diabetes are on the rise in Australia. Between 1991 and 1996, the rate increased 2.9 per cent per annum among males, although no change was noted among females. Some of this increase may be ascribed to changing propensity to identify diabetes as the underlying cause of death.

Health status

Indicator 6.1: Self-assessed health status

- Slightly more than 60 per cent of persons with diabetes responding to the 1995 NHS rated their health as good to very good, to excellent. This contrasts with self assessment of health status by respondents in the general population, with almost 84 per cent reporting their health as good through to excellent.

These indicators give an assessment of the health of persons with diabetes in Australia. The information is based on wide-ranging sources, but limited time series, so no clear picture of diabetes trends emerges.

3 Prevention, early detection and management

This chapter provides an overview of the current status of prevention, early detection and management of diabetes and its complications. For each of these areas, information is provided on the size of the problem, current practice, and the cost-effectiveness of interventions.

3.1 Primary prevention of diabetes

Possible primary prevention strategies differ for the two types of diabetes because of their different pathophysiologies. Type 1 diabetes is typically an autoimmune process with no clearly established environmental risk factors, whereas Type 2 diabetes is a chronic disease related to lifestyle.

By looking for genetic markers and auto-antibodies, it is now possible to identify children at high risk of Type 1 diabetes. It may be possible in the future to prevent or delay the onset of Type 1 diabetes in such children, but the studies that address this question have not yet been completed. The rest of this section therefore deals with Type 2 diabetes.

Lifestyle factors such as obesity and physical inactivity have a known association with the development of Type 2 diabetes. Primary prevention, namely strategies to reduce the onset of illness in the whole population, population groups or individuals, can be used to reduce levels of these risk factors and prevent or delay the onset of Type 2 diabetes. The same strategies also have a role in the secondary prevention of diabetes, by raising awareness of the lifestyle changes necessary to manage the condition and delay the onset of complications, and providing the means by which those changes can be made.

As diabetes shares many of its risk factors with conditions such as cardiovascular disease and some cancers, prevention strategies that reduce levels of these risk factors are likely to have widespread health benefits.

Approaches to primary prevention of Type 2 diabetes

Broadly speaking, prevention can be aimed at the whole population, an approach which seeks to alter or eliminate lifestyle and environmental risk factors (the 'population' approach). The focus can also be narrowed to particular individuals or groups, especially those at high risk of developing diabetes. This is termed the 'high-risk' approach.

The first approach aims to improve risk factor levels and wider factors in the population as a whole. It is based on the knowledge that by far the greatest number of disease cases arises from that majority of the population who are not seen as 'at risk'; and that small changes in many healthy people can produce much greater community benefit than large changes in a few.

The high-risk approach aims to detect individuals and populations at higher risk and then to reduce that risk. Those with impaired glucose tolerance are at high risk of developing Type 2 diabetes, and form the primary group for this type of approach. Other individuals at higher risk are those with risk factors for diabetes such as a family history of diabetes, age over 40 years, a history of hypertension,

Prevention, early detection and management

obesity, dyslipidaemia, or physical inactivity. Certain groups are also at higher risk of developing diabetes, either due to clinical reasons, such as pregnant women, or for social or cultural reasons, such as Indigenous Australians and people from various migrant groups (see Chapter 5).

The population approach

While the population approach is expected to have a greater impact than the high-risk approach in reducing the burden of Type 2 diabetes, simply because of the size of the target group, there are limited data to demonstrate the effectiveness of population-based interventions (Colagiuri et al 1998). To some extent, the results from studies of coronary heart disease prevention can be extrapolated to diabetes, because the risk factors are similar. However, it should be noted that there have been unfavourable trends in the prevalence of the most important risk factors for diabetes, obesity and physical inactivity, and less is known about how to change long-term behaviour in these areas than smoking and high blood pressure.

The combined effect of risk factor reduction has been examined in community-wide studies of risk factors, especially in the United States, but also in Wales and in Finland (Tudor-Smith et al 1998; Puska 1995). Effects typically demonstrate significant changes in both intervention and control communities, especially for cholesterol, blood pressure and smoking (Luepker et al 1996; Winkelby et al 1997). The North Karelia project in Finland showed that community-based programs can reduce risk factor levels and coronary heart disease risk in the general population and among higher-risk groups (Jousilahti et al 1995).

The population impact of interventions may be more significant in the long term. For instance, a recent randomised controlled trial of coronary heart disease risk factors in over 12,000 males in the United Kingdom realised small changes in those risks relevant to diabetes (eg weight loss of 1 kg and 5 per cent smoking cessation) (Family Heart Study Group 1994). However, the maintenance of these small changes over the long term has been estimated to result in a 12 per cent reduction in coronary events.

Recent Australian estimates of the potential for existing prevention and treatment interventions to further reduce coronary heart disease in people aged 35–79 years suggest a possible reduction in coronary events of 38 per cent and in coronary deaths of 41 per cent (AIHW & HEALTH, in press). This indicates the potential for diabetes, as the overall benefits would go beyond coronary heart disease to a range of diseases with common risk factors.

The great challenge for diabetes prevention is to turn this theoretical scope into practice, and assess whether risk factors can be avoided or reduced in virtually all people, how Australians can become more physically active, and how the worsening trends in overweight can be reversed.

Macro-environmental factors such as healthy public policy on food supply or supportive environments providing opportunities for physical activity are now recognised as fundamental to the achievement of these goals, as outlined in the Ottawa Charter for Health Promotion (WHO 1986) and the Jakarta Declaration for Health Promotion (WHO 1997).

A further part of the challenge is to attend to the social, economic and environmental conditions behind people's daily lives. The actions of government, businesses and industry can have a large effect on people's opportunities, attitudes and skills.

Factors such as education, taxation, housing, urban design and conditions in the workplace can influence the level of risk factors as well as other social and psychological aspects that affect health. This is especially relevant to the inequalities seen in health, such as the higher rates of diabetes and its risk factors among Indigenous Australians (AIHW 1998a).

The need to address both macro and micro-environmental issues and social and economic conditions has been identified as a principle in the National Public Health Partnership (NPHP; see page 68), and is reflected in national strategies on physical inactivity and overweight and obesity. The NPHP will build on this existing work, based on a commitment to collaboration by the Commonwealth Government and the State and Territory Governments. A National Primary Prevention Strategy is also under development, to provide an integrated platform for risk factor initiatives, in the context of a national approach to non-communicable disease prevention and control.

On an individual level, GPs and other health professionals have an important role in providing all their patients with evidence-based primary prevention advice. The need for incentives to make it easier for health professionals to perform this service is discussed in Chapter 4.

The high-risk approach

Only a few studies have tested interventions for the prevention of Type 2 diabetes, all focusing on impaired glucose tolerance. Two Swedish studies showed similar results, using diet (Sartor et al 1980) and diet plus exercise (Eriksson & Lindgarde 1991) to halt the progression of impaired glucose tolerance to diabetes. The proportion of those who progressed to diabetes was about 30 per cent in the control groups in comparison to just over 10 per cent in the intervention groups. In a recent randomised controlled trial of impaired glucose tolerance in China, progression to diabetes over six years was reduced by 31 per cent through dietary interventions and by 46 per cent through exercise (Pan et al 1997). Whether these interventions prevent or just delay onset requires long-term follow-up. However, even a six-year delay in the onset of diabetes is a substantial health gain. The pharmacological interventions so far have been less than successful. A large-scale trial in the United States, the Diabetes Prevention Program, is currently evaluating the role of diet, physical activity and the drug metformin in preventing progression of impaired glucose tolerance to diabetes.

Cost-effectiveness of interventions

Cost-effectiveness analyses for the primary prevention of diabetes are scarce, and those that exist are based on a range of assumptions. A recent Australian analysis of selected weight reduction and physical activity interventions (Segal et al 1996) made numerous assumptions about the reach and effectiveness of prevention interventions in related fields. Within these parameters, the authors concluded that primary prevention programs for Type 2 risk factors would be a highly efficient use of public resources. It was estimated that these programs could achieve a substantial improvement in health status at little cost, or with a potential net saving in health care resources. For instance, direct program costs for a media campaign (with community support) were estimated to be less than the

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costs to the health system of managing cases of Type 2 diabetes that had not been prevented. In addition, while a GP lifestyle advice program was not found to result in net savings, this type of program was still found to be highly cost-effective.

When considering the cost-effectiveness of programs for the prevention of diabetes, the potential for cost saving through common strategies for each NHPA area should be considered.

Key points — Primary prevention

- Dietary and exercise interventions have been shown to at least delay the onset of Type 2 diabetes in high-risk individuals with impaired glucose tolerance.
- There are limited data demonstrating the effectiveness of population-based interventions in the prevention of Type 2 diabetes. However, evidence from populations with coronary heart disease (which shares common risk factors with diabetes) indicates the potential for this approach over the long term.
- Prevention of lifestyle-related risk factors should include environmental-based strategies that address major societal influences on levels of obesity and physical inactivity.
- There is great scope for coordination of primary prevention activities, through collaboration between governments, and the involvement of non-government organisations, general practitioners and other health professionals. This coordination should also include long-term partnerships and alliances with agencies outside the health sector.

3.2 Screening and early detection of diabetes and its complications

Early detection of diabetes is important because control of hyperglycaemia early in the course of the disease may prevent or delay chronic complications. Type 2 diabetes, for example, can remain asymptomatic for many years; up to 20 per cent of people are known to have symptoms of diabetes-related complications (eg retinopathy) at the time of diagnosis (McCarty et al 1996). The earlier a person with diabetes can be diagnosed, the sooner treatment can be given to control blood glucose levels and delay onset and progression of many diabetes-related complications. Screening for early detection of Type 1 diabetes is not recommended because the onset of hyperglycaemia is soon followed by the onset of symptoms. However, early diagnosis and aggressive treatment of gestational diabetes may be needed to reduce foetal morbidity and mortality. The case for early detection is supported by the following findings:

- intensive management of blood glucose and blood pressure reduces the risk of developing complications of diabetes (UKPDS Group 1998a; 1998b; 1998c);
- laser therapy for early diabetic retinopathy reduces progression of retinopathy (Davis et al 1997);
- drug treatment with angiotensin-converting enzyme inhibitors slows progression of nephropathy (Rodby et al 1996);

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- control of high blood pressure reduces risk of renal failure (Niskanen et al 1996);
- lipid lowering reduces risk of further coronary events (Pyorala et al 1997; Sacks et al 1996); and
- foot care education reduces risk of ulceration and amputation (Malone et al 1989).

Early detection of diabetes is hampered by its asymptomatic nature in most cases, and the lack of information on cost-effectiveness of different detection approaches. Currently, there is no nationally organised approach to early detection of diabetes. Most cases are diagnosed through opportunistic screening by GPs and other health professionals, although a number of non-government organisations such as Diabetes Australia (see page 62) and Lions Clubs carry out community screening programs.

There is broad agreement that opportunistic assessment through general practice remains the most feasible method of detecting diabetes and its preclinical states at earlier stages as:

- 80–85 per cent of the population visit a GP each year (ABS 1997a);
- GPs can assess, test and provide follow-up care and referral;
- large-scale testing by GPs is feasible (Welborn et al 1997); and
- national screening and management guidelines for GPs can be disseminated through the Royal Australian College of General Practitioners (RACGP) and the National Divisions Diabetes Program (NDDP).

Successful early detection programs require systems to ensure follow-up for diagnosis and continuing management (Overland et al 1997).

Target group

Population-based screening for diabetes is not cost-effective, even though Type 2 diabetes remains undiagnosed in a large proportion of cases. Screening, if any, therefore should be targeted at high-risk groups.

The Australian Diabetes Society (see page 62) identifies the target group for early detection as those who have two or more of the following risk factors:

- positive family history in a first degree relative;
- previous history of gestational diabetes;
- ethnicity (Indigenous Australian, Pacific Islander, South European, Asian Indian, Chinese);
- age over 40; and
- other high-risk characteristics (obesity, high blood pressure, dyslipidaemia).

Diagnostic tests

The oral glucose tolerance test is considered to be the definitive test for the diagnosis of Type 2 diabetes. However, recent recommendations for changes to the diagnostic criteria mean that a fasting blood glucose test with a lower cut-off point could be used for the detection of diabetes (American Diabetes Association 1997; Alberti & Zimmet 1998). The impact of these proposed changes to the diagnostic criteria on the early detection of diabetes has not been fully determined. The

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evidence so far would tend to suggest that application of the new criteria as opposed to the oral glucose tolerance test will reduce the number of people with diabetes that will be diagnosed (Davies 1998).

The testing methods and diagnostic criteria used for pregnant women are more sensitive than those for men and non-pregnant women.

In its 1997 position statement, the Australian Diabetes Society identified the laboratory procedures for establishing diabetes. These guidelines have not yet been endorsed nationally, but are consistent with international recommendations.

Costs and cost-effectiveness

Comprehensive cost-benefit analyses are limited by a lack of data on the prevalence of undiagnosed diabetes. Estimates of testing people with two or more risk factors range from \$353 for each newly diagnosed case (Colagiuri et al 1998) to \$183 (Easton & Segal 1998).

Key points — Early detection

- There is a need to improve community awareness of the importance of early detection of Type 2 diabetes.
- Opportunistic assessment through general practice is likely to remain the most feasible method of detecting diabetes at earlier stages. Early detection rates among general practitioners could be improved through the implementation of guidelines on screening and detection, and the development of incentives for GPs to spend more time assessing and referring patients who are at risk of diabetes.
- The overall cost and cost-effectiveness of increasing early detection should be examined.

3.3 Management of diabetes

For people with diabetes, an array of health services is required on account of the complexity of the disease, and its potential to affect all systems of the body. Effective care should be provided by a health care team that includes a GP, a diabetes educator, a dietitian, and other health care professionals as indicated by specific problems, at the time of diagnosis.

Following initial evaluation, professionals can help people with diabetes establish treatment goals, develop a management plan, care for complications and reduce risk factors. Patient education and continuing support are also central to diabetes management. Nonetheless, diabetes management is mostly about self care and management of the disease on a daily basis. Self monitoring of blood glucose levels using home glucometry has become an essential part of diabetes management.

Providers of long-term care for people with diabetes include GPs; specialists in the fields of diabetology, obstetrics, cardiology, renal medicine and vascular surgery; diabetes nurses; diabetes educators; other allied health professionals (dietitians, podiatrists, optometrists, psychologists, social workers, Aboriginal health workers); pharmacists; and non-government organisations (eg Diabetes Australia).

Approaches to treatment

The argument for strict control of blood glucose levels in Type 1 diabetes, noted over a decade ago (Gifford & Zimmet 1986), has been confirmed by recently completed randomised controlled trials (DCCT Research Group 1993; Reichard et al 1996). A meta-analysis of previously conducted randomised controlled trials has also validated these observations (Wang et al 1993). These studies have shown that strict blood glucose control prevents or delays the progression of diabetes-related complications such as nephropathy, retinopathy and neuropathy in Type 1 diabetes. According to the Diabetes Complications and Control Trial (DCCT), intensive glucose control reduces the risk of all microvascular complications by between 40 and 70 per cent (DCCT Research Group 1993).

The UKPDS has made a similar observation for Type 2 diabetes. This randomised controlled trial has also shown that in comparison to conventional treatment, intensive blood glucose management reduces microvascular complications (mainly the need for retinal laser treatment) by 25 per cent (UKPDS Group 1998a). Intensive glucose control also reduces the number of heart attacks, although the difference was not statistically significant, and there was no influence on mortality.

Another aspect of the UKPDS, intensive blood pressure control, revealed a 32 per cent reduction in deaths related to diabetes, a 37 per cent reduction in microvascular disease, and a 47 per cent reduction in the risk of significant deterioration of vision. In addition, strokes were reduced by 44 per cent (UKPDS Group 1998c).

There is consensus that the best practice in the management of diabetes is to achieve glycosylated haemoglobin (HbA_{1c}) levels within 1–2 per cent of the upper limit of normal (Colagiuri et al 1998). This level of control is feasible for the majority of people with diabetes, but only through a collaborative effort involving the person with diabetes, carers and health service providers (Colagiuri et al 1998).

Treatment modalities for people with diabetes

The treatment goals for people with diabetes vary, and are largely guided by the type of diabetes. People with Type 1 diabetes need insulin therapy for survival, and all other aspects of treatment are secondary to this. Those with Type 2 diabetes, on the other hand, can achieve glucose control in the early course of their disease through dietary management, weight reduction and regular, sustained exercise. Treatment modalities may also vary depending upon the presence of other risk factors and complications.

Type 1 diabetes

The options to treat this form of diabetes are limited. The biggest limitation is that there are no injectable insulin products that can maintain glucose levels over a long period. Multiple daily injections or use of an infusion pump are the predominant strategies. Diet is another essential factor in avoiding hyperglycaemia or hypoglycaemia, requiring the development of a diet program to synchronise with insulin action and physical activity patterns (Bishop et al 1993).

Type 2 diabetes

People with Type 2 diabetes have many more treatment and disease management options available to them. Reductions in risk factors, such as overweight/obesity and physical inactivity, alone can often help achieve acceptable glucose levels.

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Controlling nutrition and caloric intake is another option. Use of oral hypoglycaemic agents, in combination with reductions in risk factors, is an option for those who are still capable of some endogenous insulin secretion. Insulin injection therapy can also be used for controlling hyperglycaemia, although occasionally very high doses of insulin are required.

Gestational diabetes

Aggressive management of gestational diabetes can reduce foetal morbidity and mortality. The goal should therefore be to achieve maternal and child outcomes for women with gestational diabetes equivalent to those of non-diabetic pregnancies. However, some concern has been expressed about following this approach, in particular for women with a glucose level in the lower diagnostic range (Colagiuri et al 1998). There is also some concern that overly aggressive management of gestational diabetes may result in a small-for-gestational age baby (Langer et al 1989). However, providing women with advice about modifiable risk factors before discharge from hospital should be standard practice.

Management of pregnancy in women with pre-existing diabetes should also aim at achieving best outcomes for the mother as well as the infant.

Diabetes-related complications

As indicated by DCCT and UKPDS studies, glycaemic control among people with diabetes helps reduce diabetes-related complications. Nonetheless, monitoring for these complications should be an integral part of any management program. Conducting annual eye examinations for diabetic retinopathy, foot examinations and regular checking for albuminuria are essential to diabetes management.

Cost-effectiveness of interventions

A cost-effectiveness analysis of the DCCT data (DCCT Research Group 1996a) has found that the discounted cost of therapy aiming to achieve HbA_{1c} levels within 1–2 per cent of normal (intensive therapy) was cost-effective at an estimated cost of A\$31,000 per quality-adjusted life year. Using DCCT treatment costs, the use of intensive therapy among people with newly diagnosed Type 2 diabetes (rather than among people who have had the disease for some time) has been predicted to be even more cost-effective (Eastman et al 1997).

The UKPDS performed a cost-effectiveness analysis for blood pressure control in Type 2 diabetes (UKPDS Group 1998d). Intensive blood pressure control has higher therapy costs than conventional treatment, but the cost of complications is reduced. For example, the mean drug cost per patient was £740 more in the tight control group, but since there were fewer complications in this group, the mean cost of treating complications was £949 less per patient.

However, the true cost of a national program to implement control of diabetes from diagnosis onwards is unknown, because the number of people with diabetes and their current level of glycaemic control are not known. Estimates of population glycaemic control suggest that over one-third of non-Indigenous Australians, over one-half of Indigenous Australians and over two-thirds of children with Type 1 diabetes could benefit from intensive diabetes control.

Secondary prevention of established complications is also important. For example, laser treatment in diabetic retinopathy reduces the risk of developing visual impairment by 50 per cent (Davis et al 1997). Using angiotensin converting enzyme (ACE) inhibitors in people with Type 1 diabetes and micro-albuminuria reduces the number of people who progress to renal failure or die by 50 per cent (Lewis et al 1993). If education about foot care is provided to people at high risk of foot ulceration, the amputation and ulceration rates can be cut by up to two-thirds (Malone et al 1989). Since these interventions generally achieve the best results if started in the early asymptomatic stages, and complications can progress to an advanced stage before symptoms develop, regular medical screening for diabetes-related complications is essential to identify those people who require the treatment.

Key points — Management and treatment

- Providing integrated care to people with diabetes is a major challenge and crosses a range of issues, including information systems and role delineation, and collaboration at both health professional and organisational levels.
- The best practice in diabetes management is to achieve strict control of blood glucose levels. This should be feasible for the majority of people with diabetes, but only through a combined effort involving the person with diabetes, carers and health service providers.
- Evidence suggests that existing treatment interventions are both effective and cost efficient. Treatment levels could be increased through a national approach to diabetes control. However, the true cost of such a program for diabetes control is hard to estimate, because the number of people with diabetes and levels of glycaemic control are not currently known.
- There are effective treatments available to prevent the progression of diabetes-related complications. Since these interventions generally achieve the best results if started in the early asymptomatic stages, and complications can progress to an advanced stage before symptoms develop, regular medical screening is essential to identify people who require treatment for their complications.

4 Current activity in Australia in prevention, early detection and management

This chapter outlines the range of diabetes services in Australia, and the roles and responsibilities of a number of government and non-government organisations. It also describes some key initiatives in prevention, early detection and management of diabetes, at the national and State/Territory level.

4.1 Diabetes services across the continuum of care

Australia's health services are funded and delivered by both the Commonwealth Government and State and Territory Governments as well as the private sector. Broadly, the Commonwealth has a national coordinating and financing role, while the States and Territories are largely responsible for the delivery of public sector health services and the regulation of health workers in the public and private sectors. The private sector's role includes financing through health insurance and the delivery of services in private hospitals by private practitioners.

Decision making and coordination of relationships between the Commonwealth Government, State and Territory Governments and the private sector are essential for effective planning and delivery of diabetes prevention and care services. These relationships, in turn, sit within a wider context of interactions between the funders and providers of diabetes-related services.

Diabetes services in Australia exist across the continuum of care, in a variety of settings, and are delivered by a range of organisations and providers with varying roles and responsibilities. The dominant model for interdisciplinary diabetes care involves ambulatory (outpatient) services, usually delivered by hospital-based specialist centres and/or GPs. The dominant model for interdisciplinary diabetes care involves ambulatory (outpatient) services, usually delivered by hospital-based specialist centres and/or GPs, with allied health professionals working in partnership with clinicians to provide acute and long-term care.

Government

There are a number of national structures and instruments that play an important role in the development of health policy. Although they may not specifically address diabetes, they have the potential to advance the objectives of this health priority area. These include AHMAC, the NHMRC, the Office of Aboriginal and Torres Strait Islander Health (OATSIH), the Health Insurance Commission and the AIHW, as well as the overarching arrangements embodied in the Australian Health Care Agreements 1998–2003 and the NPHP.

More specifically, the Ministerial Advisory Committee on Diabetes (MACOD) was established to provide the Commonwealth Minister with independent advice on various aspects of diabetes in Australia. In addition, members of the newly established Commonwealth–State Diabetes Forum have the potential to play an important role in national public health strategy development in diabetes. By

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ensuring that all stakeholders are informed of service developments and that actions are coordinated and collaborative, appropriate links can be forged with other primary prevention activities. In addition, partnerships can be built between public health and clinical services and opportunities to implement reforms to promote better health for people with diabetes can be identified.

Governments also fund specific diabetes services such as Diabetes Centres and the National Diabetic Services Scheme:

- Diabetes Centres are discrete units comprising an interdisciplinary team of health professionals dedicated to the provision of clinical and educational services for diabetes. They are found in most major metropolitan teaching hospitals, usually have close liaison with local GPs and community health staff, and are increasingly referred to as Diabetes Ambulatory Care Centres. Services provided by Diabetes Centres are conducted on an outpatient basis and include individual and group patient education, outpatient insulin stabilisation, complication screening, foot assessment and treatment clinics, and health professional training.
- The National Diabetic Services Scheme provides blood and urine testing reagents, insulin and other drugs, and insulin syringes and needles at subsidised prices to people with diabetes. It is funded by the Commonwealth and the supplies are distributed by Diabetes Australia.

Non-government organisations

There are a number of organisations that work with government to reduce the burden of diabetes. These include the RACGP, the Australian Medical Association, Divisions of General Practice, universities, private allied health and specialist medical providers, and Indigenous and ethnic organisations, as well as a number of national and State diabetes organisations and diabetes services as outlined below.

Diabetes Australia is a not-for-profit, non-government organisation. It is a federation of 12 diabetes organisations including State and Territory associations, a professional medical, scientific and educational arm comprising the Australian Diabetes Society and the Australian Diabetes Educators Association, and a research arm comprising the Diabetes Australia Research Trust, the Kellion Foundation and the Diabetes Research Foundation of Western Australia. State and Territory associations offer a range of services including the supply of products, education and health care materials and support groups.

The *Australian Diabetes Society* is the professional organisation for specialist medical practitioners and researchers involved in diabetes care. It constitutes the medical and scientific section of Diabetes Australia.

The *Australian Diabetes Educators Association* is the professional organisation for diabetes educators. Its role is to provide its members with professional support, accredit diabetes specialist nurses and allied health workers, set professional standards and standards for patient care and advise Diabetes Australia on non-medical aspects of diabetes care and education for people with diabetes.

The *Australian Paediatric Endocrine Group* is the professional organisation for medical practitioners, primarily paediatric diabetologists and paediatricians and non-medical health professionals involved in the clinical care of children and adolescents with diabetes and endocrine disorders.

The *Australasian Diabetes in Pregnancy Society* advances clinical and scientific knowledge of diabetes in pregnancy and its effect on babies by supporting clinical research, providing a forum for researchers to discuss and organise research, disseminating scientific knowledge and providing comment on relevant issues.

The *Juvenile Diabetes Foundation Australia* is a not-for-profit, non-government organisation specialising in the needs of children and adolescents with diabetes, particularly Type 1 diabetes. The major functions of the Foundation are advocacy for the rights and needs of people with Type 1 diabetes and raising funds to support research. It also provides support and advice to people and families with Type 1 diabetes both centrally and through a network of local chapters.

The *National Association of Diabetes Centres* is a peak organisation representing specialist multidisciplinary Diabetes Centres throughout Australia. It has been jointly established by the Australian Diabetes Educators Association and the Australian Diabetes Society. The NADC aims to unite, represent and promote the role of specialist Diabetes Centres and to facilitate improved standards of diabetes care through networking, collaboration and information provision. It is a forum for conducting national programs for data collection, health professional training and other strategies aimed at improving the quality of care for people with diabetes.

General practice

The role of the GP is critical in the prevention and care of diabetes. As 80–85 per cent of the population visit a GP each year (ABS 1997a), GPs are optimally placed to screen those at risk, provide follow-up care and advice to people with or at high risk of diabetes, and link patients with other service providers in the local area.

The *Royal Australian College of General Practitioners* has produced resource documents for GPs on prevention and management (see Tables 4.1 and 4.3). The RACGP has recently developed a curriculum guide for continuing medical education in diabetes for GPs, based on currently available guidelines.

Divisions of General Practice are key structures for improving the quality of general practice and integration between general practice and other health services. There are four Support and Evaluation Resource Units (SERUs) to facilitate the programs and activities of the Divisions throughout Australia. The development of the *National Divisions Diabetes Program* (see page 73) provides an opportunity to harness current support in general practice and facilitate the provision of evidence-based care. The program draws together and builds upon the experience of more than 100 diabetes programs conducted in Divisions. It aims to:

- provide a framework for Divisional diabetes programs that is consistent with national initiatives and is evidence based;
- facilitate effective linkages between Divisions conducting diabetes programs, between Divisions and local diabetes service providers including non-government services, and between Divisions and health planners at a State/Territory level; and
- facilitate comprehensive evaluation of diabetes programs.

Aboriginal Community Controlled Organisations

The role of Aboriginal Community Controlled Organisations (ACCOs) is critical to the care of Aboriginal people. The Commonwealth funds 130 Aboriginal community controlled health and health-related services throughout Australia, most of which are members of the National Aboriginal Community Controlled Health Organisation (NACCHO). These services have been developed by Aboriginal people to provide comprehensive and culturally appropriate primary health care to their communities. ACCOs have expertise in health care delivery to Indigenous people, are aware of community needs and barriers to care, and are well positioned to give advice and collaborate on health issues faced by their people.

Intersectoral links

There is a wider inter-governmental context within which these organisations provide diabetes-specific services. For instance, the policies and practices of departments of education, sport and recreation, and local government will have an impact on the effectiveness of these services. Establishing and maintaining intersectoral links with these other sectors is necessary for diabetes-specific services to be effective.

Key points — Diabetes services

- At the organisational level, effective coordination of relationships between the Commonwealth Government and State/Territory Governments and non-government organisations will assist service delivery and will also be integral to the implementation of this report and the National Diabetes Strategy.
- At the service level, coordination between providers is important, as people with diabetes may need access to a wide range of health professionals and services at different stages in the management of their illness.
- The involvement of agencies outside the health sector is also necessary, as the organisations that work with government to reduce the burden of diabetes provide diabetes-specific services within a wider organisational framework.

4.2 Current activity at national and State/Territory levels

For this report, the Commonwealth, States and Territories provided input on current activity focused on six areas relevant to diabetes — guidelines, service collaboration, client focus, provider focus, information systems, and research and development.⁴ The results were collated and used to identify current activity in relation to prevention, early detection and improved management of diabetes, in the general population (this chapter) and among specific population groups (Chapter 5).

⁴ Data collection initially focused on five areas identified as fundamental to be effective management of chronic illness (Wagner et al 1996). The consultation undertaken for this report resulted in research and development being added as an additional area.

Current activity at national and State/Territory levels

It should be noted that this is neither a systematic review nor a comprehensive record of initiatives in diabetes. It is a summary that gives an indication of some of the key initiatives being undertaken across the nation.

At the Commonwealth level, the main focus is on developing the National Diabetes Strategy, with the aim of improving the coordination of activity and long-term strategic planning. At the State and Territory Health Department level, activity in diabetes prevention, early detection and management is being reviewed and planned through the:

- New South Wales Diabetes Taskforce;
- Victorian Diabetes Taskforce;
- Queensland Expert Advisory Group on Diabetes;
- South Australian Diabetes Health Priority Area Advisory Group;
- Western Australian Diabetes Strategy and Diabetes Services Taskforce;
- Tasmanian Diabetes Policy and Planning Support Project;
- Northern Territory Preventative Chronic Disease Strategy; and
- Australian Capital Territory Primary Health Care Integrated Diabetes Management Services.

Guidelines

In an era of evidence-based medicine, guidelines are becoming one of the critical links between the best available evidence and good quality clinical and public health practice for medical practitioners and nursing and allied health professionals. To be most effective, guidelines should involve key organisations and individuals in their development, and have specific mechanisms for dissemination and implementation. Their uptake should be evaluated, and their content reviewed and updated regularly. The NHMRC document *A Guide to the Development, Implementation and Evaluation of Clinical Practice Guidelines* (NHMRC 1998) addresses issues relating to the implementation and evaluation of guidelines. Existing guidelines are listed in Tables 4.1, 4.2 and 4.3, and guidelines being proposed or under development are described in the text.

Prevention and early detection

Guideline development in Australia has focused on clinical practice, and there are few guidelines outlining evidence-based best practice in prevention.

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Table 4.1: Guidelines on prevention

Organisation	Guideline	Comment
NHMRC (1997b)	<i>Guidelines for Preventive Interventions in Primary Health Care: Cardiovascular Disease and Cancer</i>	Examines evidence for modification of risk factors for cardiovascular disease and cancer, a number of which are common to diabetes.
RACGP (1998a)	<i>Guidelines for Preventive Activities in General Practice</i> (also known as the Red Book)	Recommends monitoring many diabetes risk factors.
RACGP (1998b)	<i>Putting Prevention into Practice</i> (also known as the Green Book)	Provides steps for implementing preventive activities.

The Commonwealth has provided funding for the production of guidelines on Type 2 diabetes for endorsement by the NHMRC. These will be early detection and management guidelines, with additional emphasis on lifestyle counselling.

Table 4.2: Guidelines on early detection

Organisation	Guideline	Comment
Australian Diabetes Screening Study (Welborn et al 1997)	<i>Australian Diabetes Screening Study</i>	Protocol for GP involvement in early detection of diabetes.
NSW Health Department (1996a)	<i>Screening for Type 2 Diabetes: a Decision Analysis Approach</i>	Part of guidelines series (see Table 4.3).
Northern Territory Coordinated Care Trial	<i>Early Detection Guidelines</i> (to be published following completion of the trial)	Covers all Indigenous people over 16 years of age (annual screen), all people with impaired glucose tolerance or women with a history of gestational diabetes (annual screen).

The Commonwealth-funded national guidelines on Type 2 diabetes referred to above will include advice on testing and early detection. Version 2 of the National Divisions Diabetes Program, to be disseminated in 1999, will include the national guidelines. General Practice Divisions Services is also undertaking a project to trial a protocol for screening in GP surgeries.

The New South Wales Health Department intends to develop guidelines on early detection of diabetes. A project to develop a model for assessing the cost-effectiveness of screening is under way at the University of Sydney.

Management

There is a range of national and State/Territory guidelines on management of diabetes. It should be noted that guidelines are only one component of evidence-based management. In the United States, guideline development is now focused on formulating decision paths, as advocated by the International Diabetes Centre. These are in use in 150 centres in the United States and at least 12 countries worldwide.

Current activity at national and State/Territory levels

Table 4.3: Guidelines on management

Organisation	Guideline	Comment
<i>National</i>		
NHMRC (1997a)	<i>Clinical Practice Guidelines: Management of Diabetic Retinopathy</i>	Currently being disseminated by Diabetes Australia.
Australian Diabetes Society (Mogyorosi & Ziyadeh 1996; Gilbert et al 1995; Best et al 1995; Yue et al 1993; Jerums et al 1994; Couper et al 1995)	Position statements cover various aspects of diabetes including hypertension, dyslipidaemia and microalbuminuria.	
Australian Podiatry Council & Diabetes Australia (1997)	<i>National Podiatric Guidelines for Diabetes</i>	Include the role of other health service providers in providing podiatry services, could form the basis for national guidelines.
Australian Diabetes Educators Association (ADEA) (1994)	<i>National Guidelines for Safe Practice for Diabetes Nurse Educators</i>	
ADEA (1991)	<i>Standards of Practice for Diabetes Educators</i>	
ADEA (1996)	<i>National Core Competencies for Diabetes Educators</i>	
<i>State/Territory</i>		
NSW Health Department (1996b-h)	Portfolio of guidelines for diabetes care, including: <i>Principles of Care and Guidelines for the Clinical Management of Diabetes Mellitus in Adults</i> <i>Evidence for the Guidelines for the Clinical Management of Diabetes Mellitus — Part 1</i> <i>A Guide to Diabetes Education for Health Professionals</i> <i>Principles of Lifestyle and Nutritional Management of Diabetes</i> <i>Management of Diabetes Mellitus</i> (consumer card and poster) <i>Principles of Care and Consensus Guidelines for the Management of Diabetes Mellitus in Children and Adolescents</i> <i>Lower Limb Ulcers in Diabetes</i>	Being considered for adoption by Victoria, South Australia and Queensland.
Victorian Diabetes Taskforce (1998)	<i>Clinical Practice Guidelines for the Management of People with Diabetes</i>	Currently being disseminated to medical and allied health professionals in Victoria.
RACGP (1998c) in association with Diabetes Australia	<i>Diabetes Management in General Practice</i>	Key reference document for GPs. Different editions of this document have included the New South Wales Guidelines for the Management of Diabetes.

Current activity in prevention, early detection and management

The national guidelines on Type 2 diabetes under development referred to above will also focus on management. The NHMRC is also developing guidelines on the management of patients with diabetes undergoing surgical or diagnostic procedures during a single day admission to a hospital or day surgery centre. Other priority areas for the development of guidelines include prevention and management of foot disease, cardiovascular complications and end-stage renal disease.

The Integration SERU has included reference to existing Australian clinical guidelines in the National Diabetes Divisions Program Core Module 'Clinical management and patient recall'. The modules have been disseminated to Divisions of General Practice and other stakeholders.

Service collaboration

Service collaboration aims to:

- facilitate effective relationships between diabetes service providers (for instance between primary prevention service planning and delivery and clinicians involved in the care of people with diabetes);
- develop partnerships between organisations and sectors to streamline services and reduce duplication and fragmentation;
- examine the linkages between population-wide strategies, local community-based programs, interventions for high-risk groups and interventions conducted in clinical settings, and examine the roles of health professionals, community health services, GPs and non-government organisations in these activities;
- ensure that services reflect the needs of people with diabetes, who often require longer times with health service providers, as well as a range of services and long-term follow-up; and
- consider cultural issues in intersectoral collaborations and in the planning and delivery of diabetes prevention and care services.

This section discusses current national and jurisdictional activity which aims to improve service delivery to the general population and to people with diabetes.

Prevention and early detection

National activity

Two national developments should have a significant impact on diabetes prevention within the wider context of public health.

In 1996, Health Ministers agreed to establish the NPHP, which is a new working arrangement between the Commonwealth, States and Territories to plan and coordinate national public health activities, provide a more systematic and strategic approach for addressing public health priorities and provide a vehicle to assess and implement new directions and major health initiatives. The NPHP deals mainly with activities that aim to improve the health of whole populations.

Current activity at national and State/Territory levels

The NPHP work program focuses on a number of major public health infrastructure issues including:

- a more consistent framework for public health legislation;
- a consistent and coordinated national public health information collection;
- improved public health practice, including benchmarking and quality assurance systems;
- systems for better planning and resource allocation of public health activities;
- a strategy for investment in public health research and development;
- appropriate development of the public health workforce; and
- assessment of systems for coordination and monitoring across national public health strategies/programs.

In September 1998, the Commonwealth started work on a National Primary Prevention Strategy, which will build on the following existing initiatives:

- *Acting on Australia's Weight: a Strategic Plan for Prevention of Overweight and Obesity* (NHMRC 1997c). The NHMRC developed this report in recognition of the importance of overweight and obesity as a significant risk factor for many serious health conditions, such as diabetes and cardiovascular disease. The plan focuses on the need to make changes to the environments in which people live and work to make it easier for all Australians to be physically active and consume a healthy diet. An implementation strategy is currently being developed.
- *Australia's Food and Nutrition Policy* (DHCSC 1994). This policy aims to improve health and reduce the preventable burden of diet-related early death, illness and disability among Australians. The policy was developed through a partnership of governments, industry and the community. Its fundamental aim is to make healthy choices easier for all Australians by increasing the availability and affordability of nutritious foods and improving understanding of 'good nutrition' in the community.
- *Developing an Active Australia: A Framework for Action for Physical Activity and Health* (DHFS 1998). This resource, which promotes physical activity and health among Australians as part of a nationwide Active Australia initiative, was launched in June 1998. The framework recognises the need to develop evidence-based population-wide strategies and public policies to promote high levels of involvement in regular physical activity, in recognition of compelling evidence of links between physical activity and health outcomes. The framework also identifies intersectoral collaboration as essential for the efficient development of supportive infrastructure, environments and attitudes to encourage people to become and remain physically active.

General practice activity

The Public Health and Health Promotion SERU of the Divisions of General Practice is developing a framework for changing behaviours relevant to physical inactivity, smoking and dietary habits in the general practice setting.

Current activity in prevention, early detection and management

State and Territory activity

As with the national primary prevention strategy described above, the prevention of diabetes is being progressed through broader lifestyle or risk factor approaches which will have an impact on diabetes as well as cardiovascular disease and some cancers. The risk factor approaches are being partnered by strategies that focus on the settings in which people live and work and that provide a foundation for addressing risk conditions (eg health-promoting schools, municipal public health plans). Central to these approaches, and supported by jurisdictions, is implementation of national initiatives such as Acting on Australia's Weight, Active Australia, the National Public Health Nutrition Strategy, the National Drug Strategy and the planned National Tobacco and Environmental Health Strategies, within a settings framework.

For example, a Physical Activity Task Force was established in New South Wales in 1993 to trial the Active Australia Participation Framework. The Task Force comprises all levels of government, the fitness industry, sporting groups, education, and health and recreation sectors. Trialing the framework during 1997 involved media and marketing, training of GPs and strategies targeting specific population groups, particularly older people and children. Initial indications are that the public have responded well to the message 'Take exercise regularly, not seriously'.

In Queensland, prevention is being advanced through the establishment of integrated outcome teams within public health services (eg cardiovascular disease/diabetes/nutrition/physical activity) and through a joint venture approach with other service providers. This involves identifying and agreeing on the roles of various service providers in addressing core risk factors. The establishment of network forums for service providers will facilitate communication and provide an avenue for further discussion on role delineation.

South Australia is addressing prevention issues through its Active Australia Strategic Plan and Food and Health Policy, both to be released in 1999. The former draws upon the results of the 1998 South Australian Physical Activity Survey and is likely to include education and information programs, development of supportive environments, service improvement and policy development. The Food and Health Policy advocates a range of nutrition strategies that will benefit people with or at risk of developing diabetes, including priority populations such as Indigenous people, infants, children and young people, and older Australians.

The Kimberley Aboriginal Medical Services Council in Western Australia has developed an evidence-based approach to integrated primary prevention strategies through a systematic review (Couzos & Murray, in press). Periodic health examination of the Aboriginal population, through establishment of recall frequencies and assessment of potential performance indicators for providers to evaluate preventive care delivery, is recommended.

The Northern Territory Coordinated Care Trial focuses on reducing risk factors and improving role delineation among service providers. In addition, the Northern Territory is developing a Chronic Disease Strategy, with the aim of reducing the prevalence and impact of the major chronic diseases (diabetes, hypertension, renal disease, coronary heart disease and chronic airways disease) in the Territory within 10 years. It will do this by:

- using a unified approach to the major chronic diseases, with a balance of prevention, early detection and best-practice clinical management;

Current activity at national and State/Territory levels

- establishing a framework for the control of the common chronic diseases; and
- addressing the key risk factors underlying these diseases (overweight, physical inactivity, alcohol misuse, tobacco smoking).

To date, this has occurred through active community involvement, intersectoral action, a 'whole of life' approach, strengthening and re-orienting public health services and conducting health economic analysis of cost-effective policy options.

Other innovative prevention and early detection strategies include the following.

- In Victoria, a Food and Nutrition Policy is being implemented along with a State-wide Active for Life Physical Activity Strategy, which aims to develop quality environments, infrastructure, opportunities and services for participation in sport and recreation and incidental physical activity. An additional initiative is VicHealth's use of sports and arts settings for health promotion. This has resulted in a cost-effective and innovative approach to primary prevention using specific health messages and promoting healthy environments through policy and program development. Partnerships have been developed with Diabetes Australia, promoting generic health messages relevant to diabetes prevention.
- The sponsorship of sport and recreation organisations and the arts in South Australia, has continued to promote diabetes awareness through the 'Maybe it's Diabetes' campaign. The Smart Choice program aims to increase the availability of healthy food choices at sport, recreation and arts venues.
- The Health Department of Western Australia has been running various healthy nutrition campaigns for more than a decade. The Food Cents campaign aims to promote good nutrition by demonstrating how easy and inexpensive it is to eat healthy foods. The campaign includes supermarket visits and uses trained lay members of a community. The campaign also targets low-income families through the Healthway-sponsored Foodbank.
- Another key program in Western Australia is the Healthy Choices Awards which target eating establishments and food providers and aim to facilitate access to healthy food choices for people eating away from home. The main focus is on fostering local ownership and community empowerment, in response to current limitations on access to health services, and models such as Strong Women, Strong Babies, Strong Culture will be used.
- Tasmania has been conducting an 'Eat Well Tasmania' campaign through the Tasmanian Nutrition Promotion Taskforce for the past three years. The Taskforce is an intersectoral coalition with representation from primary producers, manufacturers, retailers, health professionals and consumers. The campaign aims to raise the profile of, and foster an intersectoral approach to promotion of good nutrition throughout Tasmania.
- In the Australian Capital Territory, early detection of Type 2 diabetes is promoted through a program aimed at supporting and encouraging best practice among GPs through accredited diabetes training courses, diabetes mini-clinics held in GP surgeries, posters, pamphlets and newsletters.

Management

Collaborative models of care

There is a growing move towards models of care in service delivery, in which increased collaboration between services and new approaches to funding promote seamless long-term care of people with diabetes.

Pilot programs based on collaboration between current diabetes services are in progress in New South Wales, in the Integrated Care Pilots jointly funded by the Commonwealth Department of Health and Family Services and the New South Wales Health Department, and in the Commonwealth/State funded Coordinated Care Trials, particularly in South Australia and the Northern Territory.

Integrated Care Pilots. In these projects, the focus is on better patient outcomes through improved coordination between service providers. The Diabetes Integrated Care Pilot Projects in New South Wales were conducted in Western Sydney (Diabetes West) and two rural areas (Mid North Coast and Far West) and were based on the hypothesis that the provision of well organised care, based on agreed guidelines for best practice, incorporating patient education and early detection of complications, will reduce the impact of diabetes and its complications. A detailed evaluation plan was developed and should be used as a framework for further development.

The following interventions were introduced in each of the three pilot project locations at the beginning of the project:

- allocation of funding which allowed a minimum standard of care to be accessed locally by people with diabetes;
- dissemination of clinical management guidelines for diabetes;
- training of GPs and other service providers in accordance with the clinical management guidelines for diabetes;
- introduction of Diab-Net, a diabetes-specific database for collecting patient clinical and other data and Diab-Code, a disease staging criteria for diabetes; and
- formalised communication established between Aboriginal Medical Services, Divisions of General Practice and Diabetes Centres in each pilot project location, including collaboration between these services for local planning and policy development.

The expected benefits of the diabetes integrated care pilot projects are established models of integrated diabetes care, which can be generalised to other geographical areas and other services; the identification of indicators of quality of care and outcomes for State-wide monitoring; the identification of efficiencies associated with integrated diabetes care; and the implementation of best-practice guidelines for service providers in New South Wales (defined by the *Principles of Diabetes Care and Guidelines for the Clinical Management of Diabetes Mellitus in Adults*; NSW Health Department 1996b).

Coordinated Care Trials. Improved collaboration between service providers is a focus of the Coordinated Care Trials. Structural changes to funding arrangements are also involved. The trials are exploring innovative ways of providing health care

Current activity at national and State/Territory levels

to people with continuing complex health and community care needs. After an extensive design and tracking phase, nine trials are now underway and are due to be completed by the end of 1999.

The purpose of the trials is to test a range of models, to establish whether cross-program fund pooling, combined with a care coordination/case management approach, will lead to improved health outcomes for selected client groups.

An important component of the trials will be new arrangements between the Commonwealth and the States and Territories to pool funds in such a way that, with the intervention of a care coordinator, care plans and services can be built around the needs of individual patients. Using pooled funds, and without the constraints of specific program barriers and eligibility and operating rules, the patient, the GP and the care coordinator, (who will in many cases be the GP), can decide on and obtain the most effective and appropriate mix of services. The aim is to create flexible services responsive to individual need, rather than the present segmented funding program arrangements.

Health outcome measures will be collected for all participants, and each trial will be evaluated in detail at the local level. Data from all trials will be synthesised into a national evaluation of the concept, that will determine how effective fund pooling and care coordination can be in improving individual health outcomes within existing resources. The trials will also explore the potential for using fund pooling as a lever for changing the way in which services are selected and delivered.

National Divisions Diabetes Program

As discussed in Section 4.1, the National Divisions Diabetes Program is a coordinated national approach to diabetes care in Australian general practice. The program consists of modules on planning, evaluation, and core and optional activities. These modules are designed to facilitate the implementation and evaluation of 'best-practice' diabetes care through GPs and Divisions of General Practice, working in collaboration with diabetes care providers and organisations.

The National Divisions Diabetes Program has grown out of the work undertaken by the Divisions and the Integration SERU, in response to the need to standardise and coordinate Division activity in diabetes service delivery and evaluation. The program is designed to provide a 'guide' for Divisions to facilitate systematic change in the care of patients at the general practice level. Version 1 of the National Divisions Diabetes Program identifies joint management of diabetes as a core module of the Program. Such a module would support and facilitate the increasing trend at Divisional level towards greater collaboration with State-funded community-based organisations and hospitals. There is some evidence of formal structures being established to support this collaboration. However, most collaboration appears to come from community-based interaction. Appropriate community and consumer representation on relevant Divisional programs needs to be progressed through the partnership platform recommended in the General Practice Strategy Review (see page 79).

State/Territory reviews of service delivery

A key focus of State/Territory reviews of diabetes service delivery is greater collaboration between diabetes service providers, including GPs and Divisions of General Practice.

Current activity in prevention, early detection and management

Table 4.4: Preferred models of service delivery

Type 1 diabetes

Over the past decade, management of newly diagnosed Type 1 diabetes has changed significantly from a hospital-based model to ambulatory care. In urban areas, care of children and adolescents with Type 1 diabetes is largely conducted by paediatric diabetologists, paediatricians and diabetologists.

In rural and remote areas, shared or collaborative care with specialist involvement is the most common model of care. In these areas, paediatricians and (particularly in the Northern Territory) GPs are the main carers of young people with Type 1 diabetes. (Service delivery to young people with Type 1 diabetes is discussed further in Section 5.2.)

Type 2 diabetes

A range of shared or multidisciplinary models of care are being implemented in all States and Territories. The multidisciplinary approach preferred by Queensland, Western Australia and the Northern Territory may reflect the geographically widespread population. In rural and remote areas, few medical practitioners are available and care involves nurse practitioners, Aboriginal health workers, resident or visiting practitioners and allied health professionals. A broader range of approaches is being used in New South Wales, the Australian Capital Territory and Victoria.

Gestational diabetes

Some jurisdictions manage gestational diabetes in a primary health care environment with tertiary-centred care accessed when required, while others have specialist-driven models in place. There is no systematically implemented model for gestational diabetes across the nation. (Service delivery to women with gestational diabetes and diabetes in pregnancy are discussed in Section 5.1.)

Evidence base/rationale

The main evidence base for shared or multidisciplinary care is the association between team approaches and enhanced outcomes (eg DCCT, UKPDS). Stakeholders' rationale for the increasing involvement of GPs in managing the care of people with diabetes focuses on GPs being more acceptable to patients and able to provide continuity of care for the whole range of medical problems, not just diabetes or its complications (Griffin 1998). Specialist involvement is recommended for children, who have more specific and complex needs.

While shared or integrated models of care are the preferred models for the management of diabetes, attempts to implement these models are hampered by geographical constraints and workforce limitations.

State-based networks have been established in most States and Territories by the now defunct Divisional Field Support Services and continued by the newly established State Based Organisations. The purpose of these networks is to provide support and share resources and information on projects across health departments (hospital and community providers, policy makers), non-government organisations and Divisions of General Practice.

To facilitate the increasing move towards collaborative models of care for the management of people with diabetes, service provider organisations are involved for the first time in many cases in the planning of State-wide services. Although there are generally strong relationships between non-government organisations (eg Diabetes Australia) and health departments in all jurisdictions, there is little coordinated involvement of private allied health professionals in planning and service delivery. The involvement of service provider organisations aims to increase retention of allied health professionals and subsequent access to these services.

The following projects are currently underway or planned:

- In 1994, New South Wales began the Diabetes Health Outcomes Project, which seeks to improve the continuing care of people with diabetes. The Project has developed a broad framework for approaching health outcome based service planning, collaborated with experts and consumers to develop and implement the series of Principles of Care and Guidelines for Diabetes Care (see Table 4.3), and operated the Integrated Care Pilots (see page 72).

Current activity at national and State/Territory levels

- The New South Wales Health Department is intending to investigate benchmarks for levels and types of services required by metropolitan and rural areas. It has also conducted a Nurse Practitioner Project, which explored and piloted an extended role for nurses in clinical service delivery. Results of this project are currently under consideration.
- An analysis of diabetes-related activity commissioned in Victoria reports the current state of play. This will support and inform the planning of Victorian diabetes services.
- A State-wide audit of diabetes services in Queensland, conducted by Diabetes Australia (Queensland), is establishing benchmark service levels for allied health professionals with a view to establishing minimum service standards. The contribution of allied health professionals to reducing inpatient episodes is being considered in this process.
- The South Australian Department of Human Services has implemented two parallel approaches to coordinating diabetes care. These are the Commonwealth–State funded Coordinated Care Trials (see page 72), and the State funded Diabetes Outreach Services. The Diabetes Outreach Services program focuses on better access to quality care for rural people with diabetes in order to improve population health outcomes. This involves multilevel, inter-sectoral coordination of service delivery for rural South Australia (Alexander 1998). This model is currently being reviewed by the Department for its application to metropolitan diabetes services.
- Western Australia has funded integrated care pilot projects in the inner city and three rural locations. The aim of these projects is to improve collaboration between service providers and to establish comprehensive diabetes care services. Key strategies include building of partnerships and integrating diabetes services across public and private health sectors and across clinical specialties, providing effective management guidelines and ensuring people with diabetes have access to a range of quality diabetes services.
- The Australian Capital Territory Government has recently adopted an integrated diabetes management plan for the Australian Capital Territory region following an extensive review of diabetes services. The integrated diabetes care system will be implemented during 1999 with the establishment of an overarching Australian Capital Territory Diabetes Council. The Council will advise the Department of Health and Community Care on issues for people with diabetes and their carers. The model specifies provider role delineations and systems of communication. The framework uses the complexity of individual care needs and the location of care delivery to distinguish between levels of care.

Many jurisdictions have identified a need for collaborative diabetes services to be provided *within hospitals*. Currently, most people with diabetes who are admitted to hospital with another condition (eg a cardiac event) are not identified to the hospital diabetes team. This may be due in part to a lack of coordination between various hospital departments. This issue is being addressed by separate projects in hospitals in South Australia, targeting patients admitted with cardiac conditions, and in Queensland and New South Wales by the development of clinical pathways for the management of people with diabetes admitted with another condition.

Client focus

At the population health level, client focus involves raising awareness about diabetes and its risk factors, to help people reduce their risk of developing diabetes and to encourage people with diabetes to effectively manage their condition. Raising awareness must occur as part of a wider approach that includes strategies to address the underlying factors that contribute to risk.

At the service delivery level, client focus means making the patient a treatment partner. Patient education should not consist of one way provision of information. Patient-centred approaches focus on increasing knowledge but also on securing behaviour change by ensuring that change is a priority for patients and that change is within their means. Methods used in patient-centred approaches include collaborative problem definition, goal setting, self-management training, and active follow-up initiated by the service providers.

Prevention and early detection — raising awareness

Non-government organisations including the State and Territory agencies of Diabetes Australia conduct local public awareness campaigns on diabetes and its risk factors.

As part of CADS, the Commonwealth has funded Diabetes Australia to develop and implement a National Community Awareness of Diabetes Campaign. This strategy will seek to inform the general population about the impact of diabetes and its risk factors and encourage those at risk to seek screening.

Data on awareness of diabetes, its impact and risk factors are available from the baseline survey for CADS (Woolcott Pty Ltd 1998⁵) and a Queensland Health State-wide health survey. In both surveys, about 60 per cent of people claimed to have some information about diabetes. The most commonly cited risk factors for diabetes were being overweight (35 per cent nationally, 22 per cent in Queensland), having a family history of diabetes (25 per cent nationally, 42 per cent in Queensland), and including too much sugar in the diet (17 per cent nationally, 30 per cent in Queensland). The latter is obviously a common misconception of risk. Knowledge of the complications of diabetes was not high, with only about 25–33 per cent of people citing blindness as a complication, about 25 per cent of people citing amputations, and only 10 per cent of people citing heart problems or kidney disease (Woolcott Pty Ltd 1998). These data need to be considered in the development of awareness programs.

An important aspect of enabling people to adopt healthier lifestyles is the provision of strategies that are specific to gender, socio-economic status and cultural background. The need for gender analysis to be applied to policy development is currently under consideration at the national level, and there are proposals to include gender analysis in the work program of the NHPC.

Patient-centred approaches to management

At the State and Territory level, there is evidence of a growing movement towards informing patients of their rights and empowering clients to demand evidence-based care. In New South Wales, consumer guidelines for diabetes were published in 1996 (New South Wales Health Department 1996f). Evaluation of the impact of

5 Market research conducted under the direction of Diabetes Australia with funding from the then Commonwealth Department of Health and Family Services.

Current activity at national and State/Territory levels

their dissemination is underway by the NADC. South Australia has developed an innovative model of regional networks in which service providers educate people with diabetes about evidence-based services and encourage them to demand these services from providers. The Northern Territory Preventative Chronic Disease Strategy includes active community involvement in the development of policies and strategies.

In addition, non-government organisations such as the Australian Kidney Foundation, Diabetes Australia, National Heart Foundation (NHF), Juvenile Diabetes Foundation of Australia, and Lions and Rotary Clubs have an important role in providing information to people with diabetes and assisting them in better management of their disease.

There is little coordination in these efforts, or in issues such as access to better food supplies and to medicines. Similarly, except in specialist diabetes centres, there is little evidence of innovative approaches that focus on clients as treatment partners with whom goal setting is undertaken for diabetes management. The major focus has clearly been on providing basic education to those most at need. Lack of resources to provide education, let alone conduct more innovative patient-centred approaches to education, has been cited as a key issue by all health service providers.

Examples of patient-centred approaches include the 'demand management' approach being used in the South Australian Coordinated Care Trial and the use of motivational interviewing in a project being undertaken by the Brisbane Inner South Division of General Practice.

In most jurisdictions, hospital specialists are starting to use the admission of people with diabetes, even if admitted for other conditions, as an opportunity for education and intervention.

The National Divisions Diabetes Program has included patient education, provided by either GPs or allied health professionals, in the core modules *Basic patient education provided by general practitioners* and *General practitioner and patient access to multidisciplinary care*. The program also strongly recommends that GPs provide patients with information on consumer organisations and services.

Provider focus

A provider focus involves establishing systems that allow ready access to necessary expertise. This involves establishing formal decision-support systems that provide professionals who design or conduct health promotion programs with specified channels of access to expert public health advice.

Both primary health care planning and service delivery can be enhanced by the establishment of formal decision-support systems where specialists (eg researchers, clinicians) provide expert advice to population health planners and health promotion officers on evidence-based prevention strategies.

Continuing education of health professionals through guidelines and specific training courses is also an essential component of a provider focus.

Current activity in prevention, early detection and management

Prevention

A number of jurisdictions have noted the need for greater involvement of GPs in primary prevention activities. This has been advanced in Queensland and Tasmania through joint development of a nutrition education manual for GPs. In South Australia, GPs are being educated in the prescription of physical activity for patients who are not active. At a national level, the RACGP guidelines (see Table 4.3) are valuable resource documents for GPs.

The network forums being established in Queensland will facilitate dissemination of guidelines on evidence-based primary prevention to service providers and their implementation.

The Northern Territory Coordinated Care Trial has developed care plans for patients. These can be used by service providers as sources of information on evidence-based practice for the prevention of risk factors.

Early detection

The CADS campaign will involve the development of education kits for GPs on early detection, to ensure that GPs have the skills to screen and refer people who present for screening as a result of the campaign. Consultation with GPs will be essential to the effectiveness of the campaign. A GP Working Party has been formed as part of CADS, with representation from all States and Territories, the NDDP and RACGP. Existing networks through the NDDP, State-based organisations of Divisions and the RACGP will be used to disseminate campaign materials to GPs.

Non-government organisations including the State and Territory agencies of Diabetes Australia conduct local awareness programs for service providers on the need for early detection.

Management

The establishment of the NADC, which also has State-based branches, provides an avenue for sharing information on the management of diabetes among health professionals. Other professional associations that share and increase provider expertise are the Australian Diabetes Educators Association, the State-based Diabetes Specialist Interest Groups of the Dietitians Association of Australia, the Australian Diabetes Society and the National Diabetes Network of the Australian Podiatry Council.

A significant role of non-government organisations such as Diabetes Australia is in providing information to service providers (eg dissemination of guidelines) and conducting training courses.

An assessment of current GP involvement in diabetes management has been made by the Integration SERU, which surveyed Divisions of General Practice in August 1998 about their activity in diabetes and the extent and type of diabetes data collection they were undertaking. Of the 123 divisions surveyed, 65 (53 per cent) were undertaking a diabetes program, 24 (19 per cent) planned to start a diabetes program in the next six months, and 34 (28 per cent) had no immediate plans to undertake a diabetes program.

General Practice Strategy Review and practice incentives

The report of the General Practice Strategy Review Group (1998) recommends a broad ranging program of activities to ensure general practice reaches its full potential to serve the community and consolidate its place at the centre of the health care system.

The Commonwealth Practice Incentives Program is likely to include remuneration for GP collection and transfer of data (basic data collection about the practice with a higher level of payment for a divisional database). This would provide an incentive for computerisation and encourage practices to focus on population health (General Practice Strategy Review recommendation 126). This has positive implications as a nationally accepted minimum dataset already exists and many Divisions are facilitating GP collection of diabetes data for quality assurance and recall purposes.

The Review's vision for GPs in the 21st century is to have partnerships with patients and carers that promote maximum independence, self care and self responsibility for health. It is also envisaged that GPs will be able to develop initiatives in primary health care and create opportunities for better patient care as a result of the shift of resources from hospitals to communities.

National Divisions Diabetes Program

A major focus of Division activity in diabetes has been the provision of GP education which is based on clinical management guidelines and conducted in collaboration with local and regional diabetes service providers. Version 1 of the National Divisions Diabetes Program, disseminated in July 1998, focuses on what Divisions can do for their GPs, such as providing education on accepted 'best practice', establishing clinical record and information systems, and facilitating joint management and access to multidisciplinary care. More work still needs to be done on the factors that enable GP implementation of best practice, for example, identifying the barriers to implementing clinical management guidelines, detecting diabetes in high-risk patients, and identifying appropriate incentives.

Decision-support systems

The need for decision-support systems is being investigated in the jurisdiction-wide reviews of diabetes prevention and care currently underway. Currently, decision-support systems exist within service provider groups (eg GPs, hospital endocrinology departments) and along organisational lines (eg hospital-based allied health staff can access the expertise of hospital-based diabetologists).

However, there is little evidence of decision-support systems that operate across organisations. Generally, community-based professionals (including GPs and allied health professionals) do not seek decision-support expertise from hospital-based specialists outside of a small number of well established diabetes Divisional projects. The identification of joint management as one of the core modules in the National Divisions Diabetes Program may facilitate this cross-organisational decision support.

An example of a State-wide decision-support system is the South Australian Coordinated Care Trial. This trial was designed in recognition of the importance of decision-support systems (McDonald 1998) and each project in the trial has a care mentor who provides clinical leadership.

Current activity in prevention, early detection and management

Continuing education

At the Commonwealth level, the Department of Health and Aged Care (HEALTH) has commissioned a review of general practice training. The need for re-orientation of medical undergraduate and postgraduate training towards the management of chronic illness is an issue of concern in a number of jurisdictions.

Several tertiary institutions offer postgraduate courses for health professionals in the care and management of diabetes.

The RACGP has recently developed a curriculum guide for GP continuing medical education in diabetes, which is based on currently available Australian guidelines. The guide has been distributed as a draft for comment to Divisions of General Practice and other stakeholders. A final version will be disseminated in 1999. A curriculum for a national GP Eye Skills Workshop is being developed by the RACGP and the Royal Australian College of Ophthalmologists, to assist GPs in developing common eye skills and visual screening. The Workshops will be implemented through Divisions of General Practice in each State/Territory.

The education of allied health professionals involved in the management of diabetes is occurring at a local level in New South Wales, Victoria and Tasmania. However, this education is dependent on continuing funding and there is no sustainable continuing education program on diabetes management for allied health professionals outside professional association activities.

The following State-based continuing education programs are underway.

- The NSW Health Department has published and is disseminating *A Guide to Diabetes Education for Health Professionals* (NSW Health Department 1996d), and nutrition guidelines on the optimal management of diabetes are currently being disseminated (NSW Health Department 1996e). The New South Wales clinical management guidelines for diabetes (NSW Health Department 1996b) have also been provided to medical software manufacturers to facilitate the incorporation of the guidelines in decision-support technology systems.
- In South Australia, the Department of Human Services has funded its Diabetes Outreach Services to deliver continuing professional education services to rural GPs, nurses and allied health professionals since 1989. This program is being reviewed with plans to extend the program to the metropolitan areas as part of the State's Diabetes Strategic Plan.
- The Cairns Diabetes Centre in Queensland is using the National Diabetes Outcomes Quality Review Initiative (NDOQRIN) minimum dataset to educate hospital staff about early detection of complications. Negotiation is underway for the forms to be provided to GPs.
- The Northern Territory's Chronic Disease Network will facilitate information exchange among professionals dealing with chronic illness (eg NHF, Diabetes Australia, Territory Health Services). Victoria has established a similar network.

Current activity at national and State/Territory levels

- The National Diabetes Footcare Network has two foot care projects funded by the Commonwealth through the Ministerial Advisory Committee on Diabetes. Royal Prince Alfred Hospital in Sydney has a program for health professionals on the management of diabetic foot problems, in particular ulcers and other acute problems. A high-risk foot service has been established at Liverpool Hospital and a training program in the management of ulcers and other complications has been started. A number of diabetes services have joined the program and some have attended the training sessions.
- In partnership with the Australian Podiatry Council, the NADC has established the National Diabetes Footcare Project, a training program in foot examination and care, in particular the identification of the high-risk foot, for non-diabetes specialist health professionals. This program is supported by a training package which is currently being piloted in a number of locations. It is envisaged that the project will be implemented throughout Australia from mid 1999.
- A national pilot implementing the measurement of diabetes nursing practice by peer review against standard performance indicators is being conducted in South Australia, funded by a National Diabetes Australia Research Trust Grant. Results will be available in June 1999, and it is envisaged that the Australian Diabetes Educators' Association will consider including the performance indicators and peer review process in its National Accreditation Criteria.

Information systems

Quality information is required for the prevention, early detection and management of diabetes. Information is required at several levels:

- at the policy level to inform program design and management of resources;
- at the clinical service level to facilitate evidence-based treatment; and
- at the service management level to evaluate the overall efficiency and effectiveness of services provided.

As the statistical information presented in the Overview and in the appendixes indicates, there is a range of diabetes-related data gathering activity in Australia, most of which relates to diabetes mortality, hospitalisation and self-reported disease prevalence. Recently, some information has also been collected on the clinical and risk factor profiles of people with diabetes. However, a mapping of these activities to the NHIMG Health Outcomes Framework (described in Chapter 2) shows that there are wide gaps in the information required for targeted surveillance of diabetes in Australia.

Major data sources and data collection activities

Nationally, public health monitoring of diabetes uses data from routine administrative collections, regular and ad hoc population surveys, disease registers and developmental activities (Table 4.5). Structures and procedures for handling ethical, confidentiality and privacy issues are also an integral part of the data environment. For further details on these activities, see Appendix 2.

Current activity in prevention, early detection and management

Table 4.5: Diabetes-related current and planned national or quasi-national data development activities

<p>Administrative data sources</p> <ul style="list-style-type: none"> • National Mortality Database • National Hospital Morbidity Database • Pharmaceutical Benefits Scheme Database • Medical Benefits Scheme Database • Department of Veterans' Affairs Medical Benefits Database • National Perinatal Data Collections • Census data • Population projections • Population estimates • National Diabetic Services Scheme <p>Population clinical-based surveys</p> <ul style="list-style-type: none"> • National Health Survey • National Nutrition Survey • Disability, Ageing and Carers Surveys • National Aboriginal and Torres Strait Islander Surveys • NHF Risk Factor Prevalence Surveys • Bettering the Evaluation And Care of Health • National Association of Diabetes Centres project • Integration SERU Survey • National Diabetes Prevalence pilot study 	<p>Registers</p> <ul style="list-style-type: none"> • National Death Index • Australia and New Zealand Dialysis and Transplantation Registry • National Insulin-Treated Diabetes Register <p>Developmental activities</p> <ul style="list-style-type: none"> • Indicators for diabetes monitoring • Record linkage • Data definitions and standards • National Biomedical Risk Factor Prevalence Survey • National Public Health Information Development Plan • Burden of disease including costs • National Aboriginal and Torres Strait Islander Health Information Plan • National Diabetes Monitoring System • NDOQRIN • Diab-Net and Diab-Code (developed through NSW Integrated Care Pilot)
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Data gaps and deficiencies

Despite this range of data-related activities, there are no reliable national estimates of the incidence and prevalence of diabetes, its risk factors and its complications in Australia. In the absence of relevant information, evaluation of the effectiveness of diabetes prevention, early detection and management does not occur. In addition, there is no national strategy for the dissemination of information to consumers and stakeholders.

Several different factors have contributed to this situation:

- There is no nationally applicable framework within which diabetes-related information is collected, collated, managed, analysed and disseminated.
- Different collections cover varying aspects of the disease. Incomparability of the information collected by various agencies does not allow a clear assessment of the impact of diabetes in the community.
- Diabetes does not figure prominently in health statistics as a cause of mortality, morbidity and disability. This is mainly because it tends to be seen as a risk factor contributing to other diagnoses rather than being identified as a cause of events.
- Diabetes continues to be an evolving diagnosis. WHO and American Diabetes Association (ADA) classifications have lately tended to bring some stability and consensus on criteria for the diagnosis of diabetes.

Current activity at national and State/Territory levels

- The diagnosis of diabetes involves the collection of a blood sample, using the oral glucose tolerance test or fasting blood glucose. Agencies conducting population surveys are however reluctant to include the collection of a blood sample, because blood collection and analysis costs are often prohibitive, and the collection of a blood sample may have an impact upon other aspects of the survey, in particular the response rate.
- Most of the available information on diabetes prevalence is self reported; however, this type of information has several limitations. As well as being under-reported, diabetes remains undiagnosed in a large proportion of people with Type 2 diabetes.
- The system does not have the capacity to measure the extent and impact of health-promoting lifestyles that are increasingly a focus of diabetes prevention and management.

In addition to the above-mentioned gaps and deficiencies, existing health information systems are not integrated sufficiently to permit a person-based, disease focus approach.

Priorities for diabetes data development

The following priorities in data development need to be addressed:

- data that are not currently collected nationally, or cannot be aggregated to generate a national picture; and
- the process for handling existing national data to enable extraction of information suitable for diabetes monitoring and surveillance.

The first priority relates mostly to information content, and includes:

- data on disease incidence and prevalence — there is an urgent need for a national risk factor prevalence survey which includes taking blood samples from participants, and which collects information relevant to all NHPAs;
- population-based and clinic-based data on diabetes risk factors and complications;
- information on patient compliance to prescribed treatment and management in socio-economic context; and
- extension of the National Diabetes Register to cover all cases of diabetes.

Priorities in relation to the management and handling of information include:

- value-added analysis and effective dissemination;
- improved recording of diabetes on hospital discharge and death certificates;
- standardised data elements and indicators;
- better information on diabetes comorbidity;
- integrated care through linking records;
- sentinel surveillance networks; and
- improved methodologies for making small area estimates from the national data.

Current activity in prevention, early detection and management

Several of the above priorities can be addressed through the development of an information development plan, and a national monitoring and surveillance system. Currently, the AIHW is developing a National Diabetes Monitoring System to collect and analyse data, disseminate data to public health programs, and regularly evaluate the effectiveness of the disseminated data.

Research and development

Health care is a knowledge-based industry that needs to invest in research and development to continue to improve the quality of preventive efforts, care and ultimately health outcomes. Research has increased our understanding of diabetes, its risk factors and effective treatments to control the disease and delay the onset of complications. Research needs to be continued to ensure progress is made towards a cure, as well as further improving prevention and management interventions. This should occur across the spectrum of research efforts, including epidemiology, behavioural, health system, biomedical and clinical.

Medical research

The main source of funding for medical research in Australia is the NHMRC. Funding of research into diabetes and other NHPAs by NHMRC is given below.

Table 4.6: NHMRC funding for research in NHPAs — actual expenditure and percentage of total expenditure

Year	Injury		Mental health		Cardiovascular		Cancer		Diabetes		Total \$m
	\$m	%	\$m	%	\$m	%	\$m	%	\$m	%	
1995	2.00	1.5	17.89	13.6	24.86	19.0	13.74	10.5	3.06	2.3	131.15
1996	2.37	1.5	10.69	14.3	26.73	18.4	16.13	11.1	3.07	2.1	145.20
1997	2.35	1.6	22.95	15.2	29.70	19.7	17.57	11.7	3.61	2.4	150.75
1998	4.08	2.6	25.40	16.4	30.10	19.4	21.60	13.9	4.20	2.7	154.70

Note: These figures are based on NHMRC and RADGAC funding and also include pro-rata expenditure estimates of relevant research done in NHMRC-funded research institutes where appropriate.

Source: Office of NHMRC.

Apart from the NHMRC, the main sources for diabetes research support are the Juvenile Diabetes Foundation Australia, Diabetes Australia (through the Diabetes Australia Research Trust, the Western Australian Research Fund and the Kellion Foundation) and various pharmaceutical companies.

The Juvenile Diabetes Foundation Australia supports research to find a cure for diabetes, advance therapy and prevent complications. Grants are provided on the cause of Type 1 diabetes and diabetes-related complications, prevention of diabetes through identifying a cure, optimising glucose levels, and avoidance and reversal of complications. In 1998–99, 27 grants were awarded by the Foundation totalling over \$4 million.

Current activity at national and State/Territory levels

The Menzies Centre in Hobart is funded through the support of the University of Tasmania, State and Federal Governments and the Menzies Foundation, with additional funding provided by other government bodies, research grants and commercial contractual agreements. The Menzies Centre collaborates with the International Diabetes Institute on the Diabetes Register in Tasmania.

Two innovative diabetes research projects with direct clinical applications are screening for diabetic retinopathy using non-mydratic retinal photography and the Melbourne Visual Impairment Project. In the former, a community-based screening service was offered to people with known diabetes over a four to five week period in selected townships in the Latrobe and Goulburn Valleys, resulting in the testing of 1,177 people, an estimated 40 per cent of the known diabetes population. This study demonstrated the usefulness of a screening program with non-mydratic retinal photography as an adjunct to current eye care services for the early detection of diabetic retinopathy. This study was conducted by the University of Melbourne Ophthalmology Department and the Royal Victorian Eye and Ear Hospital.

The Melbourne Visual Impairment Project was a population-based study of eye disease in a representative sample of Melbourne residents, 40 years or older, which investigated the use of eye care services by people with and without diabetes. The conclusions from this study were that nearly half of the people with diabetes in Melbourne were not receiving adequate screening or follow-up for diabetic retinopathy.

States and Territories have identified a number of priorities for diabetes research. These include:

- research to enable monitoring of the true prevalence of diabetes;
- a better understanding of the interaction of diabetes risk factors to guide strategy development; and
- effective education and support strategies (eg patient-centred approaches).

Basic and applied medical research into the causes and prevention of diabetes have also been noted as important by jurisdictions.

Research into prevention and early detection

Many primary prevention strategies are currently consensus based. Increasing the effectiveness of these strategies and ensuring value for money within competitive funding scenarios will require evidence that can only be gathered through an increased or refocused investment in research and development. Research for primary prevention needs to be focused on formative research and program evaluation to enhance capacity to generate and demonstrate evidence-based strategies. For instance, research could focus on models of effective collaboration across service providers and sectors. Strategy dissemination will further enhance the effectiveness of primary prevention. These issues are being addressed by the various working parties of the NPHP.

Research is needed on the design of early detection programs, including diagnostic criteria, target groups, screening schedule and follow-up requirements which will result in the cost-effective early detection of diabetes. A cost-effectiveness analysis of early detection has been funded by the Victorian Health Department.

Current activity in prevention, early detection and management

Key points — Current activity in prevention

- Guideline development in Australia has focused on clinical practice, and there are few guidelines outlining evidence-based best practice in primary prevention.
- The National Public Health Partnership and National Primary Prevention Strategy should have a significant impact on diabetes prevention within the wider context of public health.
- In States and Territories, lifestyle or risk factor approaches are being partnered by strategies which focus on the environmental settings in which people live and work, and national initiatives are being implemented within a settings framework.
- Awareness of diabetes in the community needs to be raised. The National Community Awareness of Diabetes Campaign will seek to inform the general population about the impact of diabetes and its risk factors and encourage healthier lifestyles in the general population.
- There should be greater involvement of GPs and other health professionals in primary prevention activities.

Key points — Current activity in early detection

- The need to raise public awareness of the importance of early detection of diabetes and its complications should be taken into account in the development and implementation of the National Community Awareness of Diabetes Campaign.
- In order to improve rates of detection among health professionals, guidelines on screening and detection should be implemented, as well as education programs to ensure that GPs are equipped to diagnose and refer people attending for diabetes screening and follow-up as a result of awareness-raising campaigns.

Key points — Current activity in management

- There is a range of national and State/Territory guidelines on management of diabetes, and more are being developed. To be most effective, guidelines should involve key organisations and individuals in their development, and have specific mechanisms for dissemination and implementation. Their uptake should be evaluated, and their content reviewed and updated regularly.
- The National Divisions Diabetes Program is a coordinated national approach to diabetes care in Australian general practice, designed to facilitate the implementation and evaluation of best-practice diabetes care through GPs and Divisions of General Practice, working in collaboration with diabetes care providers and organisations.
- There is a growing move towards models of care in which increased collaboration between services and new approaches to funding promote seamless long-term care of people with diabetes. Two examples of such models are the Integrated Care Pilots in New South Wales and the Coordinated Care Trials in a number of jurisdictions.
- All States and Territories are currently reviewing diabetes service delivery. These reviews involve diabetes service providers, including GPs and allied health professionals. A number of States are also establishing benchmarks and prioritisation criteria for allied health services, and minimum standards for services.
- There is a need for collaborative diabetes services to be provided within hospitals. Currently, many people with diabetes who are admitted to hospital with another condition are not identified to the hospital diabetes team.
- At the State and Territory level, there is a growing movement towards informing patients of their rights and empowering clients to demand evidence-based care. The lack of resources to provide education, let alone conduct more innovative patient-centred approaches to education, is seen as a key issue by health service providers.
- Sharing of information, changing funding to increase sustainability of programs, investigation of decision-support systems across organisations and sustainable and effective continuing education are seen as important mechanisms to increase health professionals' participation in diabetes programs.

Current activity in prevention, early detection and management

Key points — Current activity in information systems

- There is a range of diabetes-related data gathering activities in Australia, most of which relate to diabetes mortality, hospitalisation and self-reported disease prevalence. However, there are wide gaps in knowledge, and information on diabetes is required at several levels:
 - at the policy level to inform program design and management of resources;
 - at the clinical service level to facilitate evidence-based treatment; and
 - at the service management level to evaluate the overall efficiency and effectiveness of services provided.

Key points — Current activity in research and development

- Research has increased our understanding of diabetes, its risk factors and effective treatments to control the disease and delay the onset of complications. Research needs to be continued to ensure progress is made towards a cure, as well as further improving prevention and management interventions.

5 Special population groups

The specific management problems of pregnant women who develop gestational diabetes or have pre-existing diabetes, and of young people with Type 1 diabetes, are discussed in this chapter. The special needs of populations such as Indigenous Australians, rural and remote area residents, people from culturally and linguistically diverse backgrounds and older Australians are also considered. Key national and jurisdictional activity to address the needs of these special groups is discussed. Again, it should be noted that this is neither a systematic review nor a comprehensive record of initiatives in diabetes. It is a summary that gives an indication of some of the key initiatives being undertaken across the nation.

5.1 Gestational diabetes and diabetes in pregnancy

Diabetes is a high-risk state for both mother and unborn child, and gestational diabetes increases the risk of the woman developing diabetes following pregnancy.

There are three major reasons for focusing on gestational diabetes.

- *The effects of gestational diabetes on birthing interventions and perinatal morbidity and mortality.* Studies have shown an association between gestational diabetes and increased perinatal morbidity and mortality (eg Beischer et al 1996). However, it is unclear whether this association is confounded by other variables (eg age, obesity, poor past obstetric history, ethnicity). In addition, many studies have reported that women who are labelled as having gestational diabetes have higher birthing intervention rates, although the situation in Australia is unclear.
- *The effects of gestational diabetes on childhood development.* Children from a pregnancy complicated by gestational diabetes have an increased risk of obesity and the early development of impaired glucose tolerance and Type 2 diabetes (Silverman et al 1995; Plagemann et al 1997).
- *The effects of gestational diabetes on future maternal risk of developing Type 2 diabetes.* There is a 6–10 fold increase in the risk of developing diabetes in the two decades following the index pregnancy (Oats 1997).

High glucose levels in pregnant women with established Type 1 diabetes are associated with increased risk of miscarriage and congenital malformations (Hanson et al 1990), while timely institution of intensive therapy can reduce this risk (DCCT Research Group 1996b). Pre-pregnancy counselling to encourage improved diabetes control is therefore a way of reducing the risk of poor pregnancy outcomes.

Current activity

Guidelines

In 1998, the Australasian Diabetes in Pregnancy Society published guidelines for the management of diabetes during pregnancy, screening for gestational diabetes and the follow-up of women who have had a gestational diabetes pregnancy (Hoffman et al 1998). Most jurisdictions intend to adopt the guidelines and closely monitor outcomes.

Special population groups

The RACGP has provided guidelines to GPs which include the management of women with gestational diabetes, as well as related issues such as contraception and hormone replacement therapy (RACGP 1998c).

It should be noted that in New South Wales, the Expert Working Group for Diabetes could not reach consensus on guidelines for women with gestational diabetes.

Service collaboration

Collaborative action on the services provided to pregnant women who have diabetes and follow-up services for women who have had gestational diabetes is being considered in the State-wide diabetes planning exercises in progress in all jurisdictions. The introduction in November 1998 of a new Medicare item for gestational diabetes should facilitate this process.

Coordinated care occurs within major tertiary hospitals and shared-care antenatal care arrangements are commonplace. The Mercy Hospital in Victoria is conducting its own follow-up study program for women who have had gestational diabetes. However, there is no systematic collaboration with GPs for the follow-up of women who have had gestational diabetes.

The lack of a systematic approach to follow-up reflects disagreement within and across jurisdictions on cost-effective models (eg method, frequency of screening).

Client and provider focus

Key issues across all jurisdictions in promoting a client focus include:

- pre-pregnancy counselling for women who have diabetes — across jurisdictions, only about a third of women with diabetes attend pre-pregnancy counselling;
- education on optimal management of diabetes during pregnancy — lack of access to dietitians and diabetes educators is a barrier;
- the pivotal role of bilingual GPs in caring for women with limited English; and
- education on increased risk of developing Type 2 diabetes following gestational diabetes. This information is not systematically provided across jurisdictions. Some hospitals have systems in place to remind women about their increased risk but there are no links with GPs to determine the effectiveness of these strategies.

Little systematic education and training of GPs occurs on the management and follow-up of women who have had a gestational diabetes pregnancy. Automated reminders to women who have gestational diabetes may assist GPs in screening this high-risk population.

Information systems

There is support for agreement on recall mechanisms for women who have had gestational diabetes. Several jurisdictions have considered and decided against linking recall to the Cervical Cancer Registry. The role of pathology laboratories in recall systems needs to be explored.

Gestational diabetes and diabetes in pregnancy

The need for improved information on the incidence and prevalence of gestational diabetes is being considered in many jurisdictions. Currently, databases exist in the Australian Capital Territory (50 per cent capture since 1991), at the Mater Hospital in Brisbane since 1994, in New South Wales (Wollongong) and in Victoria (Mercy Hospital, 1971–1996).

Research and development

The area of gestational diabetes requires research. Of particular importance is the area of mild hyperglycaemia in pregnancy and associated health outcomes for the mother and baby. This may have significant potential to reduce unnecessary maternal and neonatal morbidity.

A number of specific research projects are of relevance to this area, including:

- the Hyperglycaemia and Adverse Perinatal Outcome Study, which aims to examine the relationship between glucose tolerance during pregnancy and maternal and perinatal outcomes;
- the Victorian gestational diabetes study, which uses a combination of information provided to the Perinatal Data Collection by midwives and the Victorian Inpatient Minimum Dataset to determine the incidence of gestational diabetes in Victoria, women at risk of gestational diabetes and adverse maternal and child outcomes;
- the Royal Women's Hospital Gestational Diabetes Study, which aims to compare the effects of 'normal obstetric' versus 'conventional gestational diabetes' management in approximately 300 women with newly diagnosed gestational diabetes on maternal and foetal outcomes; and
- the Australian Carbohydrate Intolerance in Pregnancy Study, which will study the effects on the mother and baby of active management and treatment of glucose intolerance during pregnancy.

Key points — Gestational diabetes and diabetes in pregnancy

- Review of the services provided to pregnant women who have diabetes and follow-up services for women who have gestational diabetes is being considered in the State-wide diabetes planning exercises in progress in all jurisdictions.
- While coordinated care of women who have gestational diabetes occurs within hospitals, there is no systematic collaboration with GPs for the follow-up of women or education about their increased risk.
- There is support for jurisdictional agreement on recall mechanisms for women who have had gestational diabetes. Automated reminders to women who have gestational diabetes may assist GPs in screening this high-risk population.
- Pre-pregnancy counselling for women with diabetes, to encourage improved glucose control during pregnancy, is likely to reduce the risk of adverse outcomes for both mother and baby.

5.2 Type 1 diabetes in young people

Optimising diabetes control among children and adolescents with diabetes may be more difficult than among adults, as children and adolescents have a number of additional challenges including erratic eating patterns, the tendency to get four to six viral illnesses each year, and hormonal changes associated with growth spurts and pubertal development. The psychological effects of diabetes and the need for constant monitoring may be difficult for children and adolescents. Early results of an assessment of needs by the Juvenile Diabetes Foundation Australia highlight the lack of psychological support and counselling for children with diabetes and their families.

The difficulty in achieving glycaemic control is shown by the rate of severe hypoglycaemia in children and adolescents which is almost twice that of adults and young children (Colagiuri et al 1998). Although the DCCT data did not include children under 13 years, the findings allude to the importance of good control and the regular assessment of HbA_{1c} to delay the onset of complications and enhance the quality of life for children and adolescents with Type 1 diabetes.

Continuing research into identification of those likely to develop Type 1 diabetes is needed, along with initiatives to improve the quality of and access to clinical services.

Current activity

The Commonwealth has funded a national needs assessment for children and adolescents with Type 1 diabetes. The Juvenile Diabetes Foundation Australia is leading this project and aims to identify gaps in current service delivery, unmet needs (beyond clinical care) and strategies to improve diabetes care for young people.

Guidelines

Guidelines are available for the management of children and adolescents with Type 1 diabetes, developed by the Australasian Paediatric Endocrine Group (Silink 1996). Hospital-based protocols consistent with these guidelines have been developed in most States and Territories. New South Wales has produced guidelines on management of paediatric diabetes (NSW Health Department 1996g).

Service collaboration

A specialist team approach to Type 1 diabetes is taken in the urban areas of all jurisdictions except the Northern Territory. In rural and remote areas (and especially in the Northern Territory), GPs may be the main carers of children and adolescent with Type 1 diabetes. Insufficient staff resources limit efficient role delineation of the various allied health providers in both urban and rural and remote areas.

An innovative model of service delivery in metropolitan areas is in place in South Australia, where paediatric nurses employed by the Royal District Nursing Society visit children with Type 1 diabetes in their homes and at school. These one-on-one visits have been associated with significantly reduced hospital admissions (Dr J Couper, personal communication). This model should be examined for wider

application. In Tasmania, Diabetes Nurse educators regularly visit schools and homes to educate staff and carers in the management of children with Type 1 diabetes. This is in addition to the visits that occur at the time of diagnosis.

Transition from paediatric to adult care is an important issue. The lack of clear transition paths from paediatric hospitals to adult hospitals results in some young people not having blood glucose control monitored and not being screened for complications.

Client focus

Currently, diabetes is not included as a manifest disabling condition eligible for the Childhood Disability Allowance. The current status of the Childhood Disability Allowance in relation to children with Type 1 diabetes is being reviewed, as is the possibility of automatic access of children with Type 1 diabetes to health care cards. There is strong stakeholder support for Type 1 diabetes to be included as a manifest disabling condition for children under six years of age and for all children with Type 1 diabetes under the age of 16 years to have access to a health care card. This is essential, as young people with diabetes quickly learn to associate 'cost' with services and supplies and may use this imperative to reduce their self testing and management.

At the State/Territory level, there is a strong focus on providing education to patients and their families on the management of the disease and its impact on lifestyle, in many cases in partnership with Diabetes Australia and the Juvenile Diabetes Foundation Australia (eg conducting children's camps). However, limited staff resources limit access to this education, a significant proportion of which is currently provided out of hours on a voluntary basis by committed health professionals.

Provider focus

Tertiary centres have varying levels of access to professionals trained in behavioural change techniques. This is critical for managing Type 1 diabetes in children, as the disease has an impact on the whole family.

Generally, outreach education for providers is conducted across Australia, but less so in rural and remote areas. However, New South Wales and South Australia have very strong rural and remote outreach services. Training for GPs (who may manage children) is done on a voluntary basis. In some cases this is only possible with the support of pharmaceutical companies.

Undergraduate training of medical students in the management of Type 1 diabetes is seen as important. Continuing education could occur through the Postgraduate Family Medicine Program.

Multimedia is being used in Queensland for decision support and networking. State-wide teleconferences of allied health professionals and paediatricians involve discussion of the management of children with Type 1 diabetes. Telenetworking through the tele-paediatric network is sponsored by Queensland Health.

Special population groups

Information and research

Australasian Paediatric Endocrine Group Registers are either established or being established in most States. The Tasmanian Diabetes Register for people who are treated with insulin includes young people with Type 1 diabetes. Data for the Northern Territory and the Australian Capital Territory are included in the Queensland and New South Wales Registers.

These registers cover the age group 0–15 years, and vary in the type of information collected. Data on complications are collected by major tertiary hospitals in most States. A significant amount of data are paper based, resulting in difficulties conducting outcomes analyses.

The current research focus includes:

- the prevention and cure of Type 1 diabetes;
- complications prevention and reduction;
- reducing the impact of diabetes on quality of life;
- developing non-invasive blood glucose monitoring technology;
- developing non-invasive insulin delivery for Type 1 diabetes; and
- improving monitoring to detect and prevent severe hypoglycaemia.

Key points — Type 1 diabetes in young people

- The Commonwealth national needs assessment for children and adolescents with Type 1 diabetes, being led by the Juvenile Diabetes Foundation Australia, aims to identify gaps in current service delivery and strategies to improve diabetes care for young people.
- A specialist team approach to Type 1 diabetes is taken in the urban areas of most jurisdictions. In rural and remote areas, GPs may be the main carers of children and adolescent with Type 1 diabetes, and need skills in detection and management of diabetes in this group.
- Innovative models of service delivery in some States have reduced hospital admissions and improved management. Rural and remote outreach/shared care services, including complications screening programs, need adequate funding and infrastructure to be effective.
- The lack of clear transition paths from paediatric hospitals to adult hospitals results in some young people not having adequate management and screening for complications.
- Limited staff resources restrict access to adequate education and support for young people and their families.

5.3 Indigenous populations

A major barrier to improving diabetes care for Indigenous populations is limited availability and access to necessary and culturally appropriate health care. There are a number of inter-related factors that contribute to persistent poor health among Indigenous people. The relationship between these factors is complex and current evidence does not allow an assessment of the relative importance of each factor. These include:

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

Issues specific to diabetes prevention and management among Indigenous people include:

- available information on community prevalence and incidence of diabetes, its complications and risk factors is fragmented;
- there is high staff turnover and low skill levels among diabetes staff;
- there is a shortage of specialist staff in rural and remote areas, and problems with Patient Assistance Travel Schemes;
- not enough Aboriginal Health Workers are being trained in diabetes education;
- there is no agreement on role delineation and referral criteria, particularly in regard to the services that Aboriginal Health Workers can provide;
- there is a lack of available equipment to monitor the quality of diabetes care and the development of diabetes-related complications (eg fundus cameras, DCA 2000 analysers);
- there is limited access to accessible dialysis and renal transplantation for Indigenous Australians (particularly in rural and remote areas); and
- stand-alone health promotion is not linked with NACCHO primary health care service delivery.

Current activity

Guidelines

Two systematic reviews were undertaken by the Commonwealth Department of Health and Family Services in 1997 on the prevention and management of Type 2 diabetes in Aboriginal and Torres Strait Islander populations (Kimberley Aboriginal Medical Services Council 1997 [referred to as the OATSIH guidelines]). A set of recommendations for clinical care guidelines for the prevention and management of Type 2 diabetes has been extracted from the reviews and widely

Special population groups

disseminated (Kimberley Aboriginal Medical Services Council 1998). Programs to facilitate the uptake of these recommendations through the development of local diabetes plans are currently in progress through the ACCOs.

Queensland Health is developing a Chronic Disease Strategy for Indigenous people, based on the recommendations of the systematic reviews. Queensland is also implementing components of the Strategic Plan for Diabetes in the Torres Strait.

In the Northern Territory, as part of the Coordinated Care Trial, evidence-based guidelines are being developed on the management of chronic diseases in remote Aboriginal communities. The guidelines will be implemented in all Top End Aboriginal communities. Key strategies include linking guidelines to a computerised patient record system and/or paper recall systems, training bush staff in the use of guidelines, supporting staff to improve local programs for screening and case management, and developing guidelines for patients on the care that they expect to be provided by health staff.

Service collaboration

Systematic and coordinated primary health care is essential to improve the health of Indigenous Australians.

National activity

A National Indigenous Nutrition Strategy is being developed as a component of the National Public Health Nutrition Strategy.

The Commonwealth Government has developed a strategic framework for improving Indigenous health outcomes through the support of primary health care services. As many Indigenous people seek health care from community-controlled organisations, the Commonwealth is seeking to coordinate national initiatives with NACCHO (as shown by the recent funding of a national diabetes/nutrition coordinator).

Indigenous people with diabetes are highly likely to have other coexisting conditions. Service providers require incentives to provide longer consultations, such as through the Practice Incentives Program. The South Australian Coordinated Care Trial's tiered payment system for managing complex cases should be examined in relation to Indigenous services.

State/Territory activity

At the State/Territory level, progress is varied.

- In New South Wales, there is a partnership approach where the rights of Indigenous people to self determination are acknowledged. The approach will allow Aboriginal people to determine what diabetes services are required and how those services should be configured and delivered.
- In Victoria, the Koori Diabetes Services and the International Diabetes Institute have developed a resource for health workers working with Koori people with diabetes, *Diabetes — it's in Your Hands*, which includes a poster, video, leaflets and the book, *Health Worker Manual* (Vickery et al 1998). This will be provided to the health workers who complete the 'train the trainer' program conducted by the International Diabetes Institute and Koori Diabetes Services. The community information leaflet is provided to the individual with diabetes and contains information about diabetes to empower them to manage their condition. At Rumbalara Aboriginal Coop Ltd in Mooroopna, a diabetes screening program linked with eye health is coordinated by trained Aboriginal health workers.

- In Queensland, the Strategic Plan for Diabetes in Torres Strait Islanders is being implemented and there is a Well Person's Check for Indigenous people in far north Queensland. Local collaborative planning teams are being developed which involve Aboriginal service providers. A collaborative approach to the acute treatment of Indigenous people with diabetes is being developed with the Queensland Ambulance Service.
- In South Australia and Tasmania, Indigenous diabetes services are in the planning stages. The inclusion of Indigenous-specific performance indicators in hospital funding agreements in South Australia should facilitate greater collaboration between hospital and Indigenous-specific services. Similarly, the framework agreements on Aboriginal Health and collaborative planning processes in Tasmania should facilitate effective planning and service delivery.
- The Perth Aboriginal Medical Service provides a comprehensive diabetes clinic using a multidisciplinary team from nearby mainstream services. The Kimberley Aboriginal Medical Services Council in Western Australia has undertaken a systematic review of the primary care management of important Aboriginal health problems including diabetes (Couzos & Murray, in press). This also formed the basis for a clinic computerised recall program. The diabetes chapter was further developed in the OATSIH Systematic Review (Kimberley Aboriginal Medical Services Council 1997), together with recommendations for local guideline development (Kimberley Aboriginal Medical Services Council 1998), and has been disseminated nationally to ACCOs.

Client focus

There are two important aspects to client focus for Indigenous people — access to services and access to information about diabetes and its evidence-based management.

An example of the importance of access to services is the availability and appropriateness of Patient Assisted Transport Schemes for Indigenous people. These schemes provide an important mechanism to overcome problems of distance for Indigenous people seeking specialist services such as dialysis, and should assist in maintaining their links with their families who remain in remote Aboriginal communities. These issues are critical to the acceptance and outcome of Indigenous people receiving care for diseases such as end-stage renal disease (Couzos & Murray, in press).

At the State and Territory level, a focus on increasing the awareness of diabetes and its management is undertaken in a project-based manner (eg the community programs undertaken by the Koori Diabetes Service in Victoria).

The ACCO involved in the New South Wales Integrated Care Trial has developed an innovative client focus strategy of a board game which tests diabetes management knowledge. It has also established a food cooperative that provides cheap fruit and vegetables for clients which can be picked up from the diabetes clinic. The approach taken in the Northern Territory as a part of the Coordinated Care Trial and the Chronic Disease Strategy is to focus on risk factors. This is based on qualitative research conducted with Aboriginal communities.

Special population groups

The following projects address these aspects of client focus:

- The Townsville Aboriginal and Islander Community Health Service has a diabetes support group facilitated by the Aboriginal health worker who provides the service for a diabetes clinic once per week.
- Durri Aboriginal Medical Service, Kempsey, New South Wales, is one of the few ACCOs that have an accredited Indigenous diabetes educator. There are various integrated health promotion activities, and education is provided to local schools and TAFE Colleges on healthy lifestyle and specific diabetes issues.
- In South Australia, work is underway with Tandanya (the National Aboriginal Cultural Institute) to develop a culturally specific communication tool to raise awareness of diabetes in Indigenous communities.
- Kimberley Aboriginal Medical Services Council, Western Australia, educates those with diabetes and families on the management of diabetes, the health checks required and healthy lifestyle through a play 'Change of Heart', which explores diabetes in Aboriginal people, attitudes, fears and complications.

Provider focus

The role of Aboriginal health workers, their training and their payment is a key issue. All jurisdictions have limited access to Aboriginal health workers trained in diabetes education. The Commonwealth is investigating how to increase opportunities for Aboriginal health worker training in diabetes prevention and management. There is a need to back fill positions to allow Aboriginal health workers to access training.

Aboriginal health workers must have ready access to the advice of allied health carers (podiatry, dietary advice, physiotherapy), as well as physicians and surgeons and links with hospitals through Aboriginal liaison officers. There is some evidence of decision-support systems in jurisdictions, with diabetologists visiting ACCOs to provide clinical support and Aboriginal health worker training. However, these systems are not occurring in all ACCOs. The model used in New South Wales should be expanded.

The National Divisions Diabetes Program includes an optional module on working with Indigenous populations. The module draws on existing work within the field, and provides a starting point for other Divisions working with their local ACCOs.

A CD-ROM has been developed by the Kimberley Aboriginal Medical Services Council School of Health Studies for Aboriginal health worker basic training, which includes diabetes care.

Information systems

There is a need for improved identification of Indigenous people with diabetes across health settings, particularly in hospitals.

ACCOs should be provided with and/or retain skills in data analysis as well as in data collection. If data can be analysed at the local level, they are more likely to be used in providing feedback to the community, patients and service providers.

The establishment of local recall systems is recommended by the systematic reviews of diabetes management and will be supported at the Commonwealth level. Currently, patient recall does not occur systematically across jurisdictions.

The ACCOs in Tennant Creek, Western Sydney, Broome, Kununurra, Halls Creek, Wilcannia, Gibb River, Townsville and Oenpelli have computerised information management and preventive care delivery. Primary health care patient management incorporates opportunistic recall of preventive interventions at every clinic encounter, through a customised computerised recall program, in addition to periodic health examinations. In this way, the patient receives the care required for their presenting complaint as well as the care required to manage their diabetes. The process is acceptable to staff and patients, sustainable and low in cost.

Research and development

A strategic research agenda for Indigenous health is being progressed through the NHMRC in conjunction with OATSIH. Given the high prevalence rates of diabetes and its complications among Indigenous people, there is a clear need to prioritise research on effective preventive strategies for Indigenous people and diabetes is one of the first issues being considered through this systematic process.

Key points — Indigenous peoples

- Clinical management guidelines for the prevention and management of Type 2 diabetes among Indigenous Australians have been developed. Programs to facilitate the uptake of its recommendations through the development of local diabetes plans are currently in progress through the ACCOs.
- Systematic and coordinated primary health care is essential to improve the health of Indigenous Australians. This is being progressed at national and State/Territory level.
- Two important issues are access to services and access to information about diabetes and its evidence-based management. The availability and appropriateness of Patient Assisted Transport Schemes for Indigenous people should be considered. At the State and Territory level, a focus on increasing the awareness of diabetes and its management is undertaken in a project-based manner.
- A key issue, especially in rural and remote areas, is the role of Aboriginal health workers, their training and their payment. At present, there is limited access to diabetes education for Aboriginal health workers.
- The establishment of local recall systems is recommended by systematic reviews of diabetes management and will be supported at the Commonwealth level. Currently, patient recall does not occur systematically across jurisdictions.

5.4 Rural and remote area populations

The disadvantages facing people living in these areas in gaining access to adequate and appropriate health care have been largely identified (Strong et al 1998b) and include:

- distance;
- shortage of health professionals and inadequate training;
- poor economic infrastructure;
- continuing logistical and communication problems;
- fewer or less comprehensive hospital services and other local health services that are inadequate to meet the needs of the population;
- difficulties with intersectoral coordination;
- financial pressures and decreasing services;
- unemployment; and
- lifestyle and cultural attitudes towards health (Fitzpatrick & Manderson 1995).

Retention rates of health service providers are problematic with major barriers including lack of support, skills, educational opportunities and resources and work-related stress.

Current activity

Service collaboration

Difficulties gaining access to allied health services were noted by most jurisdictions.

The concept of the local health team coordinating the care of people with diabetes is important to rural and remote practitioners. In redesigning diabetes services, referral systems must ensure that local health teams are informed of results and management plans. Community involvement in planning coordinated diabetes services is also important, as local issues and local capacity vary widely across rural and remote areas.

The South Australian Department of Human Services has developed minimum service standards for rural and remote areas. These standards resulted from a partnership approach to diabetes service provision and involved community health practitioners including ACCOs, hospital-based clinicians and Divisions of General Practice. They were developed through a collaborative process involving agreement on the model of care in terms of services required, roles of service providers and referral criteria and calculation of minimum staffing levels required to service the estimated number of people with diabetes in the local area. The standards have been funded in four rural/remote health regions, with funding decisions yet to be made in the remaining three health regions.

The South Australian Department of Human Services has seed funded diabetes prevention and health promotion projects in two rural regions. The projects are a collaboration between the community, general practitioners and multidisciplinary health service providers and focus on prevention and early detection, targeting

lifestyle issues such as overweight, physical activity and appropriate nutrition. The South Australian Women's and Children's Hospital also runs a State-wide diabetes paediatric service, sending visiting diabetes specialist medical and nursing staff to rural and remote sites, as well as training metropolitan Royal District Nursing Society staff.

In rural and remote areas of Queensland and Tasmania there is a shortage of GPs to provide primary health care services. Negotiations with the Commonwealth have enabled access by State-funded salaried medical practitioners to Medicare Benefits Scheme funded services, which has achieved equity in terms of availability of GP-type services and enabled revenue retention to enhance acute care services.

The Smithton Diabetes Clinic in north-west Tasmania has been conducted annually since 1992. It is a collaborative approach between a rural General Medical Practice, State Government and Diabetes Australia and involves bringing a comprehensive team of health professionals to Smithton for three days to assess all people with diabetes in the area. The aims of the clinic are to increase awareness and detection of diabetes in the community; improve knowledge of the nature and management of diabetes including self management; improve blood glucose control and prevent or delay complications; and improve quality of life for all people with diabetes, their carers and families.

Future planning of diabetes services should be coordinated with development of the National Rural Health Strategy and the implementation of other initiatives (eg Acting on Australia's Weight). There is strong support for incentive packages to be developed for nurses in rural and remote areas, which include increased leave and access to specialist decision support.

Client focus

Efforts are made across jurisdictions to provide people with diabetes and those at risk in rural and remote areas with information about the disease. However, workforce issues restrict this education in most areas.

The regional networks in South Australia (as discussed in Section 4.2) are a good example of client focus in rural and remote areas.

Provider focus

National activity

The Commonwealth Rural Health Education, Support and Training program supports the implementation of the National Rural Health Strategy and focuses on improving the rates of recruitment and retention of rural and remote health care workers through increased support, education and training opportunities. It also complements the objectives and strategies underpinning the Rural Incentives Program for GPs. University Departments of Rural Health are being established to provide training and support for rural health professionals and those interested in rural practice.

State/Territory activity

Outreach services are provided by all jurisdictions to some rural and remote areas. However, this is not comprehensive and there is a need for greater continuing education opportunities for service providers in rural and remote areas.

Special population groups

South Australia has provided rural health professionals with comprehensive continuing education through its Diabetes Outreach Service since 1989. The programs include CME, Regional Diabetes Education Series, audio and teleconference education in partnership with the tertiary education sector and other partners.

Diabetes Australia (New South Wales) conducts a teleconference service for service providers in rural and remote areas to assist information sharing.

Telehealth provides opportunities for provider education and is used in most jurisdictions. South Australia has embedded this technology within a systematic approach to provider education, which includes two distance learning courses and tele-tutorials. Telehealth also provides an opportunity for case consultation and management. For example, in New South Wales, the Royal Prince Alfred Hospital Diabetes Footcare Network uses digital camera images which are emailed to the centre for telephone consultation.

Providing incentives for rural and remote GPs to extend consultation times for people with or at risk of diabetes may not be effective, simply because of the number of GPs in these areas and their case loads.

The Specialist Locum Relief Program should be targeted to provide diabetes/endocrinology specialist locums and enable resident specialists to attend professional development courses.

Information systems

Information on the prevalence of diabetes and its risk factors is necessary for effective services to be planned. This information is also a prerequisite to community involvement in diabetes services.

Key points — Rural and remote area populations

- A range of disadvantages face people living in rural and remote areas in accessing adequate and appropriate health care.
- Several States have innovative rural service delivery models which involve visits to rural and remote areas by multidisciplinary health care teams. Future planning of diabetes services should be coordinated with development of the National Rural Health Strategy and the implementation of other national initiatives.
- Continuing education is being provided to health professionals in rural and remote areas through the Commonwealth Rural Health Education, Support and Training program and State/Territory outreach services. Telehealth provides opportunities for provider education and is used in most jurisdictions.

5.5 People from culturally and linguistically diverse backgrounds

People from culturally and linguistically diverse backgrounds experience disadvantages in terms of access to the range of diabetes services available (because of language barriers), access to appropriate education and information for effective self management and access to ongoing community support. It is likely that these groups suffer a high rate of diabetes-related complications because of this inadequate access to health services (McCarty et al 1996). There is a lack of data evaluating the effectiveness of diabetes care for these people.

Current activity

Service collaboration

The collaborative planning approaches in all jurisdictions recognise the need to specifically address populations of culturally and linguistically diverse backgrounds and have multicultural policy representatives on advisory committees or taskforces.

A central issue in providing effective prevention and care services to people from these populations is access to appropriate services. Western Australian data indicate that a significant proportion of immigrant populations attend tertiary-based services or GPs. The move towards collaborative models of care emphasises the role of hospital-based services for the treatment of acute conditions and community-based services for chronic illnesses. Encouraging people from immigrant populations to use community-based services in addition to their GP will be the key to the successful implementation of collaborative models of diabetes prevention and care services. Western Australia is currently conducting a needs assessment to identify appropriate service locations for people from culturally and linguistically diverse backgrounds with diabetes. A number of pilot programs will be conducted on the basis of these results, with the goals of increasing access to quality diabetes services for these people.

There is a growing recognition across jurisdictions that immigrant groups should be considered separately in the identification of health needs and in subsequent service planning. Targeting scarce resources at identified ethnic groups will maximise their effectiveness — ie primary prevention programs for newer, younger migrant groups (those from China, Malaysia, Latin America) and early detection and prevention of complications for older, more established groups (those born in Greece, Italy, India, Poland etc).

In New South Wales, strategies for people from specific backgrounds have been developed as a part of the Diabetes West NSW Health Diabetes Integrated Pilot Project in western Sydney. These strategies focus on improving access to services such as interpreter services. In Western Australia, the inner city integrated care pilot project is also seeking to address the unique diabetic needs of people from certain backgrounds.

Special population groups

Client focus

Awareness raising

Providing information to people from culturally and linguistically diverse backgrounds on diabetes, its prevention and management is essential to changing behaviours and achieving health gain. This is an area that needs urgent attention. The expense of providing specific tailored resources for the large number of different cultural groups in Australia is an obvious barrier. However, jurisdictional collaboration on this issue is occurring slowly and proving to be effective.

As with the prevention and management of diabetes among Indigenous populations, awareness raising strategies are generally conducted in an ad hoc, project-based manner (eg Western Australian swimming groups for Muslim women, establishment in Queensland of links with the ethnic food industry). The lack of sustainable funding for these projects is a barrier and their effectiveness is also hampered by the lack of attention to macro-environmental issues (eg access to safe exercise facilities, access to healthy food choices).

Access to services

In South Australia, \$1.5 million has been provided for the establishment of mechanisms for effective communication between service providers and people from culturally and linguistically diverse backgrounds. However, these funds are only available to people seeking services in the public sector, and the majority of people from such backgrounds seek advice from GPs. There is a need to increase GPs' access to and knowledge of effective use of interpreter services.

Interpreter services also facilitate the use of patient-centred techniques such as goal setting or motivational interviewing which depend on patient participation. An innovative approach to this issue is the use of interpreter services through video-conferencing technology. This approach should be examined for wider applicability. Video-conferencing is of particular benefit to immigrants in rural and remote areas who have no access to face-to-face interpreting assistance.

State-based Diabetes Australia organisations are important service providers for people with diabetes from culturally and linguistically diverse backgrounds. These organisations provide education to these people through support groups in most jurisdictions.

Provider focus

The *National Diabetes Strategy and Implementation Plan* report recommendation that health service providers receive cross-cultural training in undergraduate courses (Colagiuri et al 1998) was supported across jurisdictions but with this recommendation expanded to include continued training. One option for continuing education is the inclusion of cross-cultural training as a core component of the Family Medicine program conducted through the RACGP.

Undergraduate cross-cultural training will provide service providers with an understanding of the needs of people from different backgrounds. The continuing education will remind service providers of these needs and how to best meet them (eg through the appropriate use of interpreter services). Innovative approaches being used to increase service provider's awareness of cross-cultural issues include the establishment of community-based forums (eg New South Wales Integrated Care Trial) and the production of resource guides for GPs.

People from culturally and linguistically diverse backgrounds

Cross-cultural training should also be provided to organisations (eg hospitals, community health centres) in addition to actual service providers. Organisational commitment will support providers to implement service changes to ensure that needs are met.

While there was broad agreement that training health service providers in cross-cultural issues is vital to addressing diabetes among populations of culturally and linguistically diverse backgrounds, to be effective this training must be accompanied by increased access to interpreter services, as discussed above.

Information systems and research and development

Service collaboration activities focus on providing people from culturally and linguistically diverse backgrounds with increased access to quality health services. Monitoring this access is an important information requirement.

Computerised recall systems being established should consider the needs of people who have culturally and linguistically diverse backgrounds (and who may have low levels of English literacy).

There was support across jurisdictions for reliable and valid diabetes incidence and prevalence data among people from culturally and linguistically diverse backgrounds. This information is essential for effective planning of services to prevent diabetes and associated complications among such populations. There was also strong support for national surveys to include questions on country of birth, first language and need for interpreter assistance. South Australia is progressing this issue through its Diabetes Clearing House while New South Wales is collecting qualitative and quantitative information through focus groups and State-wide surveys.

The Commonwealth Government recently funded a three-year research project on the health needs of Chinese Australians which includes the prevention and management of diabetes (Chinese Australian Better Health Research Project).

There is a dearth of information on effective prevention and treatment strategies for the various cultural groups in Australia. Even when projects have been conducted, in many cases there has been no evaluation. A key research and development issue is for enhanced investment in research on effective diabetes prevention and care strategies for populations at risk (to prevent diabetes onset) and for populations with high health status (to maintain this status). Funding criteria for this research must include evaluation and strategies for the dissemination of results.

Key points — People from culturally and linguistically diverse backgrounds

- It is likely that people of culturally and linguistically diverse backgrounds suffer a high rate of diabetes-related complications because of inadequate access to health services (caused by language barriers) and lack of access to appropriate education and information for effective self management.
- The collaborative planning approaches in all jurisdictions recognise the need to specifically address populations of culturally and linguistically diverse backgrounds and have multicultural policy representatives on advisory committees or taskforces.

continued

Special population groups

Key points — People from culturally and linguistically diverse backgrounds (continued)

- There is a growing recognition across jurisdictions that immigrant groups should be considered separately in the identification of health needs and in subsequent service planning.
- Providing culturally appropriate information on diabetes, its prevention and management is essential to changing behaviours and achieving health gain, and is an area which needs urgent attention.
- There is a need to increase GPs' access to and knowledge of effective use of interpreter services. The use of interpreter services through video-conferencing technology should be examined for wider applicability.
- Innovative approaches being used to increase service provider's awareness of cross-cultural issues include the establishment of community-based forums and the production of resource guides for GPs.

5.6 Older Australians

Older people with diabetes may be less able to recognise and react to the warning symptoms of hypoglycaemia. If hyperglycaemia is left untreated, the risk of acute and longer term diabetes-related complications is increased. As yet there are no data from a randomised trial in older people to establish the optimal blood glucose level which maximally reduces risk of complications while minimising the risks of therapy.

Issues specific to older people, such as multiple pathology, polypharmacy, social isolation and depressed cognitive function complicate the provision of effective preventive and management services. The provision of care for people with diabetes in residential or nursing homes is often inadequate and staff may not receive the necessary training.

Patient participation in health care is difficult for older people because they are more likely to have disabilities such as impaired cognition, poor vision and hearing, and reduced mobility. Dietary changes are difficult to achieve because of the condition of mouth and teeth, transport difficulties in accessing food outlets, cost of healthy foods and lack of interest in cooking. Physical activity may be difficult due to other medical problems (eg arthritis).

Current activity

The care of older people who have diabetes involves a large range of health professionals due to the increased number of comorbidities. GPs are central to the provision of effective prevention and care services for people with diabetes and to coordinating the care provided by the various health professionals. Because of increased comorbidities, longer consultations are required for older people and incentives should be provided to encourage this change.

Older people who have chronic illnesses have better health outcomes (and higher satisfaction with the health system) if they have access to multidisciplinary clinics, well coordinated care between hospitals and local services and access to allied health services (Australian Pensioners' and Superannuants Foundation 1991).

In both nursing homes and hostels there is usually a mix of nursing and non-nursing staff, depending on the care needs of the residents. Each resident has a care plan that the Residential Care Standards require to be reviewed on a regular basis by the care team. This team includes the staff of the facility, a GP and other relevant health workers. Training of staff in providing diabetes prevention and care services is required. Alternatively, specialist assistance to staff could be provided (eg diabetes educators).

Key points — Older Australians

- Issues specific to older people, such as multiple diseases, polypharmacy, social isolation and depressed cognitive function complicate the provision of effective preventive and management services.
- GPs are central to the provision of effective prevention and care services for people with diabetes and to coordinating the care provided by the various health professionals. Because of increased comorbidities, longer consultations are required for older people.
- Nursing home staff require training in diabetes prevention and care or access to specialist assistance.

6 Opportunities and future directions

Diabetes is a common, chronic disease that contributes significantly to mortality, morbidity, disability and health costs in Australia. Both the incidence and prevalence of diabetes are on the rise and will continue to increase unless effective prevention strategies are put into place. Control of diabetes also requires improvements in early detection of people with diabetes, further improvements in the quality of diabetes care, (especially prevention programs for diabetes-related complications), and progress in patient management and recall systems. In addition, the greater burden of diabetes on Indigenous Australians and other special populations must be addressed. All of these changes will require better national information to monitor the incidence and prevalence of diabetes and a continued commitment to research into diabetes prevention and care.

As discussed in previous chapters, the diabetes field is changing rapidly, and there is already a wide range of activity in many aspects of diabetes prevention and care. Future directions in diabetes should build on this activity and recognise existing opportunities for achieving change, encourage coordination of effort where appropriate, and should focus on several unresolved issues.

This chapter outlines a number of areas in which action could improve diabetes prevention, early detection, management, monitoring and research in Australia. Within these areas, summary boxes highlight specific opportunities that have been identified in the report. There is also a discussion of more general opportunities for achieving change.

Important future directions may be summarised as follows:

- coordinating primary prevention strategies across major health issues;
- establishing processes and mechanisms for the early detection of diabetes;
- coordinated management of diabetes, including diabetes-related complications;
- disease management strategies that involve the patient and are culturally appropriate;
- addressing issues of access to services and information of higher-risk groups;
- sustainable continuing education of health professionals;
- standardising recommendations of care for pregnant women with gestational diabetes or diabetes;
- systematic development of diabetes datasets and a national diabetes monitoring system; and
- gaining a better understanding of diabetes, its causes and interventions that may reduce its impact, through research.

6.1 Prevention of Type 2 diabetes

The most effective strategy to reduce the impact of diabetes and its complications is to prevent people from developing the disease. Type 1 diabetes cannot be prevented at present, although this possibility is being researched, but there is evidence that Type 2 diabetes can at least be delayed through modification of risk factors. The consultation for this report identified an enhanced commitment to primary prevention as a high priority.

Coordinating primary prevention across National Health Priority Areas

Several risk factors for diabetes and its complications, such as obesity, inappropriate nutrition, lack of exercise, high blood pressure and smoking, are common to other NHPAs such as cardiovascular disease and some cancers. This means that a consistent set of messages can be applied across the different programs relating to diabetes prevention, cardiovascular health and cancer control. To do this requires strong coordination and secure, long-term funding. There is already preliminary work in progress on a National Primary Prevention Strategy aimed at major non-communicable diseases. The proposed strategy integrates physical activity, diet, tobacco and alcohol issues and provides a base on which to build. Future activity in diabetes-specific strategies should forge further links with this strategy.

Important points in developing a national integrated primary prevention strategy include:

- primary prevention takes many years to have full effect and must therefore be maintained long term;
- actions aimed at primary prevention of chronic disease will not achieve this full effect and reduce social inequalities in health until they begin to pay due attention to social and economic issues; and
- partnerships between the health sector and other sectors and agencies are required, implementing approaches that will increase access to healthy food choices and safe physical activity options.

The NPHP will oversee the development of the National Primary Prevention Strategy as part of its broader role in planning and coordinating national public health activities.

Health professionals

To encourage lasting behavioural change, the messages in primary prevention campaigns and CADS should be reinforced by GPs and other health workers. Strategies are required which provide suitable training for GPs and other health workers in giving appropriate advice and lifestyle counselling, and also make it easier for health professionals to provide this service.

Summary of opportunities

Encourage evidence-based practice through:

- implementation of guidelines (eg NHMRC primary prevention guidelines, RACGP guidelines on preventive activities for GPs) which involves a variety of methods including training of health professionals; and
- development, endorsement and implementation of guidelines on Type 2 diabetes which will include information on lifestyle counselling.

Improve collaboration through:

- planning and coordination of national public health activities and strategies through the NPHP;
- National Primary Prevention Strategy to coordinate national risk factor initiatives; and
- State/Territory diabetes strategies and chronic disease strategies.

Improve public awareness and encourage behaviour change through:

- National Community Awareness of Diabetes Strategy; and
- consideration of macro-environmental risk factors in government policy.

Facilitate preventive activities by health professionals through:

- mechanisms such as the Practice Incentives Program to implement incentives for GPs to provide evidence-based primary prevention advice; and
- the development of other incentive programs with relevant health professional organisations.

6.2 Early detection of diabetes

Early detection of Type 2 diabetes can prevent or delay the onset of debilitating and costly complications.

As with prevention, increased awareness of diabetes in the population and among health professionals is necessary before rates of early detection can increase. By raising awareness of diabetes, CADS is expected to increase diagnosis among people with diabetes who do not know they have the condition. This strategy requires both jurisdictional support and government commitment.

However, in order to convert increased awareness into greater rates of diagnosis, health professionals need appropriate skills in case finding, testing and follow-up. It is also important to investigate incentives for GPs to spend more time assessing, educating and appropriately referring patients who are at risk of or who have diabetes.

Summary of opportunities

Improve public awareness of the importance of early detection through:

- National Community Awareness of Diabetes Strategy.

Improve early detection rates by health professionals through:

- development of guidelines on screening and detection of diabetes;
- implementation of National Community Awareness of Diabetes Strategy (including education kits for GPs);
- investigating incentives for GPs to spend more time assessing and appropriately referring patients who are at risk of diabetes;
- improved access to allied health professionals; and
- engaging health service providers at the local level (eg pharmacists, community health workers, aboriginal health workers, community-based organisations) in early detection initiatives.

6.3 Management of diabetes

Effective management of diabetes is critical to improving the health-related quality of life of people with diabetes, as it reduces the chance of developing and severity of complications as well as premature mortality. Australia has a strong network of diabetes treatment services that provide routine care for people with diabetes, either through primary care physicians or through interdisciplinary, ambulatory care centres. Effective communication between the service providers, including allied health services, is important for the delivery of optimum care.

Improving the capacity of the health system to deliver and manage services

The infrastructure for diabetes services in Australia is complex. This partly reflects the complexity of the Australian health system, with different levels of government, private practitioners, peak bodies and private industry all having an important role to play.

Mechanisms need to be in place to ensure that a coordinated approach to diabetes is undertaken in Australia. The establishment of a National Diabetes Advisory Committee to report to Australian Health Ministers through AHMAC would facilitate the achievement of this goal. This approach would allow a streamlining of the existing advisory mechanisms. The committee would be asked to provide Health Ministers with wide ranging advice but with particular attention to a number of areas including those outlined below.

Promoting best practice

There is a wide range of evidence-based knowledge upon which to base management of diabetes and its complications. People working in the diabetes and primary care fields need to be aware of the latest evidence-based knowledge to ensure best practice. A number of guidelines relevant to diabetes have been produced or are under development, as discussed in this report.

Once endorsed by the NHMRC, the guidelines on detection, testing and management of Type 2 diabetes currently being developed should be effectively disseminated and implemented to encourage their adoption by all health workers in the diabetes field.

Implementation of guidelines should, at a minimum, involve training of health professionals, especially Aboriginal health workers. All guidelines should be evaluated and regularly reviewed.

Improving quality of care

The role of diabetes centres in increasing quality of care has been significant, as they provide outpatient care by multidisciplinary teams of health workers. The NADC has an important role in sharing information between centres and in providing training and support in relation to the management and treatment of diabetes, as part of the implementation of guidelines and also in areas where evidence-based guidelines are yet to be developed.

Management should include the following:

- *Patient education that uses patient-centred approaches.* Information provided by health workers should be relevant, up-to-date and culturally appropriate, and facilitate self management by increasing patient awareness of the importance of properly managing diabetes. Strategies such as health professional networks and consumer workshops may result in informed consumers who demand evidence-based care.

Opportunities and future directions

- *Recall systems for people with diabetes, and periodic monitoring.* As diabetes is a condition that needs to be continually monitored, effective recall and reminder systems play an important part in management. The use of routinely collected data in patient recall should be further investigated in consultation with the States and Territories (and the National Divisions Diabetes Program) to guide the development of an appropriate effective method of patient recall that can be implemented in each jurisdiction.

Managing diabetes-related complications

Effective management of diabetes-related complications as they arise is critical. There should be a national program to encourage the provision of evidence-based, coordinated services to prevent the development or progression of complications. Retinopathy guidelines have already been developed and the Commonwealth is currently funding projects to further raise awareness of health professionals and people with diabetes about retinopathy and appropriate screening. There is a need for development and effective implementation of other evidenced-based national guidelines that meet NHMRC requirements, for areas such as foot care, end-stage renal disease and cardiovascular disease.

Access to health professionals

Diabetologists and other specialists are generally located in major urban areas, making diabetes management more difficult for people in rural and remote areas. Access issues will need to be considered during the development of programs for the control of diabetes-related complications.

Access to allied health professionals was identified as important during the consultation for this report, and will require an examination of alternative funding models and the most efficient use of current resources, as well as current numbers of allied health professionals and their distribution across Australia. Allied health professionals should be more closely involved in health planning for diabetes services at national, State and Territory levels, as well as in service delivery at the local level.

Continuing education of allied health professionals

The education of allied health professionals involved in the management of diabetes is occurring at a local level but is dependent on short-term funding. Sustainable continuing education programs on diabetes management for allied health professionals are required. Continuing funding for Aboriginal health worker training is particularly important, with a key issue being the extension of Aboriginal health worker training in diabetes to primary prevention strategies. The provision of cross-cultural training to health professionals dealing with people who have diabetes and who come from culturally and linguistically diverse backgrounds is also important.

Summary of opportunities

Promote better practice through:

- rapid dissemination of research results about effective treatments to prevent the progression of complications;
- effective implementation of current management guidelines (eg NHMRC guidelines on diabetic retinopathy, New South Wales clinical management guidelines); and
- development and effective implementation of national guidelines on diabetes, and specific guidelines on diabetes-related complications.

Promote collaborative models of care through:

- examination of models such as the Integrated Care Trials and Coordinated Care Trials;
- State/Territory reviews of service delivery;
- the development of prioritisation criteria for allied health services and minimum service standards; and
- development of hospital clinical pathways for people with diabetes admitted for another condition.

Promote consumer participation in their care through:

- health information for consumers in appropriate formats;
- consumer guidelines and networks; and
- exploring models of patient-centred approaches to management.

Improve health professionals' understanding of diabetes and participation in diabetes programs through:

- mechanisms for sharing information (eg NADC);
- implementation of National Divisions Diabetes Program recommendations;
- outcomes-based funding for Divisions of General Practice to increase sustainability of programs;
- review of recommendations of the General Practice Strategy Review;
- investigation of decision-support systems across organisations;
- sustainable and effective continuing education (access to training in clinical management guidelines, incentives for undertaking continuing training);
- continuation and further development of the role of pharmacists in providing consumers with advice and supplies; and
- exploration of video-conferencing and tele-health for continuing education and decision support systems for rural and remote GPs and other health professionals, along with consideration of appropriate payment mechanisms.

6.4 Special populations

As discussed in Chapter 5, a wide range of issues is faced by populations either at higher risk of developing diabetes or with specific management needs.

Gestational diabetes and management of pregnancy among women with diabetes

A major issue in the management of gestational diabetes is follow up after the pregnancy. Effective follow-up requires women with gestational diabetes to be aware of their increased risk of developing Type 2 diabetes, GPs to be trained in management and follow up of women who have had a gestational diabetes pregnancy, and adequate patient recall systems to be in place.

Pre-pregnancy counselling for women with diabetes, to encourage improved glucose control during pregnancy, is likely to reduce the risk of adverse outcomes for both mother and baby. An advantage is that women are in contact with health services and likely to be highly motivated to self care during pregnancy.

Review of the services provided to pregnant women who have diabetes and follow up services for women who have gestational diabetes is being considered in the State-wide diabetes planning exercises in progress in all jurisdictions.

Summary of opportunities

- Existence and dissemination of Australasian Diabetes in Pregnancy Society Guidelines for the detection and management of gestational diabetes. The development of nationally coordinated guidelines on the testing for and detection of gestational diabetes is a high priority.
- Pilot programs for collaboration with GPs for the follow-up of women who have had a gestational diabetes pregnancy.
- Investigation of recall mechanisms for screening women with gestational diabetes, in consultation with the States and Territories (and the National Divisions Diabetes Program).
- Databases on gestational diabetes incidence and prevalence in some States/Territories and development of linkages with perinatal data collections.
- Raising awareness of the risk associated with pregnancy for women with diabetes and specific promotion of pre-pregnancy counselling services and appropriate referral for testing.

Type 1 diabetes in young people

There are a number of areas in which the specific needs of young people with diabetes should be addressed:

- continuing education and support for young people and their families;
- training for health professionals in detection and management of diabetes in young people;
- investigating models of service delivery that reduce hospital admissions and improve management; and
- providing clear transition paths between paediatric and adult care.

Summary of opportunities

- Innovative service delivery in South Australia through the Royal District Nursing Society.
- The Childhood Disability Allowance does not include diabetes as a manifest disabling condition. The scheme is currently under review.
- National needs assessment for children and adolescents with Type 1 diabetes by the Juvenile Diabetes Foundation Australia.
- Adequate funding and infrastructure for outreach/shared care services, including complications screening programs.
- Development of improved transition mechanisms between paediatric and adult services.
- Development of improved psychological services and support for young people and their families to enable them to cope with diabetes and the effect that it has on all their lives.
- Support of camps for young people with diabetes, and the development of television advertising along the lines of advertisements by Canteen and Camp Quality to facilitate diabetes becoming a 'socially acceptable' disease.

Indigenous Australians

While there is a high level of awareness of diabetes among Indigenous communities, and the existence of systematic reviews and guidelines that provide a good basis for action, a major barrier to improving diabetes care for Indigenous populations remains limited availability to culturally appropriate health care. Access to information about diabetes and its evidence-based management is also important.

A key issue, particularly in rural and remote areas, is the role of Aboriginal health workers, their training and payment.

Summary of opportunities

- Aboriginal self determination in health care (eg through Aboriginal community controlled health services).
- Policy developments in providing and facilitating environments for healthy eating and physical activity and coordination of activity (eg NPHP, national strategies and plans on overweight, physical activity, tobacco smoking, environment).
- Existence of clinical management guidelines for the prevention and management of diabetes among Indigenous Australians and involvement of primary care service providers, including Aboriginal health workers, in their development.
- Evidence-based reviews on related matters (breastfeeding, nutrition and healthy food supply).
- National Indigenous Nutrition Strategy being developed as a component of the National Public Health Nutrition Strategy.
- Subsidised access to blood and urine testing strips, insulin syringes and injection pen needles.
- Existence of suitable information systems for community-based programs.
- Policy developments in the provision of dialysis (eg incentives for home dialysis).
- Optional module in the National Divisions Diabetes Program for working with Indigenous populations.

Rural and remote populations

People in rural and remote areas face disadvantages in terms of access to health care, caused by a range of factors including distance and a shortage of health professionals. Innovative service delivery models in some States should be investigated for wider application. Future planning of diabetes services should be coordinated with the development of the National Rural Health Strategy and the implementation of other national initiatives.

Summary of opportunities

- Linking local service provision to National Rural Health programs such as the Rural Education, Support and Training program, the Rural Health Strategy and the Rural Incentives Program.
- Disseminating and implementing innovative rural service delivery models (eg South Australia).
- Improving access to tele-health and video-conferencing facilities for information sharing and continuing education.

People from culturally and linguistically diverse backgrounds

Language barriers, lack of access to culturally appropriate education and information for effective self management, and lack of continuing community support all contribute to the higher rate of diabetes-related complications among people from culturally and linguistically diverse backgrounds.

The collaborative planning approaches in all jurisdictions recognise the need to specifically address populations of culturally and linguistically diverse backgrounds and have multicultural policy representatives on advisory committees or taskforces. There is a growing recognition across jurisdictions that immigrant groups should be considered separately in the identification of health needs and in subsequent service planning.

Summary of opportunities

- Bilingual GPs, allied health workers and health workers.
- Existing experts training in cross-cultural issues.
- Successful pilot programs which could be generalised.
- Strong community networks and organisations.
- Clearly identified target groups.
- Interpreter services.

Older Australians

Issues specific to older people, such as multiple diseases, multiple medications, social isolation and depressed cognitive function complicate the provision of effective diabetes preventive and management services.

Summary of opportunities

- Education of staff in nursing homes about the management of older patients with Type 2 diabetes.
- Investigation of incentives for health professionals to provide longer consultations to older people.

6.5 Information systems

Currently, there are few national data on the incidence and prevalence of diabetes and its complications in Australia. The information on diabetes risk factors is also not up to date. This information is required at local, State and national levels, as well as on various population groups, for health planning and resource allocation.

Data development

The development of appropriate data for diabetes monitoring, surveillance and evaluation needs to occur within a defined framework. This will not only involve the identification of data gaps and deficiencies but also include standardisation of data elements in order to achieve comparability between various data sources. An integrated approach to data development should include a diabetes information development plan that is organised around a minimum dataset.

Data collection

The data environment within which diabetes-related information is currently collected has been described in Chapter 4. Some of the current activities to collect this information are also listed in Appendix 2. However, two critical pieces of information that the current data collection activities will not be able to provide are baseline national incidence and prevalence of Type 2 diabetes and its complications. The National Biomedical Risk Factor Survey, currently under consideration by the National Public Health Information Working Group, should help fill some of this data gap. The National Diabetes and Lifestyle Study, to be conducted by the International Diabetes Institute in 1999, will also provide quasi-national information on various aspects of diabetes.

Data linkage

No central mechanism to promote data linkage across various service settings for diabetes currently exists, although the issue is being considered by all jurisdictions in their strategic planning for diabetes. At a national level, AIHW is responsible for undertaking a project to test the feasibility of national record linkage. This project could form the basis for undertaking efficient and cost-effective record linkages by various jurisdictions. The AIHW could also play an important role in undertaking cross-jurisdictional linkages of data. The National Health Information Management Advisory Council, the creation of which was agreed to by Health Ministers in July 1998, should also have a role in considering diabetes record linkage issues. Any solutions need to be achieved in the context of appropriate privacy and security.

Summary of opportunities

Improvement of information base through regular population-based surveys:

- National Health Survey 2001;
- National Biomedical Risk Factor Survey (proposal under consideration);
- State-based Computer-Assisted Telephone Interview (CATI) surveys; and
- conversion of one-off collections, such as the National Nutrition Survey and the National Aboriginal and Torres Strait Islander Survey, to regular time series.

Maximizing the value of the information collected through:

- systematic collection, linkage and analysis of data; and
- ethical and timely dissemination of information

Initiatives to improve quality of diabetes data:

- National Diabetes Outcomes Quality Review Initiative (NDOQRIN);
- new diagnostic criteria and classification of diabetes by American Diabetes Association and World Health Organization;
- minimum data sets for diabetes monitoring (ANDIAB);
- NHPA diabetes indicators with standardised definitions of data elements (AIHW); and
- determining gaps and deficiencies in data content (AIHW).

Use of high-quality, provisional or quasi-national surveillance data:

- National Association of Diabetes Centres survey;
- quasi-national data, eg population-based study of diabetes-related complications and risk factors in South Australia;
- Integration SERU survey of general practitioners;
- National Diabetes Register; and
- various record linkage projects.

Enhancement of diabetes monitoring and information systems:

- national diabetes monitoring (AIHW); and
- State-based diabetes monitoring systems.

Progress in national health information policy environment:

- National Health Information Management Group;
- National Public Health Information Working group;
- National Health Priority Committee; and
- National Health Information Agreement.

Improvement of information development and management:

- National Public Health Information Development Plan (in preparation); and
- National Health Information Development Plan (under revision).

6.6 Research and development

Research has increased our understanding of diabetes, its risk factors and effective treatments to control the disease and delay the onset of complications. Research needs to be continued to ensure progress is made towards a cure, as well as further improving prevention and management interventions.

Areas for future research include the following:

- *Reviewing allocation of research funding for diabetes.* The *National Diabetes Strategy and Implementation Plan* report has highlighted the need for a review of research funding for diabetes (Colagiuri et al 1998).
- *Establishing research priorities within diabetes.* These include strategic research in epidemiology, behavioural sciences and health policy, with the aim of reliably monitoring the true prevalence and trends of diabetes (and other non-communicable diseases) in populations, and understanding their determinants.
- *Cost modelling the effects of diabetes and the effect of different interventions.* Research on health outcomes achieved for people who receive different types of care is needed to indicate if current resource investment is achieving the most effective results possible. Similarly, information on the costs incurred in achieving patient outcomes through the various types of care will indicate if the current resource investment is achieving the most efficient results possible.
- *Adequately funded dissemination of research.* Research results need to be disseminated widely to facilitate incorporation into policy decisions and the provision of evidence-based practice. If service providers, in particular, who are not involved in projects implementing clinical management guidelines, become aware of better health outcomes associated with the use of clinical management guidelines, those service providers are likely to adopt the better practice.

Summary of opportunities

Enhance research into diabetes through:

- establishing research priorities;
- encouraging increased levels of funding for diabetes research; and
- cost modelling the effects of diabetes and the effect of different interventions.

6.7 Future directions

Future directions in diabetes will be shaped by the development and implementation of a National Diabetes Strategy, which will be considered by Health Ministers in July 1999. It is proposed that the Strategy will be implemented and further activities developed under the direction of a National Diabetes Advisory Committee.

The National Diabetes Strategy will be based on the results of consultation taken in the development of the *National Diabetes Strategy and Implementation Plan* report, and this report to Health Ministers. It will use the two reports as a platform from which the Commonwealth Government and State and Territory Governments can identify priorities and agree on an approach to diabetes prevention, management and research, in partnership with peak organisations and service providers. Integral to this process will be consideration of the needs of populations who face significant issues in diabetes prevention and care, including Indigenous Australians, people from culturally and linguistically diverse backgrounds, people living in rural and remote areas, children and adolescents, and older Australians.

As well as ensuring that appropriate attention is given to primary prevention, effective high quality management of diabetes, monitoring and research, the National Diabetes Strategy should establish an effective partnership between governments, health care professionals, non-government organisations and consumers and carers.

It is important that the implementation of the National Diabetes Strategy involves long-term strategic planning and sustained funding, as most gains in health outcomes will only come with continuous work over a long time. It is also important that future action recognises past experience and successes and builds on current activity.

Appendix 1

NHPA indicators for diabetes

Diabetes in Australia: indicator-based reporting

This appendix brings together national data for the purpose of reporting progress against NHPA indicators of diabetes. The appendix has been developed by the AIHW with input and support from various individuals and organisations, in particular Dr Jeff Flack, Director of the Diabetes Centre at Bankstown-Lidcombe Hospital in Sydney.

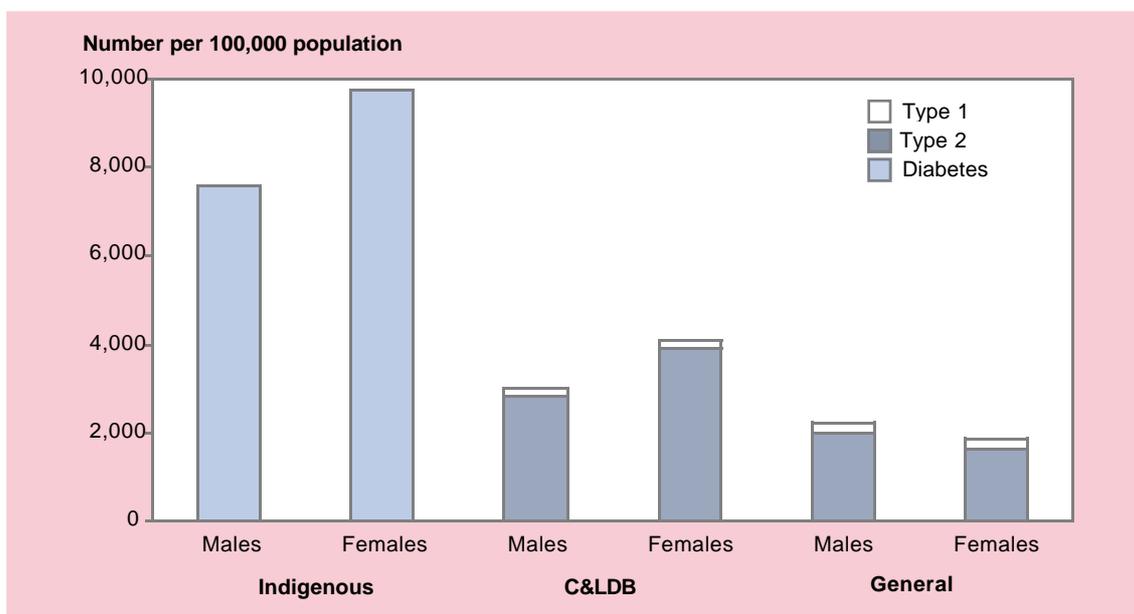
The format used for indicator-based reporting aims to provide information in a succinct manner. While the statistical information presented is confined to meeting the data requirements for each indicator, the interpretation offered is somewhat broader than the design of the indicator would suggest. This is in accordance with the basic tenet of indicator-based reporting.

Every attempt has been made to use the best available data, health service clinic-based or population-based, for reporting. Where available, time-series or other collateral information has been included to enhance interpretation. No attempt has been made to provide a comprehensive overview of the health issue in question. It is recommended that this appendix be read in conjunction with the epidemiological overview of diabetes given in Chapter 1.

While considerable progress has been made in developing and reporting indicators for other NHPAs, this is the first time that information has been put together for diabetes indicators in this format. The quality and comparability of much of the data presented here is variable. These problems, with appropriate caveats, are discussed throughout the appendix. Data issues specific to each indicator have also been discussed. For detailed statistical and data issues, see Appendix 2.

NHPA indicators for diabetes

Indicator 1.1: Prevalence rates for Type 1 and Type 2 diabetes in the general population, Indigenous population, and among persons from culturally and linguistically diverse backgrounds



Population	Indigenous population	People from C&LDB		General population	
	Diabetes	Type 1	Type 2	Type 1	Type 2
Males	7,597	146	2,627	223	1,846
Females	9,763	158	3,609	210	1,508
Persons	8,767	149	3,103	218	1,662

Notes: Data not available by diabetes type for the Indigenous population. Rates, age standardised to the 1991 Australian population, are given as prevalence per 100,000 persons. C&LDB = Culturally and linguistically diverse backgrounds.

Sources: ABS (1997b; 1996).

- The prevalence of diabetes varies considerably among population groups in Australia. Many different factors contribute to this variation, including differences in incidence, management, treatment, mortality and population structure.

Operational definition

- This indicator provides a comparative picture of the prevalence of Type 1 and Type 2 diabetes in the general population and two specific population groups — Indigenous Australians and people from culturally and linguistically diverse backgrounds.
- Available national statistics to report against this indicator are not based on diagnostic criteria. Self-reported information, generated through various national surveys, has therefore been used as proxy data. It is expected that this indicator will be tracked with the national Biomedical Risk Factor Survey.

Prevalence rates

General population

- Based on the 1995 NHS self reports, the prevalence rate for Type 1 diabetes is estimated to be 235 per 100,000 persons in the general population.
- The prevalence rate for Type 2 diabetes is much greater (almost eight times the rate for Type 1 diabetes) at 1,794 per 100,000 population.
- Males show higher prevalence of both types of diabetes than females.

Indigenous population

- The prevalence of diabetes is significantly higher among people of Indigenous origin. According to 1994 NATSIS (ABS 1996a), the self-reported prevalence rate among Indigenous people is five times that in the general population.
- The prevalence rate is almost 30 per cent higher among Indigenous females than among Indigenous males.
- Estimation of prevalence rates by type of diabetes is not possible from the NATSIS collection. Nor is it possible to determine the correction factor for undiagnosed diabetes at this stage.

Persons from culturally and linguistically diverse backgrounds

- Diabetes is also more commonly prevalent among persons from culturally and linguistically diverse backgrounds, at almost twice the rate in the general population. Type 2 diabetes accounts for this difference. In contrast, Type 1 diabetes is less prevalent among this group.
- As is the case for Indigenous people, females from culturally and linguistically diverse backgrounds have higher prevalence of diabetes (both Type 1 and Type 2) than do their male counterparts.
- At this stage, it is not possible to determine the correction factor for undiagnosed diabetes among persons from this group.

Time trends and projections

- Several studies have indicated that the prevalence of diabetes is on the rise worldwide, including in Australia. It is projected that diabetes will affect about 950,000 Australians by the year 2010 (Amos et al 1997).
- While some of this rise may be attributed to improved management of the disease over the past several decades, rising incidence, ageing of the population and changing ethnic composition of the population may have also contributed to this trend.

- Due to the lack of a regular time series, it is not possible to quantify trends in diabetes prevalence at a national level.
- A comparison of self-reported prevalence rates, estimated from 1989–90 and 1995 NHS datasets, reveals a 30 per cent increase in prevalence. While some of this may be attributed to increase in incidence, better detection, management and awareness of the disease may have contributed to increased reporting during the 1995 NHS.

Data sources

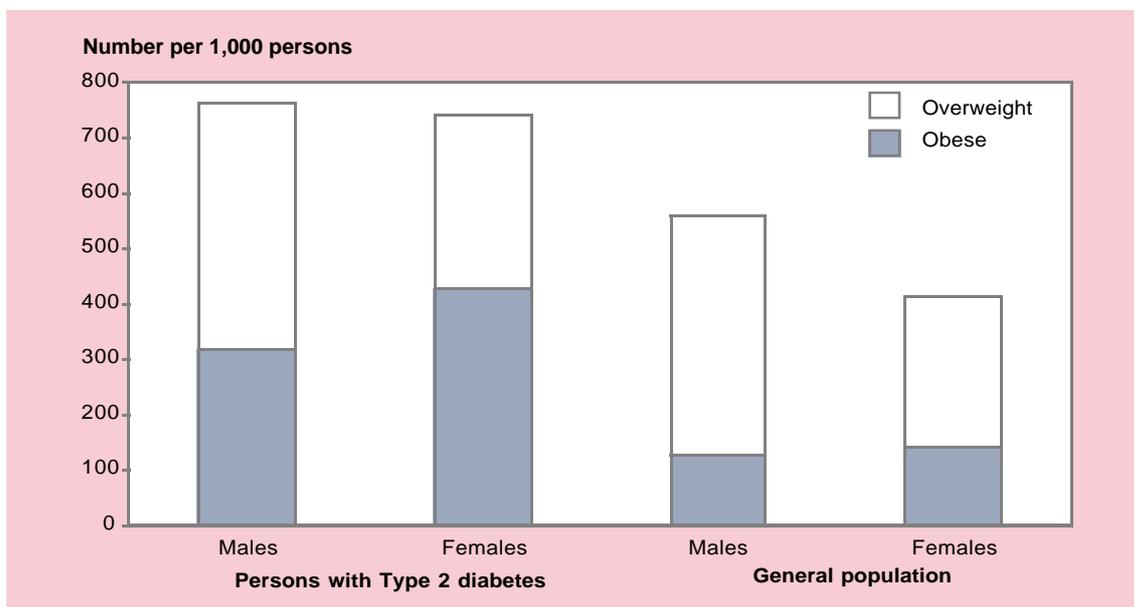
- The NHS, conducted by the ABS, provide self-reported information on diabetes prevalence in the general population, as well as among persons from culturally and linguistically diverse backgrounds. Several State-based surveys also collect this information.
- Self-reported national information on diabetes among Indigenous Australians was collected through the 1994 NATSIS (ABS 1996a). An oversampling of the Indigenous population during the 1995 NHS has also provided a reliable estimate of the disease in the Indigenous population.

Data issues

- No national information based on diagnostic criteria is available on the prevalence of diabetes in Australia. The information provided here is therefore based on self reports.
- Estimates based on self reports are known to substantially underestimate the prevalence of diabetes in the community since a large proportion of Type 2 diabetes remains undiagnosed.
- It has been suggested that for every known case of Type 2 diabetes there is a person in the population whose diabetes has not been detected. Under-reporting may occur for diagnosed cases as well.
- Attempts to correct for some of these underestimations have yielded prevalence estimates of up to 4,300 per 100,000 persons, a total of 780,000 persons with diabetes in Australia in 1995 (Colagiuri et al 1998). Other similar corrections yield much lower estimates.
- Since the rising prevalence of diabetes has strong implications for health resources, accurate information on prevalence by type of diabetes is crucial to developing a clear strategy. A National Biomedical Risk Factor Survey that includes diagnostic tests will help obtain a more reliable estimate of the prevalence of diabetes in Australia.

NHPA indicators for diabetes

Indicator 2.1: Prevalence rates for obesity and being overweight (as measured by BMI) among persons with Type 2 diabetes and in the general population



Population group (aged 30 years and over)		Crude rates		Age-standardised rates	
		Overweight	Obese	Overweight	Obese
Persons with Type 2 diabetes	Males	476	256	445	317
	Females	339	372	313	428
General population	Males	434	132	430	129
	Females	275	139	274	139

Note: Rates, age standardised to the 1991 Australian population, are given as prevalence per 1,000 persons.

Source: ABS (1997b).

- Overweight/obesity increases the risk of developing Type 2 diabetes and its complications. In particular, it increases predisposition of persons with diabetes to cardiovascular disease.
- The prevalence of overweight/obesity is on the rise in Australia. This may have implications for the population at risk of developing diabetes — those aged 40 years and above, and those belonging to certain population groups.

Operational definition

- This indicator provides a comparison of the prevalence rates for obesity and being overweight among persons with Type 2 diabetes and in the general population. The indicator focuses both on the population at risk of developing diabetes, and those who are at increased risk of developing diabetes-associated complications. In view of the age distribution of Type 2 diabetes, this indicator monitors only those aged 30 years and over.
- Overweight and obesity are determined using BMI, expressed as weight/height squared. No account is taken of excessive amount of body fat for a given body weight in this definition.
- Overweight is defined as a BMI score between 25 kg/m² and 30 kg/m². A BMI score of more than 30 kg/m² is termed obese (WHO 1998). For details on calculating BMI, see Appendix 2.
- Available national strategies for this indicator are not based on measurements. Self-reported heights and weights have been used for calculating BMI. The diabetes status of the person is also self reported.

Prevalence rates

- According to the 1995 NHS (ABS 1997b), more than three-quarters of males (aged 30 years and over) with Type 2 diabetes are overweight or obese, with an age-standardised prevalence rate of 762 per 1,000 persons. The rate is slightly lower among females with diabetes in that age range (741 per 1,000).
- Corresponding estimates for their counterparts in the general population are 559 and 413 per 1,000 persons.

Overweight (BMI = 25–30 kg/m²)

- A much larger proportion of males with diabetes is overweight in comparison to females (445 against 313 per 1,000 persons). The difference between the two sexes is much larger in the general population.
- No significant difference is noted in the proportion of overweight males with diabetes and those in the general population (445 and 430 per 1,000 persons respectively). The proportion of overweight females with diabetes in comparison is 14 per cent higher than that in the general population.

Obesity (BMI ≥ 30 kg/m²)

- In contrast to the pattern observed for being overweight, among people with diabetes obesity is more commonly prevalent among females than among males (428 versus 317 per 1,000 persons). The difference in prevalence rates between the two sexes is lower in the general population.
- Obesity is more commonly prevalent among persons with diabetes than in the general population. Males with diabetes are almost two-and-a-half times more likely to be obese than males in the general population. The ratio is more than three times between the two female groups.

Time trends

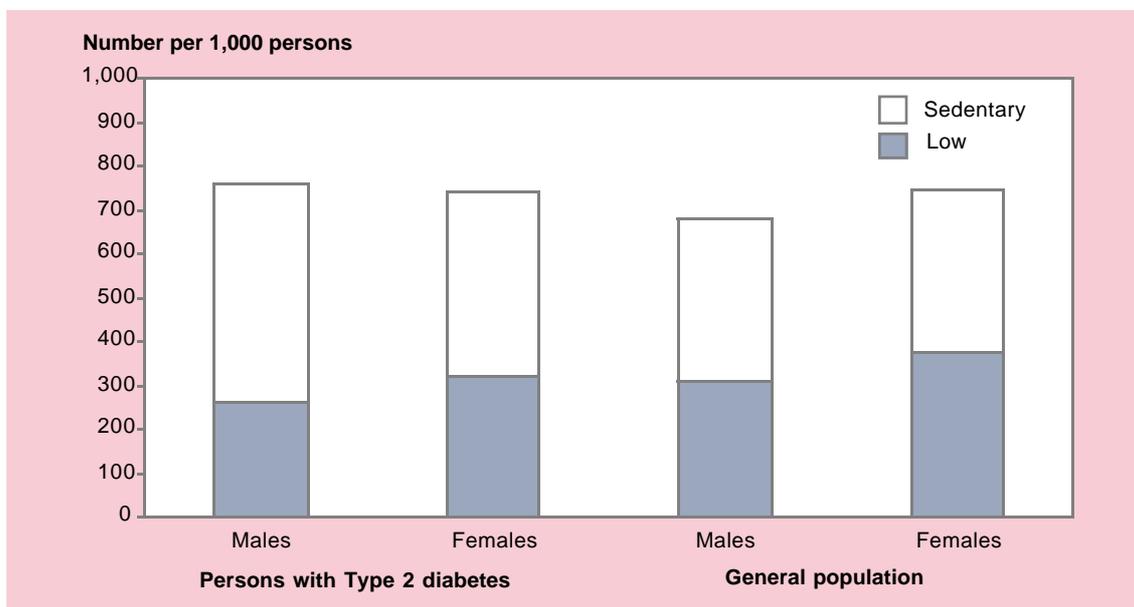
- There has been a steady increase in the proportion of overweight/obese persons in Australia. The proportion of overweight/ obese among those aged 18 years and over increased by almost 7 per cent points between the 1989–90 NHS and 1995 NHS among males, and by about 5 per cent points among females.
- Assessment of changes in the proportion of overweight/obese persons with diabetes is not possible from the NHS data for technical reasons. However, comparisons of overweight/ obesity rates among those with diabetes and in the general population reveal that the gaps may have widened further between the 1989–90 and 1995 surveys.

Data issues

- Both age and overweight/obesity are independent risk factors for diabetes. The older age distribution of those with diabetes compared with the general population is likely to account for part of the difference in overweight/obesity prevalence between the groups. However, adjustment for differences in age distributions in estimation has removed some of this effect.
- The accuracy of self-reported body weight and height has been questioned. Using measured weights and heights, ABS (1998) has determined that a large proportion of respondents under-reports bodyweight and over-reports height, resulting in lower BMI scores.
- The definition of overweight/obesity based on body weight and height alone is inadequate because it does not take into account body composition of the individual. It has been suggested that excessive amount of total body fat, in particular the presence of excessive abdominal (visceral) fat, is an important risk factor for diabetes in some populations.

NHPA indicators for diabetes

Indicator 2.2: Rates for non-participation in regular, sustained, moderate aerobic exercise among persons with Type 2 diabetes and in the general population



Population group (aged 30 years and over)		Unadjusted rates by level of exercise		Age-standardised rates by level of exercise	
		Low	Sedentary	Low	Sedentary
Persons with Type 2 diabetes	Males	353	410	259	496
	Females	347	471	323	418
General population	Males	308	372	307	373
	Females	375	375	377	370

Note: Rates, age standardised to the 1991 Australian population, are given as number per 1,000 persons.

Source: ABS (1997a).

- Lack of physical activity is one of the known modifiable risk factors for Type 2 diabetes. Physical activity is also an important adjunct to the maintenance of body weight which is central to the management of diabetes.
- Physical activity not only protects against the development of diabetes but also improves insulin and glucose homeostasis. It can also appropriately reduce the levels of blood pressure and cholesterol, thus minimising the risk of cardiovascular disease.
- It has been shown that increased physical activity reduces the risk of developing diabetes between 30 and 50 per cent (Spelsberg & Manson 1995).
- No reliable estimates of the effect of increased physical activity in reducing heart, stroke and vascular disease are available.

Operational definition

- The operational definition for this indicator is the proportion of adults, with or without diabetes, who do not participate in vigorous or moderate levels of physical activity for recreation or fitness.
- Based on self-reported information, this indicator measures the proportion of people who have not undertaken that level of activity over a two-week period.
- Two different levels are identified — those who do not participate in any physical activity, referred to here as sedentary, and those who undertake low level of activity. People with a sedentary lifestyle, or undertaking only low levels of physical activity, fail to gain the health benefits that moderate intensity physical activity can confer. For details on physical activity type and level, see Appendix 2.
- A comparative perspective is sought between people at risk of developing diabetes and those who already have the condition, using lack of physical activity as an indicator.
- The indicator may also be interpreted as an indirect measure of the success of diabetes education and management programs that include physical activity as an integral component.

Non-participation rates

- According to the 1995 NHS, almost one-half of males with diabetes do not participate in any physical activity. Another 26 per cent undertake only low levels of activity.
- The proportion of females not undertaking any physical activity is reported to be lower among those with the condition, but is higher for low level physical activity.
- The proportion of males not participating in any physical activity is much higher among those with diabetes than among those in the general population.
- Data from the cross-sectional surveys do not enable us to establish if people are not participating in physical activity because they have diabetes, associated risk factors, or poor health, or if indeed lack of physical activity has contributed to the development of diabetes.

Time trends

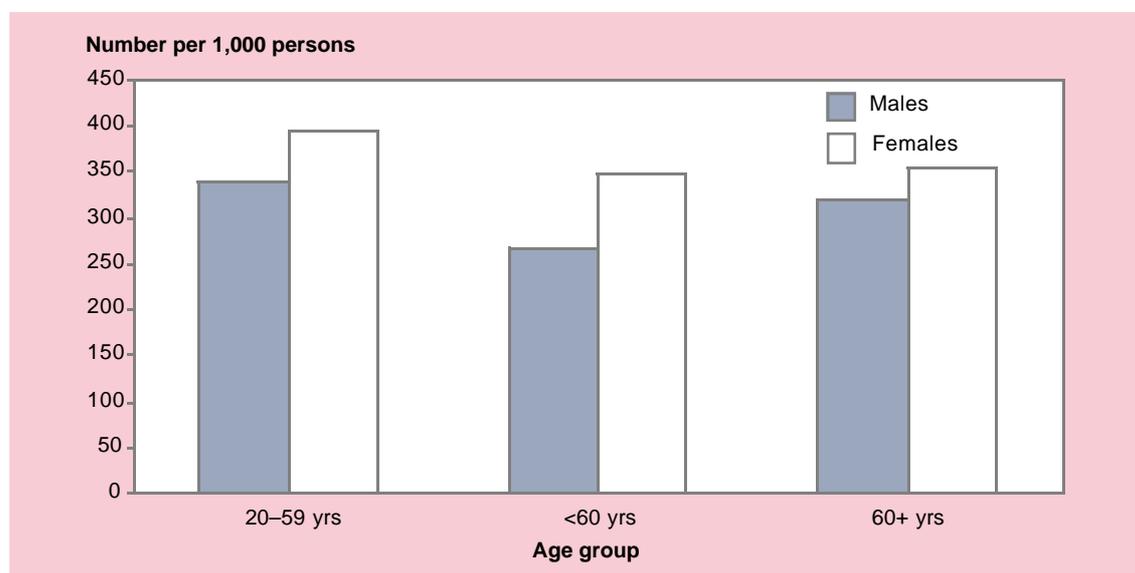
- There is some evidence that Australians are now participating in physical activity more often. The proportion of those not engaged in physical activity decreased by around 6 per cent between 1989–90 and 1995.
- The increase in physical activity was mainly due to an increase in participation among people aged 35–54 years. Walking, a moderate physical activity recommended for health, increased in popularity during the 1990s with 45 per cent of males and 53 per cent of females walking for recreation or exercise in 1995 compared with 41 per cent and 49 per cent respectively in 1989–90.
- However, no time series is currently available on physical activity among persons with diabetes to provide a comparative picture.

Data issues

- Physical activity that reduces the risk of developing diabetes and its complications does not require a structured or vigorous exercise program. Because the majority of benefits of physical activity can be gained by performing moderate-intensity activities outside of formal exercise, this indicator has been designed to determine the rates for non-participation in regular, sustained, moderate aerobic exercise.
- However, data from the NHS do not provide validated information on the frequency or duration of the activity performed to assess this indicator as defined. Participation in any moderate or vigorous physical activity has been used as the proxy indicator.
- Self-reported data reflect the respondent's perception of the activity undertaken, its intensity, and his/her level of fitness. The AIHW is undertaking a validation study of moderate physical activity to reduce the effect of this problem in future surveys. Further validation of these data is required to assess the role of physical activity in preventing diabetes and improving outcomes of diabetes management.
- Currently, the AIHW is developing a physical activity questionnaire that will enable future surveys to collect the type of data needed to inform the indicator as defined above.
- Several variables influence the adoption of a physically active lifestyle by various population groups. These factors should be taken into consideration in comparing rates.

NHPA indicators for diabetes

Indicator 2.3: Prevalence rates for high blood pressure among persons with Type 2 diabetes, aged less than 60 years or aged 60 years and over



Population group	Age group		
	20–59 years	<60 years	60+ years
Males	340	266	319
Females	395	347	354
Persons	382	328	335

Note: Rates, age standardised to the 1991 Australian population, are given as prevalence per 1,000 persons.

Source: NADC (1998).

- High blood pressure is known to be associated with diabetes, presenting often with central (upper body) obesity and dyslipidaemia.
- High blood pressure may be a risk factor for diabetes. High blood pressure could be present for up to 10 years before the detection of diabetes. The evidence is accumulating that the two may have a common aetiological factor.
- High blood pressure is an independent risk factor for cardiovascular disease, as well as renal disease. But in combination with hyperglycaemia and other risk factors such as hyperlipidaemia, it becomes more powerful a factor for diabetes-associated complications.

Operational definition

- The indicator has been designed to provide a comparative picture of the prevalence of high blood pressure in association with diabetes. In view of the strong association of high blood pressure with age, two different age-based cut-off points have been set up.
- High blood pressure for the purpose of this indicator is defined as:
 - ≥ 140 mmHg systolic and/or 90 mmHg diastolic for people aged less than 60 years; and
 - ≥ 160 mmHg systolic and/or 90 mmHg diastolic, for people aged 60 or more years.
- Since the indicator has been designed to determine prevalence rather than management outcomes for high blood pressure among persons with diabetes, those on treatment for high blood pressure are included in estimating the prevalence rates.

- Although the indicator has been designed to cover all age ranges, separate information is also provided for the age range 20–59 years, for more focused tracking of trends over time.
- It is expected that this indicator will be tracked with the National Biomedical Risk Factor Survey. Proxy data from the NADC will be used until that data becomes available.

Prevalence rates

Clinic-based data

- Based on the NADC survey, the prevalence rates for high blood pressure are estimated as 266 per 1,000 males and 347 per 1,000 females with Type 2 diabetes and under the age of 60 years. The proportions are slightly higher among those aged 20–59 years.
- The prevalence rates for high blood pressure among persons with diabetes and over the age of 60 years are similar to those noted for persons under the age of 60 years. Although blood pressure is age associated, the higher cut-off point for systolic pressure may have offset some of the difference.

Population-based data

Measured

- No population-based, national estimates of prevalence of high blood pressure among persons with diabetes, based on actual measurements, are available. However, in a survey in South Australia, Phillips et al (1998) have found that:
 - almost one in three persons with Type 2 diabetes (321 per 1,000) have blood pressure $\geq 160/95$ mmHg; and
 - the proportion of those with blood pressure $\geq 140/90$ mmHg is 597 per 1,000.
- The two cut-off points in the South Australian survey are not age specific. However, the population-based survey reveals slightly higher prevalence rates than the clinic-based data if the cut-off point of 140/90 mmHg is applied.

Self-reported

- The proportion of people with diabetes who reported high blood pressure during the 1995 NHS is 441 per 1,000. This figure has not been age and sex standardised because of the relatively small number of people with diabetes in the NHS sample.
- As both Type 2 diabetes and high blood pressure are associated with age, these prevalence rate ratios must be carefully interpreted.
- Also, the information is based on self reports, rather than actual measurement, which may lead to underestimation of the prevalence rate.

Diabetes-related risk factors and high blood pressure

- Almost one out of three respondents (310 per 100,000) at high risk of developing diabetes — over the age of 40 years and overweight or obese — reported high blood pressure during the 1995 NHS (ABS 1997a).
- This compares with a rate of 441 per 1,000 among persons with Type 2 diabetes and 100 per 1,000 persons without diabetes.
- Again, these figures are not age and sex standardised and therefore should be used carefully.

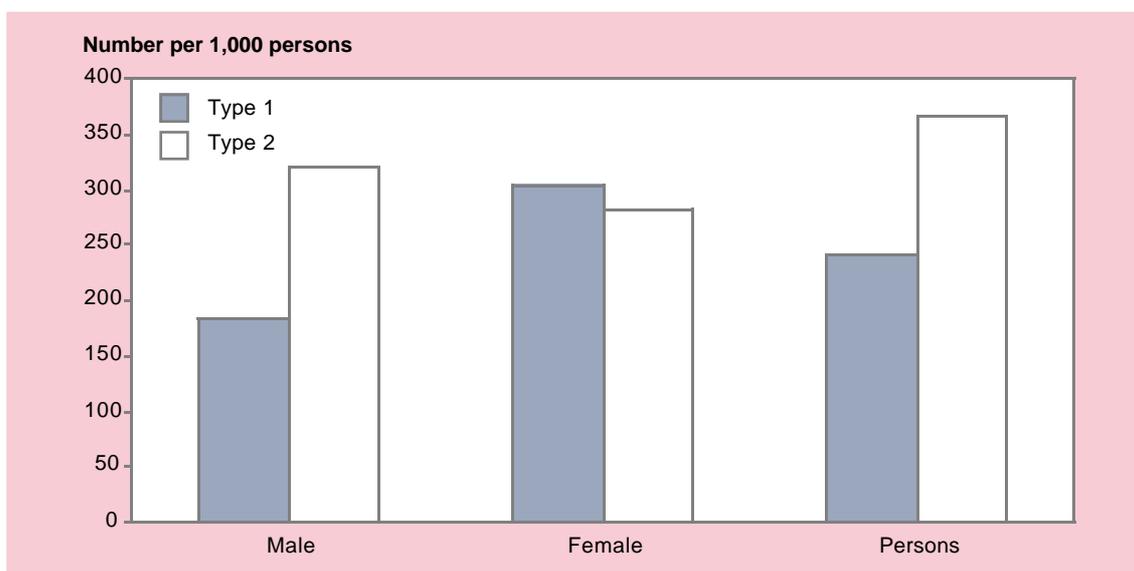
Time trends

- During the 1980s, average blood pressure levels in Australia declined significantly. The trend has continued into the 1990s (HEALTH & AIHW, in press).
- This trend has positive implications for diabetes outcomes. Evidence has long existed that managing blood pressure reduces diabetes-related complications, in particular cardiovascular disease and renal outcomes.

Data issues

- No direct comparison of the prevalence rates for high blood pressure among persons with diabetes, as estimated from three different types of survey, is possible. While the NADC survey included patients under the clinical care of specialist diabetes services, the other two surveys were population based. The two population-based surveys also used different methodologies.
- No reliable measurement-based benchmarks are currently available for self-reported blood pressure among persons with diabetes. Although, the 1995 National Nutrition Survey collected measured information on blood pressure to benchmark 1995 NHS self reporting, these results are not extendable to persons with diabetes.
- The NADC survey is based on an audit of patients attending specialist diabetes centres. It includes persons with diabetes requiring specialist clinical management, in particular those who have had poor control of their diabetes. A major limitation of the sample is that it does not accurately reflect the conditions prevailing in the general community.
- A more appropriate national dataset would be based on a population-based study. The proposed National Biomedical Risk Factor Survey is likely to provide suitable information.

Indicator 2.4: Prevalence rates for high levels of lipoproteins among persons with Type 1 and Type 2 diabetes



Population group (ages 20 years and over)	Prevalence of high cholesterol levels	
	Type 1 diabetes	Type 2 diabetes
Males	182	319
Females	303	282
Persons	242	366

Note: Rates, age standardised to the 1991 Australian population, are given as prevalence per 1,000 persons.

Source: NADC (1998).

- High levels of lipoproteins, or dyslipidaemia, and diabetes are known to be associated. There is some evidence that dyslipidaemia may precede abnormal glucose tolerance. Hyperglycaemia on the other hand is known to contribute to high levels of lipoproteins. Resistance to insulin action is considered to act as a common aetiological factor.
- The presence of lipoproteins at high levels constitutes a strong risk factor for atherosclerosis that may be intensified by diabetes. The impact of dyslipidaemia and diabetes may be even greater in combination with other cardiovascular disease risk factors such as high blood pressure and overweight/obesity.
- Although high levels of lipoproteins promote atherosclerosis in a similar manner in both types of diabetes, higher prevalence of overweight/obesity among persons with Type 2 diabetes may augment the risk for cardiovascular disease complications differently from that for Type 1 diabetes.

Operational definition

- The indicator has been designed to provide a comparative picture of the prevalence of dyslipidaemia in association with two major forms of diabetes, Type 1 and Type 2.
- Two different compounds, cholesterol and high-density lipoproteins, are measured and monitored with the following cut-off points:
 - total plasma cholesterol ≥ 5.5 mmol/L; and
 - high density lipoproteins < 1.0 mmol/L.
- It is expected that this indicator will be tracked using population-based biomedical risk factor data. However, in the absence of these data, information collected by the NADC survey will be used as proxy data.

Prevalence rates

Clinic-based data

- According to the NADC survey, age-standardised prevalence rate for high blood cholesterol (≥ 5.5 mmol/L) among persons with Type 1 diabetes is 182 per 1,000 males and 303 per 1,000 females with Type 1 diabetes.
- The rates are respectively 319 and 282 per 1,000 among persons with Type 2 diabetes.

Population-based data

Measured

- In South Australia, more than half of the respondents (523 per 1,000 persons) with Type 2 diabetes had cholesterol levels ≥ 5.5 mmol/L (Phillips et al 1998).
- In more than one out of three persons with high cholesterol, the level was ≥ 6.5 mmol/L.
- High density lipoprotein was present at levels < 1.0 mmol/L in almost 46 per cent of persons with diabetes.

Self-reported

- The proportion of people with diabetes who reported the presence of high cholesterol during the 1995 NHS is 165 per 1,000 persons. This rate is over three times as high as the rate among those without diabetes (49 per 1,000 persons).
- No distinction was made between persons with Type 1 or Type 2 diabetes in this analysis.

Time trends

- No clear time trends were observed in the plasma cholesterol levels in Australia in 1980s. No new information on this important risk factor — to track the trend further — has become available in 1990s.

Data sources

- Information on the prevalence of dyslipidaemia among those attending diabetes centres was collected in 1998 through an NADC survey. The NADC survey is based on an audit of patients attending specialist diabetes centres. The survey included 1,681 persons, aged 20+ years, presenting at 32 specialist diabetes service centres in the country. Of these, 83 per cent have Type 2 diabetes.
- Self-reported information on high cholesterol levels in the general population and among persons with diabetes was collected during the 1995 NHS. This information was not backed up by a laboratory-based test.

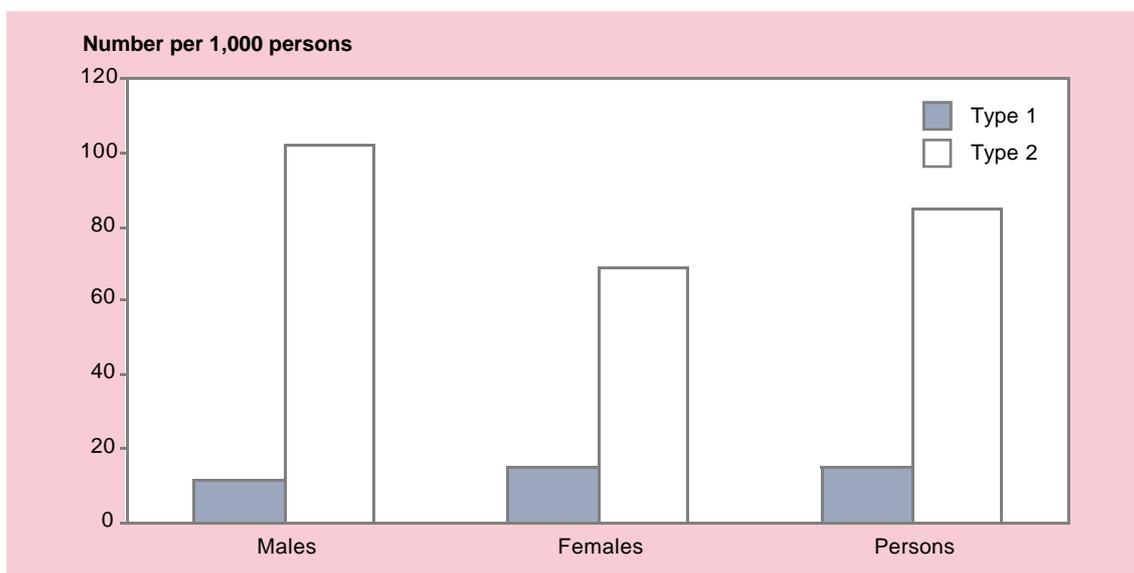
- No national benchmark, population-based information on cholesterol levels based on laboratory measurements, among persons with diabetes or in the general population, has become available since the 1989 Risk Factor Prevalence Survey by the NHF.
- Population-based, regional information on the prevalence of cholesterol and high density lipoproteins among persons with Type 2 diabetes has been generated through a survey in South Australia (Phillips et al 1998). No comparable regional information from another State/Territory is currently available.

Data issues

- No direct comparisons of lipid levels between the NADC and South Australian data are possible because of different sampling strategies. While the former includes patients under clinical care, the latter survey is population based. The two estimates were also generated using different standard populations for age adjustments.
- An order of magnitude difference has been noted in the estimates of prevalence rates for high cholesterol among males based on self reports during 1989–90 NHS and measurement of cholesterol during the 1989 Risk Factor Prevalence Study.
- The NHS data are based on self reports, rather than measured levels of cholesterol, which may lead to the underestimation of prevalence rates. While some of this discrepancy may result from the recent lowering of the cut-off point for high cholesterol from 6.5 mmol/L to 5.5 mmol/L, the awareness of this risk factor in the general population may not be high.
- The cholesterol cut-off point of 5.5 mmol/L, used here, is in accordance with the recommendations of the NHF.
- The NHS estimates are not age and sex standardised because of the relatively small number of people with diabetes in the NHS sample (ABS 1997a).
- The NADC survey is based on an audit of patients attending specialist diabetes centres. It includes persons with diabetes requiring specialist clinical management, in particular those who have had a poor control of their diabetes. A major limitation of the NADC sample is that it does not accurately reflect the conditions prevailing in the general community.
- A more appropriate national dataset would be based on a population-based study.

NHPA indicators for diabetes

Indicator 2.5: Prevalence rates for fasting hypertriglyceridaemia among persons with Type 1 and Type 2 diabetes



Population group	Type of diabetes	
	Type 1	Type 2
Males	11.8	102.3
Females	15.4	69.2
Persons	15.0	84.8

Note: Rates, age standardised to the 1991 Australian population, are given as prevalence per 1,000 persons.

Source: NADC (1998).

- Hypertriglyceridaemia, or high triglyceride levels, represents an increase in both circulating chylomicrons and very low density lipoproteins in blood. Elevated triglyceride levels have been consistently associated with Type 2 diabetes, impaired glucose tolerance and Syndrome X.
- Increased triglyceride levels might possibly induce insulin resistance through interference with peripheral insulin binding and action. Conversely, persistent hyperglycaemia in combination with obesity may lead to high levels of triglycerides. Often it is impossible to determine which of the two metabolic disorders in this relationship has primacy.
- Hypertriglyceridaemia is also an independent risk factor for cardiovascular disease. It is considered that elevated levels of triglycerides play an important role in the pathogenesis of macroangiopathy.

Operational definition

- This indicator has been designed to provide a comparative picture of hypertriglyceridaemia in persons with Type 1 and Type 2 diabetes. Since insulin therapy is known to be highly effective in reducing triglycerides, a comparison of triglyceride levels would be useful for monitoring the management of the two forms of diabetes.
- Hypertriglyceridaemia for the purpose of this indicator is defined as fasting triglyceride levels above 4.0 mmol/L.
- It is expected that this indicator will be tracked using population-based biomedical risk factor data. However, in the absence of these data, information collected by the NADC survey will be used as proxy data.

Prevalence rates

Clinic-based data

- According to the NADC survey, the age-standardised prevalence rate for high triglycerides was estimated to be 15 per 1,000 among persons with Type 1 diabetes. The rate is much higher among individuals with Type 2 diabetes, almost 85 per 1,000 persons.
- The prevalence rate for hypertriglyceridaemia is much higher among males with Type 2 diabetes when compared to females, with a rate ratio of 1.5. However, the numbers are too small to make an objective assessment of triglyceride levels among persons with Type 1 diabetes.

Population-based data

- No population-based, national information on the distribution of triglycerides by type of diabetes is available. However, a regional study conducted in South Australia by Phillips et al (1998) included laboratory measurement of triglycerides among persons with Type 2 diabetes.
- According to this study, triglyceride levels above 4.0 mmol/L are prevalent at a rate of 136 per 1,000 persons. But almost half of the persons with Type 2 diabetes (478 per 1,000 persons) have triglycerides above 2.0 mmol/L.
- These prevalence rates are slightly higher than the rates estimated from the NADC study. The lower rates in the NADC study may partly reflect the clinical setting of the sample and regular diabetes care it offers.

Data sources

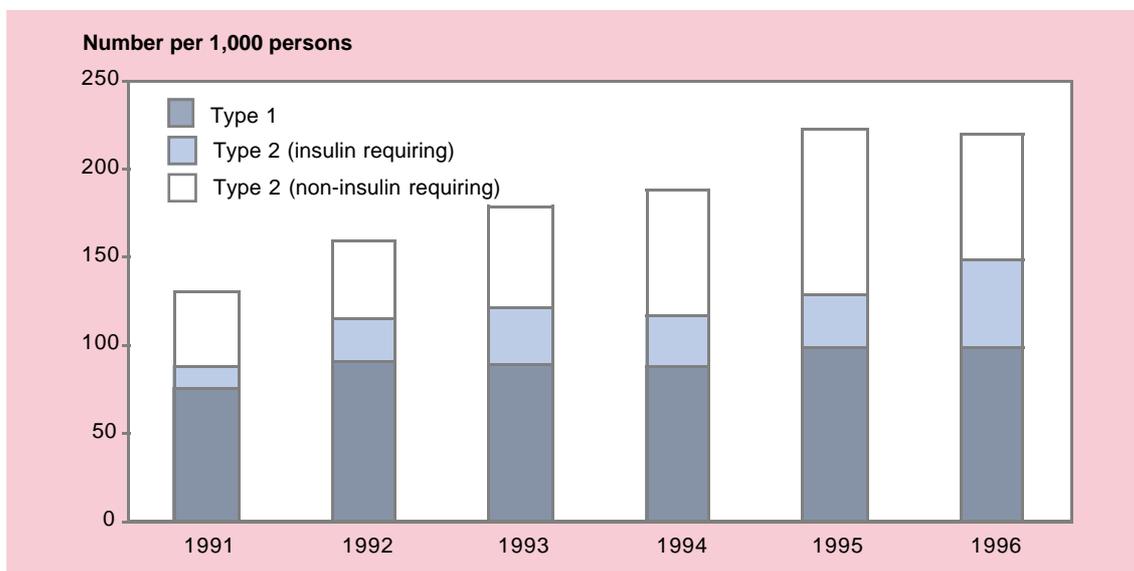
- No national benchmark, population-based information on triglyceride levels, self-reported or based on laboratory measurements, has become available since the 1989 NHF Risk Factor Prevalence Survey.
- Population-based, regional information on the prevalence of triglyceride levels among persons with Type 2 diabetes has been recently generated through a survey in South Australia (Phillips et al 1998). The study was based on a sample of 173 persons.
- Information on the prevalence of hypertriglyceridaemia among those attending diabetes clinics has been recently collected through an NADC survey. The NADC survey is based on an audit of patients attending specialist diabetes centres. The survey included 1,681 persons, aged 20+ years, presenting at 32 specialist diabetes service centres in the country. Of these, 83 per cent have Type 2 diabetes.

Data issues

- No direct comparison of lipid levels between the NADC and South Australian data is possible because of different sampling strategies. While the former includes patients under clinical care, the latter survey is population based. Besides, the two sets of estimates have been obtained using different standard populations for age adjustments.
- A population-based study of the prevalence of hypertriglyceridaemia among persons with and without diabetes is required for generating baseline information.

NHPA indicators for diabetes

Indicator 3.1: Proportion of persons with end-stage renal disease with diabetic nephropathy as a causal factor



Type of diabetes	Year					
	1991	1992	1993	1994	1995	1996
Type 1	76.0	91.0	90.0	88.0	97.7	97.9
Type 2 (insulin requiring)	11.5	24.0	31.0	29.0	30.8	50.0
Type 2 (non-insulin requiring)	42.0	44.0	57.0	70.9	94.9	71.0
All types	130.0	158.8	178.5	188.0	223.5	219.1

Note: Rates, age standardised to the 1991 Australian population, are given as number per 1,000 persons.

Source: Estimates based on data derived from the 1996 and 1997 ANZDATA Registry Annual Reports (Disney 1996; Disney et al 1997).

- Diabetic microvascular complications include disorders of the kidney. Some aspect of diabetic state (possibly hyperglycaemia) contributes directly to nephropathy that progresses to end-stage renal disease. In several cases, this necessitates transplantation or regular dialysis for survival.
- Several other factors contribute to end-stage renal disease. These include analgesic nephropathy, glomerulonephritis, high blood pressure, polycystic kidney and reflux, the effect of some of which may be accentuated further by the presence of diabetes.
- During the 1995 NHS, about 7 per cent of persons with diabetes reported the presence of kidney disease, more than four times the rate noted among persons without diabetes (ABS 1997a). More than one out of three persons with Type 2 diabetes in a South Australian survey were found to have poor glomerular filtration rate (Phillips et al 1998).

Operational definition

- This indicator measures the proportional contribution of diabetic nephropathy to the incidence of end-stage renal disease in Australia.
- Since the natural history of nephropathy in persons with Type 1 is known to differ from the course among persons with Type 2 diabetes, the contributions from two forms of the disease are presented separately.

Number of cases

- A total of 260 persons registered with Australia and New Zealand Dialysis and Transplant Registry in 1996 for end-stage renal disease had diabetes (Disney 1996).
- Persons with diabetes as the primary cause of renal disease account for almost one in five new registrants in the age group 25–84 years. The proportion declines from one in four among those aged 25–34 years to less than one in sixteen among those aged 75–84 years.
- More than a quarter of new end-stage renal disease registrants in 1996 — with diabetes as the primary cause of renal disease — had Type 1 diabetes. Another third of the registrants that year had Type 2 diabetes, but were on insulin treatment.
- The proportion for persons with Type 1 diabetes — with diabetes as the primary cause of renal disease — changes from 75 per cent in the age group 25–34 years to almost nil among those aged 75–84 years.

Time trends

- Concomitant with increases in new end-stage renal disease registrants over the last several years (from 982 in 1991 to 1,405 in 1996), new cases of end-stage renal disease with diabetes as the primary cause of renal disease also increased over five years (1991–1996). The proportional increase was however much higher — more than two-fold, from 123 in 1991 to 260 in 1996.

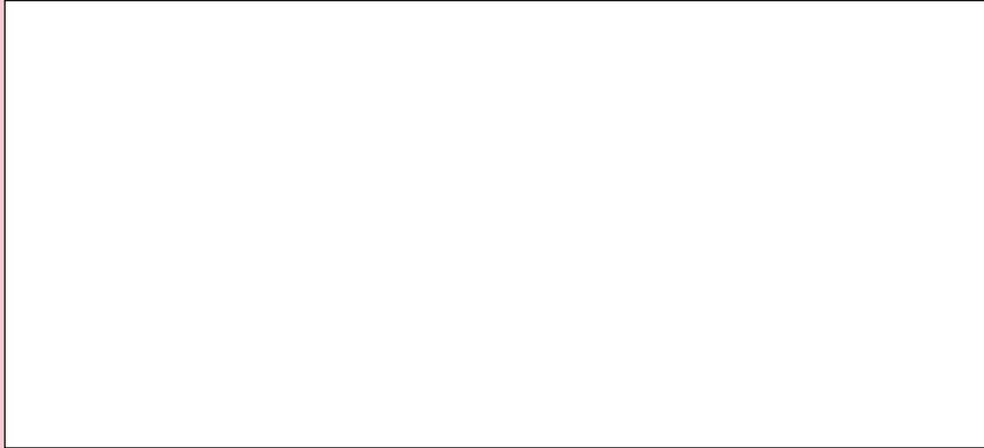
- In comparison, the number of new cases of end-stage renal disease without diabetes as the primary cause of renal disease increased by only 33 per cent during the same period, from 859 to 1,145.
- The proportion of end-stage renal disease cases with diabetes has increased from around one in seven cases in 1991 to more than one in five in 1995. This proportion however declined slightly in 1996. This proportional increase has been noted in all three groups of persons with diabetes identified here.
- A large part of this proportional increase is accounted for by increases in the number of persons with Type 2 diabetes, by almost 60 per cent between 1991 and 1996. The proportional rise for Type 1 diabetes was 29 per cent during this period.
- As the population ages further, this shift in relative contribution to end-stage renal disease from diabetes, in particular Type 2 diabetes, is likely to continue.

Data issues

- When age standardised, the relative contributions of various forms of diabetes to end-stage renal disease changes significantly. This is mainly because the age structure of persons with Type 1 diabetes and end-stage renal disease is very different from that for persons with Type 2 and end-stage renal disease.
- Age adjustment can sometimes produce bizarre results, in particular when two disparate distributions are pooled. Therefore, the results presented in the Figure and the accompanying Table should only be used for following time trends for each form of diabetes separately.

NHPA indicators for diabetes

Indicator 3.2: Incidence rate for eye disease among clinically diagnosed persons with diabetes



Population group	Incidence of blindness
Males	NA
Females	NA
Persons	8

Note: Rates, age standardised to the 1991 Australian population, are given as incidence per 1,000 persons.

Source: NADC (1998).

- Diabetic retinopathy is a common, though largely preventable, cause of blindness in Australia. Cataracts and glaucoma, two other major causes of blindness, are also more common among persons with Type 2 diabetes.
- The appearance and progression of diabetic retinopathy, and the resultant visual loss, is known to be associated with hyperglycaemia. High blood pressure, early age of onset of diabetes and duration of disease are other known risk factors.

Operational definition

- This indicator has been designed to monitor the incidence of eye disease among clinically diagnosed persons with diabetes.
- The diseases/conditions to be covered include vision-threatening retinopathy, cataracts, glaucoma and blindness.
- The indicator does not include persons who already have had vision-threatening retinopathy or blindness at the time of diagnosis of diabetes.
- The indicator is based on four hard end points. No account is taken of progression to various intermediate stages.

Incidence rates

- No information is available on the national incidence of vision-threatening retinopathy, cataracts and glaucoma.
- The NADC data suggest an annual incidence rate for technical blindness of 8 per 1,000 persons.

Prevalence rates

Retinopathy

- No national estimates of the prevalence of diabetic retinopathy are available.
- According to a South Australian survey, almost one in five persons with Type 2 diabetes (190 per 1,000 persons) have retinopathy. This includes both non-proliferative and proliferative retinopathy (Phillips et al 1998).
- The Newcastle study on the other hand reveals a prevalence rate for vision-threatening retinopathy of 130 per 1,000 among persons with clinically diagnosed diabetes (Mitchell 1985).
- Wide variation occurs in the prevalence of diabetic retinopathy among different populations. Several different factors contribute to this variation including genetic susceptibility and differences in prevalence rates for diabetes.

Cataracts and glaucoma

- According to the 1995 NHS, the prevalence rate for cataracts among those with diabetes is 99 per 1,000 persons in comparison to 16 per 1,000 persons among those without the disease.
- Glaucoma is also reported to be prevalent almost five times more often among those with diabetes during the 1995 NHS. The prevalence rates among persons with and without diabetes are 34 and 7 per 1,000 respectively.

Blindness

- According to the 1995 NHS, blindness is present in almost 57 out of 1,000 persons with diabetes, more than six times the rate among persons without diabetes.

Time trends

- No information on trends in the incidence of vision-threatening diabetic retinopathy is available. However, with increasing prevalence of diabetes and ageing of the population, the rates are likely to rise further.

Risk factors

- Increasing duration of diabetes and age over 40 years are two major predictors of diabetic retinopathy. The four-year relative risk of blindness among persons with diabetes has been estimated to be almost 29 times that in the general population.
- Retinopathy is much more common among persons with Type 1 diabetes than among those with Type 2 diabetes, reflecting mostly differences in the mean duration of the disease. However, persons with Type 2 diabetes are more likely to have an eye complication at the time of diagnosis.
- Large clinical trials in the United States (DCCT) and the United Kingdom (UKPDS) have demonstrated the benefits of good diabetes care and control in reducing the risk of retinopathy. These trials have also established the efficacy of laser photocoagulation in preventing visual loss from proliferative retinopathy and maculopathy.

Data issues

- Data to monitor eye diseases among persons with diabetes are highly variable in quality and content.
- The NADC survey is based on an audit of patients attending specialist diabetes centres. It includes persons with diabetes requiring specialist clinical management, in particular those who have had a poor control of their diabetes. A major limitation of the NADC sample is that it does not accurately reflect the conditions prevailing in the general community.
- A more appropriate national dataset would be based on a population-based study.
- Further work is required to develop a suitable operational definition. Since retinopathy progresses over time through various grades, the incidence rate may be computed on the basis of progression to the next stage of the disease (see, for example, Mitchell 1985).

NHPA indicators for diabetes

Indicator 3.3: Prevalence rate for foot problems among clinically diagnosed persons with diabetes



Population group	Prevalence of foot ulcers	
	Current	Previous
Males	NA	NA
Females	NA	NA
Persons	25	58

Source: NADC (1998).

- Diabetic foot problems include ulcers, gangrene and loss of sensitivity to pain and trauma. Peripheral neuropathy or vascular disease are usually the underlying complications. It is estimated that more than one in seven persons with diabetes will develop foot problems.
- Progression of these conditions often leads to amputations. Diabetes accounts for approximately half of all non-traumatic amputations.
- Most of the amputations are of lower level, that is amputations of toe, foot and ankle. Secondary amputations are also not uncommon.
- Mortality among persons with diabetes who develop foot problems, in particular if ulceration, infection, or gangrene occurs, is known to be high. Three-year survival rates of less than 50 per cent have been reported among diabetic amputees.

Operational definition

- This indicator has been designed to monitor the prevalence of foot problems among clinically diagnosed persons with diabetes. Presence of foot ulcers and lower leg amputations are used as the two endpoints for monitoring.
- Prior history of foot ulcers is an important indicator of the presence of undercurrent neuropathic or vascular complications. Information on previous foot ulcers is therefore important and included here for comparisons.

Prevalence rates

Foot ulcers

- Based on the 1998 NADC data, the prevalence rate for current foot ulcers is estimated to be 25 per 1,000 among persons with clinically diagnosed diabetes. In addition, almost 58 persons (using 1,000 as the denominator) had ulcers on previous occasions.
- The above estimates are based on persons with diagnosed diabetes, and attending a diabetes clinic regularly. A large proportion of persons with diabetes in the general population may be under less regular care for their condition than those included in the NADC survey.
- Health care factors and diabetic history are important in the development of foot problems. The prevalence of diabetic foot problems therefore could be more common in the general population. Conversely, the NADC sample may represent a more severe end of the spectrum of the disease.

Amputations

- Absence of limbs was reported at a rate of 18 per 1,000 persons with diabetes during the 1995 NHS. Despite the higher mortality of diabetic amputees, the rate was more than three times greater than that among persons without diabetes.
- Most of the amputations among persons with diabetes are those of toe, foot and ankle. However, more disabling amputations, including those above the knee, are equally common among those with and without diabetes.
- The incidence of lower limb amputations is estimated to be 1.1 per 1,000 persons among persons attending the NADC clinics.

Risk factors

- A variety of risk factors have been identified for foot problems among persons with diabetes. These include age, sex, ethnic background, peripheral neuropathy, peripheral vascular disease, diabetes type, glycaemic control and clinical duration of diabetes.
- A positive history of retinopathy is also a factor in increased risk of foot problems.

Data sources

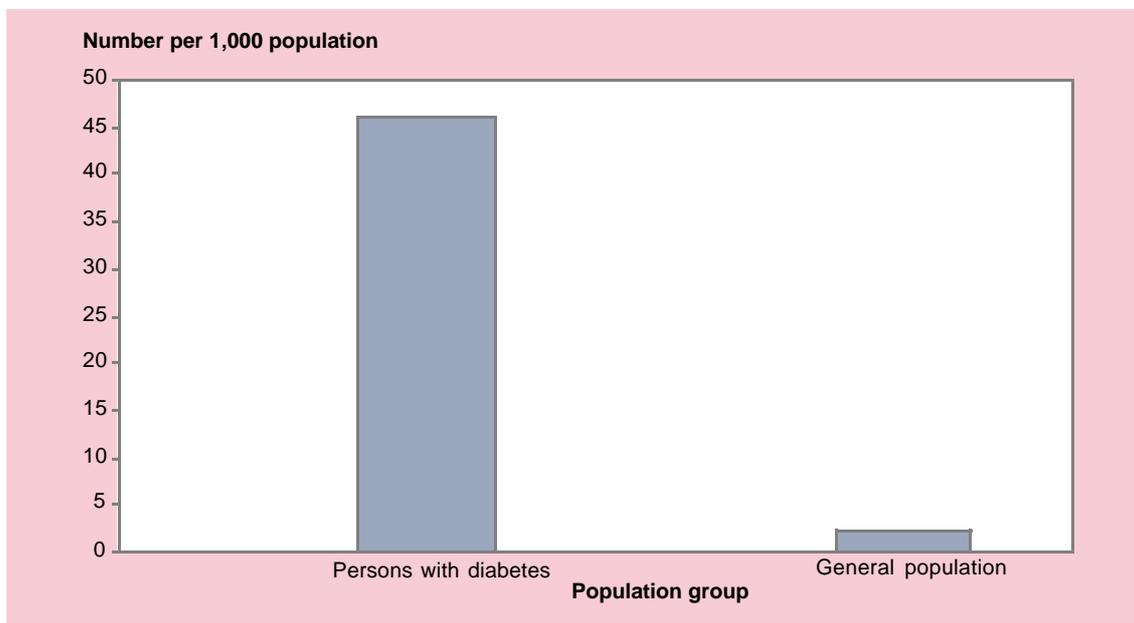
- 1995 NHS for lower limb amputations data; self-reported.
- Estimates for foot ulcers are based on the NADC data, which is an audit of patients attending specialist diabetes centres.

Data issues

- The majority of foot ulcers are treated in outpatient settings, which limits effective surveillance of the problem. Some information on the extent of the foot problems however may be obtained from hospital separations data.
- There are no population-based, national data on foot problems among persons with diabetes. The information obtained through the NHS is less specific since it pertains to lower limb amputation in general than to specific parts of the foot.
- The NADC survey includes persons with diabetes requiring specialist clinical management, in particular those who have had a poor control of their diabetes. Its major limitation is that it does not accurately reflect the conditions prevailing in the general community.
- A more appropriate national dataset would be based on a population-based study.

NHPA indicators for diabetes

Indicator 3.4: Incidence rate for coronary heart disease and stroke in clinically diagnosed persons with diabetes and the general population



Population group (aged 35–69 years)	Heart attack*		Stroke	
	Persons with diabetes	General population	Persons with diabetes	General population
Males	NA	3.5	NA	NA
Females	NA	1.2	NA	NA
Persons	42	2.3	24	NA

* Estimated rates for fatal and non-fatal heart attacks, age group 35–69 years, financial year 1995–96, not age standardised.

Sources: AIHW (unpublished data); NADC (1998).

- People with diabetes have a higher risk of coronary heart disease and stroke. Along with renal disease, coronary heart disease and stroke are two of the major causes of death among persons with diabetes, accounting for more than half of the deaths.
- In contrast to persons without diabetes, coronary heart disease occurs at younger ages among persons with diabetes. Furthermore, persons with diabetes are known to have relatively poor prognosis following a heart attack or stroke.
- Hospitalisation statistics also reveal diabetes as a co-diagnosis with coronary heart disease and stroke in almost 19 per cent of separations.
- During the 1995 NHS, about 15 per cent of persons with diabetes reported the presence of heart disease, at almost six times the rate reported by persons without diabetes. An additional 4 per cent reported having suffered a stroke, again at a higher rate (ABS 1997b).

Operational definition

- Disease prevalence rates are a function of disease incidence and its management. This indicator has been designed to follow the incidence of diabetes among persons with clinically diagnosed diabetes, in comparison to the rate in the general population.
- The indicator provides a proxy for treatment and management of hyperglycaemia and other cardiovascular disease risk factors present among persons with diabetes.
- No distinction is made between Type 1 and Type 2 diabetes. Persons among whom diabetes is diagnosed at the time of or following a coronary heart disease or stroke event are not covered by this definition as this may inflate the rate of ascertainment.
- No data are available for the incidence of coronary heart disease. Information on non-fatal, first heart attack has been presented here instead.
- In correspondence with Indicator 2.1 for NHPA Cardiovascular Health (HEALTH & AIHW, in press), the age range for the indicator is set at 30–79 years. However, the data are currently available for ages 35–69 years only, and have been reported as such.

Incidence rates

- Based on the NADC data, the incidence rate for heart attack is estimated as 42 per 1,000 persons with clinically diagnosed diabetes. In comparison, the incidence of heart attack in the general population has been estimated to be 2.3 per 1,000 persons, at one-twentieth the rate noted among persons with diabetes.
- The incidence of stroke among persons with clinically diagnosed diabetes, based on the NADC data, has been estimated as 24 per 1,000 persons. No comparable information is available on the incidence rate in the general population but the rate is likely to be much lower.

Risk factors

- Persons with Type 2 diabetes suffer exceptionally high rates of coronary heart disease because they share many of the risk factors for heart disease, including central obesity, high blood pressure, hypertriglyceridaemia and high cholesterol (McCarty et al 1996). The excess risk of heart disease occurs with Type 1 diabetes as well.
- Persons with diabetes who have had a heart attack are at an increased risk of having another (potentially fatal) heart attack or stroke.

Time trends

- Trends in incidence of coronary heart disease and stroke among persons with diabetes may be influenced by a variety of factors. These include, besides ageing of the population and mean duration of diabetes, management of hyperglycaemia and other common risk factors such as overweight/obesity, hyperlipidaemia and high blood pressure.
- No data are currently available to determine trends in the incidence of coronary heart disease and stroke among persons with diabetes in Australia.

Data sources

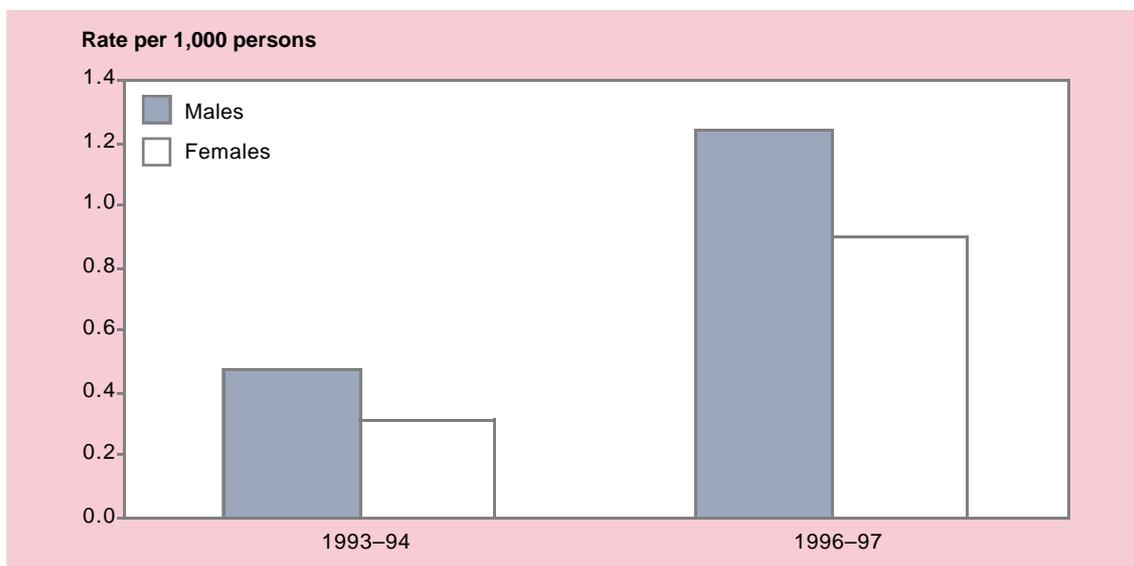
- No national data are available on the incidence of coronary heart disease and stroke among Australians with diabetes. The information reported is based on a survey of those attending specialist diabetes clinics (the NADC survey).
- Information on the incidence of heart attack in the general population was obtained using methodology developed by the Universities of Newcastle and Western Australia, and Queensland Health. No information is currently available on the incidence of stroke.

Data issues

- Population-based studies are required to determine the true incidence of diabetes-related complications such as coronary heart disease and stroke.
- Patients attending diabetes clinics are likely to represent the more severe end of the spectrum of the disease than those under less organised care, and therefore may yield biased estimates. But patients under regular care are likely to have better management of their disease and associated risk factors.
- Also, there is virtually no information available on non-fatal outcomes to determine the pattern of incidence of cardiovascular disease complications among persons diagnosed with diabetes. The study by Phillips et al (1995) however provides some information on this aspect for coronary heart disease.
- Self reports through NHS also provide a picture of the relative risk of heart disease and stroke among persons with and without diabetes. However, these studies do not readily yield incidence data.
- Several population-based studies have compared the risk of fatal heart attack or stroke among persons with and without diabetes. The suitability of this information to follow trends in the management of diabetes and its complications needs to be determined.

NHPA indicators for diabetes

Indicator 4.1: Hospital separation rate for end-stage renal disease with diabetes as an additional diagnosis



Population group	Year	
	1993-94	1996-97
Males	0.5	1.2
Females	0.3	0.9
Persons	0.4	1.0

Note: Rates, age standardised to the 1991 Australian population, are given as separations per 1,000 persons.

Source: AIHW National Hospital Morbidity Database.

- Kidney-related problems including renal failure constitute the single largest cause of hospitalisation in Australia (AIHW 1998a). Hospitalisation for dialysis is the most commonly listed reason for hospitalisation.
- Diabetic nephropathy is one of the major contributors to renal failure. During the 1995 NHS, about 7 per cent of persons with diabetes reported the presence of kidney disease, more than four times the rate noted among persons without diabetes (ABS 1997a). More than one in three persons with Type 2 diabetes in a South Australian survey were found to have poor glomerular filtration rate (Phillips et al 1998).
- Because of the limitation of the hospital separation data — episode rather than individual based — it is not possible to generate information on the impact of diabetes on hospitalisation for renal failure on an individual basis. However, hospital-based information provides an indication of the extent of morbidity associated with a disease and impact on the community.

Operational definition

- This indicator tracks hospital separations where both renal failure (ICD-9-CM: 584–585) and diabetes (ICD-9-CM: 250) are listed as co-diagnoses, with neither of them necessarily the principal diagnosis.
- Although renal failure is much more prevalent among persons with Type 1 diabetes than those with Type 2 diabetes, no distinction is made between the two in this report.

Hospital separation rates

- In 1996–97, both renal failure and diabetes recorded as co-diagnoses for a total of 20,344 separations. These accounted for approximately 7.9 per cent of all separations with renal failure as a listed diagnosis.
- Almost one in thirteen males admitted to hospital with renal failure have diabetes as a co-diagnosis. The ratio is slightly higher among females. The proportion is markedly higher for patients over the age of 34 years with an upward trend all through the later age groups.
- Age-standardised hospital separation rate for diabetes and renal failure as co-diagnoses is estimated to be 1.0 per 1,000 persons in 1996–97. The rate is greater among males, almost 40 per cent higher than the rate among females.

Time trends

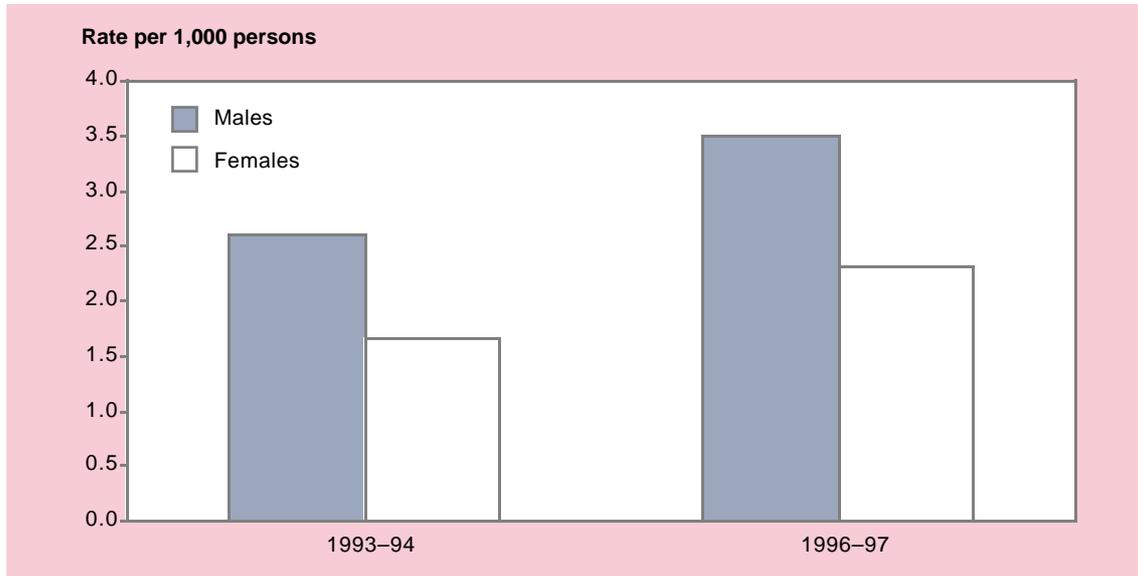
- A large increase (34.6 per cent) in the rate of separations with diabetes and renal failure listed as co-diagnoses has been noted between 1993–94 and 1996–97. This increase partly reflects the upward trend noted in the relative proportion of persons with diabetes among end-stage renal disease patients (see Indicator 3.1).

- The number of separations with renal failure as a diagnosis increased by more than 160 per cent during the same period. This increase is attributed to increased inclusion of dialysis and dialysis catheter procedures as hospital separations.
- The gap between the change in hospital separation rates for renal failure as co-diagnosis, and renal failure as a diagnosis, between 1993–94 and 1996–97 is inexplicable. Over time, there has been a greater propensity to list diabetes as a diagnosis, however this increased propensity is not fully reflected in co-diagnoses for renal failure.

Data issues

- The validity of using hospital separations data to assess the burden of hospitalisation associated with diabetes has been questioned. This is mainly because the presumption that every hospitalisation for persons with diabetes should have the condition listed as a comorbid diagnosis is met varyingly.
- Accordingly, under-reporting of hospital separations of people with diabetes is likely to occur. In a large proportion, it is likely that diabetes is not listed as principal or as one of the diagnoses. The extent of this under-reporting in Australia has not been determined.
- The indicator has not been designed to provide information on the proportion of persons with diabetes who are hospitalised for renal failure. This is because of the limitation of the hospital separation data — it is episode rather than individual based. Nonetheless, this indicator, in combination with information derived from the NHS, provides a useful picture of the kidney-related morbidity among persons with diabetes.

Indicator 4.2: Hospital separation rates for coronary heart disease or stroke with diabetes as an associated diagnosis



Population group	Year	
	1993-94	1996-97
Males	2.6	3.5
Females	1.7	2.3
Persons	2.1	2.9

Note: Rates, age standardised to the 1991 Australian population, are given as separations per 1,000 persons.

Source: AIHW National Hospital Morbidity Database.

- Persons with diabetes are highly prone to coronary heart disease and stroke. Furthermore, they are also known to have worse prognosis following a stroke (Kuller 1995). Hospitalisation for the two problems is therefore common among persons with diabetes.
- Persons with Type 2 diabetes suffer exceptionally high rates of coronary heart disease because they share many of the traditional risk factors for heart disease including central obesity, high blood pressure, hypertriglyceridaemia and high cholesterol (McCarty et al 1996). The co-presence of diabetes and these risk factors accentuates the situation further. Persons with Type 1 diabetes are also at increased risk to develop cardiovascular disease problems.
- During the 1995 NHS, about 15 per cent of persons with diabetes reported heart disease, at almost six times the rate noted among persons without diabetes. In addition, more than 4 per cent of respondents have had a stroke, eight times more often than among those without diabetes (ABS 1997a).

Operational definition

- This indicator tracks hospital separations for which diabetes (ICD-9-CM: 250) is a comorbid diagnosis with coronary heart disease (ICD-9-CM: 410–414), or stroke (ICD-9-CM: 430–438), or both.
- Since persons with both Type 1 and Type 2 diabetes are at an increased risk for coronary heart disease and stroke, no distinction is made between the two types of diabetes.

Hospital separation rates

- In 1996–97, there were 272,227 hospital separations for which coronary heart disease or stroke was one of the listed diagnoses. For 56,256 separations, diabetes was listed as one of the diagnoses in combination with coronary heart disease or stroke. In comparison, a total of 267,449 hospital separations listed diabetes as a diagnosis.
- Almost one out of six males admitted to hospital with coronary heart disease or stroke as a diagnosis have diabetes. The proportion is slightly higher among females.
- Age-standardised hospital separation rate for the diagnosis of diabetes, in conjunction with coronary heart disease or stroke as additional diagnoses, is estimated to be 2.9 per 1,000 persons in 1996–97. The rate is higher among males than females.

Time trends

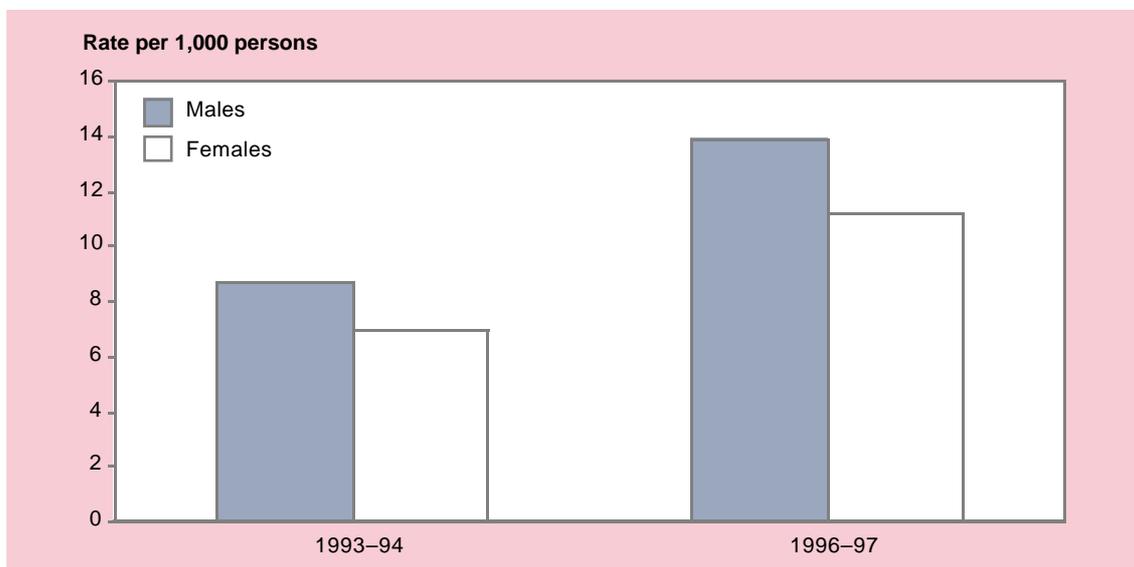
- A significant increase (more than 38 per cent) has been noted in the proportion of separations with diabetes and coronary heart disease or stroke as co-diagnoses between 1993–94 and 1996–97. This contrasts with limited increase in separation rates during that period for coronary heart disease or stroke as listed diagnoses, irrespective of whether diabetes was a diagnosis or not.
- A greater propensity to code diabetes as one of the diagnoses may account for this trend. Changes in the pattern of incidence and prevalence of coronary heart disease and stroke, combined with population ageing, may have also contributed to increase in diabetes as an associated diagnosis.

Data issues

- The validity of using hospital separation data to assess the extent of morbidity associated with diabetes has been questioned. This is mainly because the presumption that every hospitalisation for persons with diabetes should have the condition listed as a comorbid diagnosis is met varyingly.
- Under-reporting of hospital separations of people with diabetes is likely to occur. In a large proportion of pertinent cases, it is likely that diabetes is not listed as a diagnosis. The extent of this under-reporting in Australia has not been established.
- The indicator has not been designed to provide information on the proportion of persons with diabetes who are hospitalised for cardiovascular disease-related problems. This is because of the limitation of the hospital separation data — it is episode-based, rather than individual-based.
- Another major limitation of hospital separation data in respect of diabetes is the coding bias. For example, diabetes is likely to be classified as a principal diagnosis in less than one out of twelve hospital separations (8.6 per cent in 1996–97) that list diabetes as one of the diagnoses.
- In contrast, coronary heart disease or stroke are more likely to be listed as primary diagnosis, in more than three-quarters of hospital separations (76.3 per cent in 1996–97), if two conditions are listed as one of the diagnoses.
- Nonetheless, this indicator, in combination with NHS information, provides a useful profile of cardiovascular disease morbidity among persons with diabetes.

NHPA indicators for diabetes

Indicator 4.3: Hospital separation rates for conditions other than end-stage renal disease and coronary heart disease/ stroke for persons for whom diabetes was reported as the principal diagnosis or an additional diagnosis



Population group	Year	
	1993-94	1996-97
Males	8.7	13.9
Females	6.9	11.2
Persons	7.7	12.4

Note: Rates, age standardised to the 1991 Australian population, are given as separations per 1,000 persons.

Source: AIHW National Hospital Morbidity Database.

- Persons with diabetes are hospitalised more often than those without diabetes. Both Type 1 and Type 2 diabetes lead to conditions that require hospitalisation more often.
- According to the 1995 NHS, respondents with diabetes are admitted to hospital, based on episodes during the two weeks prior to the interview, at a rate of 19 per 1,000 persons.
- This rate is almost three times the rate reported by those without diabetes, 7 per 1,000 persons (ABS 1997b). While a substantial proportion of this difference is caused by end-stage renal disease and cardiovascular disease problems, the rate is high in respect of several other conditions and problems as well.
- In addition, persons with diabetes visit a hospital day clinic at more than twice the rate. Most of this difference is accounted for by visits in relation to the management of diabetes and its complications.
- Because of the limitation of the hospital separation data — episode rather than individual based — it is not possible to generate hospital-based information on an individual basis. However, an indicator can be designed to indirectly capture information on morbidity associated with diabetes from hospital separation data where diabetes is a listed diagnosis.

Operational definition

- This indicator tracks hospital separations where diabetes (ICD-9-CM: 250) is a listed diagnosis, but excludes coronary heart disease, stroke and renal failure as co-diagnoses. Since persons with both Type 1 and Type 2 diabetes are at an increased risk for hospitalisation, no distinction is made between the two types of diabetes.
- For the purpose of this report, the indicator also does not cover the following diseases and conditions: infectious and parasitic diseases, neoplasms, mental disorders, congenital anomalies, injury and poisoning, factors influencing health status and contact with health services (V codes, including visits for dialysis).

Hospital separation rates

- In 1996–97, there were 241,146 separations where diabetes is listed as a co-diagnosis, accounting for 6.1 per cent of all separations for other conditions excluding end-stage renal disease and coronary heart disease/stroke.
- This proportion increases steadily from about 1 per cent for the 20–24 years age group, to about 12 per cent in the 60–64 years age group, and remains high. The female age-specific separation rates stagger the male rates by about a five-year cohort.
- Almost one out of twelve males admitted to a hospital had diabetes as an additional diagnosis. The proportion was much lower among females.
- Age-standardised rate for hospital separation in 1996–97 for diabetes listed as a diagnosis in conjunction with other diagnoses is estimated to be 12.4 per 1,000 persons. The rate is greater among males, more than 24 per cent higher than the rate among females.

Time trends

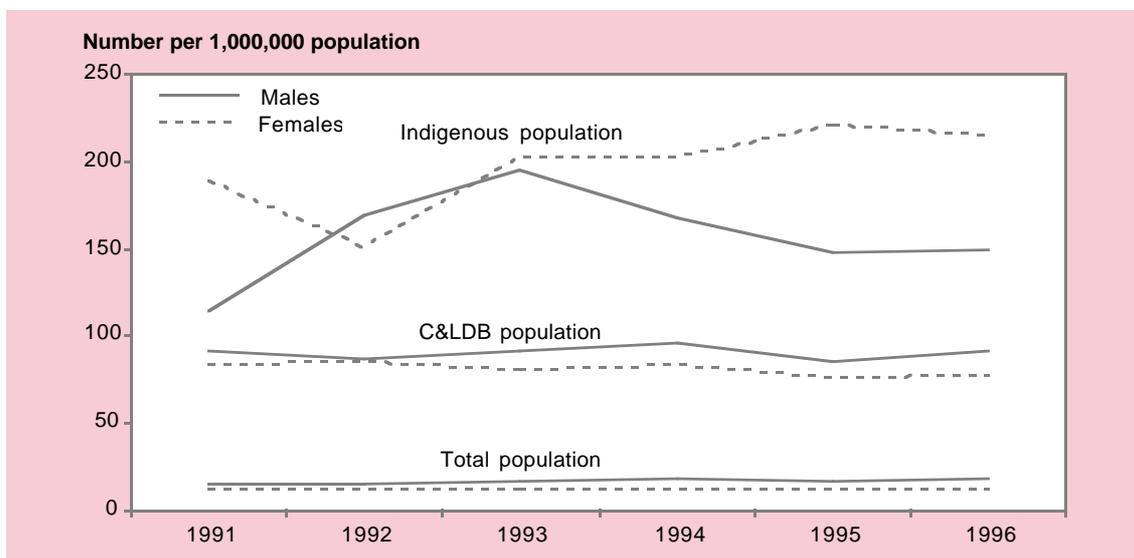
- The number of separations where diabetes is a co-diagnosis increased by more than 60 per cent between 1993–94 and 1996–97. The rate of growth was much higher than for all diagnoses (excluding the ones listed earlier), less than 12 per cent during the same period. These differences in growth rates mostly reflect a changing propensity to code diabetes as one of the diagnoses.

Data issues

- The validity of using hospital separation data to assess the burden of hospitalisation associated with diabetes has been questioned. This is mainly because the presumption that every hospitalisation for persons with diabetes should have the condition listed as a comorbid diagnosis is met varyingly.
- Accordingly, under-reporting of diabetes hospital separations is likely to occur. In a large proportion of cases, it is likely that diabetes is not listed as one of the diagnoses. The extent of this under-reporting in Australia has not been established.

NHPA indicators for diabetes

Indicator 5.1: Death rates for diabetes in the general population, Indigenous population and among people from culturally and linguistically diverse backgrounds



Population group		Year					
		1991	1992	1993	1994	1995	1996
Indigenous	Males	114.8	169.0	194.5	167.7	148.1	148.7
	Females	188.3	150.7	203.5	202.2	220.5	215.5
C&LDB	Males	91.7	87.0	91.1	95.9	85.4	91.3
	Females	84.1	85.9	81.2	83.7	75.9	77.1
General	Males	15.8	15.5	16.8	17.8	16.5	18.3
	Females	11.5	12.0	11.9	12.2	11.9	12.3

Note: Rates, age standardised to the 1991 Australian population, are given as number per 100,000 persons.
C&LDB = Culturally and linguistically diverse backgrounds.

Source: AIHW National Mortality Database.

- Diabetes, with its complications, is one of the leading causes of death in Australia. It ranked seventh as the primary cause of death in 1996, a rank it has held for many years.
- It also contributes to deaths caused by several conditions and diseases. In particular, diabetes is known to contribute to deaths caused by cardiovascular disease and renal problems.
- Premature mortality is a hallmark of diabetes. Death rates among Australians with diabetes are more than twice as high as in comparison to the rate in the general population. The death rate ratios are in particular high among Indigenous people.
- Statistics suggest that more than one-seventh of persons with Type 1 diabetes will die by the age of 40 years, at which time the death rate ratio will be more than 20 in comparison to the rate in the general population (Portuese & Orchard 1995).
- Among middle-aged persons with Type 2 diabetes, life expectancy is estimated to be reduced by 5–10 years (Geiss et al 1995). Reduction in life expectancy is greater for those with complications, but decreases with increasing age at diagnosis.

Operational definition

- This indicator has been designed to generate a comparative picture of diabetes-associated mortality in Australia over time.
- Although death rate is an indicator of the net impact of diabetes and its associated complications, in the absence of reliable information on diabetes as an underlying cause of death, this indicator focuses on diabetes (ICD: 250.0–250.9) as the primary cause of death.
- Two major population groups covered by the indicator are the Indigenous population and persons with a culturally and linguistically diverse background, known to have high prevalence of the condition.
- Sex-specific information is also generated to emphasise differences in mortality patterns, in death rates between males and females with diabetes as well as in mortality ratios in comparison to those without diabetes.
- No distinction is made between the various forms of diabetes.

Death rates

General population

- In 1996, diabetes was cited as the underlying cause of 2,991 deaths in Australia, accounting for 2.3 per cent of deaths from all causes. It was the seventh leading cause of death that year, with an age-standardised rate of 16 per 100,000 persons (ABS 1997c). The rate is almost 50 per cent higher among males than females.

Indigenous population

- Death rates from diabetes are much higher among Indigenous people, with age-standardised rates of 149 per 100,000 males and 216 per 100,000 females, with rate ratios respectively of 8.1 and 17.5 in comparison to the total population in 1996.
- Diabetes is highly prevalent among Indigenous people, with rates varying between 10 to 30 per cent in some population groups (Colagiuri et al 1998), which contributes to higher death rates.
- The impact of diabetes on the Indigenous population is accentuated further by low survival. According to Phillips et al (1995), the eight-year survival rate among Indigenous people diagnosed with Type 2 diabetes is less than 56 per cent.

Persons from culturally and linguistically diverse backgrounds

- Death rates from diabetes are also much higher among people from culturally and linguistically diverse backgrounds, with age standardised rates of 91 per 100,000 males and 77 per 100,000 females, with rate ratios respectively of 5.0 and 6.3 to the total population in 1996.
- Diabetes is highly prevalent among Micronesians, Polynesians and certain Melanesian Pacific Islanders, migrant Asian Indians and Chinese, some Arab populations, and some European communities, especially those from Southern Europe (McCarty et al 1996).

Time trends

- Dramatic changes have been noted in the pattern of mortality from diabetes this century. After the introduction of insulin in 1920s, not only did the survival rates improve for persons with diabetes but a major shift also occurred in the causes of death, in particular among those with Type 1 diabetes.
- Availability of oral hypoglycaemic agents and other therapies has also contributed to improvement in the survival of persons with other forms of diabetes.
- The impact of the availability of improved therapies on diabetes-associated mortality may now be leveling off. Death rates for diabetes are instead on the rise in Australia. Between 1991 and 1996, the death rate for diabetes increased at a rate of 2.9 per cent annually among males although no change was noted among females.
- The reversal of the trend may be attributed to ageing of the population and increasing incidence of diabetes. An increasing propensity to identify diabetes as the primary cause of death may also contribute to this increase.
- Death rates from diabetes among Indigenous males peaked in 1994, but continue to rise 5.1 per cent annually among Indigenous females.
- The death rate decreased among females from culturally and linguistically diverse backgrounds at an annual rate of 2.2 per cent during 1991–1996 but was stable among their male counterparts during that period.

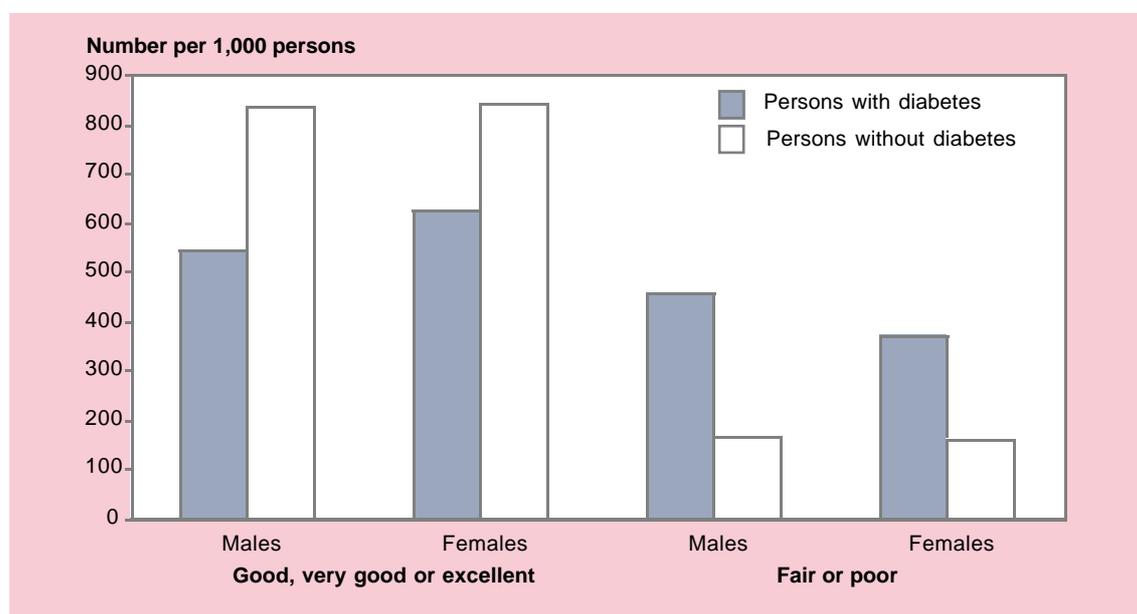
Diabetes-associated mortality

- Diabetes contributes to a much larger proportion of deaths than the above figures suggest. The figures given above indicate only the number of deaths directly attributable to diabetes.
- In 1995, for example, there were 8,839 deaths where diabetes is mentioned on the death certificate but is not reported as the underlying cause of death. This number is in addition to 2,708 cases where diabetes is given as the primary cause of death.
- Thus, diabetes could have contributed to almost seven per cent of total deaths, with an age-standardised rate of 49 per 100,000 population that year (ABS 1997c), and even that may be an underestimate.
- Cardiovascular disease is the major cause of death among persons with diabetes (Phillips et al 1990). However, renal disease was the direct cause of death in more than 22 per cent of Indigenous persons with diabetes (Phillips et al 1995), followed by infections (21 per cent) and coronary heart disease (14 per cent).
- The death rate ratio for people with diabetes, in comparison to those without diabetes, is estimated to be around two-fold. For people with Type 2 diabetes, the death rate for people with diabetes has been estimated to be between 20 to 80 per cent higher than for the general population in Western Australia (Knuiman et al 1992; McCann et al 1994). The ratios are higher among people with Type 1 diabetes.

Data issues

- The validity of deaths data in the context of diabetes has been questioned because of problems with sensitivity and specificity of death certificates. The presumption that diabetes should be recorded as one of the causes of death for all persons with diabetes is met varyingly on death certificates. According to Phillips et al (1995), 44 per cent of death certificates in Central Australia make no mention of diabetes.
- The problem is accentuated further with only one underlying (previously known as primary) cause of death coded. Since diabetes contributes to many causes of death, albeit to a variable degree, lack of information on diabetes as an additional cause of death masks its overall contribution to mortality.
- Beginning with deaths reported in 1997, the ABS has commenced coding all underlying causes of death reported on death certificates. This will improve information on the cause-of-death patterns for persons with diabetes. Further improvement is also needed in listing underlying causes of death on certificates.

Indicator 6.1: Self-assessed health status of persons with and without diabetes



Health status	Population group (aged 30 years and over)	Self assessment	
		Persons with diabetes	Persons without diabetes
Good, very good or excellent	Males	543	827
	Females	626	834
	Persons	605	837
Fair or poor	Males	457	173
	Females	374	166
	Persons	395	163

Note: Rates, age standardised to the 1991 Australian population, are given as number per 1,000 persons.

Source: ABS (1997a).

- A positive feeling of health is linked to resilience and resistance to disease. In the context of a lifelong disease such as diabetes, it not only implies current well being but also presages future management of the disease.
- Several studies during the past decade have revealed negative psychosocial aspects of chronic diseases such as diabetes. Structured diagnostic interviews have revealed increased prevalence of depression among persons with diabetes. There is also evidence that anxiety disorders, in particular generalised anxiety disorder and simple phobia, are more common in this group (Lustman & Gavard 1995).
- It is a prevalent clinical belief that depression and other psychological problems in diabetes are secondary to psychosocial hardship brought on by the chronic nature of the disease and its complications. However, the nature of psychological problems in diabetes is complex, and a range of biological, genetic and environmental factors are likely to contribute to their occurrence.
- Self assessment of health in this context provides a window on an individual's ability to cope with chronic diseases, institute changes in health-related behaviours and react to the newly acquired health risk status. The information is highly relevant to understanding health-related life-style behaviours and health service utilisation.

Operational definition

- This indicator compares self-assessed health status of persons with and without diabetes in the general population, using a global measure of health status based on the question:
In general would you say your health is:
Excellent, very good, good, fair or poor?
- Two different categories are considered, namely those rating their health as: 'good, very good or excellent' and 'fair or poor'. In the absence of national data on assessed health status of children with diabetes, the indicator is limited to those aged 18 years and over.

Health profile

- Slightly more than 60 per cent of adults with diabetes, responding to the 1995 NHS question, rate their health as 'good to very good to excellent'. This contrasts with almost 84 per cent of persons who tend to rate their health in that category. While no difference is found between the two sexes, males with diabetes were more likely to report their health as 'fair or poor'.
- Self-assessed health status is age-related, both among persons with and without diabetes. Only five per cent of persons with diabetes aged 18–30 years, most of them with Type 1 diabetes report their health as 'fair or poor'. In comparison, one out of ten persons with diabetes in the age range 55–74 years, report their health as 'fair or poor'.

- SF-36 scores, also generated by the 1995 NHS, support the above results. Those with diabetes and aged 18 years or over had statistically significant lower standardised mean scores than those without diabetes across all eight SF-36 scales. General health and role limitations due to physical health problems reveal the largest differentials (ABS 1997a). For details on SF-36 scales, see Appendix 2.
- The self-assessed health status data are of a subjective nature, ie in the context of health as well-being. Any number of factors that may not be related to health may influence perceptions. However, the more objective assessment of health status using the SF-36 questionnaire confirms the health impact of diabetes.

Data issues

- The health self-assessment question has been included in several national health surveys, including the 1989–90 and 1995 NHS. It is also included in the SF-36 questionnaire. In due course, it may be possible to have time series information for this indicator at a national level.
- On account of small numbers, the NHS data have not been adjusted for several of the factors that may influence the responses. These include level of family income, family composition and other markers of social support.

Appendix 2

Data and statistical issues

Data and statistical issues concerning individual indicators have been described in relevant sections of the report. However, there are several common issues that need to be discussed more generally. These relate mostly to the nature and quality of data, their comparability, timeliness, gaps and deficiencies. Notes on statistical procedures for converting data into useful information, such as age standardisation, estimation of rates and ratios, and life tables, also need to be assembled.

The NHPA *goals and targets* approach has implications for the range of information collected, and its analysis. The adoption of a set of defined indicators requires the development of standard definitions and standardised data elements. The establishment of baselines and appropriate time series for regular reporting are equally important. The data collections may need to be tailored to meet the reporting requirements, or new data collections instituted.

As the diabetes indicators are being reported here for the first time, several data definition and collection issues need to be resolved. This appendix briefly describes some of these issues. For a general discussion of sources, developments and deficiencies in Australian health statistics, see *Australia's Health 1998* (AIHW 1998a).

Data issues

Data sources

Sources of data for monitoring diabetes are wide and varied. Many of the data collections that are used for diabetes monitoring are the by-products of administrative collections (eg deaths and hospital separations). Other collections are specifically designed to monitor the prevalence of diabetes and its complications. Most of the latter collections however are not national in scope or coverage at this stage.

Diabetes-related information for this report was extracted from several national and quasi-national data sources. These include the National Mortality and National Hospital Morbidity databases, the NHS, the National Nutrition Survey, NADC Surveys, ANZDATA and NATSIS. In addition, there are several other data sources that have the potential to yield useful information for diabetes monitoring.

National Mortality Database

Registration of deaths in Australia is the responsibility of the State and Territory Registrars of Births, Deaths and Marriages. Information on the cause of death is supplied by the medical practitioner certifying the death, or by a coroner. Other information about the deceased is supplied by a relative or other person acquainted with the deceased or by an official institution where the death occurred. Registration of death is a legal requirement in Australia, and compliance is virtually complete.

Information on deaths is provided by the Registrars to the ABS for coding of information and compilation into national statistics. AIHW maintains these data in a national database.

Deaths data remain the most comprehensively collected national data pertaining to health. The reliability of these data depends principally on the information listed on the death certificate, or that available in coroners' records, as well as on the reliability of the application of ICD-9 codes by the ABS to that information. In particular, deaths relating to diabetes are substantially under-reported on death certificates as well as in ABS coding which, until 1996, was based on a single underlying cause of death (Phillips et al 1995). The latter issue is now being addressed through multiple cause-of-death coding by ABS (introduced in 1997).

The ABS has also introduced an automated coding system for deaths data.

A further difficulty encountered in using the mortality database is the poor identification of Indigenous people in New South Wales and Victoria, and (until recently) lack of information on Indigenous deaths in Queensland. Analysis of Indigenous mortality for diabetes has therefore been limited to the Northern Territory, Western Australia and South Australia where more than 90 per cent of Indigenous deaths are identified (ABS 1997c).

National Hospital Morbidity Database

The AIHW National Hospital Morbidity Database is a compilation of electronic summary records collected in admitted patient morbidity systems in public and private hospitals. Almost all hospitals in Australia are included. The exceptions are public hospitals not within the jurisdiction of a State or Territory health authority or the Department of Veterans' Affairs (that is, hospitals operated by the Department of Defence, for example, and hospitals located in offshore Territories). In addition, data were not able to be supplied for 1995–96 for the one private hospital in the Northern Territory, the private free-standing day hospital facilities in the Australian Capital Territory and the public psychiatric hospitals in Queensland (AIHW 1998b).

Hospitals collect clinical and administrative information about the patients they treat, including socio-demographic, diagnostic, duration-of-stay data and the procedures performed.

This information is collated, on an inpatient basis, by the various State and Territory health authorities, and by the Department of Veterans' Affairs. The AIHW then receives the collections from these agencies, and maintains them without unique identifiers in a national hospital morbidity database.

A perceived deficiency in hospitalisations data is in the level of identification of Indigenous status on hospital records. This is likely to vary considerably. While the hospital separation rate in 1995–96 for the Indigenous population (440 per 1,000) was much higher than for the overall population (285 per 1,000), large variations among the States and Territories cast doubt on the coverage of Indigenous hospitalisations.

Hospital separations data also have the limitation that they cannot usually be used to identify multiple admissions for the same patient. The feasibility of addressing this problem by linking records is being investigated. The numbers and trends in hospital separations are also affected by differing admission practices, differing levels and patterns of service provision, and changes in coding practices over time.

Diabetes is considered to be under-reported in hospital separations. Not only is diabetes not always listed as the principal diagnosis, it is likely that it is not

always recorded as an associated underlying condition. The extent of this under-reporting in Australia has not been determined.

National Health Surveys

The NHS conducted by the ABS provide self-reported information on health risk factors, complications, the use of health services, self-assessed health status, and a range of socio-demographic information. Data on diabetes, its risk factors and its complications are also collected.

Under the NHS, adults (aged 18 years and over) respond for themselves and children aged 15–17 years are interviewed with their consent and with the permission of a parent or responsible adult. A parent, guardian or close relative is interviewed on behalf of children aged 0–14 years.

A recall period of two weeks is mostly used in the NHS to get information on a range of topics including illness conditions, the use of health services, physical activity and smoking. Even with a short recall period of two weeks, some people, particularly older respondents, can under-report information owing to memory lapse.

During the 1995 NHS, recent illness conditions were ascertained using an ‘actions-based’ approach. The respondents were asked whether they had, in the two weeks before the survey, taken any actions (consultations with doctors and other health professionals, use of medications, hospitalisation, days away from school or work) in relation to their health. For each action taken, the respondents were asked to state the illness condition or the reasons for taking the action. While this approach has its own merits in capturing actions taken for dental and eye problems which are often not perceived as ‘illness’, many minor conditions for which no action was taken may not have been reported. It is very likely that the respondents only reported those conditions that had a greater effect on them.

Under-reporting of long-term conditions experienced by respondents may also have occurred, particularly in respect of those conditions which are controlled by treatment, recur infrequently or to which respondents have become sufficiently accustomed to no longer consider it an illness. Furthermore, illness conditions that the respondent was reluctant to discuss may have been omitted. Since no clinical tests were carried out to confirm the respondents’ claims, the data reflects descriptions of conditions that are probably based on earlier medical diagnosis. Self-reported information is considered to considerably underestimate the true prevalence of certain conditions and illnesses. In particular, diabetes is considered to be highly under-reported in the NHS data, mainly because Type 2 diabetes often remains undetected in the community. The 1995 NHS self-reported information by type of diabetes is also not considered reliable. However, these biases have largely been minimised by the adjustments to assign those who did not know their type of diabetes to a specific category.⁶

6 The ABS designed a technique to incorporate additional self-reported information collected in the survey — ie age at diagnosis of diabetes, type of diabetes treatment and/or medication — to produce more reliable estimates of prevalence by type of diabetes. For example, those respondents who reported they had never been diagnosed with diabetes but currently had high sugar levels in the blood/urine and took insulin treatment for that condition, were included in the alternate estimate. People who reported insulin dependence but were overweight and commenced insulin treatment after the age of 40 were assigned to the category of Type 2 diabetes (ABS 1997b).

Data and statistical issues

Self-reported information is of a subjective nature for many other aspects of diabetes as well. This is particularly the case in relation to collecting weight and height information. Momentary or short-term circumstances can influence the respondent's perception of health, particularly in relation to self-assessed health status. The discussions the respondents had with the interviewers on illnesses and the use of medication may have compelled them to alter their responses on health status (the SF-36 questionnaire was distributed to the respondents before the main interview to overcome the possible bias this could have had on the responses). The presence of others at the time of interview can also affect the responses.

National Aboriginal and Torres Strait Islander Survey

The 1994 NATSIS included about 15,700 Indigenous Australians. The survey collected information on people aged 13 years and over through self reports. For children younger than 13 years, the child's parent or guardian usually provided the information.

The NATSIS collection includes information on diabetes, its risk factors and some of the complications. As is the case with prevalence estimates derived from the NHS, self-reported NATSIS collection may yield lower estimates of the prevalence of diabetes and its complications in the Indigenous population.

National Nutrition Survey

The 1995 National Nutrition Survey obtained information on diet and nutrition of Australians. In addition, the survey collected measured data on body weight, height and blood pressure. The survey was based on a subsample of the 1995 NHS.

The National Nutrition Survey and NHS data can be linked to obtain relevant information on persons with diabetes. However, the National Nutrition Survey sample size for persons with diabetes is too small to yield reliable estimates for most of the indicators.

National Association of Diabetes Centres Survey

The NADC Survey provides annual cross-sectional data on disease incidence, prevalence, risk factors, complications and demographic information from persons attending specialist diabetes service centres. The collection provides a snapshot of the clinical condition of individuals and information on their current status. The data are not representative of all persons with diabetes.

The first data collection was undertaken for a one-month period in March 1998. A standardised dataset, developed by NDOQRIN (including demographic, clinical and biochemical data) was recorded by 30 diabetes centres and three specialist endocrinologists in private practice, in all States.

Integration SERU Survey of General Practitioners

This survey, initiated in 1998, assesses the extent and type of diabetes data collection being undertaken in general practice. Of those Divisions operating a diabetes program, 65 per cent have started collecting practice and patient outcome data, most using a Division-based patient register incorporating the NDOQRIN dataset.

The extent of GP coverage achieved within a Division is influenced by its size, the length of time the program had been operating, the method of data collection used and whether or not incentives for data collection were offered.

The proportion of people with diabetes registered on a Division of General Practice patient register depends on the extent of GP participation in the program and the length of time the program has been operating. Unless adequate GP involvement can be attained, there is likely to remain a large proportion of people with diabetes for whom there is no systematic collection of management or health outcome information.

Australia and New Zealand Dialysis and Transplantation Register

The ANZDATA Register collects data biennially from all dialysis and transplant units in Australia, and maintains records on people who are on dialysis treatment and/or await kidney transplantation or have undergone the operation. The Register dates back to 1977 when the previously separate dialysis and transplant registries were combined. The database contains information such as incidence, primary renal disease, comorbidity, duration of known renal failure, pubertal status and use of growth hormone in children, acute rejection, treatment given and response, quality of life, date and cause of death, and demographic data including country of birth and race.

National Diabetes Register

A National Diabetes Register, based at the AIHW, has been set up to collect information on diabetes in Australia. The register will initially focus on new cases of insulin-treated diabetes. It will keep records of persons using the National Diabetic Services Scheme and the Australian Paediatric Endocrine Group State-based registers as sources of ascertainment. Inclusion in the Register will be voluntary. The data from the register will be used for monitoring national diabetes indicators. The register will also provide information for epidemiological and clinical studies on the aetiology, prevention and complications of diabetes in Australia.

Quasi-national data

Population health surveys have been conducted in some jurisdictions, and are planned in others. These surveys yield estimates of the prevalence of diabetes, associated comorbidity, and those at risk of developing diabetes. A representative survey of adults, conducted by the South Australian Department of Human Services, for example, is a useful source of population-based information on diabetes-related complications and risk factors (Phillips et al 1998).

South Australia has also established a Diabetes Clearing House, to provide timely and relevant information about diabetes to help direct policy and program development. The role of the clearing house includes reviewing and evaluating literature, providing comprehensive epidemiological information and recommending, refining and developing descriptors of diabetes that will be useful in measuring and monitoring health outcomes.

Registers on children and adolescents with Type 1 diabetes exist in all States. A register of patients treated with insulin has existed in Tasmania since 1984.

Data gaps and deficiencies

There are large gaps and deficiencies in the national health information base in relation to diabetes. The existing data sources fail to provide sufficient information for assessing the impact of diabetes on the Australian community and comprehensive surveillance of diabetes nationally. These deficiencies include the following.

- There are currently no national data on screening for diabetes, its incidence, diabetes care, or long-term outcomes of care. Nor is information available by type of diabetes.
- There is a lack of national trend information about diabetes and its complications and a lack of trend data on diabetes-related disease costs.
- Information on disease incidence and prevalence is based on self reports alone. This information is not supported by laboratory-based, diagnostic criteria. In the absence of good quality incidence and prevalence data, it is not possible to reliably assess the magnitude of the problem.
- Information on risk factors is available from sources that fail to cover several important risk factors for diabetes. Little information has been collected on the biomedical aspects of risk factors for diabetes and its complications over the last decade.
- Few data collections are nationally representative, have sufficient numbers from priority populations, use nationally agreed instruments, undertake routine validation of self reports, or include biological measurements.
- There are no agreed definitions for diabetes data elements.
- No linking of records to generate profiles of diabetes management occurs.

This lack of relevant information makes it difficult to assess the effect of public health measures on the development of the disease, or the effect of health services and interventions on diabetes-related complications.

Data development activities

Several data development activities are now in progress, or are being planned, to address some of the issues mentioned above. These activities include the following.

- A set of diabetes indicators for priority reporting has been finalised, and indicators for routine monitoring are currently being developed and refined by the AIHW.
- The AIHW has also developed operational definitions for priority diabetes indicators. These definitions will be refined further following the development of standard definitions for diabetes-related data elements.
- A proposal for a national biomedical risk factor survey that includes blood sampling is being developed under the auspices of the National Public Health Information Working Group. The survey will help generate national estimates of diabetes prevalence.
- Work on monitoring diabetes mortality and morbidity has been initiated by the AIHW, and an outline for a national monitoring system for diabetes is being prepared.

- A Pre-Hospital Emergency Care Survey is being developed to combine State and Territory ambulance service emergency data into a national minimum dataset which will include identification of people with diabetes.
- A Disease Costs and Impact Study is being undertaken by the AIHW, to generate estimates of the direct costs of diabetes. The estimates cover hospital, home, medical, other health professionals and pharmaceutical costs.
- The University of Sydney and the AIHW are collaborating to undertake an annual audit of patients seen, problems managed and the management techniques provided in general practice in Australia. The survey, called BEACH (Bettering the Evaluation And the Care of Health), will also generate useful information on the primary care of diabetes.
- The International Diabetes Institute is planning to conduct a study on the prevalence of diabetes. The study will be conducted in three states — Victoria, New South Wales and Western Australia.
- There is growing support for the coordination of data collection for cardiovascular disease and diabetes. In South Australia, a state-wide program for secondary prevention of cardiovascular disease and diabetes is under development through the Divisions of General Practice. A combined database, CARDIAB, will be available in early 1999 for Divisions undertaking data collection in both diabetes and cardiovascular disease programs.
- A current activity of the NDOQRIN Management Committee is development of standard definitions and measures for diabetes, for inclusion in the *National Health Data Dictionary*.
- Definitions and measurement standards for overweight and obesity have been developed, and standards for smoking and physical activity are being developed under the umbrella of the National Health Information Agreement.
- The process is commencing for developing data definitions of high blood pressure and high cholesterol for use in both epidemiological and health care settings.

Other initiatives to improve diabetes-related data quality

The National Diabetes Outcomes Quality Review Initiative

The National Diabetes Outcomes Quality Review Initiative (NDOQRIN, pronounced endocrine) aims to promote the collection and management of nationally standardised clinical diabetes information based on a core minimum dataset. The NDOQRIN dataset is being used by the NADC to collect and pool national data on diabetes care and complications in people attending specialist services. The NDOQRIN dataset has been disseminated to all Divisions through the National Divisions of Diabetes Program modules, and Divisions have been encouraged to include the dataset and definitions in their database/register. The indicators in the National Division of Diabetes Program Evaluation Module assume collection of the NDOQRIN dataset.

Indigenous data

Although diabetes is highly prevalent among Indigenous people, there is a lack of reliable information to obtain a national picture. The need to improve the quality of Indigenous health information, including diabetes-related data, has been identified

Data and statistical issues

as a national health information priority (AIHW & AHMAC 1995). A plan was presented to the October 1997 AHMAC meeting (AIHW & AHMAC 1998) to address the problem. The plan's major recommendations include:

- development of specific protocols for the sensitive handling of data concerning Indigenous peoples, with the active involvement of communities;
- establishment of permanent and long-term positions for Indigenous personnel, to facilitate substantial improvements in the quality of information;
- ensuring all major health and related collections in all jurisdictions have the capacity to differentiate between Indigenous and other Australians; and
- use of common identification classifications and collection protocols in all major collections.

Representatives from NHIMG and relevant Indigenous health organisations are working together to help implement the plan. The ABS and AIHW have accepted lead roles in working with organisations to implement Indigenous identification in priority information systems. The ABS has this role for vital statistics and AIHW for hospital separations, perinatal data and cancer registrations.

Incentives for data collection

A major issue to be addressed is the question of who collects the data and appropriate, standardised incentives for this collection. Some method of standardising payments for data collection is required. Payment for data collection is ad hoc across jurisdictions. The method used in the South Australian Coordinated Care Trial of providing a capped sum provides a model for wider application.

Minimum dataset for diabetes prevention and care

Data collection is inconsistent within service provider organisations, and within and across jurisdictions. Some diabetes services collect data consistent with the NDOQRIN minimum dataset, while others collect fewer or more data items. In addition, data collection in many diabetes outpatient services is paper-based which impedes analysis.

Among Divisions of General Practice, a range of registers and recall systems have been established. Through the National Divisions Diabetes Program, Divisions have been encouraged to include the NDOQRIN dataset and definitions in their registers. The National Divisions Diabetes Program will work with Divisions and their State-based organisations to facilitate the collation of de-identified data at a State/Territory and national levels. The funding of \$50 million over three years for information technology announced as part of the Review of General Practice Strategy should facilitate this process.

Similarly, the commitment of the South Australian, Australian Capital Territory and Queensland Governments to the Community Health Information Management Enterprise (CHIME)⁷ initiatives should facilitate the collection of standardised, computer-based diabetes-related data in community health services.

7 The CHIME project will deliver a client-focused operational information system for community-based and ambulatory health services.

Recall systems

Effective long-term care of people with diabetes requires systems for encouraging patients to have regular assessment and screening for complications. A recall system for annual complication screening is planned for Southern Tasmania (Tasmanian Department of Health). Of the 65 Divisions with a diabetes program surveyed by the Integration SERU in August 1998, 75 per cent used their patient registers to recall patients for review by their GP.

The use of pathology laboratories in the collection of data and recall of patients is being trialed in New South Wales by the Central Sydney Division of General Practice. A small number of other Divisions are keen to explore opportunities to collaborate with pathology laboratories in this regard.

Record linkage

The integration or linkage of data across the health continuum is being considered by all jurisdictions in current strategic planning for diabetes. There is support across jurisdictions for the development of 'seamless' data systems that allow all service providers access to complete patient history (eg hospital admissions, medications prescribed, GP interventions, community-based interventions). Record linkage via smart cards or a unique patient identifier is commonly suggested, consistent with the recent recommendation of the Taskforce on Quality in Australian Health Care to pilot patient-held, portable, electronic smart cards (AHMAC 1996).

A number of jurisdictions have recognised the need to identify persons with diabetes, to ensure that they receive diabetes education and screening. There are activities to address this issue in all jurisdictions, raising questions about duplication of effort and whether national coordination would be more efficient.

In Western Australia, the Linked Database Project is a collaborative effort by the University of Western Australia's Centre for Health Services Research and the Health Department of Western Australia, to link health records from different databases from 1980 onwards. Similarly, the Australian Capital Territory is currently looking at developing a central system that all providers can access.

Data linkage is a principle underpinning the Coordinated Care Trials. For example, in the South Australian Coordinated Care Trial, Health Insurance Commission data have been provided by the Commission at the individual patient level. This information is linked to hospital admissions data and will also soon be linked to district nursing, domiciliary care, hospital outpatient and allied health data. Data is supplied to GPs and Care Mentors on a monthly basis on CD-ROM or as hard copy reports and also online through the real-time intranet-based Care Planning On-Line system. The key to this data linkage was a unique identifier based on patient name, date of birth, gender, Medicare card number and/or Department of Veterans' Affairs number. A new Medicare number was only used for a small number of patients where there was more than one individual listed on the existing card.

There is support among clinicians for Health Insurance Commission data to be provided at patient level. Trials on this data provision are being established with Divisions in New South Wales. The Health Insurance Commission will provide information to GPs in selected Divisions on patients who have had HbA_{1c} tests. Divisions will use this information as the basis for diabetes recall registers.

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At the national level, the AIHW is responsible for undertaking a National Health Record Linkage Project. The AIHW's primary role in this project is to define and implement demonstration record linkage projects by acting as a broker for cross-jurisdictional record linkage activities and presenting these results to the community. The AIHW will test the feasibility of this role via a proposed record linkage project involving the Western Australian Linked Database Project, the Health Insurance Commission and the Commonwealth Department of Health and Aged Care. The proposed project will examine patterns of inpatient and community ambulatory care among people with diabetes in Western Australia.

Specifically the project will report on utilisation rates of services according to year and demographic factors, risk of hospital admission and death in relation to intensity of ambulatory care and pharmaceutical interventions and risk of readmission following hospitalisation for complications of diabetes and effects of community-based care. Results will be obtained from linking data from the Western Australian Linked Database (hospital morbidity, mortality) to the National Death Index and the Medicare and Pharmaceutical Benefits Scheme databases. Of particular importance will be an examination of the feasibility of undertaking a similar project in a national context by using the AIHW's National Hospital Morbidity Database.

While there is strong support among clinicians for data to be linked to patients, there is also significant concern among service providers (particularly Indigenous providers) about linking data at any level other than the local level. The benefit of data linkage at regional, jurisdictional or national levels needs to be justified before agreement can be reached on this issue. However, the impetus to link records should come from individuals and health providers, rather than from governments and regulators (Madden 1998).

Data analysis and dissemination

Use of data for decision support

There is strong support for analysed data to be provided to clinicians to inform their practice. This shifting emphasis from data collection to decision-support systems is evident in CHIME, which is underway in Queensland, New South Wales, South Australia and the Australian Capital Territory.

The South Australian Department of Human Services is investigating the broader application of data linkage to decision-support systems, and is embedding guidelines in data systems and including templates for scheduling appointments.

Definitions of terms and measures

Body mass index (BMI)

The BMI is calculated as weight in kilograms divided by the square of height in metres. The scores are grouped into four categories:

<20 kg/m² = underweight

20–24.9 kg/m² = acceptable weight

25–30 kg/m² = overweight

>30 kg/m² = obese

Physical inactivity

Information on physical activity is collected by asking the respondents whether, in the last two weeks, they did any walking for sport, recreation or fitness; moderate exercise (apart from walking); and vigorous exercise. Respondents are also asked the number of times they exercised in the reference period and the total amount of time spent on exercise.

The ABS defines, for the purpose of the survey, moderate exercise as exercise or other activities (undertaken for recreation, sport or fitness) that cause a moderate increase in the heart rate or breathing of the respondent. Vigorous exercise is defined as including exercise or other activities (as above) that cause the respondent to perspire and/or increase the respondent's heart rate or breathing.

These definitions of moderate and vigorous exercise levels reflect the respondent's perception of the activity undertaken, level of intensity and their level of fitness.

From the information on frequency, duration and intensity of exercise, an exercise level is derived for each person. The level is based on a score, derived from:

Number of times activity undertaken \times Average time per session \times Intensity

Intensity values of 3.5 for walking, 5.0 for moderate exercise and 9.0 for vigorous exercise are used to reflect more recent developments in the field of exercise statistics. The exercise level score ranges are:

<100 = sedentary;

$100 < 1,600$ = low exercise level;

$1,600\text{--}3,200$ or $>3,200$ and <2 hours vigorous exercise = moderate exercise level; and

$>3,200$ and 2 hours or more of vigorous exercise = high exercise level.

General health and well being (SF-36)

Indicators for eight dimensions of health are derived from responses given to the questions in SF-36 form the basis of this health assessment. The eight dimensions of health included physical functioning, role limitation due to physical problems, bodily pain, general health, vitality, social functioning, role limitation due to emotional problems, and mental health.

Items and scales for the eight dimensions of health are scored in three stages.

- *Item recoding*, for those eight items in the scale for which the response categories are listed in reverse order. This stage of scoring also incorporates imputation of missing values where possible. The SF-36 scoring rules allow for values of missing items to be imputed if at least 50 per cent of the items for a scale are present. The algorithm used in the imputation process substitutes a person-specific estimate for the missing item — the estimate is the average score across completed items in the same scale for that respondent.
- *Computing raw scores for each dimension*, by summing across component items.
- *Transforming the raw dimension scores to a 0–100 scale*. The formula converts the lowest and highest possible score to zero and 100 respectively; scores between these values represent the percentage of the total possible score which had been achieved (ABS 1996b).

Statistical methods

This section describes all the rates and ratios presented in this report and the methods used to calculate these measures. Most estimates in this report are age standardised to the 1991 Australian Population. However, in some instances both the crude rate and the standardised rate are given. Crude rates and age-specific rates are necessary precursors to deriving age-standardised rates, therefore, information on how to obtain these estimates is also mentioned in this section.

Crude rates

A crude rate is defined as the number of events (eg births, deaths, disease) occurring in a specified period (usually a year) divided by the total average population in the same period (usually 30 June that year). For example, crude death rate in 1998 is the total number of deaths in 1998 divided by the total population at 30 June 1998. The rates are generally expressed as per 1,000 or 100,000 population and can be calculated for males, females, persons or a subset of the population.

Age-specific rates

An age-specific rate is calculated by dividing the number of events occurring in a particular age by the total number of persons at that age. The size of age categories used varies according to the phenomenon studied, but five-year age groups are most common. The rates can be expressed either as per 1,000 or 100,000 population.

Rate ratio

Rate ratios are produced by dividing one number by another when the two numbers are not related in the way necessary for the calculation of a rate. This is useful for comparing the difference between two or more rates, using one as the index. For example, the ratio of diabetes prevalence between the Indigenous and the general population, using the general population as the index, is obtained by dividing the Indigenous rate by the general rate. The result can be expressed as the Indigenous rate being 'n' times higher or lower than that of the general population.

Age standardisation

To control for any effects of varying age structures of populations, direct age standardisation is applied to death rates, incidence rates, prevalence rates and hospital separation rates. The total estimated resident population of Australia at 30 June 1991 is used as the standard (Table A2.1).

The usual convention of using age-specific rates for five-year age groups, as shown in Table A2.1, is followed using the following formula:

$$SR = \frac{\sum \{R_i \times P_i\}}{\sum P_i}$$

where SR = the age-standardised rate;

R_i = the age-specific rate for age group i ; and

P_i = the standard population in age group i .

It should be noted that trends in age-standardised estimates obtained using this standard population might differ from those obtained using another standard population.

Table A2.1 Age composition of the Australian population by sex, 30 June 1991

Age group	Males	Females	Total
0-4	652,302	619,401	1,271,703
5-9	652,418	619,790	1,272,208
10-14	638,311	603,308	1,241,619
15-19	698,773	665,301	1,364,074
20-24	707,124	689,640	1,396,764
25-29	702,728	696,935	1,399,663
30-34	713,784	711,951	1,425,735
35-39	664,228	664,159	1,328,387
40-44	655,138	639,133	1,294,271
45-49	526,498	502,647	1,029,145
50-54	433,762	413,172	846,934
55-59	367,302	358,648	725,950
60-64	366,779	370,089	736,868
65-69	320,142	351,248	671,390
70-74	228,494	282,261	510,755
75-79	158,993	225,502	384,495
80-84	84,413	145,415	229,828
85 and over	44,220	110,027	154,247
Total	8,615,409	8,668,627	17,284,036

Source: ABS.

Acronyms and abbreviations

ABS	Australian Bureau of Statistics
ACCO	Aboriginal Community Controlled Organisation
ACE	angiotensin converting enzyme
ADA	American Diabetes Association
ADEA	Australian Diabetes Educators' Association
AHMAC	Australian Health Ministers' Advisory Council
AIHW	Australian Institute of Health and Welfare
ANZDATA	Australia and New Zealand Dialysis and Transplantation Registry
BMI	body mass index
C&LDB	culturally and linguistically diverse backgrounds
CADS	Community Awareness of Diabetes Strategy
CHIME	Community Health Information Management Enterprise
DCCT	Diabetes Complications and Control Trial
DHHCS	Commonwealth Department of Health, Housing and Community Services
DHSH	Commonwealth Department of Human Services and Health
DHFS	Commonwealth Department of Health and Family Services
GP	general practitioner
HEALTH	Commonwealth Department of Health and Aged Care
HbA _{1c}	glycosylated haemoglobin
MACOD	Ministerial Advisory Committee on Diabetes
NACCHO	National Aboriginal Community Controlled Health Organisation
NADC	National Association of Diabetes Centres
NATSIS	National Aboriginal and Torres Strait Islander Survey
NDDP	National Divisions Diabetes Program
NDOQRIN	National Diabetes Outcomes and Quality Review Initiative
NHF	National Heart Foundation
NHIMG	National Health Information Management Group
NHMRC	National Health and Medical Research Council
NHPA	National Health Priority Areas
NHPC	National Health Priority Committee
NHS	National Health Surveys
NIDDM	non-insulin-dependent diabetes mellitus
NIH	National Institutes of Health (United States)
NPHP	National Public Health Partnership
OATSIH	Office for Aboriginal and Torres Strait Islander Health
RACGP	Royal Australian College of General Practitioners
SERU	Support and Evaluation Research Unit
UKPDS	United Kingdom Prospective Diabetes Study
WHO	World Health Organization

Glossary

Methodology terms

Additional diagnosis: diagnosis of conditions that affect a person's care in terms of requiring therapeutic treatment, clinical evaluation, diagnostic procedures, extended length of hospital stay or increased nursing care and/or monitoring. These include comorbid conditions (co-existing conditions) and complications.

Goal: a general statement of intent and aspiration describing outcomes that might be reasonably achieved in the light of current knowledge and resources. Goals apply to the broad population with priority populations identified when different strategies are required to achieve equitable outcomes.

Health outcome: a change in the health of an individual, a group of people or a population, which is wholly or partially attributable to an intervention or series of interventions.

Indicator: a specific measure for assessing progress towards goals. In terms of health outcomes, an indicator is a statistic or other unit of information which reflects, directly or indirectly, the performance of a health and welfare intervention, facility, service or system in maintaining or increasing the well being of its target population.

Meta-analysis: method used to combine the results of several independent studies to generate firm evidence. It effectively increases sample size and decreases sampling errors.

Patient-centred approach: an approach that requires the active involvement of the patient. It is different from patient education which in the context of this report refers to the one-way imparting of knowledge (eg from health service provider to patient).

Principal diagnosis: the diagnosis established after study to be that chiefly responsible for occasioning the patient's episode of care in hospital.

Randomised controlled trial: an experimental study in which subjects are randomly assigned to treatment and control groups.

Separation: the process by which a patient completes an episode of care that can be a total hospital stay (from admission to discharge, transfer or death) or a portion of a hospital stay beginning or ending in a change of type of care (eg from acute to rehabilitation).

Target: a specific and measurable amount of change in population health gain that could be expected within a given timeframe. Targets are specific to indicators of mortality, quality of life, disability, disease states, risk factors and other aspects of health.

Medical terms

Atherosclerosis: nodular thickening or hardening of the layers in the wall of an artery; characterised by irregularly distributed lipid deposits in the intima of large and medium sized arteries.

Cataracts: clouding of the lens of the eye or its capsule creating reduced vision.

Comorbidity: a concomitant but unrelated pathologic or disease process that indicates co-existence of two or more disease processes.

Coronary heart disease: conditions such as heart attack and angina caused by blockages in the coronary arteries that supply blood to the heart muscle.

Dialysis: a method of removing waste products from the blood when the kidneys are unable to work effectively.

Gangrene: death of body tissue due to a lack of blood supply.

Glaucoma: a group of diseases of the eye resulting in pathological changes in the optic disk and typical visual field defects and eventually blindness if not successfully treated.

Glucose: the main sugar that the body uses for energy. Glucose comes from the breakdown of carbohydrates as well as from the breakdown of glycogen (the storage form of glucose found in the liver and muscles) in the liver.

Glycosylated haemoglobin (HbA_{1c}): the binding of glucose to haemoglobin molecules. Levels of glycosylated haemoglobin provide an indication of the extent of glucose control over an extended period, say two to three months.

Hyperglycaemia: high blood glucose levels (ie above 10 mmol/L).

Hypoglycaemia: a low blood glucose level (ie 3.5 mmol/L or less) due to too much insulin or because not enough carbohydrates were eaten at the correct time. A hypoglycaemic reaction causes unpleasant symptoms of hunger, sweating and confusion.

Impaired glucose tolerance: an abnormality where fasting blood glucose levels and results of oral glucose tolerance tests fall between normal values and those that meet criteria for diabetes.

Insulin: a hormone produced by β cells in the pancreas that helps glucose molecules to enter body cells and be used for energy.

Ketoacidosis: uncontrolled blood glucose and ketone (chemical substances from the breakdown of fats) levels that cause dehydration, concentration of body fluids, build up of acids and coma. This condition mainly occurs in Type I diabetes. The excessive glucose is unable to be used for energy and the body starts breaking down stored fat as an alternative energy source, resulting in build up of ketones in the blood (ketosis) and urine (ketonuria).

Macrosomia: greater body size.

Oral glucose tolerance test: a two-step diagnostic test for diabetes. An initial fasting blood glucose test is followed by another test after a concentrated sugar drink.

Pancreatic β cells: insulin-producing cells in the pancreas.

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