



Computer
Assisted
Telephone
Interviewing
Technical
Reference
Group

Population Health Monitoring and Surveillance:
Question Development Background Paper

Diabetes in Australia

May 2003

CATI Technical Reference Group
National Public Health Partnership

Computer Assisted Telephone Interviewing (CATI) is a methodology widely used for surveillance of health behaviours and health outcomes in populations in Australia. The National CATI Health Survey Technical Reference Group (CATI TRG) is an advisory committee to the National Public Health Information Working Group under the National Public Health Partnership. Members of the CATI TRG include representatives from State/Territory Health Departments, the Commonwealth Department of Health and Ageing (DoHA), the Australian Bureau of the Statistics, the Australian Institute of Health and Welfare and the Public Health Information Development Unit at the University of Adelaide. Since its inception in 1999, the CATI TRG has been a forum for the development and promotion of national standards, valid methods and capacity for CATI health surveys and health surveillance.

To embark in the efforts towards 'harmonisation' of CATI health surveys in Australia, the CATI TRG has identified the need to develop question modules for behavioural risk factor and chronic disease topics based on well-developed conceptual frameworks that underpin the data requirements for health surveillance. The proposed question modules are set to undergo a rigorous process of cognitive and field-testing under the guidance of the CATI TRG and the results will be published in a question module manual as a key reference to those interested in CATI health surveys in Australia.

This paper has been prepared by the CATI TRG as part of a series, with funding predominantly from the DoHA. Its preparation has involved input from all State and Territory jurisdictions, DoHA, the Australian Bureau of Statistics, the Australian Institute of Health and Welfare and the Public Health Information Development Unit at the University of Adelaide as well as recognised content experts.

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Contents

1	Introduction	1
2	Profile of diabetes	2
2.1	Types of diabetes.....	2
2.2	Burden of disease	2
2.3	Morbidity and mortality.....	2
2.4	Population groups at higher risk	2
2.5	Health system costs.....	3
3	Factors influencing the health of people with diabetes	4
3.1	Prevention of diabetes	4
3.2	Risk factors	4
3.3	Complications	4
3.4	Management of diabetes	4
4	Data requirements and concepts to be measured by CATI.....	6
4.1	Rationale for monitoring.....	6
4.2	Monitoring prevalence and incidence	7
4.3	Monitoring risk factors for diabetes and complications	7
4.4	Monitoring complications	7
4.5	Monitoring quality of life and disability	8
4.6	Monitoring use of health services for diabetes and complications	8
4.7	Monitoring the management of diabetes and health maintenance by people with diabetes.....	8
4.8	Monitoring the provision of education and health promotion programs.....	8
5	Issues in measurement.....	9
5.1	Measuring current diabetes prevalence.....	9
5.2	Type and age of onset of diabetes	9
5.3	Diabetes treatment and management	9
5.4	Measuring related conditions.....	10
5.5	At risk of getting diabetes.....	10
	References	11

Diabetes in Australia

1 Introduction

The purpose of this background paper is to present the conceptual framework that underpins the concepts and data requirements for the ongoing monitoring and surveillance of diabetes in Australia. This will assist in the development of nationally agreed computer assisted telephone interview (CATI) survey questions to monitor the prevalence of diabetes and its associated impact on individuals.

According to the 2001 National Health Survey, 2.9% of the population reported they had been diagnosed with diabetes mellitus and considered they may still have the condition and a further 0.3% reported current high blood glucose levels (ABS 2001). Of those aged 18 years or over, 3.9% had diabetes and 0.4% had high blood glucose levels. The Australian Diabetes, Obesity and Lifestyle Study (AusDiab) have provided national estimates of diabetes prevalence based on blood tests rather than self reported data. The prevalence of diabetes in the Australian population aged 25 years and older was 7.5% (Dunstan et al 2001). For every known case of diabetes, there was one undiagnosed case. It should be noted, however, that the AusDiab study was based on a clustered sample, and had a response rate of 55.3%, which may bias the results.

When diabetes was recognised as a National Health Priority Area in 1996, the systematic development of diabetes datasets and a national monitoring system were seen as important future directions (DHAC & AIHW 1999). Information systems need to be in place to effectively plan and monitor services for the prevention and management of diabetes, complications and risk factors. An understanding of the incidence, prevalence and changing trends related to diabetes is essential for the development of services and regional, state and national decision-making. Monitoring is also essential in reaching the goals of advancing knowledge and understanding about the prevention, cure and care of diabetes, and improving the capacity of the health system to deliver, manage and monitor services for the prevention of diabetes and the care of people with diabetes (DHAC 1999, Colagiuri et al 1998).

This paper is divided into five sections. Section 2 provides a summary profile of diabetes. Section 3 describes factors that influence the health of people with diabetes. Section 4 identifies the data requirements and concepts that need to be measured for the ongoing monitoring and surveillance of diabetes. Section 5 outlines a number of issues and methodologies applicable to the monitoring of diabetes. This paper will provide a valuable resource to those interested in the monitoring and surveillance of diabetes.

2 Profile of diabetes

2.1 Types of diabetes

Type 1 diabetes, or insulin dependent diabetes mellitus, is caused by deficient insulin production and accounts for approximately 10% of people diagnosed with diabetes. It is more likely to appear at younger ages.

Type 2 diabetes, or non-insulin dependent diabetes mellitus, is the most common form of diabetes, accounting for 85-90% of all diabetes. It is characterised by resistance to insulin action followed by inability to produce sufficient insulin. Diagnosis usually occurs after the age of 40 years, although it can be asymptomatic for many years.

Gestational diabetes mellitus (GDM) occurs in about 4-6% of pregnancies and remits after birth. It is associated with increased risk of perinatal morbidity and mortality and adverse maternal outcomes. Women who have had GDM are also at increased risk of developing Type 2 diabetes.

2.2 Burden of disease

Diabetes was recognised as a health priority area because of the significant burden that it places on the community in terms of health, social, economic and emotional costs. Australia-wide, it is estimated that there are over 700,000 people with diabetes, many of whom do not know they have it (McCarty et al 1996) and this prevalence is increasing.

2.3 Morbidity and mortality

In 2001, diabetes was the underlying cause of 3,078 registered deaths and there were 7,247 deaths where diabetes was mentioned on the death certificate but not reported as the underlying cause (ABS Cause of Death Collection Data available on request). Cardiovascular disease, followed by renal disease, is the leading cause of death among people with diabetes (Phillips et al 1990).

Diabetes can result in long term health problems including heart disease, stroke, blindness, kidney failure, neuropathy, and lower limb amputations if undetected or poorly controlled (DHAC & AIHW 1999, DHAC 1999). In 1996-97, a total of 267,449 hospital separations listed diabetes as a diagnosis, with 9% of these listing diabetes as the principal diagnosis.

2.4 Population groups at higher risk

People aged 50 years and over are a priority population not only because the prevalence of diabetes and co-morbidities increase with age but also because older people represent a growing proportion of the population with diabetes as a result of the overall ageing of the population (Colagiuri et al 1998, Parsons et al 2000).

Indigenous Australians experience higher prevalence rates of diabetes and related risk factors and complications, and develop diabetes at an earlier age than the non-Aboriginal population (Braun et al 1996, Hoy et al 1995, Phillips et al 1995). The overall prevalence of

Diabetes in Australia

diabetes among Aboriginal adults is at least two to four times that of the non-Aboriginal population (DHAC 1998).

Certain migrant groups are also more likely to develop diabetes because of their genetic disposition and adjusting to lifestyles that feature less physical activity and a high-fat, low-fibre diet resulting in obesity (Colagiuri et al 1998, Parsons et al 2000). National Health Survey data showed a higher prevalence of diabetes among people born in southern Europe, other European countries and Asia compared with those born in mainly English-speaking countries (DHAC & AIHW 1999).

Australians living in rural and remote areas have been shown to have higher rates of risk factors and mortality from diabetes than their metropolitan counterparts (Colagiuri et al 1998, AIHW 1998a, AIHW 1998b).

Type 1 diabetes is the most common form among children and adolescents and the frequency of hypoglycaemic events are almost twice as common in children and adolescents as they are among adults with type 1 diabetes. Management difficulties may also be more prominent among children and adolescents as they are required to deal with managing their diabetes in the context of growing up and the associated characteristics such as hormonal changes, erratic eating patterns, exercise, and peer group pressure (Colagiuri et al 1998, Parsons et al 2000).

2.5 Health system costs

Diabetes is a major cause of chronic disability and premature death, according to disability-adjusted life years, years lost due to disability and years of life lost (AIHW 1999). Diabetes has been named at number seven on the list of conditions that account for disease burden and is a costly condition, with direct health system costs estimated at \$1.2 billion per year (Colagiuri et al 1998, McCarty et al 1996). This does not include the indirect costs associated with diabetes, such as days lost from work, nor the personal costs associated with reduced functioning.

3 Factors influencing the health of people with diabetes

3.1 Prevention of diabetes

The planning, development, and monitoring of services for the prevention of diabetes and complications requires an understanding of the incidence, prevalence and changing trends related to diabetes (DHAC 1999). Preventing or delaying the onset of diabetes is important in reducing the future burden of diabetes. Many Australians though, do not regard diabetes as a serious condition, and are not willing to change their lifestyle to reduce their risk of developing diabetes. Primary prevention of diabetes, aimed at the whole population or high risk groups, is linked to other chronic conditions, such as cardiovascular diseases, through the common risk factors of obesity, diet, physical inactivity, hypertension and smoking. Primary prevention of Type 2 diabetes forms a major part of the draft NHMRC guidelines for diabetes management (ACDS 2000).

3.2 Risk factors

In the case of Type 1 diabetes, no modifiable risk factors have been identified although genetic and environmental factors have been suggested in its pathogenesis. Age, family history of diabetes, obesity, inactivity, and being of Aboriginal or ethnic origin are associated with increased risk of developing Type 2 diabetes. Risk factors for GDM are similar to Type 2 diabetes and include increasing maternal age, obesity, and a family history of diabetes.

Modifiable/Not modifiable risk factors – many cases of diabetes could be prevented or delayed through simple lifestyle changes that lower the risk of diabetes and other chronic diseases such as cardiovascular disease and cancer. These risks include obesity, poor diet, physical inactivity, smoking and alcohol.

3.3 Complications

Complications of diabetes can be classified as microvascular, macrovascular and those associated with pregnancy. Microvascular complications include nephropathy, retinopathy, and neuropathy. Other visual disorders such as cataracts and glaucoma are also more common among people with diabetes. Macrovascular complications include coronary heart disease, stroke and peripheral vascular disease. Diabetes is also associated with intra-uterine complications such as foetal malformations, foetal distress, and neonatal complications.

Risk factors for developing diabetes complications, in addition to age, duration of disease and genetic factors, include hyperglycaemia, obesity, high blood pressure, high cholesterol, smoking, lack of self-management skills and poor access to care.

3.4 Management of diabetes

The management of diabetes requires a multidisciplinary approach because of its potential to affect all systems of the body. Effective care requires a health team that includes a general practitioner, a diabetes educator, and a dietitian. Podiatrists, endocrinologists, psychologists,

Diabetes in Australia

Aboriginal health workers, obstetricians, cardiologists, renal physicians and ophthalmologists are among other specialists that may be required depending on severity and progression of complications. Patient education and support are integral to management success, although diabetes management is largely about self care (Colagiuri et al 1998).

Two recent landmark studies, the Diabetes Complications and Control Trial in the United States and the United Kingdom Prospective Diabetes Study, have advanced knowledge about the treatment and management of diabetes (UK Prospective Diabetes Study Group 1998, Mazze et al 1995, DCCT Research Group 1993). They have shown that strict glucose control substantially reduces the risk of complications.

Multiple daily injections of insulin and diet control are the main ways to manage Type 1 diabetes. Management of Type 2 diabetes involves reduction of risk factors such as obesity and physical inactivity, and controlling caloric intake and nutrition. Oral hypoglycaemic agents and insulin injections can be used to control hyperglycaemia for some people with Type 2 diabetes. Management of gestational diabetes is aimed at achieving maternal and child outcomes equivalent to those of non-diabetic pregnancies.

4 Data requirements and concepts to be measured by CATI

4.1 Rationale for monitoring

Quality information is required for the prevention, early detection and management of diabetes at all levels including policy and program design, clinical services and service management levels. Nationally, public health monitoring of diabetes uses data from a range of sources including routine administrative collections, regular and ad hoc population surveys, disease registers and developmental activities (DHAC & AIHW 1999).

In Australia, the best health-related indicators agreed on to date are listed in the National Health Data Dictionary (AIHW 2001). It is recommended that data standards for diabetes data should conform to definitions in the National Health Data Dictionary (Colagiuri et al 1998).

The National Health Priority Areas diabetes indicators were designed across the continuum of care for diabetes using a health outcomes framework developed by the National Health Information Management Group (NHIMG) Working Party on Health Outcomes Activities and Priorities, and endorsed by the Australian Health Ministers' Advisory Council (AHMAC). They were designed to provide a baseline for assessing progress towards the overall goal of reducing diabetes and its impact on the population. Mapping of data collection activities to this NHIMG framework shows that gaps exist in the information required for targeted surveillance of diabetes in Australia (DHAC & AIHW 1999). Specific deficiencies include:

- no national data on screening for diabetes, incidence, diabetes care, or long-term outcomes of care;
- information not available by type of diabetes;
- lack of national trend information about diabetes, complications and costs;
- incidence and prevalence based on self-reported information alone. Not supported by laboratory-based diagnostic criteria, therefore cannot reliably assess magnitude of problem (for example, do not know extent of undiagnosed problem);
- little information has been collected on biomedical aspects of risk factors for diabetes and its complications;
- few data collections are nationally representative, have sufficient numbers from priority populations, use nationally agreed instruments, undertake routine validation of self reports or include biological measurements; and
- no linking of records to generate profiles of diabetes management.

CATI surveys could be used to address the majority of these deficiencies, although biomedical surveys would be necessary to investigate the extent of the undiagnosed problem and other aspects of risk factors for diabetes and its complications.

4.2 Monitoring prevalence and incidence

Monitoring prevalence and incidence is necessary for determining the increase in diabetes over time in the Australian population and for comparing these rates among different subgroups. It is recommended that prevalence and incidence rates be monitored for gestational diabetes in the general population, and for both Type 1 and Type 2 diabetes in the general population, indigenous population, and among people from culturally and linguistically diverse backgrounds (DHAC & AIHW 1999). CATI surveys determine self-reported diagnosed diabetes and may therefore underestimate prevalence rates since up to half of people with diabetes do not know they have it.

4.3 Monitoring risk factors for diabetes and complications

Obesity

Overweight and obesity increase the risk of developing diabetes and related complications. Measures of overweight and obesity are obtained by calculation of body mass index (BMI) from self-reported height and weight. BMI is calculated as follows:

$$\text{BMI} = \text{weight (kg)} / \text{height}^2 \text{ (m)}$$

A calculated BMI greater than 25 is classified as overweight, and greater than 30 is classified as obese. The National Health Data Dictionary provides guidance on the measurement of BMI from self-reported height and weight (AIHW 2001).

Exercise

Regular physical activity is recommended to reduce the risk of Type 2 diabetes (ACDS 2000). Participation of people with diabetes in regular, sustained, moderate aerobic exercise needs to be monitored (DHAC & AIHW 1999).

Blood pressure and cholesterol

High blood pressure is a known risk factor for cardiovascular disease and puts people with diabetes at risk for a cardiovascular event. High blood pressure also contributes to microvascular complications such as lower extremity amputations, end-stage renal disease, and retinopathy. Tight control of blood pressure has been shown to reduce morbidity and mortality from macrovascular and microvascular complications. High levels of lipoproteins, or dyslipidaemia, may also precede abnormal glucose tolerance (DHAC & AIHW 1999). People with diabetes are at a higher risk of hyperlipidemia than the general population, putting them at higher risk of developing heart disease and circulation problems.

Blood pressure and cholesterol are optimally monitored with clinical measurements although indicators of high blood pressure and cholesterol may be obtained through self-reported information.

4.4 Monitoring complications

Self-reported prevalence of diabetes complications including kidney disease, retinopathy and eye disease, foot problems, coronary heart disease, and stroke should be monitored (DHAC & AIHW 1999).

4.5 Monitoring quality of life and disability

Quality of life can be measured in population surveys using generic instruments such as the SF-36, which has been validated for use in Australia (McCallum 1994). Such instruments provide insight into how diabetes impacts on the lives of those who have the condition in terms of their physical and mental functioning.

4.6 Monitoring use of health services for diabetes and complications

Health service use by people with diabetes and complications can be obtained from hospital activity databases such as the AIHW National Hospital Morbidity Database or the Integrated South Australian Activity Collection. Use of hospitals and other health services such as general practitioners, dieticians, nurse educators, podiatrists, and ophthalmologists, can also be obtained from self-reported information.

4.7 Monitoring the management of diabetes and health maintenance by people with diabetes

Depending on the type and severity of diabetes, management of the condition may involve use of insulin, medication, diet and weight control. Monitoring of the proportion of people with diabetes who are tested for glycosylated haemoglobin (HbA1c) at least every six months is recommended (DHAC & AIHW 1999). HbA1c is a measure of blood glucose control in people with diabetes. Elevated HbA1c indicates poor glucose control, which increases the risk of diabetes-related complications.

4.8 Monitoring the provision of education and health promotion programs

This is not considered a National Health Priority Area indicator. Evaluation of the uptake and effect of education and health promotion programs, however, is useful for planning and improving such services.

5 Issues in measurement

This section discusses the methods and issues involved in measuring the data requirements for the surveillance of diabetes. One concern that is common to all of the separate issues related to the reporting of diabetes is that proxy respondents are likely to under-report on all of the issues involved.

To date there have been few data collections that are nationally representative, have sufficient numbers from priority populations, use nationally agreed instruments, undertake routine validation of self reports or include biological measurements. CATI surveys could be used to address the majority of these deficiencies, although biomedical surveys would be necessary to investigate the extent of the undiagnosed problem and other aspects of risk factors for diabetes and its complications.

5.1 Measuring current diabetes prevalence

The self reported measurement of diabetes is a major concern with AusDiab estimating that only half of those with diabetes (diagnosed from clinically assessed measures) reported that they had diabetes (Dunstan et al 2001). In addition, with the exclusion of persons in institutional settings from most population health surveys there is also concern that there may also lead to an under-estimation of the prevalence of diabetes.

A number of frequently asked questions are interpreted differently across cultural groups and between different age cohorts. For some groups diabetes can be known under different terms such as “sugar diabetes”, “a touch of sugar” or “high sugar”.

5.2 Type and age of onset of diabetes

As documented earlier there are three types of diabetes - Type 1, Type 2 and gestational diabetes. Additional questions related to the onset of diabetes are required to clarify the type of diabetes. In particular, for gestational diabetes women are asked whether or not they were pregnant when they were first diagnosed with diabetes.

For a large proportion of individuals that have been diagnosed with Type 1 diabetes, answering questions concerning their disease are often straightforward. Type 1 diabetes affects the life of the individual considerably; unlike Type 2 diabetic patients who often have less pronounced symptoms and have an easier treatment. For these individuals the risk of misunderstanding or answering questions concerning diabetes incorrectly is increased.

Accurate recollection of the onset of diabetes is related to the reliability of a respondent's ability to recall the time (and their age) when a health professional first advised them that they have diabetes. There is concern over the ability to recall the time and the subsequent estimation of respondent's age.

5.3 Diabetes treatment and management

People with diabetes have varying degrees of knowledge about what they need to do to achieve better health outcomes (Parsons et al 2000). The treatment and management of the three different types of diabetes differ substantially and non-compliance to treatment plans

Diabetes in Australia

is not adequately understood. In addition, a number of diabetic patients whose condition is managed by diet often believe that they no longer have the disease.

The inter-relationship of different issues related to an individual with diabetes provides a number of measurement complications. For example, physical problems related to diabetes can hamper appropriate physical activity levels for the successful management of diabetes.

5.4 Measuring related conditions

Cardiovascular disease, renal disease, eye diseases/conditions and foot problems have been identified earlier as examples of conditions associated with diabetes. The incorporation of questions on related conditions, such as these, indicates that there is a need for comprehensive questionnaires to adequately cover these conditions. With interview time in population health surveys at a premium, the capacity to include an extensive set of questions on related conditions becomes an important factor, especially when the survey is not just centred on diabetes.

5.5 At risk of getting diabetes

In light of the associated risk factors documented earlier, conjoint information on physical activity or obesity, diet, alcohol consumption, smoking and access to care is required. In addition, Parsons et al (2000) reported that family history of diabetes is an additional risk factor for developing Type 2 diabetes. Specific measurement issues related to this information, particularly for CATI population health surveys, are associated with difficulty in self reporting height and weight and bias in reporting smoking behaviour. However, with risk factors common for a number of diseases there is a need to resolve these reporting issues.

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Diabetes in Australia

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