Introduction

Purpose of report

The National Diabetes Data Working Group's Diabetes Indicators Review Subcommittee, under the direction of the National Diabetes Strategies Group (NDSG), has developed a national set of 33 diabetes indicators. Of these indicators, 11 have been selected as the highest priority and endorsed by the NDSG.

The main purpose of this report is to describe the process undertaken by the Subcommittee in developing and setting priorities for the full set of indicators (that is, the 33 indicators), and to provide operational definitions for the recommended set of 11 indicators. The full set of indicators is listed at Appendix A.

Indicators

Health indicators are standardised measures, which can be used by governments, policy makers and service providers to provide standardised and consistent information for:

- establishing benchmarks
- monitoring and comparing the health status of population groups over time
- monitoring and evaluating the effectiveness of health policy, prevention and management strategies.

Attributes of indicators

An indicator should meet some or all of the following criteria developed by the National Health Performance Committee (NHPC 2001):

- be worth measuring
- be measurable for diverse populations
- be understood by people who need to act
- galvanise action
- be relevant to policy and practice
- reflect results of actions when measured over time
- be feasible to collect and report
- comply with national processes of data definitions.

What is an operational definition for an indicator?

An operational definition for an indicator defines what is to be measured and the steps to follow to measure it consistently, reliably and validly over time and by different people (AIHW 2004a). In this report, operational definitions for the recommended diabetes indicators include the following information:

- intent of the indicator
- rationale for measurement
- target population
- numerator and denominator
- available data sources
- presentation and frequency of reporting
- further development required.

The operational definitions in this report also include a section noting issues relating to the quality of the indicator; and the quality and timeliness of the available data sources.

Policy context for diabetes indicator development

In November 2005, the Australian Health Ministers' Conference (AHMC) endorsed a national strategic policy approach to manage and improve chronic disease prevention and care in the Australian population.

The proposed national approach to chronic disease prevention and management comprises three complementary components:

1. the National Chronic Disease Strategy
2. the National Service Improvement Frameworks
3. the Blueprint for Chronic Disease Surveillance.

National Chronic Disease Strategy

The National Chronic Disease Strategy provides an overarching national framework for improving chronic disease prevention and care across Australia (NHPAC 2006a). It is a nationally agreed agenda that aims to encourage coordinated action in response to the growing impact of chronic disease on the health of Australians and the health-care system.

The primary objectives of the National Chronic Disease Strategy are to:

- prevent and/or delay the onset of chronic disease for individuals and population groups
- reduce the progression and complications of chronic disease
- maximise the wellbeing and quality of life of individuals living with chronic disease and their families and carers
- reduce avoidable hospital admissions and health-care procedures
- implement best practice in the prevention, detection and management of chronic disease
- enhance the capacity of the health workforce to meet population demand for chronic disease prevention and care into the future.

National Service Improvement Frameworks

The National Service Improvement Frameworks cover the national health priority chronic conditions of diabetes; heart, stroke and vascular disease; asthma; cancer; and osteoarthritis, rheumatoid arthritis and osteoporosis (NHPAC 2006b). The Frameworks identify opportunities where Australia might most usefully invest to improve prevention and care for these chronic diseases.

The Frameworks aim to encourage the delivery of more person-centered, equitable, timely, effective, affordable and cohesive health-care for all Australians (NHPAC 2006b). In particular, the frameworks are intended to:

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

The National Service Improvement Framework for Diabetes includes the following critical intervention points:

- for the well community, including those at increased risk of diabetes, to:
  - reduce the risk of diabetes
  - diagnose diabetes early.
- for people with diabetes, to provide the best care and support:
  - during the early stages of the condition
  - in the long term
  - for acute episodes.

The Framework also identifies nine initial priority actions:

1. Provide improved support for comprehensive health promotion efforts in the key area of nutrition, smoking and physical activity.
2. Establish integrated and networked diabetes services to improve continuity of care at each point along the care continuum.
3. Provide improved support for multidisciplinary care in hospitals and the community.
4. Develop agreed diabetes plans at national, state, territory and local levels, as appropriate, to monitor all aspects of diabetes management for the purpose of quality improvement, including performance indicators.
5. Provide evidence-based consumer information about environmental, behavioural and genetic risks of diabetes.
6. Continue to assist primary care workers to offer high-quality assessment of risk, early detection of diabetes, referral to treatment, coordination of treatment and supportive care.
7. Assist people with diabetes to understand and manage their diabetes through national, state, territory and local approaches.
8. Implement and evaluate culturally appropriate programs to improve diabetes prevention and management with special emphasis on the needs of disadvantaged

groups, Aboriginal and Torres Strait Islander peoples, and those from culturally and linguistically diverse backgrounds.

9. Review the evidence, gaps in research and opportunities for action within a specific timeframe, at least every 3 years.

Blueprint for Chronic Disease Surveillance

The Blueprint for Chronic Disease Surveillance is a framework for local and national public health surveillance of preventable chronic disease and the determinants of chronic disease (NPHP 2006). The Blueprint sets out the essential elements of a national surveillance system, describes an Australian Priority Setting Tool for agreeing information priorities and methods, and proposes immediate actions to establish the system.

The Healthy for Life Program

The Healthy for Life Program is an Australian Government initiative aimed at improving the:

- availability of child and maternal health-care
- prevention, early detection and management of chronic disease
- long-term health outcomes for Aboriginal and Torres Strait Islander Australians
- Aboriginal and Torres Strait Islander health workforce (DoHA 2007).

A set of *Healthy for Life* Program performance indicators has been developed by the Office for Aboriginal and Torres Strait Islander Health.

Existing diabetes indicator sets

National Health Priority Areas—diabetes indicators

In 1996, the Australian Health Ministers agreed that diabetes become a National Health Priority Area (NHPA). The NHPA initiative focused public attention and health policy on health conditions that contributed most to the burden of illness in the community, particularly areas where it is possible to reduce that burden through prevention and treatment programs.

A set of priority indicators covering prevention, screening and early intervention, treatment and management of the condition was developed. A complete list of the diabetes indicators, which are described in the 1998 National Health Priority Areas report on diabetes mellitus (CDHAC & AIHW 1999), is provided in Appendix B.

National Health Performance Committee indicators

The National Health Performance Committee (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 and the Aboriginal and Torres Strait Islander Health Performance Framework: health status and outcomes; determinants of health; and

health system performance. Dimensions within the last tier include effectiveness, appropriateness, accessibility, responsiveness, safety, continuity, capability and sustainability. Of the set of 44 NHPC indicators, the following are relevant to diabetes:

- Management of diabetes—proportion of persons with diabetes mellitus who have received an annual cycle of care within general practice
- Potentially avoidable mortality
- Mortality for NHPA diseases and conditions
- Hospital separation rates for potentially preventable chronic conditions
- Adult smoking
- Physical inactivity
- Overweight and obesity
- High blood pressure.

Benchmark data for these indicators are presented in the National Report on Health Sector Performance Indicators 2003 (NHPC 2004).

Why was a new set of diabetes indicators developed?

The National Diabetes Information Framework proposed by Armstrong et al. (2002) included a draft set of 74 national diabetes performance indicators as a minimum data set relating to key outcomes and health-care interventions. To progress this work and develop a smaller, prioritised set of diabetes indicators, the National Diabetes Strategies Group identified six questions addressing its priorities for diabetes information:

1. Are we preventing or delaying the development of Type 2 diabetes?
2. Is case detection occurring optimally?
3. Is access equitable?
4. Is care (prevention, early detection and management) provided according to guidelines?
5. Are we improving the quality of clinical management for people with diabetes?
6. Are we reducing the death rate and serious health effects of diabetes?

The National Diabetes Data Working Group (NDDWG), through its National Diabetes Indicators Review Subcommittee, was then given responsibility for developing indicators that addressed these six questions and determining priorities for developing a national set of diabetes indicators. The result of this process was a national set of diabetes indicators including a 'Top 11' recommended indicators. These recommended indicators support the Diabetes National Service Improvement Framework and the National Diabetes Strategy, and incorporate the priorities of the NDSG. The steps undertaken in the development of the indicators are briefly described below.

Indicator development process

1. Development of the indicator matrix

The first step undertaken by the Review Subcommittee in developing a national minimum data set was to identify different areas of indicator development for diabetes, including:

- the six questions that covered the NDSG's current priorities for diabetes information
- the stakeholders involved in diabetes management—that is, funder-policy makers; service organisations; health-care practice; and consumers
- the spectrum or setting of diabetes care, including primary, secondary and tertiary care; population health; and infrastructure
- the continuum of diabetes care, including prevention, detection, and management of diabetes and its complications.

The Review Subcommittee of the NDDWG developed a two-dimensional matrix framework that encompassed all of these indicators (see Appendix A for the complete matrix). In doing so, consistency with relevant indicator work being carried out by the National Health Performance Advisory Group and international organisations was taken into account as much as possible.

For each cell of the matrix, the Review Subcommittee developed questions, which were used to determine priorities for developing a national set of diabetes indicators, including information on the indicators' data availability.

2. Indicator assessment

The following data assessment was undertaken for each of the diabetes indicators included in the indicator matrix:

1. Are the data available already - both denominator and numerator?
2. If not, can the data be collected? If yes, how difficult and at what cost?
3. What is, or will be the quality of the data (for example, validity, reliability, completeness)
4. What subgroup categories need to be considered (for example, Type 1 versus Type 2 diabetes; population subgroups such as Aboriginal and Torres Strait Islander peoples, people of culturally and linguistically diverse backgrounds; and so on)? Do the available data have sufficient power for subgroup analysis?
5. How often should the data be collected (that is, frequency for monitoring)?

This assessment was then used to yield the following feasibility options for data availability:

A. Available or feasible at low cost with little development work

B. Feasible, but needs development and some cost

C. Not feasible at present.

3. Indicator prioritisation

The next step involved setting priorities for the indicators in any cell of the matrix where there was more than one indicator in that cell. Following this, the Diabetes Indicators Review Subcommittee chose, by consensus and in a non-prioritised manner, a list of

11 indicators to be recommended to the NDSG as the highest priority indicators for monitoring.

4. Consultation with state and territory jurisdictions

A draft of the indicators matrix was sent to all state and territory jurisdictions in April 2004 for comments. Comments were received from four state jurisdictions—Victoria, Queensland, South Australia and Western Australia. Most of the comments received related to data development issues and the need for a data development plan. All jurisdictions that responded received feedback from the Review Subcommittee.

A list of the jurisdictions consulted is provided in Appendix C.

5. Preliminary consideration by the NDSG

Following the consultation with the jurisdictions, the Diabetes Indicators Review Subcommittee refined the draft set of indicators and selected its non-prioritised list of the top 11 indicators as described above. The revised set of draft indicators and the list of the 11 highest priority indicators were then submitted for consideration to the NDSG's July 2005 meeting. In response, the NDSG asked the Review Subcommittee to consult with consumers about the consumer-specific indicators and to undertake a second round of consultation with the state and territory jurisdictions.

6. Second round of consultation with state and territory jurisdictions

A second consultation was conducted with jurisdictions between September and October 2005. Responses were received from three jurisdictions—South Australia, Western Australia and Tasmania. On the whole, the comments received from these jurisdictions were encouraging. Further, the Review Subcommittee decided that development of the operational definitions would probably address the issues raised.

7. Consumer consultation

Consultation with consumers was undertaken through a forum set up by Diabetes Australia NSW in October 2005. On the whole, the consumers consulted were in agreement with the indicators developed.

A list of the consumers consulted is provided in Appendix C.

8. Endorsement by NDSG

Following the consumer consultation and the second round of state and territory jurisdiction consultation, the Review Subcommittee finalised the draft indicator set and the list of the 11 priority indicators and submitted them for endorsement to the November 2005 meeting of the NDSG. At this meeting, the NDSG endorsed the full indicator set and the 11 recommended priority indicators. The NDSG also authorised the Diabetes Indicators Review Subcommittee secretariat to draft a technical report (that is, this report), that would include:

- the background and context to the indicator development
- the operational definitions for the 11 recommended priority indicators
- the complete indicator matrix.

The recommended priority diabetes indicators

The 11 recommended priority indicators are listed below (with the corresponding matrix indicator number in brackets). Note, the 11 recommended indicators are not numbered by order of priority. Operational definitions for each of these indicators are provided in the next chapter. It should be noted that data are not currently available to measure all of these indicators and, where data are available, not all data sources are complete. Possible data sources will need to be identified and evaluated for many of these indicators and some will require further data development.

1. Prevalence of Type 2 modifiable diabetes risk factors over time (1B.1.1)

    1.1 Prevalence of overweight and obesity over time.

        1.1.1 Prevalence of overweight, but not obese

        1.1.2 Prevalence of overweight

        1.1.3 Prevalence of obesity

    1.2 Proportion of people not following guidelines for physical activity over time.

    1.3 Proportion of people not following Australian dietary recommendations over time.

2. The proportion of people at risk of Type 2 diabetes who correctly identify that they are at risk and who are taking steps/actions to reduce their risk (2C.1.1)

3. The proportion of people at risk of Type 2 diabetes who are being opportunistically screened, and the proportion of those undergoing appropriate opportunistic screening (as defined by current evidence-based guidelines) (2B.1.1)

    3.1 The proportion of people at risk of Type 2 diabetes who are being opportunistically screened.

    3.2 The proportion of people at risk of Type 2 diabetes undergoing appropriate opportunistic screening (as defined by current evidence-based guidelines).

4. The number and characteristics of diabetes (Type 1, Type 2 and gestational) and at-risk programs, initiatives and services for (3A.1.1):
    - Aboriginal and Torres Strait Islander people
    - people of culturally and linguistically diverse backgrounds
    - people of different socioeconomic status
    - people from different geographic areas.
5. Ability for people to access services (Type 1, Type 2 and gestational diabetes) that are culturally suitable (3C.1.1)
6. The number and characteristics of diabetes (Type 1, Type 2 and gestational) guidelines identified (4A.1.1)
7. The proportion of people with diabetes mellitus (Type 1, Type 2 and gestational) who have had an annual cycle of care (4B.1.1)

8. The proportion of people with diabetes (Type 1, Type 2 and gestational) who meet guideline targets for (5B.1.1):
   - 8.1 HbA1c
   - 8.2 Blood pressure
   - 8.3 Cholesterol
   - 8.4 Weight/body mass index.
9. The diabetes-related death rate (includes Type 1, Type 2 and gestational diabetes) over time among (6B.1.1):
   - the general population
   - Aboriginal and Torres Strait Islander people
   - people of culturally and linguistically diverse backgrounds
   - people of different socioeconomic status
   - people from different geographic areas.
10. Quality of life of people with diabetes (Type 1, Type 2 and gestational) (measured by standardised questionnaire) (6C.1.1)
11. Prevalence and incidence of diabetes (Type 1, Type 2 and gestational), its complications and comorbidities over time (6B.2.1) among:
    - the general population
    - Aboriginal and Torres Strait Islander people
    - people of culturally and linguistically diverse backgrounds
    - people of different socioeconomic status
    - people from different geographic areas.

    11.1 Prevalence of diabetes (Type 1, Type 2 and gestational) over time

    11.2 Incidence of diabetes (Type 1, Type 2 and gestational) over time

    11.3 Prevalence of cardiovascular disease among people with diabetes over time

    11.4 Incidence of cardiovascular disease among people with diabetes over time

    11.5 Prevalence of visual loss among people with diabetes over time

    11.6 Incidence of visual loss among people with diabetes over time

    11.7 Prevalence of end-stage renal disease among people with diabetes over time

    11.8 Incidence of end-stage renal disease among people with diabetes over time

    11.9 Prevalence of non-traumatic amputation among people with diabetes over time

    11.10 Incidence of non-traumatic amputation among people with diabetes over time.

How do the recommended indicators complement Australian Government initiatives for chronic disease and diabetes?

The recommended diabetes indicators deal with aspects of diabetes across the continuum of care, including prevention, detection, management and complications. The indicators also focus on equitable access for all people who have diabetes or are at risk of diabetes.

Furthermore, the indicators have been developed across three stakeholder settings—health-care organisation, health-care practices and consumers. The framework within which the indicators have been developed is consistent with the themes shared by the Australian Government's National Chronic Disease Strategy, the National Service Improvement Frameworks and the Blueprint for Chronic Disease Surveillance, which include:

- emphasis on health promotion, prevention and monitoring population trends in the risk factors for chronic disease
- supporting integrated service provision and multidisciplinary care
- promoting and supporting self-management within the health system
- progressing mechanisms to improve quality of care
- improving access to chronic disease prevention and care services by Aboriginal and Torres Strait Islander people and other under-serviced population groups.

The recommended set of indicators listed above should be considered along with other indicators when an agreed prioritised set of national indicators for chronic diseases and associated determinants are developed to guide policy.