The National System for Monitoring Diabetes in Australia

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The National System for Monitoring Diabetes in Australia

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Preface

The National System for Monitoring Diabetes in Australia report describes the aims, scope and processes for monitoring diabetes in Australia. It provides a firm foundation for monitoring diabetes into the future.

The diabetes monitoring system in Australia has developed over the last decade. A number of key committees have been instrumental in this development, including the Ministerial Advisory Committee on Diabetes (MACOD), the National Diabetes Register Management Committee, and more recently the National Diabetes Strategies Group (NDSG) and the National Diabetes Data Working Group (NDDWG). The Chairs and members of these committees have played an active role in developing the monitoring system for diabetes in Australia.

The AIHW, with strong support from the former Director Dr Richard Madden, has played a key role in the development of this monitoring system as the home for the National Centre for Monitoring Diabetes and the National Diabetes Register. The Monitoring Centre and the Register have been funded by the Australian Government Department of Health and Ageing and that support is gratefully acknowledged.

The monitoring system has already enabled the publication of a number of diabetes monitoring reports, such as *Diabetes: Australian Facts 2002*. The AIHW also manages the National Diabetes Register as well as holding de-identified data on all users of the National Diabetes Services Scheme. These datasets will allow sophisticated analysis by AIHW and other health researchers of the characteristics and outcomes of people with diabetes.

We are now in a position to build on this firm foundation for monitoring diabetes in Australia. I commend this report on the monitoring system to you, and anticipate that we can continue to work together to ensure that diabetes monitoring provides the firm basis needed to guide policy and research into the future.

Dr Ching Choi

Acting Director

January 2006

1 Introduction

1.1 Background

Diabetes has become one of the leading threats to the health of Australians. It has been estimated that around one million Australians (7.6% of the population) have diabetes, with 85–90% of these people having Type 2 diabetes (ABS 1997, p.19; Dunstan et al. 2002). Evidence suggests that up to half of all people with Type 2 diabetes may not be aware that they have the condition (Dunstan et al. 2002). The burden of diabetes is even greater in certain population groups in Australia. For example, among some Aboriginal and Torres Strait Islander communities it has been reported that at least half of the community have diabetes (Bottrell 2004).

Diabetes has a major impact on life expectancy and quality of life, especially if it remains undetected or is poorly controlled. In 2002, it was the ninth and tenth leading cause of death among males and females respectively in Australia (AIHW 2004). Over the course of the disease, diabetes can damage various parts of the body, especially the heart and blood vessels, eyes, kidneys and nerves. Complications can be life-threatening and include diseases of the large blood vessels (macrovascular disease), such as coronary heart disease, stroke and peripheral vascular disease, and diseases of the small blood vessels (microvascular disease), such as some forms of kidney disease and eye disease. Diabetes also contributes to many pregnancy-related complications both before and after birth, and for the mother and baby.

Diabetes imposes a large burden on our health care system in terms of expenditure on hospitalisations, aged and other care, medications, diagnostic services, and other out-of-hospital medical care including general practitioners (GPs) and community health services. Total health system expenditure on diabetes in 2000–01 was estimated at almost $814 million or 1.7% of allocatable health expenditure, ranking diabetes fifteenth out of around 200 disease and injury categories compared. This included $289 million (36.8%) on hospital services, $183 million (23.3%) on out-of-hospital medical services, and $234 million (29.8%) on pharmaceuticals (AIHW: Dixon 2005).

Rates of diabetes in the Australian community are increasing at a dramatic rate. Since the early 1980s the prevalence of diabetes among Australian adults has more than doubled. In 1999–2000 the age-adjusted prevalence of diabetes was estimated to be 7.2%, compared with 3.4% in 1981 (Dunstan et al. 2002). In an attempt to contain this growing epidemic, diabetes was recognised as a National Health Priority Area (NHPA) in 1996 by the Australian Government. The NHPA initiative focuses public attention on diseases that present a significant health burden and where there is potential for health gain through prevention and treatment programs.

1.2 Purpose of report

This report describes the National System for Monitoring Diabetes in Australia, which is implemented through the National Centre for Monitoring Diabetes, located at the Australian Institute of Health and Welfare (AIHW). Monitoring of diabetes is needed to provide appropriate, timely and valid information to inform policy makers, service providers and the public about the magnitude of the diabetes problem. Information is also necessary in order to develop best-practice guidelines and strategies, evaluate the cost effectiveness of interventional strategies and generate baselines for monitoring progress.

The National System for Monitoring Diabetes is in line with the recommendations of the *National Diabetes Strategy and Implementation Plan* (Colagiuri et al. 1998). A chronic disease prevention and control approach (NPHP 2001) was used in this report to identify key areas for monitoring diabetes across the continuum of care. These are organised under six broad categories: public health; identification of people at risk; detection and prevention of diabetes and related complications; management and related services; rehabilitation and disability care; and palliative care and mortality.

2 Rationale for the National System for Monitoring Diabetes

2.1 Why monitor diabetes?

Diabetes in Australia is a large health, social and economic burden for individuals and the community. It is in epidemic proportions with over one million Australians estimated to have diabetes, many of whom do not know they have it, and available evidence suggests that the rate of diabetes is increasing (AIHW 2002; Craig et al. 2000). At the same time, Type 2 diabetes is recognised as one of the most preventable of all chronic diseases (Diabetes Australia 2004). International studies have shown lifestyle modification, including dietary changes and exercise, can reduce the risk of developing Type 2 diabetes by 58% (DPPRG 2002; Tuomilehto et al. 2001). Diabetes complications may also be prevented or minimised through the early detection and effective management of the disease. These factors, coupled with the benefits of primary intervention approaches, highlight the considerable potential for health, social and economic gains through diabetes monitoring. An integrated monitoring system for diabetes is essential to improve Australia's capacity to make decisions for cost-effective allocation of resources, plan preventive and treatment services, target priority population groups and track the impact of environmental change and prevention and control strategies.

2.2 Scope and objectives of the National System for Monitoring Diabetes

The purpose of the National System for Monitoring Diabetes is to help reduce the health, social and economic burden of diabetes in Australia by developing, collating and interpreting data relevant to diabetes prevention, detection, management and care. This information will then be available to policy makers, clinicians, consumers and the public.

Diabetes monitoring (Figure 2.1) is guided by the continuum of care for chronic disease as outlined in *Preventing Chronic Disease: A Strategic Framework* (NPHP 2001) and builds on the recommendations of the *National Diabetes Strategy and Implementation Plan* (Colagiuri et al. 1998). The continuum of care for diabetes covers public health; identification of people at risk; detection and prevention; management and related services; rehabilitation and disability care; and palliative care and mortality.

The National System for Monitoring Diabetes needs to continually define, plan and review diabetes-related data. This promotes a more rigorous, relevant and collaborative approach to data development. It should also provide a clear picture of the type of data required. The monitoring system also helps systematically identify gaps and deficiencies in current data sources.

The specific objectives of the National System for Monitoring Diabetes are to:

- coordinate and develop national data collections related to diabetes

- monitor trends and differentials in diabetes and related issues
- provide information for the cost-effective allocation of health funds
- provide data for and report on indicators associated with diabetes, its incidence and prevalence, management, treatment and outcomes
- address gaps and deficiencies in the diabetes data environment
- promote uniformity in statistical standards, methods and definitions.

The system makes use of other relevant national monitoring systems such as that for cardiovascular disease and other data collections such as those for physical activity and nutrition

Australian population					
Population without diabetes	**Population at risk of diabetes**	**Population with diabetes (diagnosed or undiagnosed)**			
Public health and health promotion (primary prevention)	**Identification of people at risk (primary prevention)**	**Detection and prevention of diabetes and related complications (secondary prevention)**	**Management and related services (tertiary prevention)**	**Rehabilitation and disability care (tertiary prevention)**	**Palliative care and mortality**
• Promotion of healthy behaviours and environments across the life course. • Universal and targeted approaches. • Primary prevention of diabetes, aimed at the whole population or high-risk groups, will have benefits that go beyond diabetes, because the modifiable risk factors of obesity, low physical activity levels, poor nutrition, high blood pressure and smoking also play a major role in the development of other common conditions.	• Identify and treat asymptomatic persons who are predisposed to developing diabetes; or have already developed risk factors or preclinical disease but in whom the condition is not clinically apparent (e.g. screening). • Predisposing factors: e.g. demographic, social, environmental and family history. Risk factors: behavioural—low physical activity levels, poor nutrition; biomedical—overweight and obesity, high blood pressure, gestational diabetes, glucose intolerance, impaired fasting glucose, low birthweight.	• Early detection • Screening • Case detection • Periodic health examinations • Early intervention Identification of risk factors for complications and co-morbidity—overweight and obesity, low physical activity levels, smoking, poor nutrition, high blood pressure, high cholesterol and triglycerides.	• Clinical management—medical and surgical care for diabetes and related complications: GP and specialist care, emergency and hospital care, for example, pregnancy and obstetric care, coronary and stroke care, dialysis, renal transplants, laser eye surgery, amputations. Personal management: e.g. diet, physical activity, glucose self-monitoring, compliance with treatment.	• Post acute care In-hospital and post-hospital rehabilitation care for complications, e.g. cardiovascular disease, renal transplants, rehabilitation and disability following stroke, amputations.	• Care to improve quality of life for patients with severe progressive disease or complications. • Fatal outcome due to diabetes as an underlying or contributory cause, in or out of hospital.

⇧ Prevent movement to the 'at risk' group

⇧ Prevent progression to established disease and hospitalisation

⇧ Prevent/delay progression to complications and prevent readmissions

⇧ Prevent/delay premature death

Source: Adapted from Preventing Chronic Disease: A Strategic Framework (NPHP 2001) and Outline of a National Monitoring system for Diabetes Mellitus (AIHW 1999).

Figure 2.1: Diabetes and the health system: critical points for intervention

3 The National System for Monitoring Diabetes

As part of the National Health Priority Area program, the Australian Government Department of Health and Ageing (DoHA) has allocated funding for a range of national diabetes initiatives including the establishment of the National System for Monitoring Diabetes. Although Australia previously had national data sources relevant to the monitoring of diabetes, it lacked an integrated system to coordinate these resources and their analysis (AIHW 1999). Accordingly, DoHA funded the AIHW to establish an integrated national monitoring system to produce accurate and reliable data effectively and efficiently.

The National System for Monitoring Diabetes is structured with a view to integrating both existing information and data development efforts of information providers. This is achieved by involving key information providers in a structure around a national monitoring centre with advice from an expert working group.

The National System for Monitoring Diabetes (Figure 3.1) encompasses:

- key areas for monitoring diabetes in Australia (Table 3.1)
- the National Centre for Monitoring Diabetes (NCMD), located at the AIHW
- committees:
    - the NCMD's advisory committee—the National Diabetes Data Working Group (NDDWG)
    - the National Diabetes Strategies Group (NDSG) which reports to the National Health Priority Action Council (NHPAC)
- information providers and experts
- outputs, including data, reports and information
- guidelines (including clinical guidelines), indicator sets and metadata.

The system monitors diabetes, its risk factors, complications, treatment and health outcomes. The National Health Service Improvement Framework for diabetes will be incorporated when it is finalised.

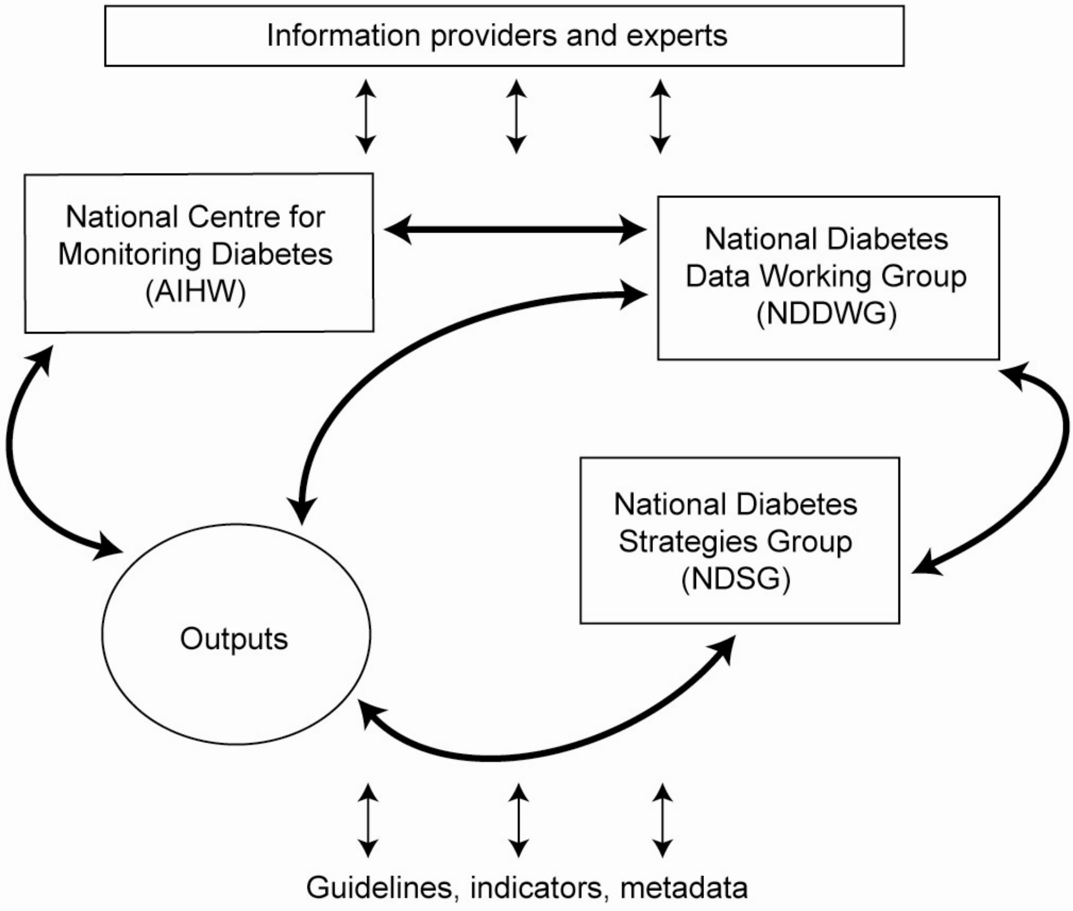

Figure 3.1: The National System for Monitoring Diabetes

3.1 Key areas for monitoring diabetes in Australia

The key areas for monitoring diabetes in Australia are detailed in Table 3.1. As stated in Chapter 2, the key areas are derived from the comprehensive model of chronic disease prevention and control outlined in *Preventing Chronic Disease: A Strategic Framework* (NPHP 2001), and build on the recommendations of the *National Diabetes Strategy and Implementation Plan* (Colagiuri et al. 1998). This NPHP framework aims to provide a model of chronic disease control across the continuum of care.

The key areas for monitoring diabetes (including prevention, detection, screening, management, treatment, rehabilitation and palliation) represent critical intervention points that offer the greatest potential for improving health outcomes for people with diabetes. Monitoring can provide valuable information, including trends, regarding the:

- burden and impact of disease
- size of the population at risk
- use and effectiveness of interventions.

The key areas for monitoring diabetes, related data sources and indicators, and information gaps and deficiencies are described in more detail in Chapter 5.

Table 3.1: Key areas for monitoring diabetes

Areas	Definition and description of key areas for monitoring diabetes
Primary prevention	
Public health and health promotion	Healthy public policy and health promotion, e.g. general practitioner (GP) and specialist training and patient counselling, mass media campaigns, and workplace and school programs, to increase awareness of diabetes and its risk factors and reduce risk factor levels in the population
Identification of people at risk	Identification and treatment of asymptomatic persons who are at risk but in whom the condition is not clinically apparent (e.g. screening tests) Predisposing factors: demographic, social, environmental and genetic factors Modifiable risk factors: *behavioural:* e.g. low physical activity levels, poor nutrition *biomedical:* e.g. gestational diabetes, overweight and obesity, glucose intolerance, low birthweight
Secondary prevention	
Detection and screening	Early detection is one of the keys to controlling the impact of diabetes. There is evidence that tight control of glucose, lipids and blood pressure levels is effective in preventing complications in both Type 1 (DCCT Research Group 1993) and Type 2 diabetes (UKPDSG 1998).
Identification of people with diabetes	Incidence and prevalence of diabetes (including symptoms, age at onset)
Risk factors for complications	*Behavioural*: e.g. smoking, low physical activity levels, poor nutrition, poor glycaemic control, high alcohol intake *Biomedical:* e.g. high blood cholesterol, high triglycerides, overweight and obesity, high blood pressure, proteinuria, hyperglycaemia
Identification of complications and comorbidities	Coronary heart disease, stroke, nephropathy, neuropathy, retinopathy, peripheral vascular disease, infections, problems during pregnancy and birth
Tertiary prevention	
Management and related services	Non-hospital and emergency care for complications — GPs, specialists, allied health professionals, regular clinical assessment, ambulance service/paramedics, hospital emergency department Specialised and surgical care for complications (e.g. hospital and specialist care, coronary and stroke care, thrombolysis, coronary surgery, angiography, dialysis, renal transplants, laser eye surgery, amputations) Personal management — e.g. diet, physical activity, glucose self-monitoring, compliance with treatment
Rehabilitation and disability care (post-acute care)	In-hospital and post-hospital care following CVD, renal transplants, stroke, amputations etc.
Palliative care	In hospitals, residential aged care facilities, and patients' homes
Death	Fatal outcome due to diabetes as an underlying or contributory cause, in or out of hospital

3.2 Role of the National Centre for Monitoring Diabetes

The National Centre for Monitoring Diabetes ('The National Centre') is a key initiative of the National Diabetes Strategy and receives financial assistance from the Australian Government Department of Health and Ageing. The National Centre, located at the Australian Institute of Health and Welfare, aims to improve information on diabetes by coordinating national efforts to monitor diabetes, its risk factors and complications.

The National Centre receives advice from the National Diabetes Data Working Group (NDDWG), which in turn reports to the National Diabetes Strategies Group. The mission of the National Diabetes Strategy is to contribute to the improvement of the general level of health in Australia by reducing the personal and public burden of diabetes. National monitoring of diabetes is an important component of this strategy. The National Centre is strongly aware of the need to work closely with those with clinical and diabetes management expertise and regularly seeks relevant advice from members of the NDDWG.

The functions of the National Centre are to:

- contribute to the development and coordination of national data collections and databases related to the monitoring of diabetes and its complications
- monitor and report on trends and differentials in diabetes, its risk factors and complications and related issues
- monitor progress in reducing the national burden of diabetes
- provide data for evaluation of preventive, diagnostic and treatment interventions
- provide data for use in planning and managing health services related to diabetes
- address any identified gaps and overcome deficiencies in data that are required for monitoring purposes
- undertake and promote information development relating to diabetes monitoring
- promote uniformity in statistical standards, methods and definitions.

3.3 Committees

3.3.1 Role of the National Diabetes Data Working Group (NDDWG)

The NDDWG includes clinicians, policy makers, researchers, consumers and others nominated for their expertise in the fields of diabetes and related research. The terms of reference for the NDDWG are as follows:

1. Identify the national information needs and requirements for data reporting on diabetes in Australia.
2. As the national advisory committee for diabetes data reporting to the National Diabetes Strategies Group (NDSG), provide timely responses to requests for comment, and proactive advice where appropriate, on relevant diabetes data issues.
3. As the advisory committee to the National Centre for Monitoring Diabetes at the AIHW, provide timely responses to requests for comment, and advice where appropriate, on relevant diabetes data issues.
4. To ensure high-quality data, advocate for consistency in and widely promote appropriate use of diabetes data items using standardised definitions, in all areas including health care practice, population health surveys, and other relevant data sources.
5. Maintain and update the diabetes data set (and relevant subsets) in the National Health Data Dictionary.
6. Promote the collection, collation, analysis, reporting and publication of diabetes data in all appropriate avenues/venues.

7. Liaise with all relevant local, state, national and international bodies on relevant data issues.
8. Establish and administer appropriate committee management through documented proceedings and regular reporting mechanisms to relevant stakeholders.
9. Elect a chairperson annually, and review the terms of reference biennially.

3.3.2 Role of the National Diabetes Strategies Group (NDSG)

The NDSG is the consultative mechanism providing expert advice to the Australian Government on National Diabetes Strategy initiatives. The National Diabetes Strategy covers diabetes prevention, management and care, helping governments and service providers to identify key areas for action to improve the health of Australians with, or at risk of, diabetes.

The NDSG reports to the National Health Priority Action Council. The Council endorsed the establishment of the NDSG to oversee the National Diabetes Strategy and the National Integrated Diabetes Program. The NDSG brings together state/territory, consumer, general practice, Indigenous health, public health and clinical expertise.

3.4 Role of information providers

Various organisations and groups provide information which feeds into the monitoring system. The roles of the key national information providers are outlined in Table 3.2.

Table 3.2: Involvement of key information providers

Organisation/group	Monitoring activities
Australasian Diabetes in Pregnancy Society (ADIPS)	Information relating to diabetes in pregnancy
Australasian Paediatric Endocrine Group (APEG)	Data and information on diabetes in children
Australian Bureau of Statistics (ABS)	Collects and disseminates Census and survey data, including the National Health Survey, and maintains the cause of death data collection
Australian Government Department of Health and Ageing (DoHA)	Provides funding for various research, intervention and monitoring activities, e.g. the Australian Diabetes, Obesity and Lifestyle study (AusDiab); the National Diabetes Services Scheme; the National Integrated Diabetes Program; and the Diabetes Prevention Pilot Initiative Program
Australian Institute of Health and Welfare (AIHW)	Location of the National Centre for Monitoring Diabetes, and custodian of the National Death Index, National Diabetes Register, National Hospital Morbidity Database, National Mortality Database, as well as a range of other relevant data sets. Coordinates, develops, analyses and disseminates national statistics on diabetes, its risk factors, complications, and effects
Diabetes Australia	Administers the National Diabetes Services Scheme (NDSS)
International Diabetes Institute (IDI)	Diabetes-related research, including epidemiological surveys such as AusDiab and the Australian Prospective Diabetes Study (APDS)
National Association of Diabetes Centres (NADC)	Australian National Diabetes Information Audit and Benchmarking (ANDIAB) collection targeting people whose diabetes requires specialist clinical management
National Divisions Diabetes Program (NDDP)	Data from general practice, including CARDIAB (a database designed for Divisions of General Practice)
National Health and Medical Research Council (NHMRC)	Coordinates the preparation of best-practice guidelines; supports diabetes-related research

3.5 Outputs from the National System for Monitoring Diabetes

The monitoring system, through the National Centre for Monitoring Diabetes, routinely collects and reports on the key areas for monitoring diabetes (Table 3.1), encompassing information related to diabetes, its clinical types and its complications, with particular attention to variation by demographic, socioeconomic and geographic factors. Various data are used, particularly those from registers (including the National Diabetes Register), surveys and administrative systems. Special population groups, such as Aboriginal and Torres Strait Islander peoples and overseas-born population groups at high risk, are also monitored where feasible. In addition, the system undertakes generic data development tasks, such as indicator development and review. A number of indicator sets for diabetes monitoring and reporting have been developed and their place in the system is discussed in Chapter 5.

The outputs of the monitoring system may include reports and analysis in relation to:

- trends, including national estimates and state/territory estimates
- cross-sectional data and comparisons, such as national, international, socioeconomic status, cultural background, and urban, rural and remote comparisons
- cohort analyses, such as disease progression, where such data are available.

3.6 Guidelines

Guidelines are an important link between the best available evidence and quality clinical and public health practice for medical practitioners and nursing and allied health professionals. There are a range of national and state/territory guidelines for diabetes, including both evidence-based guidelines (e.g. *NHMRC National Evidence Based Guidelines for the Management of Type 2 Diabetes Mellitus. Primary Prevention. Case Detection and Diagnosis*), and consensus guidelines (e.g. *Australian Diabetes in Pregnancy Society Gestational Diabetes Management Guidelines*). Note that guideline development in Australia has focused mainly on clinical practice. There are few guidelines outlining best practice in prevention.

To be most effective, guidelines have to involve key organisations and individuals in their development, and their adoption and use need to be evaluated regularly. Specific mechanisms for dissemination and implementation of available guidelines will also enhance outcomes for people with diabetes.

3.7 Indicator sets

The National Centre for Monitoring Diabetes collates and reports information for the National Health Priority Area indicators and the National Health Performance Committee indicators. Another set of indicators for diabetes is currently being developed by the National Diabetes Data Working Group. These indicator sets are listed in full (indicators relevant to diabetes only) in the Appendix. Data sources for these indicators, and their place in the monitoring system, are described in Chapters 4 and 5 of this report.

3.7.1 National Health Priority Area (NHPA) indicators

The NHPA indicator set for diabetes was developed in 1998 to monitor and report on progress towards reducing the health problems associated with diabetes (CDHAC & AIHW 1999). They relate to issues across the disease continuum, namely:

- risk factors for diabetes
- screening (for gestational diabetes)
- prevalence and incidence of diabetes
- diabetes management
- self-assessed health status of people with diabetes
- risk factors for complications
- incidence and prevalence of complications
- hospital separations for complications
- mortality.

Indicator sets relating to other NHPA conditions, for example cardiovascular disease and cancer, also exist. Recent data on the NHPA indicators can be found in *Australia's Health 2004* (AIHW 2004).

3.7.2 National Health Performance Committee (NHPC) indicators

The NHPC indicators provide an overview of the performance of the Australian health system and the potential for improvements in health (NHPC 2004). They cover various dimensions across the three non-hierarchical tiers of the National Health Performance Framework: health status and outcomes; determinants of health; and health system performance. Dimensions within the latter tier include effectiveness, appropriateness, accessibility, responsiveness, safety, continuity, capability and sustainability. The set of 44 NHPC indicators includes one directly concerning diabetes, three including data on diabetes as well as other conditions, and three relating to risk factors for diabetes. Benchmark data against these indicators are presented in the *National Report on Health Sector Performance Indicators 2003* (NHPC 2004).

3.7.3 National Diabetes Data Working Group (NDDWG) indicators

Under instruction from the National Diabetes Strategies Group (NDSG), the NDDWG is developing a set of indicators to support general monitoring of diabetes. They are currently in draft form but have been endorsed by the NDSG. The indicators are based around a matrix of questions and settings developed by the NDSG Expert Indicator Panel. At least one indicator is proposed for each cell within the matrix (see Appendix). Three settings are considered—health care organisations, health care practices, and consumers—with indicators assessing the following six questions across the care continuum:

- Are we preventing or delaying the development of Type 2 diabetes?
- Is case detection occurring optimally?
- Is care provided according to guidelines?
- Are we improving the quality of care for people with diabetes?
- Is access equitable?

- Are we reducing the death and serious health effects of diabetes?

Benchmark data for these indicators have not yet been reported. This report includes the draft indicators as they were presented to the March 2005 meeting of the NDSG, and further refinement is continuing.

3.8 Metadata—Diabetes (clinical) Data Set Specification (DSS)

The Diabetes (clinical) DSS is a metadata set concerned mainly with the clinical and research use of diabetes data. It aims to ensure national consistency in relation to defining, monitoring and recording information on patients diagnosed with diabetes. It is not prescribed for collection but is recommended as best practice for health and health-related establishments that create, use or maintain records on health care clients.

The Diabetes (clinical) DSS relates to the clinical status of, the provision of services for, and the quality of care delivered to individuals with diabetes, across all health care settings including general practitioners, divisions of general practice, diabetes centres, specialists in private practice, community health nurses and diabetes educators.

The Diabetes (clinical) DSS:

- provides concise, unambiguous definitions for items/conditions related to diabetes quality care
- aims to ensure standardised methodology of data collection in Australia.

The expectation is that collection of this data set facilitates good quality of care, contributes to preventive care and has the potential to enhance self-management by patients with diabetes. The underlying goal is improvement of the length and quality of life of patients with diabetes, and prevention or delay in the development of diabetes-related complications.

The Diabetes (clinical) DSS is included in the National Health Data Dictionary, Version 12 (NHDC 2003), and is available on the AIHW website <www.aihw.gov.au>.

4 Relevant data sources

This chapter describes the major data sources available for providing information relevant to monitoring diabetes, its risk factors, complications, management and impacts. The information currently available for diabetes monitoring, as listed in Table 4.1, consists of national administrative data sources, register data sources, survey data sources and other existing and developmental data sources. These data sources are also referred to in the following chapter.

Table 4.1: Current Australian diabetes data environment

National administrative data sources	Register data sources	Survey data sources	Other existing and developmental data sources
AIHW National Hospital Morbidity Database	Australian and New Zealand Dialysis and Transplant Registry (ANZDATA)	Australian Diabetes, Obesity and Lifestyle Study (AusDiab)	AIHW Disease Expenditure Database
AIHW National Mortality Database	Australasian Paediatric Endocrine Group (APEG) registers	Australian Longitudinal Study on Women’s Health	Burden of Disease and Injury in Australia study
Medicare Benefits Scheme (MBS)	National Death Index (NDI)	Australian National Diabetes Information Audit and Benchmarking (ANDIAB)	Diabetes Clearing House
Perinatal data collections	National Diabetes Register (NDR)	Australian Prospective Diabetes Study (APDS)	Diabetes Prevention Pilot Initiative Program
Pharmaceutical Benefits Scheme (PBS) and Repatriation Pharmaceutical Benefits Scheme (RPBS)	Tasmanian insulin-treated diabetes register	BEACH (Bettering the Evaluation and Care of Health) Survey of General Practice	Drug Utilisation SubCommittee Database
National Diabetes Services Scheme (NDSS)		Census of Population and Housing (and Estimated Resident Population)	National Diabetes Improvement Projects (NDIP)
		Disability, Ageing and Carers Surveys	National Divisions Diabetes Program (NDDP) Data Collation Project
		Exercise, Recreation and Sport Survey (ERASS)	National Integrated Diabetes Program (NIDP)
		National Aboriginal and Torres Strait Islander Survey (NATSIS)	Service Activity Reporting (SAR)
		National Aboriginal and Torres Strait Islander Health Survey (NATSIHS)	Vision Impairment Prevention Program (VIPP)
		National Dietary Survey of Adults	International data sources, e.g. the Surveillance of Risk Factors report (SuRF 1)
		National Drug Strategy Household Surveys	
		National Health Surveys	
		National Nutrition Survey	
		National Physical Activity Surveys	
		Population Survey Monitor	
		Risk Factor Prevalence Studies	
		State-based surveys (e.g. CATI)	

4.1 National administrative data sources

AIHW National Hospital Morbidity Database

The AIHW National Hospital Morbidity Database is maintained by the AIHW from data supplied by state and territory health authorities using standard definitions contained in the National Health Data Dictionary. It contains data on episodes of care for patients admitted to hospital in Australia. Since 1996–97 the data cover almost all hospitals, both public and private, including psychiatric and day hospital facilities. The database includes information on sex, age, Indigenous status, area of usual residence, and diagnosis and procedures based on The International Statistical Classification of Diseases and Related Health Problems, Australian Modification (ICD–AM), 9th revision from 1993–94 to 1998–99 and 10th revision from 1998–99 (note that both ICD–9–AM and ICD–10–AM codes were included on the database for 1998–99). Since the data are episode-based, it is not possible to count patients individually, and therefore estimates of disease incidence and prevalence cannot normally be calculated.

AIHW National Mortality Database

The AIHW National Mortality Database contains information pertaining to deaths registered in Australia. Data are provided by the state and territory Registrars of Births, Deaths and Marriages and are coded by the Australian Bureau of Statistics (ABS). Information available includes sex, age at death, date of death, area of usual residence, Indigenous status, country of birth, and cause of death. Causes of death are coded using the International Classification of Diseases (ICD)—9th revision from 1979 to 1996 and 10th revision from 1997. Before 1997 only a single cause of death (the underlying cause) was coded, but from 1997 multiple causes (underlying and all associated causes of death recorded on the death certificate) are coded.

Medicare Benefits Scheme (MBS)

The Australian Medicare program provides payment for certain medical services in and out of hospital and is administered by Medicare Australia. Data on the volume and value of Medicare services are available via the Medicare Australia website, <www.medicareaustralia.gov.au>. Information on specific Medicare items or groups of items can be obtained by state, age and sex for various time periods. Standard monthly and quarterly reports are also produced. MBS items relevant to diabetes monitoring include tests for glycosylated haemoglobin (HbA1c), microalbumin and lipids, and eye examinations.

Perinatal data collections

Information on pre-existing maternal and gestational diabetes is included in the perinatal data collections of all states and territories and collated nationally. Data elements for maternal medical conditions and complications of pregnancy are included in the National Health Data Dictionary, but they are not currently included in the perinatal national minimum data set. National data on maternal diabetes are available from the National Perinatal Statistics Unit.

Pharmaceutical Benefits Scheme (PBS) and Repatriation Pharmaceutical Benefits Scheme (RPBS)

The Pharmaceutical Benefits Scheme (PBS) and Repatriation Pharmaceutical Benefits Scheme (RPBS) aim to provide affordable access to medications for Australians by subsidising costs of prescription medications. Around 80% of all prescription medications available in Australian pharmacies are listed on the PBS or RPBS. Data on the value and volume of PBS and RPBS services are processed by Medicare Australia. These data are available via the Medicare Australia website <www.medicareaustralia.gov.au>, and are also provided to the Drug Utilisation SubCommittee for inclusion on their database for community prescription monitoring. Further data on volume, government and patient costs by state and drug type are available on the PBS website <www.health.gov.au/pbs/>.

National Diabetes Services Scheme (NDSS)

This is a government-funded subsidy scheme operated by Diabetes Australia on behalf of the Australian Government Department of Health and Ageing. It was set up in 1987, and provides self-management products and services for people with diabetes, including syringes, insulin pump consumables, needles for special injection systems, and testing strips for blood and urine. It also provides educational and information services to help people use these products and manage their diabetes. At 30 July 2003 almost 615,000 people were registered with the NDSS. Registrants provide personal information, some demographic data, details of the type of diabetes they have and how it is treated. The diagnosis must be verified by a medical practitioner or credentialed diabetes educator. Diabetes Australia estimates that the NDSS covers around 95% of all persons diagnosed with diabetes.

4.2 Register data sources

Australia and New Zealand Dialysis and Transplant Registry (ANZDATA)

This is a register of the delivery of kidney replacement therapy (dialysis and transplantation) in Australia and New Zealand. It contains data on all patients receiving kidney replacement therapy where the intention to treat is long term (i.e. kidney function will not recover). Cases of acute kidney failure are excluded. Data include demographic details, type of treatment, and cause of kidney failure.

Australasian Paediatric Endocrine Group (APEG) registers

These are state-based registers which cover all areas of Australia. They collect information on insulin-dependent diabetes in people aged less than 15 years. Case ascertainment is via diabetes clinics, diabetes educators, general practitioners, and endocrinologists, supplemented by data from the National Diabetes Services Scheme (in New South Wales) and hospital morbidity data (in Western Australia).

National Death Index (NDI)

The NDI contains records of all deaths occurring in Australia since 1980. Data are obtained from the state and territory Registrars of Births, Deaths and Marriages, and are held by the AIHW. Along with demographic and cause-of-death information, NDI records contain details of full names and aliases, and maiden names of females. Use of the NDI is governed by the AIHW Ethics Committee and is strictly confined to medical research purposes. Linkage with data sets provided to the AIHW by researchers is possible subject to approval by the Ethics Committee. Linkage between the NDI and the National Diabetes Register facilitates case-fatality ascertainment and more accurate estimates of diabetes-related mortality.

National Diabetes Register (NDR)

This database, held by the AIHW, collects information on people who use insulin as treatment for diabetes, either Type 1, Type 2, or other diabetes. It covers only those people who began to use insulin from 1 January 1999. Data for the register are obtained from two main sources: the NDSS and the APEG state-based registers. NDR data can be used to estimate the incidence of insulin-treated diabetes in Australians.

Tasmanian insulin-treated diabetes register

This is a voluntary register which began in 1984 to collect information about Tasmanians who use insulin to manage their diabetes. The register is a collaborative project between the Menzies Centre for Population Health Research and the International Diabetes Institute. It is estimated to have 84% coverage, with 95% coverage of people under 30 years of age, and regular questionnaires are used to keep registrant information up to date.

4.3 Survey data sources

Australian Diabetes, Obesity and Lifestyle Study (AusDiab)

The AusDiab study was conducted in 1999–2000 by the International Diabetes Institute and was partially funded by the then Commonwealth Department of Health and Aged Care. It is the most comprehensive study to date on the prevalence and impact of diabetes in Australia. The study was designed to provide estimates of the prevalence of diagnosed and undiagnosed diabetes, and self-reported chronic conditions such as heart disease. It collected measured data on blood pressure, blood lipids, blood glucose, body fat, height, weight, and waist and hip circumference, as well as self-reported information on smoking, physical activity, alcohol consumption, diet, general wellbeing, complications of diabetes, health knowledge and use of health services. The study collected information from over 11,000 adults (aged 25 and over) throughout non-remote Australia (excluding the Australian Capital Territory).

Australian Longitudinal Study on Women's Health

This study aims to examine the health of Australian women over a 20-year period. In 1996 over 41,000 women in three age groups (18–23, 45–50 and 70–75 years) agreed to participate in the study, which is designed to follow women through all the critical stages of their lives. Women from rural and remote areas were oversampled to allow for meaningful comparisons between geographic areas. Each age cohort is surveyed once every 3 years. The surveys collect a wide range of information including demographics, physical and mental health, risk factors and behaviours, and use of health services. Participants are also involved in substudies focusing on specific areas of health. A substudy assessing quality and accessibility of health care for women with diabetes was conducted in 2002.

Australian National Diabetes Information Audit and Benchmarking (ANDIAB)

This collection by the National Association of Diabetes Centres (NADC) is based on an audit of patients attending a selection of specialist diabetes centres and endocrinologists in private practice. Data were collected over 1-month periods in 1998, 1999, 2000, 2002 and 2004. The target sample is people with diabetes requiring specialist clinical management, in particular those who have had poor control of their diabetes. For this reason the sample does not accurately reflect the conditions of people with diabetes in the general community. Information reported includes demographic details, presence and treatment of risk factors, previous and current complications, and assessment of management practices against the NSW Clinical Management Guidelines for Diabetes.

Australian Prospective Diabetes Study (APDS)

This study is intended as a follow-up to the AusDiab study, which was conducted by the International Diabetes Institute in 1999–2000. AusDiab participants will be followed up to examine changes in diabetes status, risk factors, health status, and the development of complications in those with diabetes. Additional information on family history of chronic diseases, cardiovascular disease events and related use of health services, and the use of medications will be collected. The survival status of AusDiab participants will also be tracked through linkage with the National Death Index.

BEACH (Bettering the Evaluation and Care of Health) Survey of General Practice

This is an ongoing survey looking at the clinical activities of general practitioners (GPs), conducted by the General Practice Statistics and Classification Unit (an AIHW collaborating unit) at the University of Sydney. BEACH began in April 1998 and involves a random sample of approximately 1,000 GPs each year, collecting information on almost 100,000 GP–patient encounters. Data collected include GP and patient characteristics, reasons for encounter, problems managed and management techniques, and details of pharmacological and non-pharmacological treatments prescribed.

Census of Population and Housing (and estimated resident population)

The Census is an enumeration of all people in Australia on Census night (currently a Tuesday in August every 5 years), excluding foreign diplomats and their families. Visitors to Australia are included and any Australian absent from the country is excluded. Census data relevant to diabetes monitoring include sex, age, ethnicity, Indigenous status, country of birth, language usually spoken, and area of usual residence.

Estimates of the resident population (ERPs) of Australia and the states and territories are based on the results of the previous census. These are commonly used in the calculation of statistics including prevalence and mortality rates. ERPs are available for sex, age, country of birth and various geographical levels of Australia.

Disability, Ageing and Carers Surveys

These are a series of surveys conducted 5-yearly by the Australian Bureau of Statistics, most recently in 2003. They collect information on disability levels of Australians, causes of disability, care needs, the extent to which these needs are met, characteristics of those with unmet need, and the role of carers. They also provide information on participation in economic and community activities.

Exercise, Recreation and Sport Survey (ERASS)

The ERASS is a quarterly computer-assisted telephone interview collection which began in 2001. It is a joint initiative of the Australian Sports Commission and the state and territory departments of sport and recreation. It collects similar physical activity information to that previously included in the ABS Population Survey Monitor, which ceased collection in November 2000. ERASS aims at collecting information from around 3,400 people aged 15 years and over each quarter. The survey collects data on the frequency, nature and type of activities engaged in for sport, recreation or exercise over the previous 12 months.

National Aboriginal and Torres Strait Islander Survey (NATSIS)

This survey was conducted by the ABS in 1994. It was the first comprehensive survey of Australia’s Indigenous people and covered Aboriginal and Torres Strait Islander peoples throughout Australia, including those in prisons and special dwellings, surveying 15,700 Indigenous people. The survey provided data on the social, economic and self-assessed health status and risk factors for the Indigenous population.

National Aboriginal and Torres Strait Islander Health Survey (NATSIHS)

The first National Aboriginal and Torres Strait Islander Health Survey (NATSIHS) was conducted by the ABS in 2004–05, with results expected to be published at the state/territory level in early 2006. The report will include general demographic information, health-related actions, health risk factors, health status indicators and women’s health. Comparisons with selected results from the 2001 National Health Survey will also be included. Future NATSIHSs are to be conducted every 6 years (every second NHS).

National Dietary Survey of Adults

This was conducted by the Commonwealth Department of Health and the National Heart Foundation of Australia in 1983 as a component of the second Risk Factor Prevalence Survey. It was designed to obtain national information on dietary intake in order to determine food composition and nutrient intake of Australians aged 25–64 years. Data were collected from a sample of around 6,000 people in the six state capital cities (Canberra and Darwin were excluded).

National Drug Strategy Household Surveys

This series of surveys began in 1985, with the most recent (eighth in the series) conducted in 2004. The surveys collect information on drug-related knowledge, attitudes, consumption and behaviours from Australians aged 14 years and over. Data relevant to diabetes monitoring include smoking status and alcohol consumption levels. In 2004, self-reported information was also collected on diagnosis and/or treatment of Type 1 and Type 2 diabetes.

National Health Surveys

These surveys, previously conducted approximately every 6 years by the ABS, are designed to obtain national information on the health status of Australians, their use of health services, and health-related aspects of their lifestyle. Data available from these surveys include self-reported diabetes status, type of diabetes treatment, and self-reported information on risk factors including body weight, high blood pressure, and physical activity. From 2001 the National Health Surveys are to be conducted every 3 years.

National Nutrition Survey

This survey was conducted in 1995 by the ABS and is the most comprehensive dietary survey undertaken in Australia to date. Information on food and nutrient intake, dietary habits, and body measurements was collected from a subsample of National Health Survey participants, almost 14,000 people aged 2 years and over. Data relevant to diabetes monitoring include measured blood pressure, body weight, and waist and hip circumference, and self-reported food intake and dietary habits.

National Physical Activity Surveys

These surveys give an assessment of physical activity patterns and knowledge of the health benefits of physical activity among adult Australians (18–75 years). They were conducted during November and December of 1997, 1999 and 2000 using a computer-assisted telephone interview method, with a random sample population.

Population Survey Monitor

This quarterly survey was conducted by the ABS between August 1993 and November 2000. It covered all areas of Australia (excluding remote and sparsely settled areas), sampling 2,000 (from 1993 to 1995) or 3,000 (from 1996 to 2000) adults each quarter. Information collected included participation in organised sporting activities, and occasional health-related topics including smoking and fruit and vegetable consumption.

Risk Factor Prevalence Studies

These studies were conducted in 1980, 1983 and 1989 by the National Heart Foundation of Australia. They were designed to obtain national information on biomedical and behavioural risk factors, and to monitor trends over time. In total the three studies collected information from around 22,000 adults living in capital cities of Australia (Canberra and Darwin were not included in the 1980 and 1983 surveys). The studies collected measured data on blood pressure, blood lipids, height, weight, waist and hip circumference, as well as self-reported information on smoking, alcohol consumption, physical activity, diet, and medical history of cardiovascular disease and diabetes. Blood glucose measurements were taken in 1983.

State-based surveys

Surveys in this section have been classified as computer-assisted telephone interview (CATI), computer-assisted personal interview (CAPI), or paper-based (self-completed).

Australian Capital Territory

Although the Australian Capital Territory has no formal population survey system in place, ACT Health occasionally commissions NSW Health to include the Australian Capital Territory in its population surveys. In 1999, ACT residents were included in the NSW Older People's Health Survey, and in 2001 ACT residents were included in the NSW Children's Health Survey.

New South Wales

Adult Health Survey (CATI)

Population surveys of adults (16 years and over) in New South Wales were conducted in 1997 and 1998. Over 17,000 randomly selected persons were included in each year. Data of relevance to diabetes monitoring include self-reported risk factor status, self-reported diabetes status, information about diabetes management, and access to health services.

Schools Fitness and Physical Activity Survey (paper-based plus physical examination)

This survey was conducted in 1997 in around 90 state, Catholic, and independent schools across non-remote areas of New South Wales. Over 5,500 students from years 2, 4, 6, 8 and 10 participated. All students provided demographic information, self-reported their height and weight, and had height and weight measured; for those in year 4 and above, skinfolds, waist and hip girths were measured and fitness and motor skill tested. Students in years 8 and 10 also provided information on physical activity patterns and factors related to participation.

Children's Health Survey (CATI)

This population survey was conducted in 2001, and collected information about almost 10,000 children aged 0–12 years (including 500 from the Australian Capital Territory). Data of relevance to diabetes monitoring include nutrition and physical activity items.

Older People's Health Survey (CATI)

The NSW Health Survey Program conducted an older people's health survey in 1999. This covered over 9,000 people aged 65 years and over (including over 500 ACT residents). Information relevant to diabetes monitoring includes self-rated health, use of health and community services, risk factors, self-reported diabetes status, and foot and eye checks among people with diabetes.

The Schools Physical Activity and Nutrition Survey (SPANS) (paper-based plus physical examination)

This survey was conducted during 2004, surveying around 8,000 students from over 90 schools across New South Wales. Data were collected on physical activity and nutrition patterns of students in Kindergarten and years 2, 4, 6, 8 and 10. The survey also gathered data on fundamental movement skill proficiency and measured height, weight, waist circumference and blood pressure in all students. Blood testing in year 10 students was also undertaken to look at risk factors for Type 2 diabetes, heart disease and liver disease.

Continuous Health Survey Program (CAPI)

The Continuous Health Survey Program began data collection in January 2002. The program covers people of all ages through ongoing data collection in all NSW area health services, completing at least 2,000 interviews each month. The survey combines items from the previous adult, children and older people surveys in a series of modules intended for one-off, continuous, biennial or triennial collection. Specific questions may be added as required to meet local or state priorities. Modules of relevance to diabetes monitoring include self-reported risk factor status (nutrition, smoking, physical activity, hypertension, high cholesterol, and overweight), self-reported diabetes status, self-rated health, and measures of accessibility of and satisfaction with health care services. Demographic information recorded in the survey includes country of birth and language spoken at home.

Northern Territory

Health and Wellbeing Survey (CATI)

This was the Northern Territory component of the Collaborative Health and Wellbeing Survey run across the Northern Territory, Western Australia and South Australia in 2000. In the Northern Territory almost 2,500 adults (aged 18 years and over) were interviewed. Data of relevance to diabetes monitoring include diabetes status, risk factor status, health service usage, and mental health items.

Queensland

General Health Survey (CATI)

This was last conducted in 2001, and sampled 1,625 Queenslanders aged 18 years and over. Information of relevance to diabetes monitoring includes diabetes status, presence of risk factors, and knowledge of risk factors for and health outcomes of diabetes.

Diabetes Management Survey (CATI)

This survey was specifically designed to gather information about a range of topics relevant to diabetes management. It was run concurrently with the General Health Survey in 2000 and collected information from 1,105 Queensland adults (aged 18 years and over) who reported ever being told they had diabetes. Data collected included presence of risk factors for complications, presence of complications, health service use, current management practices, knowledge of long-term outcomes of diabetes, and knowledge of symptoms of hypoglycaemia.

South Australia

Health Omnibus Survey (CATI)

The annual SA Health Omnibus Survey provides government and non-government organisations with data which can be used to plan, implement and monitor health programs and other initiatives. It collects information from a representative sample of over 4,000 adults each year, and can provide data on prevalence and incidence of health problems, health knowledge and behaviours, uptake of new health programs, and evaluation of health interventions.

Health Monitor (CATI)

Health Monitor is a telephone-based monitoring system which supplements the Health Omnibus Survey. Surveys of 2,000 South Australian households are conducted three times a year. This enables collection of information at different times of the year compared with the Omnibus survey.

SA Monitoring and Surveillance System (SAMSS) (CATI)

SAMSS was designed by the SA Department of Human Services to provide timely, quality, representative data on South Australians of all ages. It began in June 2002 as a continuing monthly survey, and approximately 600 interviews are conducted each month. SAMSS monitors departmental issues, key risk factors and population trends in priority chronic disease and related areas. The data are used to check on departmental, state and national priority areas and can be linked to key indicators. The monthly nature of the survey enables seasonal or short-term trends to be monitored.

Social, Environmental and Risk Context Information System (SERCIS) (CATI)

SERCIS is a flexible, telephone-based monitoring system designed to provide health data on large population samples. Unlike SAMSS or the Health Monitor, SERCIS conducts issue-specific surveys when required. It can be used for direct self-report information on specific health issues or as a means of recruitment for other surveys or clinical studies. SERCIS was used in 2000 to conduct the Collaborative Health and Wellbeing Survey of South Australia, Western Australia and the Northern Territory.

Tasmania

Healthy Communities Survey (paper-based)

This was the first comprehensive statewide population health survey for Tasmania, and was conducted in 1998. Information was received from more than 15,000 adults aged 18 and over. Data of relevance to diabetes monitoring include risk factor status, diabetes status, and quality of life.

Victoria

Victorian Population Health Survey (CATI)

This is an annual series of surveys which began in 2001. The surveys cover adults (18 years and over) resident in Victoria. Data of relevance to diabetes monitoring include risk factor status, diabetes status, screening for diabetes, risk factors and complications, and use of and satisfaction with health services.

Western Australia

Health and Wellbeing Survey (CATI)

Over 2,500 people were interviewed in the WA component of the collaborative survey run in 2000 across Western Australia, Northern Territory and South Australia. The WA Health Department collected an additional 7,500 interviews 2 months later to increase the number to 10,000 adults 18 and over, the usual state health survey sample. Data of relevance to diabetes monitoring include diabetes status, risk factor status, health service usage, and mental health items.

Child Health and Wellbeing Survey (CATI)

This survey gathered information on almost 1,000 children aged 12 and under in 2001. Topics covered included the National Health Priority Areas, other chronic diseases, health risk factors, and use of health services.

Child and Adolescent Physical Activity and Nutrition Survey (CAPANS) (paper-based plus physical examination)

This survey was run during the second half of 2003 and involved completion of a self-administered questionnaire about physical activity and nutritional intake, a 24-hour food record diary, a food frequency questionnaire, and objective measurement of physical activity (using pedometers worn over 7 days), height, weight, and waist circumference. A total of 2,800 students from years 3, 5, 7, 8, 10 and 11 in 32 primary and secondary schools across Western Australia were surveyed.

Health and Wellbeing Surveillance System (CATI)

This system began data collection in February 2002 and interviews 550 people of all ages each month. It aims to monitor population health in Western Australia and provide timely information relating to chronic diseases and their risk factors, in order to guide local and regional planning and policy. Information of relevance to diabetes monitoring includes self-reported risk factor status, diabetes status, and health service use.

4.4 Other existing and developmental data sources

AIHW Disease Expenditure Database

This project allocated total health expenditure in 2000–01 to around 200 disease and injury categories based on those used in the Burden of Disease and Injury in Australia study. For each category, total expenditure was divided into expenditure on hospital services (admitted and non-admitted patients), aged care, other medical services (including GPs, specialists, imaging and pathology), pharmaceuticals (prescription and over-the-counter), dental, other professional services, health-related research, and other expenditure. Data were presented by sex and age group. Previous disease-specific expenditure estimates were produced by the AIHW in 1998 for the 1993–94 financial year.

Burden of Disease and Injury in Australia study

This study, conducted using 1996 data, assessed the total burden of disease and injury in Australia using methods developed by the World Health Organization's Global Burden of Disease Study. 'Burden' here refers to the impact of disease or injury on 'healthy' life, in terms of premature death, illness, disability and injury. These impacts are summarised using the disability-adjusted life year (DALY) measure, which estimates the potential years of 'healthy' life lost due to disease or injury. The study examined the burden due to specific diseases, including diabetes, as well as risk factors for illness and injury. The study is currently being updated using 2003 data.

Diabetes Clearing House

The Diabetes Clearing House is an initiative of the Diabetes Health Priority Area Advisory Group. It was established by the South Australian Department of Human Services in 1998 to provide information about diabetes and its impact on public health. The internet-based clearing house 'seeks, collects and processes information, advice and expertise that are relevant to achieving the goals of both the Strategic Plan for Diabetes in South Australia and the National Diabetes Strategy'. See <www.dhs.sa.gov.au/pehs/PROS/diabetes-clearing-house.html>.

Diabetes Prevention Pilot Initiative Program

This is an initiative of the Australian Government Department of Health and Ageing, and provides funding for projects to test methods of implementing the NHMRC National Evidence Based Guidelines for the Management of Type 2 Diabetes Mellitus: Primary Prevention. This includes encouraging and helping people at risk of diabetes to increase physical activity, improve their diet, and achieve and maintain a healthy weight. The program may provide information on diabetes prevention initiatives.

Drug Utilisation SubCommittee Database

This database is held at the Australian Government Department of Health and Ageing, and monitors the community (i.e. non-hospital) use of prescription medicines in Australia. It does not include any information on drugs prescribed in public hospitals, or highly specialised drugs available to outpatients through public hospital pharmacies under section 100 of the National Health Act. The database combines information on subsidised medications from the Pharmaceutical Benefits Scheme (PBS) and the Repatriation PBS, and an estimate of unsubsidised prescriptions from the Pharmacy Guild Survey. The Pharmacy Guild Survey collects dispensing information each month from a random sample of around 250 pharmacies throughout Australia. It is estimated that around 20% of community prescriptions are not dispensed under the PBS or RPBS. Data from the database are published in the Australian Statistics on Medicines series.

National Diabetes Improvement Projects (NDIP)

The NDIP program is an initiative of the Australian Government Department of Health and Ageing. It offers funding for projects that identify barriers to good diabetes care and demonstrate practical improvements in diabetes management within health service settings. Several specific target populations have been identified as a focus for the NDIP, including Aboriginal and Torres Strait Islander peoples, culturally and linguistically diverse groups, and women with diabetes in pregnancy. The NDIP may provide some information on diabetes management within health service settings.

National Divisions Diabetes Program (NDDP) Data Collation Project

This project was conducted in 1999–2000 and comprised four components, with participation of divisions in each component dependent on the nature of their program and data availability. One component involved electronic collation of data from the Divisions database, CARDIAB. Seven Divisions of General Practice participated in this component, and provided data on 4,359 patients with diabetes. Information provided included diabetes type and treatment, health outcomes, complications, and assessment of management against quality of care indicators.

National Integrated Diabetes Program (NIDP) Practice Incentives Program

This program was set up by the Australian Government Department of Health and Ageing to provide an integrated national approach to improve the prevention, earlier diagnosis, and management of diabetes. The program was allocated funds for 4 years in the 2001–02 federal Budget, and further funds are contributed by the general practice profession through the Royal Australian College of General Practitioners, the Rural Doctors Association of Australia, and the Australian Divisions of General Practice. Components of the program include incentives to general practice to improve prevention, detection and management of diabetes. An example of the type of data that come out of this program is the number of patients with diabetes who have been recorded as completing an annual cycle of care with their GP.

Service Activity Reporting (SAR)

The Service Activity Reporting (SAR) data collection provides service level statistics on Australian Government funded Aboriginal and Torres Strait Islander primary health care services. The data collection includes information on episodes of care, service population, staffing and health related activities of these services. SAR is steered jointly by the National Aboriginal Community Controlled Health Organisation (NACCHO) and the Office for Aboriginal and Torres Strait Islander Health (OATSIH).

Vision Impairment Prevention Program (VIPP)

This program, consisting of 19 separate projects, was funded by the Australian Government in 1998–99. The VIPP aimed at reducing the incidence of, and providing better management for, diabetic retinopathy by improving screening, education, referral and treatment. Projects conducted under the VIPP included establishing retinopathy screening projects, improving access to quality eye care, and managing vision loss.

The Surveillance of Risk Factors report (SuRF 1)

This report was compiled by the World Health Organization (WHO) in 2003. It presents available prevalence data on non-communicable disease risk factors at the country level for a number of member states of WHO. These include smoking, alcohol consumption, physical inactivity, obesity, blood pressure, fruit/vegetable intake, and diabetes (measured by blood glucose).

5 Review of data sources, indicators and deficiencies for the key areas for monitoring diabetes

This chapter covers each of the key areas for monitoring diabetes (see Figure 2.1 and Table 3.1), reviewing relevant data sources and existing indicators, and detailing gaps and deficiencies in the available data and indicators. More information on the data sources is provided in Chapter 4 of this report.

Administrative information collected as part of the Medicare Benefits Schedule (MBS) and the Pharmaceutical Benefits Scheme (PBS) has the potential to provide important information relevant to monitoring. A pilot project between the AIHW and Medicare Australia is currently under way to explore this potential in relation to diabetes. This work is not reflected in this chapter as it is still in progress. However, it is expected that some of the gaps and deficiencies outlined below should be lessened using MBS and PBS data in the future.

Note that the National Diabetes Data Working Group (NDDWG) indicators were under development at the time of writing, and that these indicators are presented as they were at March 2005. In this chapter these draft indicators are marked with an asterisk (*).

5.1 Primary prevention

Primary prevention of Type 2 diabetes in Australia includes mass media campaigns specifically aimed at preventing diabetes and detection of glucose intolerance, as well as diabetes awareness strategies and general promotion of healthy lifestyle choices. A variety of organisations (such as Diabetes Australia) and health services including GPs, community health centres and other health care workers are involved in preventive, awareness and healthy lifestyle promotion activities across Australia. Government and non-government organisations are also involved in promoting healthy lifestyle choices, such as good diet, physical activity and healthy weight, all of which decrease the risk of developing Type 2 diabetes.

Data sources

Diabetes Prevention Pilot Initiative Program

Provides funding for prevention programs.

National Integrated Diabetes Program

Among other functions, provides general practice incentives and education for people at risk of developing diabetes.

Gaps and deficiencies

The available data sources provide data only on programs that receive government-allocated funding. There is currently no way of monitoring other programs relevant to diabetes prevention or risk modification which may be funded by non-government organisations, community groups or charities.

Indicators

**NDDWG 2A.1.1*	The number and characteristics of programs/initiatives identified to prevent/delay the development of Type 2 diabetes or modify the prevalence of diabetes risk factors. For each program identified: Does it follow evidence-based guidelines? Is it ongoing? What is its reach?
**NDDWG 2A.1.2*	The proportion of the population reached by preventive programs.
**NDDWG 2A.2.1*	The number and characteristics of mechanisms for monitoring the incidence of diabetes and the prevalence of diabetes risk factors. For each mechanism/data source identified: What is the type of mechanism/data source? What are the scope and coverage of data collection? What is the frequency of data collection? Are data collected according to agreed national or international standards? Are data sets routinely analysed and reported on?

5.2 Identification of people at risk

5.2.1 Predisposing factors for diabetes

Predisposing factors are those factors, such as age and sex, that increase the risk of a disease or condition but cannot be modified. Genetic factors (including having an immediate relative with the disease) have been identified as predisposing factors for Type 1 diabetes. For Type 2 and gestational diabetes, age, ethnicity and family history of diabetes are all considered to be predisposing factors.

Since by definition predisposing factors cannot be modified, they cannot in themselves be targets for preventive strategies. However, knowledge of the prevalence and geographical distribution of the various predisposing factors for diabetes can help identify populations where the risk or prevalence of diabetes is increased, so that preventive programs and treatment centres can be appropriately located within the community. Further, knowledge of the identity and location of culturally and linguistically diverse groups and Aboriginal and Torres Strait Islander communities enables promotional and educational materials and programs to be produced in appropriate languages and to account for cultural needs.

Data sources

Australian Diabetes, Obesity and Lifestyle Study (AusDiab)

National (excluding Australian Capital Territory) non-remote population sample aged 25 years and over, conducted in 1999–2000. Data of interest include age, sex, country of birth, language spoken at home and family history of diabetes.

Census of Population and Housing (and estimated resident population)

Enumeration of all people (excluding foreign diplomats and their families) in Australia on Census night. Undertaken every 5 years, most recently in 2001. Census data relevant to diabetes monitoring include sex, age, ethnicity, country of birth and language usually spoken.

Estimates of the resident population (ERP) of Australia and the states and territories are based on the results of the previous Census. These are commonly used in the calculation of statistics including prevalence and mortality rates. ERPs are available for sex, age, country of birth and various geographical levels of Australia.

Gaps and deficiencies

'Monitoring' of predisposing factors for Type 2 and gestational diabetes is most consistently done through the 5-yearly Census, which provides almost full coverage of the geographic distribution of ages and ethnicities across Australia. National and state health surveys may also provide these data, along with information on diabetes prevalence and risk factors. Family history data may be supplied through more detailed health surveys such as AusDiab, however none of the current regular surveys collect these data. Genetic predisposition, the main predisposing factor for Type 1 diabetes, is practically impossible to monitor other than indirectly via family history.

Indicators

There are no specific indicators that monitor predisposing factors for diabetes.

5.2.2 Modifiable risk factors for diabetes

Overweight and obesity

Excess weight, particularly abdominal obesity, is strongly linked to insulin resistance. Being overweight or obese increases the risk of developing Type 2 and gestational diabetes. In those who are overweight, weight loss can reduce the incidence of diabetes and can help prevent or delay progression from impaired glucose tolerance to Type 2 diabetes.

For the existing indicators, and in most population surveys, excess weight is defined in terms of the body mass index (BMI). This is calculated as a person's weight (in kg) divided by the square of the person's height (in metres). For adult Caucasians (18 years and over), 'overweight' is generally defined as a BMI of 25 or more; 'obesity' is defined as a BMI of 30 or more. These cutoffs may not be applicable in all population groups, particularly Asians and Polynesian Islanders. They are also not suitable for use in children, and age- and sex-specific BMI values for overweight and obesity in children aged 2–17 years have been developed (Cole et al. 2000).

Data sources—measured height and weight

Australian Diabetes, Obesity and Lifestyle Study (AusDiab)

National (excluding Australian Capital Territory) non-remote population sample aged 25 years and over, conducted in 1999–2000. Also asked participants whether they considered themselves to be underweight, the right weight, or slightly or very overweight.

National Nutrition Survey

National population sample aged 2 years and over, 1995.

Risk Factor Prevalence Studies

Capital cities (excluding Canberra and Darwin in 1980 and 1983) population samples, 1980, 1983 and 1989. Ages 25–64 years in 1980 and 1983, 20–69 years in 1989.

Data sources—self-reported height and weight

Australian Longitudinal Study on Women's Health

National female population sample, 3 cohorts of young (initially 18–23 years), mid (45–50 years) and older (70–75 years) women surveyed every 3 years from 1996. Surveys also ask about changes in weight over previous 12 months, current dieting or weight loss practices and target weight relative to current weight (i.e. happy with current weight/would like to be lighter/would like to be heavier).

National Health Surveys

National population samples 1989–90, 1995, 2001, all ages.

National Physical Activity Surveys

National population samples 1997, 1999, 2000, ages 18–75 years.

State-based surveys

State population samples are available for Queensland, New South Wales, the Northern Territory, South Australia, Victoria and Western Australia at various times over the period 2000–02. New South Wales, South Australia and Western Australia have continuous health surveillance systems from mid-2002. The NSW survey also asks respondents which weight category they consider themselves to be in (underweight, acceptable weight or overweight).

Gaps and deficiencies

There are no recent measured data on height, weight or waist circumference. At present, there are no plans for these data to be collected nationally.

There is also currently no indicator (at least in the three indicator sets reviewed here) to assess abdominal overweight and obesity. Excess weight carried particularly in the abdominal area is recognised as an important risk factor for diabetes. Waist circumference measurements for Australian population samples are available from the Risk Factor Prevalence Surveys (1980, 1983, and 1989), the National Nutrition Survey (1995) and the AusDiab study (1999–00).

Indicators

NHPA 2.1a	Prevalence rates for obesity and overweight (as measured by BMI) in the general population.
NHPC 2.09	Proportion of adults overweight or obese.
**NDDWG 2B.2.1*	Prevalence of obesity over time.

All relevant data sources can provide data for all three above indicators, but different age ranges are covered by each source.

Physical inactivity

Being physically inactive increases the risk of Type 2 and gestational diabetes as well as many other health problems. It is also associated with increased weight, another important risk factor for diabetes. Physical activity has beneficial effects on glucose metabolism and can significantly improve glucose tolerance in those whose tolerance is impaired. Regular physical activity can prevent or delay the incidence of Type 2 diabetes in those at high risk, such as people with impaired glucose tolerance (DPPRG 2002; Tuomilehto et al. 2001).

Current Australian and international guidelines recommend that adults do at least 30 minutes of moderate intensity activity (such as brisk walking) on most days of the week to achieve health benefits. In monitoring terms this is generally interpreted to mean that a person reporting less than 150 minutes of at least moderate intensity activity per week (equivalent to 30 minutes per day for 5 days) is not doing enough physical activity for good health.

Data sources

Australian Diabetes, Obesity and Lifestyle Study (AusDiab)

National (excluding Australian Capital Territory) non-remote population sample aged 25 years and over, conducted in 1999–2000. The survey used the same questions as in the National Physical Activity Surveys. Able to report against the 150 minutes/5 sessions per week recommendation.

Australian Longitudinal Study on Women's Health

National female population sample, 3 cohorts of young (initially 18–23 years), mid (45–50 years) and older (70–75 years) women surveyed every 3 years from 1996. The 1996 surveys collected frequency of moderate and vigorous activities. Subsequent surveys asked about frequency and duration of walking, moderate and vigorous leisure activity and vigorous household or garden chores during previous week, and usual time spent sitting on weekends and weekdays. Able to report against the 150 minutes/5 sessions per week recommendation from 1998 onwards.

Exercise, Recreation and Sport Survey (ERASS)

National population samples of approximately 3,400 persons aged 15 years and over each quarter, beginning in 2001. Data collected relate to frequency and type of activities undertaken for sport, recreation and exercise over the previous 12 months. Able to report number of sessions per week of at least moderate activity, but data on duration of activity are not collected.

National Health Surveys

National population samples, 1989–90, 1995 and 2001. Physical activity data are collected for ages 15 and over only. Slightly different questions from the National Physical Activity Surveys, in that the recall period is 2 weeks rather than one, and walking for transport is not included. Able to report against the 150 minutes/5 sessions per week recommendation, but results will be different from surveys which include walking for transport.

National Physical Activity Surveys

National population samples, ages 18–75, 1997, 1999 and 2000. Standard questions regarding frequency and duration of walking, moderate and vigorous leisure time activity and vigorous household or yard work in the previous 7 days. Able to report against the 150 minutes/5 sessions per week recommendation.

Risk Factor Prevalence Studies

Capital cities (excluding Canberra and Darwin in 1980 and 1983) population samples, 1980, 1983 and 1989. Covered ages 25–64 years in 1980 and 1983, and 20–69 years in 1989. The 1980 survey collected frequency of walking, and moderate, vigorous and sporting activities, as well as work-related transport. The 1983 and 1989 surveys asked about frequency and duration of walking, and moderate and vigorous activities over the previous 2 weeks. The 1983 and 1989 surveys are able to report against the 150 minutes/5 sessions per week recommendation.

State-based surveys

The continuous health surveillance systems in New South Wales, Western Australia and South Australia all use the same questions as the National Physical Activity Surveys, as did the 2001 Queensland general health survey. These states are able to report against the 150 minutes/5 sessions per week recommendation. The Victorian Population Health Survey (annual from 2001) collects information on time and number of sessions for walking and vigorous activities only. Data from the Northern Territory in 2000 indicate the number of sessions for all activity types but record time for walking only. The 1998 Tasmanian Healthy Communities Survey collected information on the frequency of 30-minute sessions of activity. No non-nationally collected data on physical activity are available for the Australian Capital Territory.

Gaps and deficiencies

The main data deficiency is the non-comparability of the physical activity information from various data sources due to the use of different questions to capture activity levels. However, more surveys now appear to be moving towards a standard set of questions, which should improve comparability in the future.

There is also an issue with the indicators in that definitions have not been provided. Most measures of physical activity in the Australian population refer to activity undertaken in leisure time, i.e. not work-related or domestic activity. However, in some measures, such as the questions used in the National Physical Activity Survey, activity undertaken for transport, such as walking to and from work, is also included. Walking for transport has not previously been included in the National Health Survey questions, therefore the results of these two major national surveys are not comparable. It is also argued that work-related and domestic activities also provide benefit and should be measured as well as leisure-time activities.

Indicators

NHPA 2.2a	Rates for non-participation in regular, sustained, moderate aerobic exercise in the general population.
NHPC 2.08	Proportion of adults insufficiently physically active to obtain a health benefit.
**NDDWG 2B.2.1*	Prevalence of physical inactivity over time.

All relevant data sources are able to provide data for all three indicators, but different age ranges are covered by each source and the specification of exactly what constitutes activity or inactivity varies. With the exception of the National Health Survey and ERASS, the more recent national and state data sources (except Victoria) use the same set of questions to collect information on physical activity.

NHPA indicator 2.2a aims at capturing non-participation in 'regular, sustained, moderate aerobic exercise' but there is no explanation of what exactly such activity is. Current reports provide data relating to participation in less than 150 minutes of moderate physical activity per week for this indicator. This is also what is reported as 'insufficiently active' for NHPC indicator 2.08. Similarly, NDDWG indicator 2B.2.1 refers to the prevalence of 'physical inactivity' but does not define whether this means no physical activity at all (i.e. sedentary behaviour) or all activity levels less than the recommended 150 minutes per week. Technical specifications for the NDDWG indicators are yet to be determined and should include this definition. Consensus is needed as to what types of activity are to be measured for reporting against these indicators, in what contexts, and at what level and duration.

Impaired glucose tolerance and impaired fasting glucose

Impaired glucose tolerance (IGT) and impaired fasting glucose (IFG) are metabolic stages between normal glucose tolerance and diabetes. These two conditions are often referred to as 'pre-diabetes'. In people with IFG, fasting blood glucose levels are higher than normal but lower than that which would indicate diabetes. In people with IGT, fasting blood glucose levels are normal but glucose levels remain high for longer than normal after eating.

People with IGT or IFG are at high risk of developing Type 2 diabetes—one in three people with IGT are likely to develop Type 2 diabetes within 10 years. However it is possible to prevent or delay progression to Type 2 diabetes through a well-balanced diet, weight control and regular physical activity (Tuomilehto et al. 2001).

Data sources

Australian Diabetes, Obesity and Lifestyle Study (AusDiab)

National (excluding Australian Capital Territory) non-remote population sample aged 25 years and over, conducted in 1999–2000. Fasting glucose was measured and oral glucose tolerance tests performed in those not already taking antidiabetic medication.

Gaps and deficiencies

Population data on IGT and IFG would be available only through a biomedical survey, such as in the AusDiab study. Currently there are no plans to run such a survey at a national level in the future. Given that people with these conditions are at high risk of developing Type 2 diabetes, monitoring their prevalence may provide some indication of the likely future burden of diabetes in Australia. It would also help to identify people at high risk of diabetes for possible intervention and targeted prevention programs.

Indicators

There are currently no indicators to monitor the prevalence of impaired glucose metabolism.

Poor nutrition

Poor nutrition is linked to increased body weight, a major risk factor for diabetes. Evidence linking specific dietary factors to diabetes is inconclusive, but it is believed that increased intake of whole grains and fibre and decreased intake of saturated fats may reduce risk.

Data sources

Australian Diabetes, Obesity and Lifestyle Study (AusDiab)

National (excluding Australian Capital Territory) non-remote population sample aged 25 years and over, conducted in 1999–2000. Included a food frequency questionnaire plus short dietary questions, as well as questions on knowledge of healthy eating recommendations.

National Dietary Survey of Adults

Capital cities (excluding Canberra and Darwin) population sample, ages 25–64, conducted in 1983. A subsample of the 1983 Risk Factor Prevalence Survey participants completed a 24-hour recall food intake questionnaire.

National Health Surveys

National population samples, all ages, 1989–90 and 2001. In 1989–90, questions referred to change in diet with regard to certain types of food. In 2001 items recorded information on type of milk, fruit and vegetable consumption and added salt. The 1995 NHS did not contain any dietary questions as it was supplemented by the National Nutrition Survey.

National Nutrition Survey

National population sample, ages 2 and over, conducted in 1995. Included a food frequency questionnaire, questions on food habits and attitudes and a 24-hour recall food intake questionnaire.

Risk Factor Prevalence Studies

Capital cities (excluding Canberra and Darwin in 1980 and 1983) population samples, 1980, 1983 and 1989. Ages 25–64 years in 1980 and 1983, 20–69 years in 1989. Each survey contained short dietary questions only.

State-based surveys

Apart from the Australian Capital Territory and Tasmania, at least some diet-related information is available from each state/territory since 2000. Data on the number of serves of fruit and vegetables, and type of milk consumed, are available from each of the other five states and the Northern Territory. New South Wales, South Australia and Western Australia also collect information on the consumption of processed meat products (such as sausages and pressed sandwich meats) and potato chips/wedges. In addition, New South Wales collects information on consumption of bread and cereals, and Western Australia and South Australia record the frequency of eating ‘fast’ foods.

Gaps and deficiencies

Data on fruit and vegetable consumption and several other discrete dietary behaviours (such as type of milk consumed) are available from the National Health Survey and some state surveys, but more detailed information relating to the Australian dietary guidelines is available only from intermittent surveys. If data are to be reported regularly against the dietary guidelines this would require more information than is presently collected in the recurrent surveys.

Indicators

NHPC 2.07	Proportion of people eating sufficient daily serves of fruit and vegetables.
**NDDWG 2B.2.1*	Proportion of people following Australian dietary recommendations over time.

Indicators relevant to general risk factors for diabetes

Data sources

Australian Diabetes, Obesity and Lifestyle Study (AusDiab)

National (excluding Australian Capital Territory) non-remote population sample aged 25 years and over, conducted in 1999–2000. The study collected information on knowledge of risk factors for and symptoms of diabetes, as well as knowledge of general health issues.

Diabetes Prevention Pilot Initiative Program (DPPIP)

Australian Government initiative which provides funding for projects to test methods of implementing the NHMRC primary prevention guidelines.

National Integrated Diabetes Program (NIDP)

Aims at improving the prevention, earlier diagnosis, and management of people with diabetes. Components include incentives to general practice to improve prevention and detection, and developing education and information resources for people at risk of diabetes.

Queensland General Health Survey

This survey was conducted in 2001, and collected information on population knowledge of risk factors for diabetes.

Gaps and deficiencies

The relevant data sources for indicator NDDWG 3A.1.2 capture only those programs which receive government assistance under the DPPIP or NIDP. Programs which are community, charity or privately funded, or which receive assistance from other local, state or federal government sources, are not covered. Alternative ways of identifying such programs need to be explored.

Indicators

**NDDWG 2C.1.1*	The proportion of individuals who correctly identify the risk factors for Type 2 diabetes.
**NDDWG 2C.1.2*	The proportion of individuals at risk of Type 2 diabetes who correctly identify that they are at risk.

**NDDWG 3A.1.2* The number and characteristics of risk factor modification programs for the general population; high-risk populations; and people with evidence of impaired glucose metabolism.

For each program identified:

What is the target population?

What is the focus of the program?

Does the program follow evidence-based guidelines?

Is it ongoing?

Is it culturally appropriate?

Are there any population groups who are missed or not reached?

5.3 Detection and prevention of diabetes

In the majority of Type 1 diabetes cases, symptoms combined with high blood glucose levels are sufficient to establish the diagnosis. In Type 2 and gestational diabetes, two formal blood glucose tests are usually required. Screening for Type 1 diabetes is not practical as the risk factors for Type 1 diabetes are not well understood, symptoms generally develop rapidly, and the condition has a relatively low incidence. However, screening for Type 2 and gestational diabetes can have substantial benefits in at-risk groups (Colagiuri et al. 1998). Early detection of Type 2 diabetes is particularly important as the condition may progress to an advanced stage without symptoms, and serious complications may develop. Because careful management of blood glucose levels may reduce morbidity from complications, the risk of complications is greatly decreased if diabetes is diagnosed in the early stages.

Detection and screening

Data sources

Australian Diabetes, Obesity and Lifestyle Study (AusDiab)

National (excluding Australian Capital Territory) non-remote population sample aged 25 years and over, conducted in 1999–2000. Performed fasting blood glucose and oral glucose tolerance tests in those not already taking insulin injections or tablets for diabetes. Also recorded self-reported diabetes status, Indigenous status and country of birth.

Victorian Population Health Survey

State population sample, ages 18 and over, 2002. Participants were asked whether they had had a test/check for diabetes or high blood sugar levels in the previous 2 years. Information on age, ethnicity, geographic location and risk factors was also collected, enabling identification of individuals or groups at high risk.

Service Activity Reporting (SAR) data collection

Provides details on the number of Australian Government funded Aboriginal and Torres Strait Islander primary health care services that undertake or facilitate diabetes screening.

Gaps and deficiencies

At present there are no systems in place to determine the number of people being screened for Type 2 diabetes. This affects the collection of data for the majority of the indicators listed below.

Indicators

**NDDWG 6A.1.1*	The proportion of health care practitioners who have a system in place to screen for Type 2 diabetes, and the characteristics of these systems. For each system identified: Does it follow evidence-based guidelines? Is there a register/recall system? Is it culturally appropriate? Are primary care practices Practice Incentives Program (PIP) accredited?
**NDDWG 6B.1.1*	The proportion of people at risk of Type 2 diabetes being screened, and the proportion of these undergoing appropriate screening (as defined by evidence-based guidelines).
**NDDWG 6B.2.1*	The ratio of diagnosed to undiagnosed cases of Type 2 diabetes.
**NDDWG 6C.1.1*	The proportion of at-risk people who are aware of the need for Type 2 *diabetes screening.*

Incidence and prevalence

Data sources—measured or clinically diagnosed diabetes

Australian Diabetes, Obesity and Lifestyle Study (AusDiab)

National (excluding Australian Capital Territory) non-remote population sample aged 25 years and over, conducted in 1999–2000. Performed fasting blood glucose and oral glucose tolerance tests in those not already taking insulin injections or tablets for diabetes. Also recorded self-reported diabetes status, Indigenous status and country of birth.

Australian Paediatric Endocrine Group registers

State-based registers of 0–14-year-olds diagnosed with diabetes. Information recorded includes age, sex, date of diagnosis, type of diabetes, Indigenous status and country of birth.

National Diabetes Register

Register of people with insulin-treated diabetes. Information collected includes age, sex, date of diagnosis, date of first insulin use and Indigenous status. From mid-2003, country of birth is also recorded.

Perinatal data collections

State and territory collections of information on mothers and babies. Data include mother's age, Indigenous status, country of birth, parity, maternal medical conditions (including pre-existing diabetes), complications of pregnancy (including gestational diabetes), outcome of pregnancy, and characteristics of the baby including gestational age and birthweight.

Risk Factor Prevalence Study 1983

Capital cities (excluding Canberra and Darwin) population sample, ages 25–64. A fasting blood glucose measurement was taken and self-reported diabetes status collected. Country of birth was recorded but no information on Indigenous status was included.

Data sources—self-reported diabetes

Australian Longitudinal Study on Women's Health

National female population sample, 3 cohorts of young (initially 18–23 years), mid (45–50 years) and older (70–75 years) women surveyed every 3 years from 1996. All surveys asked respondents if they had ever been diagnosed with diabetes. Young and mid-aged cohort surveys record diabetes type. Indigenous status, country of birth, language spoken at home and parity are also recorded for all participants.

National Health Surveys

National population samples, all ages, 1989–90, 1995 and 2001. In 1989–90, recorded diabetes status only. In 1995 and 2001, also recorded diabetes type, age at diagnosis, type of treatment and age at first insulin injection if applicable. All three surveys record Indigenous status, country of birth and usual language spoken at home. The 2001 survey includes information on parity for females aged 18–65 years.

Risk Factor Prevalence Studies

Capital cities (excluding Canberra and Darwin in 1980 and 1983) population samples, 1980, 1983 and 1989. Ages 25–64 years in 1980 and 1983, and 20–69 years in 1989. In 1980, information on diabetes status and whether requires medicinal treatment (insulin injections or tablets) was recorded. In 1983 and 1989, information on diabetes status, year of diagnosis and type of treatment was collected. All surveys record country of birth but not Indigenous status.

State-based surveys

State population samples including data on diabetes status in adults (ages 18 and over) are available from all states between 1998 and 2002, with the exception of the Australian Capital Territory where data are available only for adults aged 65 and over. Most of these surveys (New South Wales, Australian Capital Territory, South Australia, Tasmania, Victoria, Queensland) recorded Indigenous status, country of birth and whether a language other than English was spoken at home. For the Northern Territory and Western Australia, Indigenous status only was recorded.

Gaps and deficiencies

Until mid 2003, inclusion on the National Diabetes Register was voluntary, thus the data do not provide total incidence estimates for Type 1 diabetes. Recent changes to the registration process mean that coverage should be nearly complete from 2004 onwards. However, the small percentage of people who do not join the National Diabetes Services Scheme or one of the APEG registers are still unlikely to be included.

There is currently no way of monitoring the incidence of non-insulin-treated Type 2 diabetes. Incidence is estimated in the Burden of Disease and Injury in Australia study and by Diabetes Australia.

Estimates of prevalence of Type 1 and Type 2 diabetes based on self-reported data may be incorrect as it has been found that many people cannot accurately report the type of diabetes they have (ABS 1997). An algorithm to assign diabetes type based on other information reported, such as insulin use, time between diagnosis and first insulin use, age and body weight, has been used in several data sets including the National Diabetes Register and 1995 National Health Survey (AIHW 2003). However, this does require that all the necessary information to apply the algorithm is collected along with diabetes status.

Indicators

NHPA 1.1	Prevalence rates for Type 1 and Type 2 diabetes in:
	(a) general population
	(b) Indigenous population
	(c) people from culturally and linguistically diverse backgrounds.
NHPA 1.2	Incidence rates for Type 1 and Type 2 diabetes in:
	(a) general population
	(b) Indigenous population
	(c) people from culturally and linguistically diverse backgrounds.
NHPA 1.3	Gestational diabetes among women aged 20–44 years, by parity.
**NDDWG 2B.1.1*	Incidence rate of Type 2 diabetes over time.
**NDDWG 4B.2.1(a)*	Prevalence and incidence of diabetes over time (by relevant population subgroups).

5.4 Risk factors for complications

Overweight and obesity

As well as being a risk factor for developing Type 2 and gestational diabetes, excess weight carries increased risk of developing coronary heart disease and peripheral vascular disease. As diabetes is also a risk factor for these conditions, the risk of developing them is greater in people who have diabetes and who are also overweight. Being overweight or obese is also associated with high blood pressure and high cholesterol, themselves risk factors for developing complications of diabetes.

Data sources—measured height and weight

Australian Diabetes, Obesity and Lifestyle Study (AusDiab)

National (excluding the Australian Capital Territory) non-remote population sample aged 25 years and over, 1999–2000, in which height and weight were measured along with self-report of diabetes status and oral glucose tolerance testing to diagnose Type 2 diabetes. Also asked participants whether they considered themselves to be underweight, the right weight, or slightly or very overweight.

Australian National Diabetes Information Audit and Benchmarking (ANDIAB)

Audit of people attending specialist diabetes centres and endocrinologists in private practice, run over 1-month periods in 1998, 1999, 2000, 2002 and 2004. Measured data on height and weight for people of all ages with diabetes requiring specialist management. Not representative population samples but provide data for those at high risk or already presenting with complications.

Australian Prospective Diabetes Study (APDS)

Follow-up of the AusDiab study cohort which began in 2004. Among other measures, in people with diabetes the development of complications and presence of risk factors for complications will be assessed.

National Nutrition Survey

National population sample of people aged 2 years and over, 1995, a subsample of that year's National Health Survey participants. Height and weight were measured, and self-reported diabetes status may be determined from National Health Survey results.

Risk Factor Prevalence Studies

Capital cities (excluding Canberra and Darwin in 1980 and 1983) population samples, 1980, 1983 and 1989. Ages 25–64 years in 1980 and 1983, and 20–69 years in 1989. Height, weight and waist circumference were measured in each survey. In the 1980 and 1989 samples, self-reported diabetes status is available; for 1983 both self-report data and fasting blood glucose measurements were collected. Provides BMI data for all types of diabetes combined only.

Data sources—self-reported height and weight

Australian Longitudinal Women's Health Study

National female population sample, 3 cohorts of young (initially 18–23 years), mid (45–50 years) and older (70–75 years) women surveyed every 3 years from 1996. Self-reported height, weight and diabetes status were collected.

National Health Surveys

National population samples 1989–90, 1995 and 2001, covering all ages. Self-reported height, weight and diabetes status were collected in each survey.

State-based surveys

State population samples of adults (18 years and over) where height, weight and diabetes status were self-reported are available for Queensland, New South Wales, the Northern Territory, South Australia, Tasmania, Victoria and Western Australia at various times over the period 1998–2002. This information is also available for ACT residents aged 65 and over for 1999. New South Wales, South Australia and Western Australia have continuous surveillance systems collecting this information from mid-2002.

Gaps and deficiencies

There are no recent measured data on height, weight or waist circumference. At present, there are no plans for these data to be collected nationally.

Also, there is currently no indicator to assess abdominal overweight and obesity in people with diabetes. Excess abdominal weight is recognised as an important risk factor in diabetes and may provide a more reliable indication of the risk of complications.

Indicators

NHPA 2.1b	Prevalence rates for obesity and overweight (as measured by BMI) among people with Type 2 diabetes.

Physical inactivity

Because participating in physical activity has beneficial effects on blood glucose metabolism, people with diabetes can improve their blood glucose control significantly by being physically active. In many cases, Type 2 diabetes can be successfully managed by regular physical activity combined with a controlled diet, without the need for medication.

People with diabetes who are not physically active have a higher risk of developing complications than do those who are active. This is particularly the case for coronary heart disease and ischaemic stroke, since physical inactivity is also an important risk factor for these conditions. Physical inactivity also affects weight, blood pressure and blood cholesterol levels and so can indirectly increase the risk of other complications such as peripheral vascular disease, kidney disease and retinopathy.

Data sources

Australian Diabetes, Obesity and Lifestyle Study (AusDiab)

National (excluding Australian Capital Territory) non-remote population sample aged 25 years and over, conducted in 1999–2000. The survey used the same questions as in the National Physical Activity Surveys and is able to report against the 150 minutes/5 sessions per week recommendation. Participants self-reported diabetes status and also undertook oral glucose tolerance testing if not already being medicinally treated for diabetes.

Australian Longitudinal Study on Women's Health

National female population sample, 3 cohorts of young (initially 18–23 years), mid (45–50 years) and older (70–75 years) women surveyed every 3 years from 1996. Able to report against the 150 minutes/5 sessions per week recommendation among women with self-reported diabetes from 1998 onward. Not all surveys collected diabetes status separately by type of diabetes.

Australian Prospective Diabetes Study (APDS)

Follow-up of the AusDiab study, beginning in 2004. Among other measures, in people with diabetes the development of complications and presence of risk factors for complications will be assessed.

National Health Surveys

National population samples, 1989–90, 1995 and 2001, with physical activity data for ages 15 years and over. Slightly different questions to the National Physical Activity Surveys, but able to report against the 150 minutes/5 sessions per week recommendation. Self-reported diabetes status was collected in each survey.

Risk Factor Prevalence Studies

Capital cities (excluding Canberra and Darwin in 1980 and 1983) population samples, 1980, 1983 and 1989. Ages 25–64 years in 1980 and 1983, and 20–69 years in 1989. All three surveys collected self-reported diabetes status; in 1983 fasting blood glucose measurements were also taken. Provide data for all types of diabetes combined only.

State-based surveys

Self-reported information on physical activity (against recommended levels) and diabetes status are available from New South Wales, South Australia, Western Australia and Queensland. Diabetes status and some information on physical activity levels are available from Victoria, Tasmania and the Northern Territory. The Australian Capital Territory has not collected any territory-based physical activity data.

Data gaps and deficiencies

As discussed in section 4.3.2, the main limitation relating to physical activity data is the non-comparability of various data sources owing to the different questions used to measure activity levels. Also there is no definition of what constitutes 'regular, sustained, moderate aerobic exercise'.

Indicators

NHPA 2.2b	Rates for non-participation in regular, sustained, moderate aerobic exercise among people with Type 2 diabetes.

Tobacco smoking

Smoking reduces insulin sensitivity and increases blood cholesterol levels, and is also a risk factor for coronary heart disease, stroke, peripheral vascular disease and retinopathy.

Data sources

Australian Diabetes, Obesity and Lifestyle Study (AusDiab)

National (excluding Australian Capital Territory) non-remote population sample aged 25 years and over, conducted in 1999–2000. The survey used Australian standard questions regarding smoking status and habits, and also collected self-reported diabetes status and tested blood glucose level in people not already being treated for diabetes.

Australian National Diabetes Information Audit and Benchmarking (ANDIAB)

Audit of people attending specialist diabetes centres and endocrinologists in private practice, run over 1-month periods in 1998, 1999, 2000, 2002 and 2004. Reports current smoking status among people of all ages who have diabetes requiring specialist management. Not representative population samples but provide data for those at high risk or already presenting with complications.

Australian Prospective Diabetes Study (APDS)

Follow-up of the AusDiab study, beginning in 2004. Among other measures, in people with diabetes the development of complications and presence of risk factors for complications will be assessed.

National Health Surveys

National population samples, 1989–90, 1995 and 2001. Smoking status and self-reported diabetes status for adults aged 18 years and over only.

Risk Factor Prevalence Studies

Capital cities (excluding Canberra and Darwin in 1980 and 1983) population samples, 1980, 1983 and 1989. Ages 25–64 years in 1980 and 1983, and 20–69 years in 1989. Data on smoking status and amount smoked, as well as self-reported diabetes status in each survey. The 1983 survey also included fasting blood glucose measurements.

State-based surveys

Self-reported information on diabetes and smoking status are available from all states and the Northern Territory. No territory-based information on smoking and diabetes is available from the Australian Capital Territory.

Gaps and deficiencies

There are no specific indicators which assess smoking prevalence among people with diabetes.

Indicators

There are no specific diabetes indicators relating to smoking, but there are two smoking indicators (separate indicators for adults and young people) within the set of NHPA indicators for general health which could be reported against with additional reference to diabetes status.

Poor nutrition

Data sources

Australian Diabetes, Obesity and Lifestyle Study (AusDiab)

National (excluding Australian Capital Territory) non-remote population sample aged 25 years and over, conducted in 1999–2000. Included a food frequency questionnaire plus short dietary questions, as well as questions on knowledge of healthy eating recommendations. Also collected self-reported diabetes status, and performed oral glucose tolerance tests in those not already being treated for diabetes.

Australian Prospective Diabetes Study (APDS)

Follow-up of the AusDiab study, beginning in 2004. Among other measures, in people with diabetes the development of complications and presence of risk factors for complications will be assessed.

National Dietary Survey of Adults

Capital cities (excluding Canberra and Darwin) population samples, ages 25–64, conducted in 1983. A subsample of the 1983 Risk Factor Prevalence Survey participants completed a 24-hour recall food intake questionnaire. Self-reported diabetes status and fasting blood glucose measurements were also collected.

National Health Surveys

National population samples, covering all ages, in 1989–90 and 2001. Included short dietary questions and self-reported diabetes status.

National Nutrition Survey

National population sample, ages 2 and over, conducted in 1995. Included a food frequency questionnaire, questions on food habits and attitudes, and a 24-hour recall food intake questionnaire. Self-reported diabetes status is available from the 1995 National Health Survey, which the National Nutrition Survey participants also completed.

Risk Factor Prevalence Studies

Capital cities (excluding Canberra and Darwin in 1980 and 1983) population samples, 1980, 1983 and 1989. Ages 25–64 years in 1980 and 1983, and 20–69 years in 1989. Short dietary questions and self-reported diabetes status were collected each year, with fasting blood glucose measurements also in 1983.

State-based surveys

Self-reported information on diabetes status and a number of dietary factors is available from all states and territories except Tasmania and the Australian Capital Territory.

Gaps and deficiencies

Data on fruit and vegetable consumption and several other discrete dietary behaviours (such as type of milk consumed) are available from the National Health Survey and some state surveys, but more detailed information relating to the Australian dietary guidelines is available only from intermittent surveys. If data are to be reported regularly against the dietary guidelines, this would require more information than is presently collected in the recurrent surveys.

Indicators

No indicators for nutrition specifically in people with diabetes exist; however, the nutrition indicators for the general population are relevant along with information on diabetes status to give an indication of the number of people with diabetes at risk of complications from poor nutrition.

High blood pressure

High blood pressure in people with diabetes is linked to the development of complications such as retinopathy, coronary heart disease, stroke, kidney disease and peripheral vascular disease.

Data sources—measured blood pressure

Australian Diabetes, Obesity and Lifestyle Study (AusDiab)

National (excluding Australian Capital Territory) non-remote population sample aged 25 years and over, conducted in 1999–2000. Blood pressure measurements were taken, and oral glucose tolerance was tested in people not already being treated for diabetes. Self-reported diabetes status and use of medication for lowering blood pressure were also collected.

Australian National Diabetes Information Audit and Benchmarking (ANDIAB)

Audit of people attending specialist diabetes centres and endocrinologists in private practice, run over 1-month periods in 1998, 1999, 2000, 2002 and 2004. Measured blood pressure and medication use was recorded for people of all ages who had diabetes requiring specialist management. Not representative population samples but provide data for those at high risk or already presenting with complications.

Australian Prospective Diabetes Study (APDS)

Follow-up of the AusDiab study, beginning in 2004. Among other measures, in people with diabetes the presence of risk factors for complications will be assessed, including blood pressure measurement.

National Nutrition Survey

National population sample, ages 2 and over, conducted in 1995 on a subsample of National Health Survey participants. Measured blood pressure data from the National Nutrition Survey can be combined with self-reported diabetes status and medication use from the 1995 National Health Survey.

Risk Factor Prevalence Studies

Capital cities (excluding Canberra and Darwin in 1980 and 1983) population samples, 1980, 1983 and 1989. Ages 25–64 years in 1980 and 1983, and 20–69 years in 1989. Measured blood pressure and self-reported diabetes status and medication use were recorded in each survey, with fasting blood glucose measurements in 1983. Provide data for all types of diabetes combined only.

Data sources—self-reported high blood pressure

National Health Surveys

National population samples, all ages, 1989–90, 1995 and 2001. Self-reported high blood pressure, medication use, and diabetes status were included.

State-based surveys

Self-reported information on diabetes status and high blood pressure is available from the NSW Adult Health Survey, the Collaborative Health and Wellbeing Survey run across the Northern Territory, Western Australia and South Australia, SA Monitoring and Surveillance System, and the Victorian Population Health Survey.

Gaps and deficiencies

There are no regular national data sources which collect measured data on blood pressure. Self-reported information on whether a person has ever been told he or she has high blood pressure is available from the National Health Survey. Although measured blood pressure data will be available from the Australian Prospective Diabetes Study it is not yet known how representative these data will be of the Australian population with diabetes.

Indicators

NHPA 2.3 Prevalence rates for high blood pressure among people with Type 2 diabetes:

- ≥140 mmHg systolic and/or 90 mmHg diastolic and aged <60 years;
- ≥160 mmHg systolic and/or 90 mmHg diastolic and aged ≥60 years; and/or
- those on medication for high blood pressure.

High cholesterol and triglycerides

People with diabetes often have high cholesterol, and are more likely than people without diabetes to have high triglycerides and low high-density lipoprotein (HDL—'good' cholesterol) levels. High cholesterol is one of the main causes of atherosclerosis, which can lead to coronary heart disease and stroke, and this process may be intensified by diabetes.

Data sources—measured blood cholesterol

Australian Diabetes, Obesity and Lifestyle Study (AusDiab)

National (excluding Australian Capital Territory) non-remote population sample aged 25 years and over, conducted in 1999–2000. The study measured total cholesterol, high- and low-density lipoproteins (HDL and LDL), and triglycerides, and performed oral glucose tolerance tests in those not already being treated for diabetes. Self-reported information on diabetes, high cholesterol, and cholesterol-lowering medication status was also collected. Provides data for indicators NHPA 2.4 and NHPA 2.5 for people with Type 2 diabetes only.

Australian National Diabetes Information Audit and Benchmarking (ANDIAB)

Audit of people attending specialist diabetes centres and endocrinologists in private practice, run over 1-month periods in 1998, 1999, 2000, 2002 and 2004. Data available include measured total cholesterol, HDL, triglycerides, and use of cholesterol-lowering drugs for people of all ages with diabetes requiring specialist management. Although the samples are not representative of the whole diabetes population, they provide data for those at high risk or already presenting with complications. Provide data for both indicators for Type 1 and Type 2 diabetes.

Australian Prospective Diabetes Study (APDS)

Follow-up of the AusDiab study, which will include blood sampling for measurement of cholesterol levels (total, HDL and LDL), triglyceride levels, and blood glucose.

Risk Factor Prevalence Studies

Capital cities (excluding Canberra and Darwin in 1980 and 1983) population samples, 1980, 1983 and 1989. Ages 25–64 years in 1980 and 1983, and 20–69 years in 1989. Each survey has measurements of total cholesterol, HDL, and triglycerides, as well as self-reported diabetes and high cholesterol status and use of cholesterol-lowering medication. Fasting blood glucose measurements were also taken in 1983. Provide data for both indicators for all types of diabetes combined.

Data sources—self-reported high cholesterol

National Health Surveys

National population samples, 1989–90, 1995 and 2001. Information collected includes self-reported high cholesterol and diabetes status, and use of cholesterol-lowering drugs, for adults 18 years and over. Provide data for indicator NHPA 2.4(a) only.

State-based surveys

Self-reported information on diabetes status and high blood pressure is available from the NSW Adult Health Survey, the Collaborative Health and Wellbeing Survey run across the Northern Territory, Western Australia and South Australia, SA Monitoring and Surveillance System, and the Victorian Population Health Survey.

Gaps and deficiencies

Self-reported data on cholesterol appear to be unreliable, probably because many people have never had their cholesterol checked. This leads to large differences in prevalence rates derived from measured and self-reported data. Further, information on LDL, HDL and triglyceride levels is usually not able to be self-reported. Therefore, obtaining reliable population-based data on cholesterol and triglyceride levels in people with diabetes requires a national blood survey.

Indicators

NHPA 2.4	Prevalence rates for high levels of lipoproteins among people with Type 1 and Type 2 diabetes: (a) total cholesterol above 5.5 mmol/L (b) high-density lipoproteins below 1.0 mmol/L
NHPA 2.5	Prevalence rates for fasting hypertriglyceridaemia among people with Type 1 and Type 2 diabetes.

5.5 Detection and prevention of complications

In addition to acute complications, such as ketoacidosis and coma, diabetes can result in a range of long-term complications affecting a number of bodily systems and functions. Compared with people without diabetes, people with diabetes are more likely to develop diseases of the large blood vessels (macrovascular diseases), such as cardiovascular disease, and the small blood vessels (microvascular diseases), such as peripheral nerve disease, retinopathy, and kidney disease. Other conditions which may arise as complications of diabetes include ulcers, liver disease, gallstones, oral diseases, and complications during pregnancy and childbirth.

Cardiovascular disease

People with diabetes are two to four times more likely to develop cardiovascular disease (CVD) than people without diabetes. Their prognosis following a heart attack or stroke, and their recovery following cardiac procedures, is also not as good as in people without diabetes. The most common forms of cardiovascular disease which occur as complications of diabetes are coronary heart disease (mainly heart attack and angina), stroke and peripheral vascular disease. The risk of developing cardiovascular disease increases when diabetes is present along with one or more other risk factors, such as smoking, physical inactivity, overweight, high blood pressure, or high cholesterol.

Data sources

AIHW National Hospital Morbidity Database

The morbidity database contains details of all episodes of admitted-patient care provided in Australian hospitals and includes principal and additional diagnoses.

AIHW National Mortality Database

The mortality database contains details of all deaths registered in Australia, including the underlying cause of death, with associated causes of death also recorded from 1997.

Australian Diabetes, Obesity and Lifestyle Study (AusDiab)

National (excluding Australian Capital Territory) non-remote population sample aged 25 years and over, conducted in 1999–2000. Includes measured and self-reported diabetes status, as well as self-reported history of heart disease and stroke.

Australian National Diabetes Information Audit and Benchmarking (ANDIAB)

One-month audits of patients attending specialist diabetes centres and endocrinologists in private practice. The sample covers patients requiring specialist clinical management, particularly those with poor control of their diabetes, and so does not reflect the general diabetic population. Data collected include demographics, previous and current complications, and management practices. Provide prevalence data for indicator NDDWG 4B.2.1(b).

Australian Prospective Diabetes Study (APDS)

Follow-up of the AusDiab study, which will include assessment of development of complications, reporting of cardiovascular events and use of health services relating to these. Will provide prevalence data for indicator NDDWG 4B.2.1(b), and may also provide incidence data for both indicators.

National Divisions Diabetes Program Data Collection Project

Electronic collation of data from seven Divisions of General Practice, covering over 4,000 people with diabetes in 1999–2000. Data include diabetes type, treatment and complications.

National Health Surveys

National population samples which record self-reported information on heart attack, angina, stroke, and diabetes for people aged 18 years and over. Provide prevalence data for indicator NDDWG 4B.2.1(b).

State-based surveys

Self-reported information on occurrence of diabetes, heart disease and stroke (prevalence data) is available from Victoria, South Australia, the Northern Territory, Queensland, Tasmania and Western Australia.

Gaps and deficiencies

Currently, data on the incidence of coronary heart disease are calculated using algorithms developed by Jamrozik et al. (2001) for people aged 35–64 years. Similar estimates cannot be made for other types of CVD. Data from the AIHW National Hospital Morbidity Database, National Mortality Database, and ANDIAB capture severe cases only. Some prevalence data are available from the National Health Surveys and AusDiab but these are based on self-reported information and it is uncertain how reliable these estimates are. Further, the incidence of cardiovascular disease with undiagnosed diabetes, or vice versa, may be high and this will affect the accuracy of self-reported information.

Indicators

NHPA 3.4	Incidence rates for coronary heart disease and stroke among people with clinically diagnosed diabetes and in the general population.
**NDDWG 4B.2.1(b)*	Prevalence and incidence of cardiovascular disease among people with diabetes, over time (by relevant population subgroups).

Eye disease

Eye diseases which may arise as complications of diabetes include retinopathy, cataracts and glaucoma. Diabetic retinopathy is the most common cause of blindness in people aged 30–69 years, and cataracts and glaucoma are also major causes of vision impairment among adults. Although age and duration of diabetes are the most important risk factors for developing eye diseases, high blood pressure or cholesterol, smoking and nephropathy (kidney disease) also increase risk.

Data sources

AIHW National Hospital Morbidity Database

Details of episodes of admitted-patient care occurring in Australian hospitals. Data include length of stay, age, sex, Indigenous status, place of usual residence, diagnoses, and procedures performed.

Australian Diabetes, Obesity and Lifestyle Study (AusDiab)

National (excluding Australian Capital Territory) non-remote population sample aged 25 years and over, conducted in 1999–2000. Included measured and self-reported diabetes status, along with retinopathy grading and self-reported history of retinopathy or eye problems among those who self-reported having diabetes. Provides prevalence data for indicator NDDWG 4B.2.1(c).

Australian National Diabetes Information Audit and Benchmarking (ANDIAB)

One-month audits of patients attending specialist diabetes centres and endocrinologists in private practice, conducted in 1998, 1999, 2000, 2002 and 2004. Data collected include demographics, previous and current complications, and management practices. Provide prevalence data for indicator NDDWG 4B.2.1(c).

Australian Prospective Diabetes Study (APDS)

Follow-up of the AusDiab study, to include retinopathy grading and self-report of eye problems. Will provide data for both indicators.

National Divisions Diabetes Program Data Collection Project

Electronic collation of data from seven Divisions of General Practice, covering over 4,000 people with diabetes in 1999–2000. Data include diabetes type, treatment, health outcomes and complications.

Queensland Diabetes Management Survey

Survey of 1,105 adults with diabetes in 2000. Participants were asked if they had ever experienced complications including eye disease or operations. Provides prevalence data for Queensland for indicator NDDWG 4B.2.1(c).

Gaps and deficiencies

Only severe problems will be captured by most of the available data sources. The incidence of mild eye problems may be high and these will not be captured in hospital or clinic data or by surveys which collect information on end-stage outcomes such as blindness. More general data will be available from AusDiab and the APDS; however, the representativeness of the

APDS sample is yet to be determined. Currently there is no means of determining the national prevalence of eye complications among people with diabetes.

Indicators

NHPA 3.2	Incidence rate for eye disease among people with clinically diagnosed diabetes.
**NDDWG 4B.2.1(c)*	Prevalence and incidence of diabetes-related visual loss over time (by relevant population subgroups).

Kidney (renal) disease

Diabetes can affect the kidneys in a number of ways, causing various conditions, the most common of which are nephropathy and end-stage kidney disease (ESKD). ESKD is the final stage of kidney function deterioration, in which dialysis or kidney transplant are necessary for survival. Diabetic nephropathy is the second most common cause of ESKD in Australia (Excell & McDonald 2005). Long duration of diabetes, poor blood glucose control, and genetic susceptibility all influence the development and progression of diabetic nephropathy, but risk is also increased by high blood pressure and smoking.

Data sources

AIHW National Hospital Morbidity Database

Details of episodes of admitted-patient care occurring in Australian hospitals. Data include age, sex, Indigenous status, length of stay, place of usual residence, diagnoses and procedures performed. Data are episode-based so provide an indication of burden on health services.

Australia and New Zealand Dialysis and Transplant Registry (ANZDATA)

Register of delivery of kidney dialysis and transplantation in Australia and New Zealand, containing data on all patients receiving kidney replacement therapy where the intention to treat is long term. Data include demographic details, type of treatment and cause of kidney failure. Provides data for indicator NHPA 3.1 and incidence data for NDDWG 4B.2.1(d).

Australian Diabetes, Obesity and Lifestyle Study (AusDiab)

National (excluding Australian Capital Territory) non-remote population sample aged 25 years and over, conducted in 1999–2000. Includes measured and self-reported diabetes status, along with self-reported history of kidney disease among those who self-reported having diabetes. Provides prevalence data for indicator NDDWG 4B.2.1(d).

Australian National Diabetes Information Audit and Benchmarking (ANDIAB)

One-month audits of patients attending specialist diabetes centres and endocrinologists in private practice. Data collected include demographics, previous and current complications and management practices. Data are not representative of the whole diabetes population but give an indication of prevalence among those requiring specialist clinical management.

Australian Prospective Diabetes Study (APDS)

Follow-up of the AusDiab study, which will include objective measurements of kidney function and diabetes status. Provides data for indicator NDDWG 4B.2.1(d).

National Divisions Diabetes Program Data Collection Project

Electronic collation of data from seven Divisions of General Practice, covering over 4,000 people with diabetes in 1999–2000. Data include diabetes type, treatment and complications.

Queensland Diabetes Management Survey

Survey of 1,105 adults with diabetes in 2000. Participants were asked if they had ever experienced complications including kidney failure or disease. Provides state prevalence data for indicator NDDWG 4B.2.1(d).

Gaps and deficiencies

From a prevention perspective it is important that people in the early stages of kidney complications are able to be identified so that progression to more severe disease may be prevented or at least delayed. Assessment of the number of people developing milder kidney complications will provide both an estimate of the future need for treatment services and a measure of the success of tertiary prevention efforts over time. The AusDiab Kidney Study (Mathew 2004), nested within AusDiab and the APDS, should provide some data on chronic kidney disease and its impacts, but it is uncertain how representative this sample will be of Australian people with diabetes.

Indicators

NHPA 3.1	Proportion of people with end-stage renal disease with diabetic nephropathy as a causal factor.
**NDDWG 4B.2.1(d)*	Prevalence and incidence of end-stage renal disease over time (by relevant population subgroups).

There is no indicator for monitoring less severe forms of diabetic kidney complications or nephropathy.

Neuropathy

Neuropathy (nerve damage) is a common complication of diabetes, generally presenting as either peripheral neuropathy (damage to non-central nerves, particularly those in the feet) or autonomic neuropathy (damage to the nerves which control involuntary bodily functions such as heart rate and digestion). Peripheral neuropathy contributes to the development of foot ulcers which, if severe, may require amputation of all or part of the affected limb.

Diabetic neuropathy is generally a result of long-term high blood glucose levels, and therefore age, duration of diabetes and poor blood glucose control are the most important risk factors. Risk may also be increased by smoking, hypertension and excess weight.

Data sources

AIHW National Hospital Morbidity Database

Details of episodes of admitted-patient care occurring in Australian hospitals. Data include length of stay, age, sex, Indigenous status, place of usual residence, diagnoses and procedures performed.

Australian Diabetes, Obesity and Lifestyle Study (AusDiab)

National (excluding Australian Capital Territory) non-remote population sample aged 25 years and over, conducted in 1999–2000. Measured and self-reported diabetes status, as well as self-reported history of nerve damage, poor circulation in the feet or legs, and gangrene among those who self-reported having diabetes.

Australian National Diabetes Information Audit and Benchmarking (ANDIAB)

One-month audits of patients attending specialist diabetes centres and endocrinologists in private practice. The sample covers patients requiring specialist clinical management, particularly those with poor control of their diabetes, and so does not reflect the general diabetic population. Data collected include demographics, previous and current complications and management practices.

Australian Prospective Diabetes Study (APDS)

AusDiab follow-up study. To include self-reported data on history of neuropathic symptoms.

National Divisions Diabetes Program Data Collection Project

Electronic collation of data from seven Divisions of General Practice, covering over 4,000 people with diabetes in 1999–2000. Data include diabetes type, treatment, health outcomes and complications.

Queensland Diabetes Management Survey

Survey of 1,105 adults with diabetes in 2000. Participants were asked if they had ever experienced complications including foot ulcers and limb amputation.

Gaps and deficiencies

For the purposes of tertiary prevention, assessment of the prevalence of less severe neuropathic disease will provide an indication of the need for treatment and success of treatment programs for the condition. Hospital admissions for neuropathy are available from the National Hospital Morbidity Database, but this provides only an estimate of the number of episodes of care and not counts of individuals or estimates of incidence or prevalence.

Indicators

**NDDWG 4B.1.2(e)*	Prevalence and incidence of non-traumatic amputation over time (by relevant population subgroups).

This indicator relates to amputation and therefore captures only a single severe outcome of neuropathy. Other manifestations of this condition are not monitored under the current indicator sets, except as leading to ‘foot problems’.

Foot complications

Peripheral neuropathy and peripheral vascular disease increase the risk of developing foot ulcers and infections. In people with diabetes, progression of these conditions may lead to lower extremity amputations, which cause disability and are associated with increased morbidity and mortality. The risk of foot complications is increased with longer duration of diabetes, poor glucose control, the presence of other neurological and vascular complications, and smoking.

Data sources

AIHW National Hospital Morbidity Database

Details of episodes of admitted-patient care occurring in Australian hospitals. Data include length of stay, age, sex, Indigenous status, place of usual residence, diagnoses and procedures performed.

Australian Diabetes, Obesity and Lifestyle Study (AusDiab)

National (excluding Australian Capital Territory) non-remote population sample aged 25 years and over, conducted in 1999–2000. Measured and self-reported diabetes status, as well as reflex, pinprick, and pressure tests and self-reported history of gangrene, poor circulation in the feet or legs, foot ulcers, and pain/discomfort in the feet or legs among those who self-reported having diabetes.

Australian National Diabetes Information Audit and Benchmarking (ANDIAB)

One-month audits of patients attending specialist diabetes centres and endocrinologists in private practice. The sample covers patients requiring specialist clinical management, particularly those with poor control of their diabetes, and so does not reflect the general diabetic population. Data collected include demographics, previous and current complications and management practices.

Australian Prospective Diabetes Study (APDS)

Follow-up of the AusDiab study. Among other measures, in people with diabetes the development of complications and presence of risk factors for complications will be assessed.

National Divisions Diabetes Program Data Collection Project

Electronic collation of data from seven Divisions of General Practice, covering over 4,000 people with diabetes in 1999–2000. Data include diabetes type, treatment, health outcomes and complications.

Queensland Diabetes Management Survey

Survey of 1,105 adults with diabetes in 2000. Participants were asked if they had ever experienced complications including 'frequent tingling, burning, pain or numbness in legs or feet', 'foot ulcer' or 'limb amputation'.

Gaps and deficiencies

The data relating to foot complications of diabetes are incomplete. Only major problems are captured by hospital or ANDIAB data. Since many people may have mild foot problems not requiring hospitalisation or treatment in a specialist clinic, the true prevalence rate is unable to be determined. In terms of amputations, although prevalence could be estimated based on a population survey there is no way of calculating incidence. The episode-based nature of the National Hospital Morbidity Database means that individuals cannot be identified and so the number of people undergoing amputation is unable to be determined.

Indicators

NHPA 3.3	Prevalence rate for foot problems among people with clinically diagnosed diabetes.

**NDDWG 4B.1.2(e)*	Prevalence and incidence of non-traumatic amputation over time (by relevant population subgroups).

Oral complications

Although uncommon in developed societies, oral complications are more common in less developed societies or lower socioeconomic groups, particularly where the diagnosis of diabetes is often delayed and access to care is limited. In Australia, oral complications of diabetes are most common among Indigenous people in remote communities.

Diabetes may lead to periodontal disease (inflammation of the tissues supporting the teeth), tooth decay and tooth loss. The risk of oral complications is higher in people whose blood glucose control is poor, and who also smoke, have poor oral hygiene and an inadequate diet.

Data sources

AIHW Dental Statistics Research Unit Data Collection

The Dental Statistics Research Unit runs a number of dental health surveys covering children, young people, adults, and older people. A 1999–2000 collection of data from several dental clinics in South Australia and the Northern Territory collected information about oral health and diabetes status in Indigenous people.

AIHW National Hospital Morbidity Database

Details of episodes of admitted-patient care occurring in Australian hospitals. Data include length of stay, age, sex, Indigenous status, place of usual residence, diagnoses and procedures performed.

Australian National Diabetes Information Audit and Benchmarking (ANDIAB)

One-month audits of patients attending specialist diabetes centres and endocrinologists in private practice. The sample covers patients requiring specialist clinical management, particularly those with poor control of their diabetes, and so does not reflect the general diabetic population. Data collected include demographics, previous and current complications and management practices.

National Divisions Diabetes Program Data Collection Project

Electronic collation of data from seven Divisions of General Practice, covering over 4,000 people with diabetes in 1999–2000. Data include diabetes type, treatment, health outcomes and complications.

Gaps and deficiencies

It is likely that any oral complications such as tooth decay and loss would be treated by a dental practitioner rather than in hospital or diabetes centres. However, the people who are most at risk of oral complications are probably the least likely to have access to treatment of any kind. It is likely therefore that the prevalence of oral complications may be underestimated by the available data sources.

Indicators

None existing.

Complications in pregnancy

Certain hormones produced during pregnancy induce insulin resistance, which can affect glucose control in mothers with existing diabetes, and cause temporary (gestational) diabetes in those with previously normal glucose levels. Complications caused by maternal diabetes can affect the foetus and newborn as well as the mother. These complications may include worsening of existing nephropathy and retinopathy in the mother, congenital malformations, stillbirth, premature birth, newborn hypoglycaemia, macrosomia (large-for-gestational-age babies), jaundice and respiratory distress in the infant, and birth trauma. The Australian Diabetes in Pregnancy Society recommends all pregnant women without existing diabetes should be screened for gestational diabetes at around the 28th week of their pregnancy.

Data sources

AIHW National Hospital Morbidity Database

Details of episodes of admitted-patient care provided in Australian hospitals. Data include length of stay, age, sex, Indigenous status, area of usual residence, principal and additional diagnoses, procedures and destination on discharge. Diabetes in pregnancy is specified as to whether or not it is pre-existing, type if pre-existing, and whether or not insulin is required if diagnosed during pregnancy.

Perinatal data collections

State and territory collections of information on mothers and babies. Data include mother's age, Indigenous status, country of birth, parity, maternal medical conditions (including pre-existing diabetes), complications of pregnancy (including gestational diabetes), outcome of pregnancy and characteristics of the baby including gestational age and birthweight.

Australian National Diabetes Information Audit and Benchmarking (ANDIAB)

One-month audits of patients attending specialist diabetes centres and endocrinologists in private practice. The sample covers patients requiring specialist clinical management, particularly those with poor control of their diabetes, and so does not reflect the general diabetic population. Data collected include demographics, previous and current complications and management practices.

Medicare benefits

Details of the number of claims for oral glucose challenge tests in pregnancy for the detection of gestational diabetes can be obtained by state and age over various time periods. Data on claims for oral glucose tolerance tests without mention of pregnancy may also be obtained.

National Divisions Diabetes Program Data Collection Project

Electronic collation of data from seven Divisions of General Practice, covering over 4,000 people with diabetes in 1999–2000. Data include diabetes type, treatment, health outcomes and complications.

Gaps and deficiencies

The only source of data on screening for gestational diabetes is the Medicare benefits system. However, examination of the age- and sex-specific data regarding oral glucose challenge tests in general and during pregnancy suggests that not all tests performed during pregnancy are correctly coded to the specific gestational diabetes item, but may be recorded as a general oral glucose tolerance test without mention of pregnancy. Further, tests performed on public patients in public hospitals are not captured by Medicare as benefits are not payable for these services. These issues create difficulties in obtaining accurate counts of the number of screening tests for gestational diabetes which are occurring and so affect estimates of the proportion of pregnant women who are being screened.

There are no national indicators to monitor the incidence of diabetes-related complications in pregnancy or the total maternal diabetes rate (i.e. gestational and pre-existing diabetes). Data from the Perinatal Data Collection and the National Hospital Morbidity Database could provide information on these issues.

Indicators

NHPA 7.1	Proportion of pregnant women being tested for gestational diabetes.

General complications of diabetes

Data sources

AIHW National Hospital Morbidity Database

Details of episodes of admitted-patient care occurring in Australian hospitals. Data include length of stay, age, sex, Indigenous status, place of usual residence, diagnoses and procedures performed.

National Diabetes Register

Register of people who use insulin to manage their diabetes. People who began to use insulin on or after 1 January 1999 are eligible to register. Data include demographics, date of diagnosis, and diabetes type. Registrants have the opportunity to provide consent for further contact for research purposes, which could provide a cohort of people with Type 1 diabetes for follow-up related to manifestation of complications.

Gaps and deficiencies

Since all people with Type 1 diabetes require insulin they are all eligible to be registered on the NDR. Until mid 2003, registration was voluntary, and so coverage of people with Type 1 diabetes was not complete. Changes to the registration process mean that coverage is increased from 2004 onwards.

Indicators

**NDDWG 4B.2.2*	The proportion of people with Type 1 diabetes with complications, by duration of diabetes.

5.6 Management and related services

Good control of blood glucose levels in diabetes can greatly reduce the incidence and severity of morbidity and complications. Adequate, accessible, timely and quality diabetes management, as well as education for self-management, is therefore essential to reduce the effects of the disease and improve the quality of life of people with diabetes.

There are four aspects of management of diabetes which should be considered.

- Are services providing diabetes management available?

- Are these services accessible and culturally appropriate?
- Is the management provided of good quality and according to best-practice guidelines?
- Are people with diabetes able to successfully self-manage their condition?

Each of these aspects is dealt with below.

Availability of management

Data sources

National Integrated Diabetes Program (NIDP)

Australian Government program to improve prevention, earlier diagnosis and management of diabetes. The program includes components relating to the provision of diabetes management services. An example of the type of data that come out of this program is the number of patients with diabetes who have been recorded as completing an annual cycle of care with their GP.

Gaps and deficiencies

Diabetes management requires the use of a variety of health services and providers. Services required by people with diabetes can include GP, diabetes education, dietary, pathology, pharmacy, specialist and psychological and social services. There is currently no coordinated system to collect data for various health contact points.

Indicators

*NDDWG 3B.2.1 The respective number and characteristics of diabetes services available.

For services which provide management for people with diabetes, what is/are the:

type of service?
cost to consumer?
hours of availability?
waiting times?
follow-up?
outreach services?
levels of use for different population groups?

Accessibility and cultural appropriateness of services

Data sources

National Diabetes Improvement Projects (NDIP)

Australian Government program offering funding for projects that identify barriers to good diabetes management. The NDIP may provide some information on diabetes management within health service settings, particularly in relation to specific target populations such as Aboriginal and Torres Strait Islander people, culturally and linguistically diverse groups, and women with diabetes in pregnancy.

Gaps and deficiencies

Data for non government-funded programs are not collected by the NDIP. Efficient ways of collecting information on programs funded by charities, non-government organisations, private companies and communities need to be developed.

Collection of data on satisfaction and cultural suitability is difficult, as it is not appropriate to collect this information via telephone surveys due to difficulties such as language barriers in culturally and linguistically diverse groups and inadequate access to telephones in some Indigenous and remote communities. It would be more appropriate to collect this information through focus groups, but these may be time-consuming and expensive. There are also difficulties in defining what constitutes a 'culturally appropriate' service.

Indicators

**NDDWG 3A.1.1*	The number and characteristics of diabetes and at-risk programs, initiatives and services for: • Aboriginal and Torres Strait Islander peoples • people of culturally and linguistically diverse backgrounds • people with different socioeconomic status • people from different geographic areas. For each program/initiative/service identified: What is the focus of the program? What is the target population? Does the program follow current evidence-based guidelines? Is it ongoing? To what extent is it culturally appropriate for all groups within the target population? Are there any population groups who are missed or not reached?
**NDDWG 3B.1.1*	The respective representation of Indigenous, culturally and linguistically diverse, socioeconomically disadvantaged, and geographically diverse groups in diabetes, at-risk and screening programs (compared with their estimated representation in the community).
**NDDWG 3C.1.1*	Satisfaction with cultural suitability of services available.
**NDDWG 3C.2.1*	Self-reported barriers to access to management services.

Quality of management

Data sources

Medicare Benefits Scheme

Since 2001 specific Medicare items have recorded whether a cycle of care for diabetes has been completed. Data on the number of these items are available disaggregated by age, sex and geographic region.

Australian Diabetes, Obesity and Lifestyle Study (AusDiab)

National (excluding Australian Capital Territory) non-remote population sample aged 25 years and over, conducted in 1999–2000. Asked people with diabetes about frequency of glycosylated haemoglobin (HbA1C) tests, foot exams, retinal exams, and visits to doctors, diabetes educators, dietitians and podiatrists. Also measured blood pressure, cholesterol, BMI and HbA1C.

Gaps and deficiencies

Information on the quality of diabetes care is not sought in many data collections. It is important to assess the quality of care both in terms of providers' adherence to guidelines and recommended practice and patients' perceptions of the care delivered. If the care delivered is perceived as unsatisfactory or inadequate, patients may be less likely to return and their diabetes may not be adequately managed, leading to complications.

Indicators

NHPA 7.1	Proportion of people with diabetes tested for HbA1C level at least every 6 months.
NHPC 3.11	Proportion of people with diabetes mellitus who have received an annual cycle of care within general practice.
NHPC 3.22	Percentage of GPs using enhanced primary care (EPC) items.
**NDDWG 1A.1.1*	The number and characteristics of diabetes guidelines identified. For each aspect of diabetes prevention, early detection and management for which guidelines exist: Are the guidelines Australian? Are they evidence-based? Have the guidelines been endorsed? If yes, by whom? Are the guidelines up to date? Are the guidelines written or available in consumer-friendly language? What is the level of dissemination of these guidelines to health care providers? Have the guidelines been implemented/incorporated into diabetes programs/initiatives? Are there mechanisms to audit diabetes prevention, early detection and management against the guidelines (in hospitals, diabetes centres and general practice)?
**NDDWG 1A.1.2*	The proportion of programs to improve prevention, early detection and management consistent with guidelines.
**NDDWG 1B.1.1*	The proportion of people with diabetes mellitus who have had an annual cycle of care (i.e. have had recorded): • a foot exam within the last 12 months • an eye exam within the last 2 years • microalbumin measured in the last year • HbA1C measured in the last 6 months

	• blood pressure measured in the last 6 months • lipids measured in the last 12 months • weight/BMI measured in the last 6 months.
**NDDWG 1B.2.1*	The proportion of GPs with register/recall systems (by Division).
**NDDWG 5A.1.1*	The adequacy of systems identified to assess quality of clinical management. For each system identified: Does it follow current evidence-based guidelines? Is it ongoing? Does it cover identified population groups?
**NDDWG 5A.2.1*	The number and characteristics of programs identified to improve the quality of clinical management. For each program identified: Does it make use of current evidence-based or consensus guidelines (as appropriate)? Is it ongoing? What is the format of the program?
**NDDWG 5B.1.1*	The proportion of people with diabetes that meet guideline targets for: • HbA1C • blood pressure • cholesterol • weight/BMI.
**NDDWG 5C.1.1*	The proportion of patients satisfied with quality of care.

Self-management

Data sources

Queensland Diabetes Management Survey

Sample of adults (18 years and over) with diabetes in 2000. Information on current management practices. State data for indicator NDDWG 1.3.1C.

Gaps and deficiencies

Information on the availability or provision of education and tools to enable self-management among people with diabetes is not sought in many data collections, resulting in very little data being available. This information would help assess the level of self-management in the community. Important aspects of successful management by persons with diabetes and their carers can be understood by including questions in population surveys on knowledge, attitudes and practices relating to diabetes and its treatment.

Indicators

NHPA 6.1	Self-assessed health status of people with and without diabetes.

**NDDWG 1C.2.1*	The proportion of people with diabetes who are aware of the existence of guidelines for management.
**NDDWG 1C.4.1*	The proportion of people with diabetes who know what their evidence-based healthy lifestyle options are.
**NDDWG 4C.1.1*	Quality of life of people with diabetes (measured by standardised questionnaire).
**NDDWG 5C.3.1*	The proportion of patients who are confident they know how to self-manage their diabetes.
**NDDWG 5C.3.2*	The proportion of patients who have attended a diabetes educator (for self-management education).
**NDDWG 5C.3.3*	The proportion of patients who have a care plan for diabetes, and their self-management.

5.7 Non-hospital and emergency care for diabetes and complications

This includes care provided by general practitioners, specialists in private practice, diabetes centres, community health workers and hospital emergency or outpatient departments. This covers the majority of care provided to people with diabetes where most management is able to be provided through primary care.

Data sources

Australian National Diabetes Information Audit and Benchmarking (ANDIAB)

One-month audits of patients attending specialist diabetes centres and endocrinologists in private practice. The sample covers patients requiring specialist clinical management, particularly those with poor control of their diabetes, and so does not reflect the general diabetic population. Data collected include demographics, previous and current complications and management practices.

BEACH (Bettering the Evaluation and Care of Health) Survey of General Practice

Beginning in 1998, random samples of around 1,000 GPs each year, covering approximately 100,000 GP–patient encounters annually. Data include GP and patient characteristics, problems managed and treatment provided.

National Divisions Diabetes Program (NDDP) Data Collation Project – CARDIAB component

Electronic collation of data from seven Divisions of General Practice, covering over 4,000 people with diabetes in 1999–2000. Data include diabetes type, treatment, health outcomes and complications.

Gaps and deficiencies

Coverage of non-hospital and emergency care for diabetes and complications is not complete. The available data sources cover GP encounters and attendances at specialist diabetes centres, but attendances at community health centres, hospital emergency or outpatient departments, and encounters with other health professionals such as community nurses and Indigenous health workers are not captured. For diabetes, where general management can in many cases be provided through primary or outpatient care, the lack of complete data in this area greatly reduces the ability to accurately report on management of the condition and associated complications.

Indicators

There are currently no indicators to monitor non-hospital and emergency care for diabetes and related complications.

5.8 Admitted-patient hospital and surgical care for diabetes and complications

Admitted-patient hospital care for diabetes includes care related to diabetes itself (e.g. treatment of ketoacidosis, initial stabilisation on diagnosis of Type 1 diabetes) and its complications.

Diabetes is much more likely to be recorded as an additional diagnosis rather than the principal diagnosis, with additional diagnoses accounting for 85–90% of all hospital episodes involving diabetes. The most common principal diagnoses recorded with diabetes as additional are cardiovascular diseases (coronary heart disease, stroke, and peripheral vascular disease) and kidney (renal) disease.

Surgical procedures for complications of diabetes include coronary artery bypass grafting and angioplasty (for heart disease), lower limb amputation (for neuropathy and peripheral vascular disease), dialysis and kidney transplants (for end-stage renal disease), and assisted deliveries in pregnancies involving diabetes.

Data sources

AIHW National Hospital Morbidity Database

Details of episodes of admitted-patient care provided in Australian hospitals. Data available include length of stay, age, sex, Indigenous status, area of usual residence, principal and additional diagnoses, procedures and destination on discharge.

Provides data for NHPA indicators 4.1, 4.2 and 4.3, NHPC indicator 3.07, and contributes to NDDWG indicator 4A.1.1.

Gaps and deficiencies

The AIHW National Hospital Morbidity Database (NHMD) has very good coverage of Australian hospital admitted-patient episodes, containing data from all public and almost all private facilities. The major limitations of the NHMD lie in the episode-based nature of the records and the lack of a unique personal identifier. This means that records cannot be assigned to individuals, and it is not possible to obtain counts of the number of patients admitted.

Indicators

NHPA 4.1	Hospital separation rates for end-stage renal disease as the principal diagnosis with diabetes as an additional diagnosis.
NHPA 4.2	Hospital separation rates for coronary heart disease or stroke as the principal diagnosis with diabetes as an additional diagnosis.

NHPA 4.3	Hospital separation rates for conditions other than end-stage renal disease and coronary heart disease/stroke among people with diabetes as a principal diagnosis or an additional diagnosis.
NHPC 3.07	Potentially preventable hospitalisations (includes diabetes).
**NDDWG 4A.1.1*	The number and characteristics of existing data sources to asses the trends in morbidity from diabetes and its complications, and their connectivity. For each data source identified: What is the type of data source? What are the scope and coverage of data collection? What is the frequency of data collection? Are data collected according to agreed national or international standards? Is the data set routinely analysed and reported on? What is the potential connectivity to other data sets?

5.9 Rehabilitation and disability care for people with diabetes

Owing to the nature of the complications associated with diabetes, rehabilitation and/or disability care may play an important part in the lives of people with diabetes. A stroke, cardiac event, severe peripheral vascular disease or amputation all may require rehabilitation, temporary or permanent assistance with daily living, or a greater degree of care such as that provided in a residential aged care facility.

Data sources

ABS Disability, Ageing and Carers Surveys

Series of surveys of people of all ages with disabilities and their carers, and people aged 60 years or over, conducted every 5 years. Unlike most population surveys, the sample includes residents of special dwellings (such as boarding houses) and health establishments (e.g. hospitals, residential aged care facilities and hospices) as well as private dwellings, and therefore provides more complete coverage of the disabled and aged populations. Data include long-term health conditions; disabilities; conditions underlying disabilities; type and extent of restrictions; degree of assistance required and received; extent to which needs are met; and participation in social, cultural, and recreational activities.

AIHW National Hospital Morbidity Database

Details of episodes of admitted patient care occurring in Australian hospitals. Data include length of stay, age, sex, Indigenous status, place of usual residence, diagnoses and procedures performed.

Gaps and deficiencies

Monitoring of the need for and use of disability and rehabilitation services by people with diabetes would provide information on any unmet need for these services and where any new services might be located to be of most benefit in the community. At present, only limited national data are available on this subject.

Indicators

There are currently no indicators to monitor rehabilitation and disability specifically among people with diabetes. However, there are indicators within the cardiovascular disease NHPA indicator set which relate to rehabilitation and disability following cardiac, stroke or vascular events. With additional information on diabetes status, these indicators may be useful for monitoring rehabilitation and disability owing to cardiovascular complications in people with diabetes.

5.10 Palliative care for people with diabetes

The National Health Data Dictionary data element 'care type' defines palliative care as '…care in which the clinical intent or treatment goal is primarily quality of life for a patient with an active, progressive disease with little or no prospect of cure' (AIHW 2003). For people with diabetes, palliative care may be required for specific complications, such as following a severe stroke, autonomic neuropathy, heart failure, or in end-stage renal disease, or generally as overall health deteriorates in people with multiple complications or other comorbidities.

Data sources

AIHW National Hospital Morbidity Database

Records of all episodes of admitted-patient care provided in Australian hospitals. Data include age, sex, length of stay, type of care provided, diagnoses and procedures.

Gaps and deficiencies

More complete coverage of diabetes-related palliative care requires data from individuals, residential aged care facilities, hospices, and community and home nursing providers (i.e. non-hospital, community-type palliative care). There are as yet no processes in place to collect such data. The ABS Disability, Ageing and Carers Survey series, which includes people from both households and cared accommodation facilities, does not specify whether the care provided is palliative in intent.

Indicators

There are currently no indicators to monitor palliative care for people with diabetes.

5.11 Death from diabetes and complications

A number of different diseases or injuries may be listed on a death certificate. One of these will be classed as the underlying cause, that is, the primary disease or injury causing the death. In addition, up to twenty associated causes may also be listed. Associated causes are all other conditions, diseases or injuries that contributed to the death.

Diabetes has been one of the top ten underlying causes of death in Australia for a number of years. However, diabetes is more commonly recorded as an associated cause of death, with more than three times as many deaths having diabetes as an associated cause rather than the underlying cause. When all deaths where diabetes was recorded are combined, diabetes was implicated in 9% of all deaths in 2002. Coronary heart disease, stroke, kidney-related diseases, and heart failure are commonly listed on death certificates where diabetes also appears.

Death rates from diabetes in Australia have been relatively stable since 1991, at around 11 deaths per 100,000 in females and 17 per 100,000 in males per year. Rates of death from diabetes are higher among people living in remote areas, lower socioeconomic groups, Indigenous Australians, and overseas-born Australians.

Data sources

AIHW National Mortality Database

De-identified (i.e. without names) records of all registered deaths in Australia since 1964, including sex, place of residence, dates of birth and death, country of birth and underlying cause of death. From 1997 all causes of death listed on the death certificate are also recorded. Indigenous status is available from 1980, but the quality of this data varies considerably by state/territory and over time.

National Death Index

Identified (i.e. with names) records of all deaths occurring in Australia since 1980. Data include sex, age, Indigenous status and underlying cause of death. Associated causes of death are available from 1997 onwards by linking with the AIHW National Mortality Database. Data from the National Death Index may be used with permission for medical research purposes only, and may be useful for identification of deaths in cohort studies or disease registers such as the National Diabetes Register.

Burden of Disease and Injury in Australia study

This study examined the burden due to specific diseases, including diabetes, as well as risk factors for illness and injury. 'Burden' refers to the impact of disease or injury on 'healthy' life, in terms of premature death, illness, disability and injury. These impacts are summarised using the disability-adjusted life year (DALY) measure, which estimates the potential years of 'healthy' life lost due to disease or injury.

Gaps and deficiencies

Identification of Indigenous people

Almost all deaths in Australia are registered. However, the Indigenous status of the deceased is not always recorded, or recorded correctly. The incompleteness of Indigenous identification means the number of deaths registered as Indigenous is an underestimate of deaths occurring in the Aboriginal and Torres Strait Islander population. In addition, comparison of mortality rates between jurisdictions and by geographic area is problematic because of differences in the level of identification by jurisdictions and by geographic area. Changes in identification over time also presents difficulties for monitoring trends in Indigenous mortality.

Identification of 'culturally and linguistically diverse' people

Difficulties also exist in the definition of 'culturally and linguistically diverse' people. Available data are usually defined based on a person's country of birth rather than their first or most commonly spoken language, or their cultural background and practices, and therefore may not accurately reflect their real circumstances with respect to cultural diversity. Further, the accuracy of country of birth information when reported by another person may be questionable, or indeed the country of birth may be unknown, and the quality and method of collection of country of birth data may change over time.

Reporting of diabetes as a cause of death

Diabetes is considerably underreported on death certificates, and is much more likely to be recorded as an associated cause of death rather than as the underlying cause. Official mortality figures, which are based on the underlying cause of death, considerably underestimate the contribution of diabetes to deaths in Australia. Multiple-cause coding should in part compensate for this underreporting. Large cohort studies and disease registers linked with the National Death Index may provide more accurate estimates of the impact of diabetes on Australian mortality rates.

A further problem lies in the identification of the type of diabetes a person has. The accuracy of coding of the type of diabetes is unknown, and may vary over time and with different classification systems. It is therefore not possible to produce mortality estimates by diabetes type based on the AIHW National Mortality Database. Data from large cohort studies or disease registers may provide some information on mortality by diabetes type.

Indicators

NHPA 5.1	Death rates for diabetes in: (a) general population (b) Indigenous population (c) people from culturally and linguistically diverse backgrounds.
NHPA 5.2	Death rates for coronary heart disease and stroke among people with diabetes in: (a) general population (b) Indigenous population (c) people from culturally and linguistically diverse backgrounds.
NHPC 1.08	Death rates for NHPA diseases and conditions.
**NDDWG 4A.1.1*	The number and characteristics of existing data sources to assess the trends in mortality from diabetes and its complications, and their connectivity. For each data source identified: What is the type of data source? What are the scope and coverage of data collection? What is the frequency of data collection? Are data collected according to agreed national or international standards? Is the data set routinely analysed and reported on? What is the potential connectivity to other data sets?
**NDDWG 4B.1.1*	The diabetes-related death rate over time, among: • the general population

- Aboriginal and Torres Strait Islander peoples
- people of culturally and linguistically diverse backgrounds
- people of different socioeconomic status
- people from different geographic areas.

**NDDWG 4B.3.1*	The diabetes-related life expectancy over time.

6 Future opportunities

6.1 Limitations of current data sources relevant to diabetes

Although Australia has an array of data sources relevant to the monitoring of diabetes, the data need to be integrated effectively and information gaps and deficiencies addressed. On the whole, few data collections are nationally representative, have sufficient numbers from priority populations, use nationally agreed instruments, use physical measurements or undertake routine validation of self-reported data. There is also a general shortage of longitudinal data on diabetes at a national level.

Major gaps and deficiencies of the current data are as follows:

- There is a paucity of national data on incidence and prevalence by type of diabetes to reliably assess the magnitude of the problem. Corresponding trend information is also sparse.
- Current information on risk factors for diabetes is mostly based on self-reported data. Limited national data have been collected on the biomedical aspects of susceptibility for diabetes and its complications.
- There is no nationally coordinated effort for early detection of those at risk of developing diabetes in Australia, and hence no corresponding data.
- The accuracy of recording diabetes type in administrative data sets, such as hospital morbidity, mortality and general practice data, is uncertain.
- Hospital separations data are episode-based rather than person-based, so it is not possible to determine the number of individuals who are admitted for a particular condition, or to identify readmissions or treatment patterns.
- Some information on aspects of clinical management comes from data collections that are not representative of the whole population of people with diabetes (e.g. the ANDIAB survey of patients attending specialist diabetes services). This makes it difficult to establish a firm denominator for such data.
- For some areas of the monitoring system there are currently limited data for monitoring (e.g. disability and rehabilitation care). Information in these areas is necessary to improve services and maintain quality of life for people with diabetes.
- Diabetes care requires the use of a variety of health services, but there is no coordinated system to collect data across these various health contact points and so provide a complete picture of service use.
- Information on awareness and understanding of and attitudes to diabetes and its treatment is not readily available. Important aspects of population knowledge about diabetes and successful management of the condition by persons with diabetes and their carers can be understood by including questions on knowledge, attitudes and practices relating to diabetes and its treatment in population surveys.

6.2 Opportunities for improving the monitoring of diabetes

Quality information is required for the prevention, early detection and management of diabetes, its complications and risk factors at all levels including policy and program planning, clinical services and service management. In view of the gaps and deficiencies in diabetes-related information identified in this report, the following strategies may provide opportunities to improve national diabetes monitoring in Australia:

- A regular biomedical survey aimed at collecting objectively measured information such as body weight, height, body fat and blood measures, that would enable monitoring of diabetes in certain population groups including Aboriginal and Torres Strait Islander people.
- Modifications and enhancements to existing health surveys to cover diabetes and related health issues in more detail.
- Further sampling of priority population groups to enable useful comparisons.
- Further collation of data from various sources and data providers at the national and subnational levels.
- Linkage of appropriate data from various sources for statistical and research purposes.

The National Centre for Monitoring Diabetes will continue to play an important role in advising on diabetes-related information that should be collected and encouraging consistent data standards. The Centre will also explore ways of nationally coordinating diabetes data collections and initiatives currently being undertaken, and those planned for the future. For example, the Centre is currently working with the National Diabetes Data Working Group to refine a set of strategic indicators for diabetes across the continuum of care. These indicators relate to a variety of settings (health care organisation, health care practice, and consumers) and will be useful for monitoring health interventions according to guidelines as well as across various levels of care (e.g. population health, primary, secondary and tertiary care). The National Diabetes Register will also be an important source of information about people with insulin-treated diabetes as trend data become available and the survival status of registrants is tracked long term. The National Centre will continue to provide timely, quality and relevant information for national monitoring of diabetes, which will contribute to the improvement of policies, practices, services, and quality of life for people with diabetes in Australia.

Appendix: Indicators relevant to diabetes

Table A.1: National Health Priority Area—diabetes mellitus indicator set

No.	Description
1	**Disease incidence and prevalence**
1.1	Prevalence rates for Type 1 and Type 2 diabetes in:
	(a) general population
	(b) Indigenous population
	(c) persons from culturally and linguistically diverse backgrounds
1.2	Incidence rates for Type 1 and Type 2 diabetes in:
	(a) general population
	(b) Indigenous population
	(c) persons from culturally and linguistically diverse backgrounds
1.3	Gestational diabetes among women aged 20–44 years, by parity
2	**Risk factors for diabetes and associated complications**
2.1	Prevalence rates for obesity and overweight (as measured by BMI) among persons with Type 2 diabetes and in the general population
2.2	Rates for non-participation in regular, sustained, moderate aerobic exercise among persons with Type 2 diabetes and in the general population
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
	(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
3	**Diabetes complications**
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 clinically diagnosed persons with diabetes
3.4	Incidence rates for coronary heart disease and stroke among clinically diagnosed persons with diabetes and in the general population

(continued)

Table A.1 (continued): National Health Priority Area—diabetes mellitus indicator set

No.	Description
4	**Hospital separations for diabetes complications**
4.1	Hospital separation rates for end-stage renal disease with diabetes as an additional diagnosis
4.2	Hospital separation rates for coronary heart disease or stroke where diabetes is an additional diagnosis
4.3	Hospital separation rates for conditions other than end-stage renal disease and coronary heart disease/stroke among persons with diabetes as a primary diagnosis or an additional diagnosis
5	**Mortality**
5.1	Death rates for diabetes in:
	(a) general population
	(b) Indigenous population
	(c) among persons 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
	(c) among people from culturally and linguistically diverse backgrounds
6	**Health status**
6.1	Self-assessed health status of persons with and without diabetes
7	**Screening and management**
7.1	Proportion of persons with diabetes tested for glycosylated haemoglobin (HbA1c) level at least every 6 months
7.2	Proportion of pregnant women being tested for gestational diabetes

Table A.2: National Health Sector Performance Indicators relating to diabetes, 2003

No.	Indicator	Description
Tier 1 Health status and outcomes		
1.08	Mortality for National Health Priority Area diseases and conditions	Death rates for National Health Priority Area diseases and conditions
Tier 2 Determinants of health		
2.07	Fruit and vegetable intake	Proportion of people eating sufficient daily serves of fruit or vegetables
2.08	Physical inactivity	Proportion of adults insufficiently physically active to obtain a health benefit
2.09	Overweight and obesity	Proportion of persons overweight or obese
Tier 3 Health system performance		
3.07	Potentially preventable hospitalisations	Admissions to hospital that could have been prevented through the provision of appropriate non-hospital health services
3.11	Management of diabetes	Proportion of persons with diabetes mellitus who have received an annual cycle of care within general practice
3.22	Enhanced primary care services	Percentage of GPs using enhanced primary care (EPC) items

Table A.3: Draft NDDWG indicator matrix for diabetes (as at March 2005)

	Setting		
National Diabetes Strategies Group (NDSG) questions across the continuum of care	A. Health care organisation (funder, policy maker, service organisation)	B. Health care practice (levels of care—population health, primary, secondary and tertiary care, provider/service organisation)	C. Consumers
1. Is care provided according to guidelines?	Indicators: 1A.1.1, 1A.1.2	Indicators: 1B.1.1, 1B.2.1	Indicators: 1C.2.1, 1C.4.1
2. Are we preventing or delaying the development of Type 2 diabetes?	Indicators: 2A.1.1, 2A.1.2, 2A.2.1	Indicators: 2B.1.1, 2B.2.1	Indicators: 2C.1.1, 2C.1.2, 2C.2.1
3. Is access equitable?	Indicators: 3A.1.1	Indicators: 3B.1.1, 3B.2.1	Indicators: 3C.1.1, 3C.2.1
4. Are we reducing the death and serious health effects of diabetes?	Indicators: 4A.1.1	Indicators: 4B.1.1, 4B.2.1, 4B.2.2, 4B.3.1	Indicators: 4C.1.1
5. Are we improving the quality of care for people with diabetes?	Indicators: 5A.1.1, 5A.2.1	Indicators: 5B.1.1	Indicators: 5C.1.1, 5C.3.1, 5C.3.2, 5C.3.3
6. Is case detection occurring optimally?	Indicators: 6A.1.1	Indicators: 6B.1.1, 6B.2.1	Indicators: 6C.1.1

Table A.4: Draft NDDWG indicators for diabetes (as at March 2005)

Question	Indicator	Definition
1. Is care (prevention, early detection and management) provided according to guidelines?		
	1A.1.1	The number and characteristics of diabetes guidelines identified. *For each aspect of diabetes prevention, early detection and management for which guidelines exist:* *Are the guidelines Australian?* *Are they evidence-based?* *Have the guidelines been endorsed? If yes, by whom?* *Are the guidelines up to date?* *Are the guidelines written or available in consumer-friendly language?* *What is the level of dissemination of these guidelines to health care providers?* *Have the guidelines been implemented/incorporated into diabetes programs/initiatives?* *Are there mechanisms to audit diabetes prevention, early detection and management against the guidelines (in hospitals, diabetes centres and general practice)?*
	1A.1.2	The proportion of programs to improve prevention, early detection and management consistent with guidelines.
	1B.1.1	The proportion of people with diabetes mellitus who have had an annual cycle of care (i.e. have had recorded): • a foot exam within the last 12 months • an eye exam within the last 2 years • microalbumin measured in the last year • HbA1C measured in the last 6 months • blood pressure measured in the last 6 months • lipids measured in the last 12 months • weight/BMI measured in the last 6 months
	1B.2.1	The proportion of GPs with register/recall systems (by Division).
	1C.2.1	The proportion of people with diabetes who are aware of the existence of guidelines for management.
	1C.4.1	The proportion of people with diabetes who know what their evidence-based healthy lifestyle options are.

(continued)

Table A.4 (continued): Draft NDDWG indicators for diabetes (as at March 2005)

Question	Indicator	Definition
2. Are we preventing or delaying the development of Type 2 diabetes?		
	2A.1.1	The number and characteristics of programs/initiatives identified to prevent/delay the development of Type 2 diabetes or modify the prevalence of Type 2 diabetes risk factors. *For each program/initiative identified:* *Does it follow evidence-based guidelines?* *Is it ongoing?* *What is its reach?*
	2A.1.2	The proportion of the population reached by Type 2 diabetes preventive programs.
	2A.2.1	The number and characteristics of mechanisms for monitoring the incidence of Type 2 diabetes and the prevalence of Type 2 diabetes risk factors. *For each mechanism/data source identified:* *What is the type of mechanisms/data source?* *What is the scope and coverage of the collection?* *What is the frequency of data collection?* *Are data collected according to agreed national or international standards?* *Is the data set routinely analysed and reported on?*
	2B.1.1	Incidence rate of Type 2 diabetes over time.
	2B.2.1	The prevalence of Type 2 diabetes mellitus risk factors over time: • obesity • physical inactivity • proportion of people following Australian dietary recommendations
	2C.1.1	The proportion of individuals who correctly identify the risk factors for Type 2 diabetes.
	2C.1.2	The proportion of people at risk of Type 2 diabetes who correctly identify that they are at risk.
	2C.2.1	The proportion of people at risk of Type 2 diabetes who know what their evidence-based healthy lifestyle options are.

(continued)

Table A.4 (continued): Draft NDDWG indicators for diabetes (as at March 2005)

Question	Indicator	Definition
3. Is access equitable?		
	3A.1.1	The number and characteristics of diabetes and at-risk programs, initiatives and services for: • Aboriginal and Torres Strait Islander people • people of culturally and linguistically diverse backgrounds • people with different socioeconomic status • people from different geographic areas *For each program/initiative/service identified:* *What is the focus of the program?* *What is the target population?* *Does the program follow current evidence-based guidelines?* *Is it ongoing?* *To what extent is it culturally appropriate for all groups in the target population?* *Are there any population groups who are missed or not reached?*
	3B.1.1	The respective representation of Indigenous, culturally and linguistically diverse, socioeconomically disadvantaged, and geographically diverse groups, in diabetes, at-risk and screening programs (compared with their estimated representation in the community).
	3B.2.1	The respective number and characteristics of diabetes services available. *For services which provide management for people with diabetes, what is/are the:* *type of service?* *cost to consumers?* *hours of availability?* *waiting times?* *follow-up?* *outreach services?* *levels of use for different population groups?*
	3C.1.1	Satisfaction with cultural suitability of services available.
	3C.2.1	Self-reported barriers to access to management services.
4. Are we reducing the death and serious health effects of diabetes?		
	4A.1.1	The number and characteristics of existing data sources for assessing the trends in morbidity and mortality from diabetes and its complications, and their connectivity. *For each data source identified:* *What is the type of data source?* *What are the scope and coverage of the data collection?* *What is the frequency of data collection?* *Are data collected according to agreed national or international standards?* *Is the data set routinely analysed and reported on?* *What is the potential connectivity to other data sets?*

(continued)

Table A.4 (continued): Draft NDDWG indicators for diabetes (as at March 2005)

Question	Indicator	Definition
4. Are we reducing the death and serious health effects of diabetes? (continued)		
	4B.1.1	The diabetes-related death rate over time, among: • the general population • Aboriginal and Torres Strait Islander peoples • people of culturally and linguistically diverse backgrounds • people of different socioeconomic status • people from different geographic areas
	4B.2.1	Prevalence and incidence of diabetes, its complications and comorbidities over time (by subgroup, as per indicator 4B.1.1): • diabetes • cardiovascular disease • visual loss • end-stage renal disease • non-traumatic amputation
	4B.2.2	The proportion of people with Type 1 diabetes with complications, by duration of diabetes.
	4B.3.1	The diabetes-related life expectancy over time.
	4C.1.1	Quality of life of people with diabetes (measured by standardised questionnaire).
5. Are we improving the quality of clinical management for people with diabetes?		
	5A.1.1	The adequacy of systems identified to assess quality of clinical management. *For each system identified:* *Does it follow current evidence-based guidelines?* *Is it ongoing?* *Does it cover identified population groups?*
	5A.2.1	The number and characteristics of programs identified to improve the quality of clinical management. *For each program identified:* *Does it make use of current evidence-based or consensus guidelines (as appropriate)?* *Is it ongoing?* *What is the format of the program?*
	5B.1.1	The proportion of people with diabetes that meet guideline targets for: • HbA1C • blood pressure • cholesterol • weight/BMI
	5C.1.1	The proportion of patients satisfied with quality of care.
	5C.3.1	The proportion of patients who are confident they know how to self-manage their diabetes.
	5C.3.2	The proportion of patients who have attended a diabetes educator (for self-management education).
	5C.3.3	The proportion of patients who have a care plan for diabetes, and understand their self-management.

(continued)

Table A.4 (continued): Draft NDDWG indicators for diabetes (as at March 2005)

Question	Indicator	Definition
6. Is case detection occurring optimally?		
	6A.1.1	The proportion of health care practitioners who have a system in place to screen for Type 2 diabetes, and the characteristics of these systems.
		For each system identified:
		Does it follow current evidence-based guidelines?
		Is there a register/recall system?
		Is it culturally appropriate?
		Are primary care practices Practice Incentives Program (PIP) accredited?
	6B.1.1	The proportion of people at risk of Type 2 diabetes that are being screened, and the proportion of these undergoing appropriate screening (as defined by evidence-based guidelines).
	6B.2.1	The ratio of diagnosed to undiagnosed cases of Type 2 diabetes.
	6C.1.1	The proportion of at-risk people who are aware of the need for Type 2 diabetes screening.

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