

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
<ul style="list-style-type: none"> 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. 	<ul style="list-style-type: none"> 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. <p>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.</p>	<ul style="list-style-type: none"> Early detection Screening Case detection Periodic health examinations Early intervention <p>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.</p>	<ul style="list-style-type: none"> 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. <p>Personal management: e.g. diet, physical activity, glucose self-monitoring, compliance with treatment.</p>	<ul style="list-style-type: none"> Post acute care <p>In-hospital and post-hospital rehabilitation care for complications, e.g. cardiovascular disease, renal transplants, rehabilitation and disability following stroke, amputations.</p>	<ul style="list-style-type: none"> 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

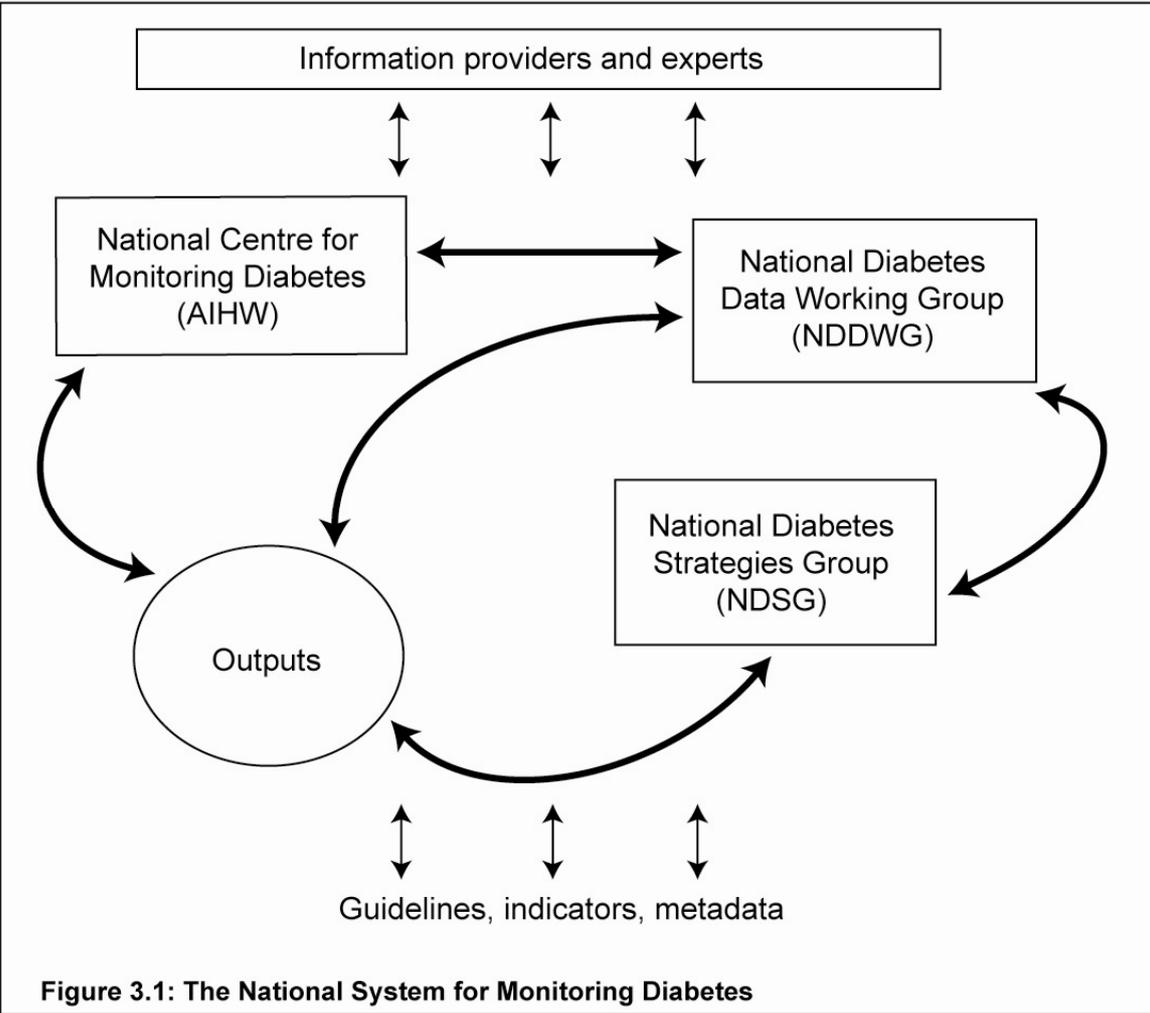
As part of the National Health Priority Area program, the Australian Government Department of Health and Ageing (DoHA) has allocated funding for a range of national diabetes initiatives including the establishment of the National System for Monitoring Diabetes. Although Australia previously had national 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.



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	<p>Identification and treatment of asymptomatic persons who are at risk but in whom the condition is not clinically apparent (e.g. screening tests)</p> <p>Predisposing factors: demographic, social, environmental and genetic factors</p> <p>Modifiable risk factors:</p> <p><i>behavioural</i>: e.g. low physical activity levels, poor nutrition</p> <p><i>biomedical</i>: e.g. gestational diabetes, overweight and obesity, glucose intolerance, low birthweight</p>
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	<p><i>Behavioural</i>: e.g. smoking, low physical activity levels, poor nutrition, poor glycaemic control, high alcohol intake</p> <p><i>Biomedical</i>: e.g. high blood cholesterol, high triglycerides, overweight and obesity, high blood pressure, proteinuria, hyperglycaemia</p>
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	<p>Non-hospital and emergency care for complications — GPs, specialists, allied health professionals, regular clinical assessment, ambulance service/paramedics, hospital emergency department</p> <p>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)</p> <p>Personal management — e.g. diet, physical activity, glucose self-monitoring, compliance with treatment</p>
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>.