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# **Diabetes prevalence in Australia**

## **An assessment of national data sources**

**October 2009**

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# Abbreviations

ABS	Australian Bureau of Statistics
AIHW	Australian Institute of Health and Welfare
AusDiab	Australian Diabetes, Obesity and Lifestyle Study
BMI	body mass index
CD	collector district
GDM	gestational diabetes mellitus
GP	general practitioner
MBS	Medicare Benefits Schedule
NCMD	National Centre for Monitoring Diabetes
NDDWG	National Diabetes Data Working Group
NDR	National Diabetes Register
NDSS	National Diabetes Services Scheme
NHS	National Health Survey
PBS	Pharmaceutical Benefits Scheme
RPBS	Repatriation Pharmaceutical Benefits Scheme

# Summary

Diabetes is known to cause substantial illness and death in Australia. Knowing how many Australians are affected by diabetes informs decision makers who plan and allocate resources for health services. The continuing availability of time series data on the prevalence of diabetes in Australia is particularly important for planning and for disease monitoring.

There are several sources of diabetes prevalence data, each providing a different estimate of the number of cases of diabetes in Australia. Given this, the National Centre for Monitoring Diabetes has assessed data sources that provide national estimates of diagnosed diabetes prevalence. These are based on cases where a diagnosis of diabetes has been certified by a doctor, nurse or credentialed diabetes educator, or where an individual has reported having been told by a doctor or nurse that they have diabetes.

## Scope

The national centre identified five national data sources that could be used to assess diagnosed diabetes prevalence: the Australian Diabetes and Obesity Lifestyle Study (AusDiab), the National Diabetes Services Scheme (NDSS) database, the National Health Survey (NHS), the Medicare Benefits Schedule (MBS) database and the Pharmaceutical Benefits Scheme (PBS) database.

Three criteria were used to describe and compare the estimates of diagnosed diabetes prevalence derived from these data sources: how much of the diagnosed diabetes population is captured (coverage), how current the data are (currency) and how often new data are made available for the purpose of time series analysis and disease monitoring (frequency).

## Findings

- The NHS and NDSS data are the best available sources for monitoring diagnosed diabetes prevalence in Australia, yielding prevalence rates of 3.6% in 2004–05.
- Users of these estimates must be aware of coverage limitations in each of the preferred sources, the limitations of self-reported data in the NHS and the fact that estimates of diabetes subtypes have not been assessed.
- Linking the NDSS database, the MBS database and the PBS database would assist in finding further cases of diabetes not counted in the NDSS data.

# 1 Introduction

## Purpose of this study

Diabetes is known to cause substantial morbidity and mortality in Australia. Estimates of diabetes prevalence (the number of cases of the condition in the population at a given time) inform decision makers who plan and allocate funding for health services. The continuing availability of trend data on the prevalence of diabetes in Australia is important for disease monitoring and for planning. But there are several different estimates of the number of cases of diabetes in Australia.

Given this, the National Centre for Monitoring Diabetes (NCMD) identified a need to assess the various sources of data that provide national estimates of diabetes prevalence. The only way to estimate total diabetes prevalence (both diagnosed and undiagnosed cases) is through blood measurements in a representative survey. The prevalence of diagnosed diabetes can be determined through counts of people using diabetes specific services and medicines and self-reports of a diagnosis in response to a national population survey (Box 1.1).

This report aims to describe and evaluate estimates of diagnosed diabetes prevalence from national data sources and to recommend a preferred source based on three main criteria – the coverage of the diabetes population, currency of the data source, and frequency of updates to the data source.

More specifically, this report aims to answer three main questions.

1. What are the main strengths and limitations of each national source of diagnosed diabetes prevalence estimates?
2. What is the preferred national source of diagnosed diabetes prevalence estimates for monitoring diabetes in Australia?
3. How can estimates of diagnosed diabetes prevalence be improved?

### **Box 1.1: Terminology used in this report**

*In this report, we use the term 'diagnosed diabetes' to refer to cases of diabetes where a diagnosis has been certified by a doctor, nurse or credentialed diabetes educator or an individual self-reports having been told by a doctor or nurse that they have diabetes. The different classes of diagnosed diabetes are described later in this chapter.*

*The term 'total diabetes' includes cases of 'diagnosed diabetes' and cases where diabetes is newly identified in individuals who reported they had not previously been diagnosed with the condition.*

## Structure of this report

This report consists of four chapters: introduction, characteristics of available data sources, comparison of estimates from the selected data sources, and discussion and conclusions.

Chapter 1 provides a brief overview of the current status of diabetes in Australia and discusses the undertaking to estimate diabetes prevalence.

Chapter 2 provides an overview of the different data sources used in this study, a detailed description of each source and a summary analysis against the criteria of coverage, currency and frequency.

Chapter 3 presents a comparison of estimates of diagnosed diabetes prevalence among Australians of all ages, by age and sex and across two time periods (2001 and 2004–05) from two preferred data sources.

Chapter 4 discusses the findings of the report and outlines directions for future analyses.

## Diabetes in Australia

Diabetes mellitus (diabetes) is a serious chronic disease causing substantial morbidity, premature death, disability, reduced quality of life and financial cost. Diabetes is marked by high blood glucose levels resulting from defective insulin production, insulin action or both (WHO 1999). There are several types of diabetes, each with different causes and clinical patterns. The three main types of diabetes are Type 1, Type 2 and gestational diabetes.

International studies show that the prevalence of diabetes is rising globally. There are a number of reasons for this, including an increase in the rates of obesity and physical inactivity, as well as population ageing (IDF 2006; Wild et al. 2004). Other factors include better detection of diabetes and longer survival of affected individuals (Colagiuri et al. 2005). Australia follows this global trend.

Self-reported data show that 4% of Australians had a diagnosis of diabetes in 2007–08 and the proportion of reported cases has more than doubled since 1989–90. In Australia in 2003, diabetes and its complications were estimated to account for over 8% of the total disease burden. In 2005, diabetes was directly responsible for 3% of all deaths and contributed to a further 6% of deaths (AIHW 2008). It is known that some population groups are at higher risk of developing diabetes, namely Indigenous Australians, Australians born overseas, Australians living in rural and remote areas and Australians living in areas of lower socioeconomic status (AIHW 2008). But due to data constraints, the analyses presented in this report are based on the total Australian population only.

## Estimating diabetes prevalence

Regular estimates of diagnosed diabetes prevalence are important for planning and providing services for people with diabetes, identifying specific population groups at high risk, developing effective prevention strategies and monitoring the effectiveness of these strategies over time and examining the impact of diabetes on the health system (Robinson et al. 1997). Although it is clear that diabetes is a major problem for the health and wellbeing of many Australians, there are several different estimates of, and methods for estimating, the number of Australians affected.

The two main types of estimates available in Australia are total prevalence and diagnosed prevalence.

## **Total diabetes prevalence**

Total diabetes prevalence includes both diagnosed and previously undiagnosed diabetes. Diagnosed diabetes includes cases where a diagnosis is certified by a doctor, nurse or credentialed diabetes educator or an individual self-reports having been told they have diabetes by a doctor or nurse. Previously undiagnosed diabetes includes cases where a diagnosis is made in an individual who has not reported a diagnosis.

Knowing total diabetes prevalence provides a count of the true number of Australians with the condition and, therefore, the number of Australians likely to require services for diabetes and treatment for diabetes complications in the future.

An estimate of total prevalence in the population is often difficult to obtain. In many cases diabetes has no obvious symptoms and can go undiagnosed, and therefore untreated, for a long time. Diabetes is diagnosed on the basis of a person's blood glucose level under certain conditions. The best estimate of total diabetes prevalence would come from a representative sample of the Australian population who were tested in this way. A survey of this nature is expensive and logistically difficult, and it has been some time since one was conducted in Australia.

The most recent measured data collected at a national level came from the 1999–2000 Australian Diabetes, Obesity and Lifestyle Study (AusDiab), now 10 years old. The AusDiab study estimated that for each case of known diabetes (diagnosed diabetes) there was a case where diabetes was found in a participant who had not indicated that they had been previously diagnosed with the condition (undiagnosed diabetes). Since this study, this 1:1 ratio has been applied to other sources of diabetes data in order to derive current total diabetes prevalence in Australia. This may now produce inaccurate estimates because it is not known if the proportion of people with undiagnosed diabetes is still the same as it was in 1999–2000. It may be that the number of undiagnosed cases has decreased over time in line with increased awareness of diabetes and its risk factors in the community and with the implementation of incentive programs for medical practitioners to monitor people at high risk of diabetes.

A national measurement survey is being developed and will provide new estimates of total diabetes prevalence in the Australian population.

## **Diagnosed diabetes prevalence**

Knowing the prevalence of diagnosed diabetes in the Australian population is important for planning the funding and delivery of diabetes-specific health services, to ensure that demand for services are met.

In contrast to measuring total prevalence, estimating the prevalence of diagnosed diabetes is a logistically easier task and there are a number of national data sources that are used for this purpose. These include administrative data sources such as the National Diabetes Services Scheme (NDSS) database, the Medicare Benefits Schedule (MBS) database and the Pharmaceutical Benefits Scheme (PBS) database as well as national population surveys such as the AusDiab study and the National Health Survey (NHS).

Each source of diagnosed diabetes prevalence is different in its collection methodology and the means by which a diagnosis of diabetes is determined. In summary, there are four types of diagnosis and these are described below.

***Self-reported:*** A diagnosis based on an individual's response to a question on whether they recall having been told they had diabetes by a doctor or nurse. The NHS is a population-based survey that asks respondents to self-report a diagnosis of diabetes.

***Measured:*** A diagnosis made on the result of a blood test performed during population screening or a survey. The AusDiab study is a population-based study that took blood samples from consenting participants to confirm a diagnosis of diabetes.

***Certified:*** A diagnosis made by a doctor and attested to by a doctor, registered nurse or diabetes educator. The NDSS requires certification of a diagnosis of diabetes before an individual can register for its services and benefits.

***Implied:*** A proxy diagnosis made on the basis of an individual accessing diabetes-specific services, medicines, pathology tests and doctors' services. Diabetes status can be implied from the MBS and PBS data.

In this report we compare the national data sources in relation to their estimates of the prevalence of diagnosed diabetes. These estimates exclude cases of gestational diabetes as it is not meaningful to estimate the prevalence of this condition due to its transient nature. Due to limitations in data availability and quality, analyses by diabetes subtypes (Type 1 and Type 2) are not presented in this report.

## 2 Characteristics of available data sources

This chapter provides background information on each data source analysed in this report. Table 2.1 gives a brief overview of the data sources. A more detailed description is provided in the following section.

The data sources assessed in this report to estimate diagnosed diabetes prevalence are:

- Australian Diabetes, Obesity and Lifestyle Study (AusDiab)
- National Health Surveys (NHSs)
- National Diabetes Services Scheme (NDSS) administrative database
- Medicare Benefits Schedule (MBS) administrative database
- Pharmaceutical Benefits Scheme (PBS) administrative database.

**Table 2.1: Overview of data sources and their characteristics**

Data source	Collection method	Scope and coverage and diagnosis type	Years of interest (diagnosed prevalence estimates)
Australian Diabetes, Obesity and Lifestyle Study baseline component	Population-based survey	<ul style="list-style-type: none"> <li>• Diagnosed and undiagnosed cases</li> <li>• Age <math>\geq</math> 25 years</li> <li>• Self-reported and measured</li> </ul>	<ul style="list-style-type: none"> <li>• 1999–2000 (3.7%, measured)</li> <li>• 1999–2000 (4.2%, self-reported)</li> </ul>
National Health Surveys	Population-based surveys	<ul style="list-style-type: none"> <li>• Diagnosed cases only</li> <li>• People living in private dwellings but excludes very remote population</li> <li>• All ages</li> <li>• Self-reported</li> </ul>	<ul style="list-style-type: none"> <li>• 2001 (3.3%)</li> <li>• 2004–05 (3.6%)</li> </ul>
National Diabetes Services Scheme	Administrative data	<ul style="list-style-type: none"> <li>• Diagnosed cases only</li> <li>• People registered with the scheme, to access subsidised diabetes management products and services</li> <li>• All ages</li> <li>• Certified</li> </ul>	<ul style="list-style-type: none"> <li>• 2000 (4.3%)</li> <li>• 2001 (3.1%)</li> <li>• 2004–05 (3.6%)</li> </ul>
Medicare Benefits Schedule	Administrative data	<ul style="list-style-type: none"> <li>• Diabetes-related medical services for which an eligible claim has been processed</li> <li>• People who had a GP annual cycle of care for diabetes and/or received a Medicare rebate for a pathology test for HbA1c or fructosamine</li> <li>• All ages</li> <li>• Implied</li> </ul>	<ul style="list-style-type: none"> <li>• 2004–05 (3.0%)</li> </ul>
Pharmaceutical Benefits Scheme	Administrative data	<ul style="list-style-type: none"> <li>• Diabetes-related pharmaceuticals for which an eligible claim has been processed</li> <li>• People who have filled a prescription for subsidised diabetes medicines or blood glucose testing strips</li> <li>• All ages</li> <li>• Implied</li> </ul>	<ul style="list-style-type: none"> <li>• 2004–05 (3.0%)</li> </ul>

# The Australian Diabetes, Obesity and Lifestyle Study

## Currency and frequency of estimates

The Australian Diabetes, Obesity and Lifestyle Study (AusDiab) was conducted by the International Diabetes Institute (now BakerIDI Heart and Diabetes Institute) from May 1999 to December 2000. The study was designed to provide national estimates of the prevalence of diagnosed (known) and undiagnosed (newly diagnosed) diabetes using a diagnostic blood test in adults aged 25 years and over. It also provided measurements of blood pressure, blood lipids, blood glucose, body fat, height and weight and waist and hip circumference. As well as self-reported information on presence of cardiovascular disease, blood pressure lowering and lipid-lowering medicine use, diet, smoking, alcohol consumption, physical activity, and general health and wellbeing. The study is the most recent national source of measured biomedical data on diabetes status currently available.

Estimates of diagnosed diabetes prevalence from the AusDiab study are weighted to the 1998 resident population.

In 1999–2000, the estimate of measured diabetes prevalence was 3.7% and the estimate of self-reported diabetes prevalence was 4.2% of the Australian population aged 25 years and over.

A smaller follow-up survey was conducted in 2005.

## Coverage of the diabetes population

Using a stratified cluster sampling method, the study selected adults aged 25 years and over residing in 28,033 private dwellings from all Australian states and territories except the Australian Capital Territory. Clusters were based on the Australian Bureau of Statistics (ABS) census collection districts (CDs) which are geographical units each containing approximately 225 dwellings. CDs were then randomly sampled. However, before sampling, some exclusions were made due to financial and logistic constraints of the project and to ensure that over-representation of known high prevalence groups did not occur. Some initially sampled CDs were replaced for various, mostly logistical, reasons (Dunstan et al. 2001).

Of the 28,033 households selected, contact was achieved with 19,214 and 17,129 of these households were considered eligible. Sixty-seven per cent (11,479) of these eligible households participated in the interview, resulting in 20,257 individuals completing the interview. Fifty-five per cent (11,247) of individuals who completed the interview also attended the biomedical examination. When the households that were unable to be contacted are taken into account, the response rate was 37% (Dunstan et al. 2002).

As the response rate declined at various stages of sample selection, the final sample at physical examination that was weighted to the total Australian population may not have been representative enough of the population at some ages and therefore bias may have been introduced. In particular, males aged 25–34 years and 35–44 years and females aged 25–34 years were under-represented in the sample, while in other age groups both males and females were over-represented.

The study (based on measured diagnosis data) yielded two diabetes groups: those with diagnosed diabetes (known) and those with previously undiagnosed (newly diagnosed) diabetes. These two groups were determined using the blood glucose concentration classifications outlined in *Diagnosis and classification of diabetes mellitus* (WHO 1999).

People with diagnosed diabetes included all those on diabetes treatment in the form of insulin or tablets (or both) at the time of the study and those who had ever been told by a doctor or nurse that they had diabetes and had fasting blood glucose or 2-hour post load glucose values over the threshold for diabetes.

People with undiagnosed diabetes were classified as those who were not taking medicines for the treatment of diabetes at the time of the study and had not previously been told by a doctor or nurse that they had diabetes, and had fasting blood glucose or 2-hour post load glucose values over the threshold for diabetes (Dunstan et al. 2001).

Total diabetes prevalence can be determined from the AusDiab data by summing those respondents in the diagnosed diabetes group and those in the undiagnosed diabetes group.

The self-reported component of the algorithm for determining those respondents with diagnosed diabetes may not be a reliable measure of diabetes prevalence and may result in an over or under-count of diabetes. An over-count may result from respondents confusing the name of the disease or recalling a doctor or nurse had mentioned the possibility of the disease without making a definitive diagnosis. It was estimated that nearly 9% of survey respondents who self-reported they had been told by a doctor or nurse that they had diabetes, did not have blood glucose levels in the diabetes range. Heightened community awareness of some conditions like diabetes may also inflate self-reports of the condition.

Conversely, an under-count may occur where a condition, like diabetes, has few or no symptoms in the early stages and requires minimal treatment and, although a diagnosis may have been made, an individual does not recall or does not report this diagnosis when surveyed. Such cases would contribute to the 'newly diagnosed' component of the prevalence of total diabetes derived from the AusDiab study.

The asymptomatic nature of early diabetes can also mean a respondent may be unaware that they have the condition, has never sought medical attention and has never been diagnosed, as was shown in the many cases of newly identified diabetes in the AusDiab study.

Women who reported they were pregnant did not undergo the biomedical test.

Consequently, cases of gestational diabetes mellitus (GDM) are not included in the AusDiab estimates of diagnosed diabetes prevalence.

The questions and methods used to identify people with diabetes are outlined in Box 2.1.

**Box 2.1: Survey questions and methods used to derive the diabetes population from the 1999–2000 AusDiab study**

***Self-reported diagnosed diabetes status***

*Have you ever been told by a doctor or nurse that you have diabetes?*

- Yes
- No

*What treatment (for diabetes) are you currently receiving?*

- Diet only
- Insulin
- Tablets
- Insulin and tablets
- Other

***Plasma diabetes status (measured)***

*Known diabetes mellitus (diagnosed) – Self-reported diabetes status response is ‘Yes’ and currently receiving treatment for diabetes and either fasting or post load glucose values are in the diabetic range.*

*New diabetes mellitus (undiagnosed) – Self-reported diabetes status response is ‘No’ and either fasting or post load glucose values are in the diabetic range.*

*Source: BakerIDI 2008.*

## **National Health Survey**

### **Currency and frequency of estimates**

The National Health Survey (NHS) is conducted periodically by the Australian Bureau of Statistics (ABS) with surveys in 1977–78, 1983 (known then as Australian Health Survey), 1989–90, 1995, 2001, 2004–05 and 2007–08. The next survey will be conducted in 2010–11.

The NHS is designed to obtain national benchmarks and provide trend data on a wide variety of health issues including health status, health service use and lifestyle behaviours that affect an individual’s health.

The estimates of diagnosed diabetes prevalence are based on self-reported information and weighted to the December 2004 non-remote, private resident population.

In 2004–05, the estimate of self-reported diabetes was 3.6% of the Australian population.

The most recent survey was conducted in 2007–08 with detailed data expected to be available in late 2009. Summary results released recently show a self-reported diabetes prevalence of 4.0% in 2007–08 (ABS 2009).

### **Coverage of diabetes population**

The ABS uses a multistage area sampling method to randomly select residences. One adult aged 18 years and older is selected from each residence to be interviewed for the survey. One

child, where applicable, is also interviewed in each household either via an adult proxy or themselves, with parental consent, if the child is aged 15–17 years.

The NHS is a survey of persons residing in private dwellings in Australia, both urban and rural, in all states and territories. Persons who resided in other dwellings at the time of survey, such as hotels, motels, hospitals, nursing homes and persons who did not normally reside in Australia are excluded.

In this report the two most recent National Health Surveys with full available data, 2001 and 2004–05, are used. In 2001, the ABS had full responses from 92% of eligible households that led to a sample size of 26,863 persons. In 2004–05, the ABS had complete responses from 90% of eligible households, resulting in a sample size of 25,906 persons.

The NHS estimates of prevalence may have a level of inaccuracy because they are based on self-reports of a diagnosis of diabetes. The limitations of self-reported data and how they affect estimates of diagnosed diabetes prevalence were mentioned previously.

As the 2001 and 2004–05 surveys used similar methodologies, most data items are considered directly comparable between surveys, within the general limits of comparability resulting from small changes in the questions about diabetes.

Only those respondents who reported diabetes as a long-term condition are included in the numerator population. Due to the high levels of error associated with estimates of Type 1 diabetes, analyses by diabetes subtype have not been included in this report.

The questions used to identify the diagnosed diabetes population are outlined in Box 2.2.

**Box 2.2: Survey questions used to derive the diabetes population from the 2001 and 2004–05 NHS**

**NHS 2001**

*Have you ever been told by a doctor or nurse that you have:*

- *Diabetes?*
- *High sugar levels in your blood or urine?*

*What type of diabetes were you told you have?*

- *Type 1 (insulin dependent diabetes mellitus/juvenile onset diabetes)*
- *Type 2 (non-insulin dependent diabetes mellitus/adult onset diabetes)*
- *Gestational (pregnancy)*
- *Diabetes insipidus*
- *Other (specify)*
- *Don't know*

*Do you currently have (diabetes/high sugar levels)?*

- *Yes*
- *No*
- *Don't know*

**NHS 2004–05**

*Have you ever been told by a doctor or nurse you have diabetes?*

- *Yes*
- *No*

*What type of diabetes were you told you have?*

- *Type I (insulin dependent diabetes mellitus/juvenile onset diabetes/Type A)*
- *Type II (non-insulin dependent diabetes mellitus/adult onset diabetes/Type B)*
- *Gestational (pregnancy)*
- *Diabetes insipidus*
- *Other*
- *Type unknown*

*Do you currently have diabetes?*

- *Yes*
- *No*
- *Don't know*

*Sources: ABS 2005, 2006.*

# National Diabetes Services Scheme database

## Currency and frequency of estimates

The National Diabetes Services Scheme (NDSS), established in 1987, is a subsidy scheme operated by Diabetes Australia Ltd for the Australian Government. The NDSS supplies blood and urine testing strips, syringes, needles and insulin pump consumables at subsidised prices to people with diabetes who register for its benefits. In order to register with the NDSS, an individual must receive certification of a diagnosis of diabetes from a doctor, nurse or credentialed diabetes educator. As an administrative database, the NDSS data are updated continuously. The AIHW receives quarterly updates and can produce annual (calendar and financial year) reports of diabetes prevalence from 1987 onwards.

For calculating rates of people with diabetes, the appropriate 30 June population was used as the denominator for calendar year estimates and the 31 December population was used as the denominator for financial year estimates.

In 2004–05, 3.6% of the Australian resident population (at 31 December 2004) was registered with the NDSS and had a certified diagnosis of diabetes.

Estimates of certified diabetes prevalence are also available for 2005–06, 2006–07 and 2007–08.

## Coverage of the diabetes population

The number of registrants on the NDSS can be counted to estimate diabetes prevalence. However, registration is voluntary and therefore, it is likely that a proportion of people with diagnosed diabetes are not registered with the Scheme. Diabetes Australia estimates that the NDSS covers 80%–90% of people with diagnosed diabetes (Diabetes Australia 2008b). In addition, some people with diabetes may not know of the existence of the NDSS or the benefits of joining. Others may manage their diabetes primarily by regulating their diet and increasing their level of physical activity and therefore not have a high level of need for the Scheme's services. Diabetes management products may also be purchased through the PBS. When these products are purchased through the NDSS, they do not count towards the PBS safety net. This fact may contribute to non-registration, as people may choose to purchase through the PBS instead in order to reach the safety net earlier and receive a higher level of subsidy for other pharmaceuticals. Although purchasing through the NDSS will not contribute to the safety net, once the PBS threshold has been reached NDSS registrants can use the resulting concessions to access NDSS products at a greatly reduced cost. For current prices of NDSS and PBS diabetes management products, see Table A1 and Table A2.

It is possible for an individual to register with the NDSS more than once – either in a different state, through a different doctor or when their insulin requirement changes. While every effort was made to remove duplicates from the data set, it is possible that the existence of duplicate records in the NDSS leads to an overestimate of the number of people with diagnosed diabetes in Australia.

An estimate of the extent of duplicate records in the NDSS data set can be derived from the National Diabetes Register (NDR). The NDR includes people with diabetes who began insulin treatment on or after 1 January 1999. The NDR is created, in part, from the NDSS database. Twenty-three per cent of the 571,000 records on the June 2008 NDSS data set were

in scope for the NDR and just over 391 (0.3%) of these records were duplicates. While this represents only a subset of the NDSS, it provides an approximation of the proportion of duplicate records entering the NDSS and the extent to which this contributes to an over-count of people with diagnosed diabetes in this data set.

Counts of the number of people on the NDSS database are used to estimate diagnosed diabetes prevalence. All registrants known to have died were removed from the analysis. The NDSS database has a death flag variable but does not record date of death. Among records with a death flag, the date when the record was last modified has been used as a proxy for the date of death. The date of last modification variable was introduced to the NDSS in late 2002. As a result, deaths that occurred before this cannot be differentiated by year and have all been removed from the analysis. A potential consequence of this is that more than the true number of deaths occurring among NDSS registrants up to and including the years 2000 and 2001 will be counted and removed from the prevalence estimates for these years, resulting in an underestimate. It is also possible that in subsequent years there may be some deaths that are not recorded on the NDSS.

Registrants with a diagnosis of gestational diabetes mellitus have been removed from the prevalence estimate.

While diabetes type is recorded on the NDSS registration form, changes in terminology affect the accuracy of diagnosis of type over time. For this reason, analyses by type of diabetes have not been included in this report.

## **Medicare Benefits Schedule database**

### **Currency and frequency of estimates**

The Medicare Benefits Schedule (MBS) covers medical services and tests subsidised by the Australian Government. Included are services for the ongoing management of diabetes such as pathology tests and general practitioner (GP) 'annual cycles of care' recommended for diabetes. Only services billed to Medicare Australia are recorded on a central database. MBS records have a unique patient identifier that can be used to track information on individual patients over time, giving a long-term picture of their medical management. This type of analysis is outside the scope of this project. However, people receiving MBS services specific to diabetes can be counted to estimate diabetes prevalence. As an administrative database the MBS is updated regularly. Comparable data on services for diabetes are available from 2001 onwards, by both calendar and financial year.

In 2004–05, the prevalence of implied diabetes was 3.0% of the Australian resident population (at 31 December 2004) based on the 'probable' and 'possible' MBS cohorts (see below).

Data are also available to calculate diabetes prevalence for 2005–06, 2006–07 and 2007–08.

### **Coverage of the diabetes population**

Clinical guidelines for the management of diabetes recommend performing an HbA1c test or fructosamine test at least once a year for ongoing diabetes management (DA & RACGP 2008) (see Box 2.3 for an explanation of these tests).

### **Box 2.3: Description of pathology tests used to monitor diabetes and explanation of the diabetes annual cycle of care**

*Both fructosamine and HbA1c tests are used as monitoring tools to help people with diabetes control their blood sugar (glucose). HbA1c is the more widely accepted test and forms part of the diabetes annual cycle of care.*

#### ***What is an HbA1c test?***

*As glucose circulates in the blood, some of it spontaneously binds to haemoglobin, the protein that carries oxygen in red blood cells. This combination is called glycated haemoglobin A1c (HbA1c) (also called glycosylated haemoglobin). The amount of HbA1c formed is directly related to the amount of glucose in the blood. If diabetes is not well controlled, blood glucose levels are high, causing higher HbA1c levels. HbA1c levels do not change quickly since red blood cells live for 3–4 months. Because of this, the amount of HbA1c in blood reflects the average amount of glucose in blood during the last few months. HbA1c is a measure of blood glucose control in patients with diabetes and gives a relatively good indication of how strict blood sugar control has been over the 3 months before the test.*

#### ***What is a fructosamine test?***

*Fructosamine test is a blood test that can detect overall changes in blood glucose control over a shorter time-span than the HbA1c test and may be useful in situations where the HbA1c cannot be reliably measured. Instances where fructosamine may be a better choice than HbA1c include: rapid changes in diabetes treatment; diabetes in pregnancy; red blood cell loss or abnormalities.*

*Since the range of fructosamine concentrations in people with well-controlled diabetes may overlap with that of people who do not have diabetes, the fructosamine test is not useful as a screen for diabetes.*

#### ***The diabetes annual cycle of care***

*The key elements to this annual cycle of care are:*

- Assess diabetes control by measuring HbA1c – at least once every year*
- Ensure that a comprehensive eye examination is carried out – at least once every 2 years*
- Measure weight and height and calculate BMI – at least twice every cycle of care*
- Measure blood pressure – at least twice every cycle of care*
- Examine feet – at least twice every cycle of care*
- Measure total cholesterol, triglycerides and HDL cholesterol – at least once every year*
- Test for microalbuminuria – at least once every year*
- Provide self-care education – patient education regarding diabetes management*
- Review diet – reinforce information about appropriate dietary choices*
- Review levels of physical activity – reinforce information about appropriate levels of physical activity*
- Check smoking status – encourage cessation of smoking (if relevant)*
- Review of medicines – medicine review.*

*Sources: DA & RACGP 2008; DoHA 2007.*

Two cohorts were established from the MBS data for 2004–05 (see Box 2.4 for the algorithm used to create the cohorts):

- The ‘probable diabetes cohort’ includes patients who had an annual cycle of care and/or had at least two HbA1c or fructosamine tests in 2004–05 or one such test in 2004–05 and another test in 2003–04 or 2005–06.
- The ‘possible diabetes cohort’ includes patients who did not have an annual cycle of care in 2004–05, had only one HbA1c or fructosamine pathology test in 2004–05 and did not have such a test in either 2003–04 or 2005–06.

These latter patients do not fit into the algorithm derived from the diabetes management guidelines and therefore there is some doubt about whether or not they have been diagnosed diabetes. It is possible that an isolated HbA1c test across a 3-year period indicates use of the test for the screening or diagnosis of diabetes. The result of such a screening test is not recorded on the MBS database. Therefore, this cohort may comprise mostly people without diabetes.

However, there are other factors that can explain why some patients with diagnosed diabetes may only have one test recorded on the MBS in a 3-year period:

- The ‘coning’ process (see page 15) may result in some tests for an individual not being recorded on the database at all.
- Patients who have changed from being a general patient to being covered by the Department of Veterans’ Affairs National Treatment Account, as well as those public patients treated (and tested) by doctors in public hospitals, outpatient clinics or emergency departments may only have one test captured by the MBS during the 3-year period.

#### **Box 2.4: Method and rules for identifying people with diabetes from MBS records**

##### ***Rules for probable diabetes cohort***

*Count the number of people who have had a ‘diabetes annual cycle of care’ (MBS items 2517, 2518, 2521, 2522, 2525, 2526, 2620, 2622, 2624, 2631, 2633, 2635) in 2004–05*

*and/or have had:*

*at least one HbA1c test (MBS items 66551, 66554) or fructosamine test (MBS item 66557) in 2004–05 and, have had a second test in 2003–04, 2004–05 or 2005–06.*

*Three years’ patient claims data are needed to estimate the probable diabetes prevalence in 2004–05.*

##### ***Rules for possible diabetes cohort***

*Count the number of people who have had only one HbA1c test (MBS items 66551, 66554) or fructosamine test (MBS item 66557) in 2004–05 and have had no such test in 2003–04 or 2005–06 and;*

*have not had a ‘diabetes annual cycle of care’ (MBS items 2517, 2518, 2521, 2522, 2525, 2526, 2620, 2622, 2624, 2631, 2633, 2635) in 2004–05.*

*Three years’ patient claims data are needed to estimate the possible diabetes prevalence in 2004–05.*

The MBS estimate of diagnosed diabetes presented here includes both the ‘probable’ and ‘possible’ diabetes cohorts. While it is likely that a proportion of people in the ‘possible’ cohort do not have true diagnosed diabetes, excluding this cohort from the total could result

in an under-count of diabetes cases in this data set. As a result the combined cohort, representing the upper limit of the MBS estimate, has been used.

Those services that qualify for Medicare subsidy, performed by a registered provider, and for which a claim has been processed by Medicare Australia as at 30 June 2007, are included in the calculation of the MBS implied diabetes prevalence estimate (both 'probable' and 'possible'). Medicare data variables used include the patient's age and sex, date of service and patient anonymous identifier. MBS item numbers included are shown in Table 2.2.

**Table 2.2: MBS items used to count people receiving management for diabetes mellitus**

Measure <sup>(a)</sup>	MBS item number
Pathology test for HbA1c	66551, 66554
Pathology test for fructosamine	66557
General practitioner consultation involving completion of minimum requirements of an annual cycle of care for a patient with diabetes	2517, 2518, 2521, 2522, 2525, 2526, 2620, 2622, 2624, 2631, 2633, 2635

(a) More detail on these measures can be found in Box 2.2.

Source: DoHA 2007.

MBS data may not capture all people with diabetes. The MBS data do not capture: services that qualify for benefits under the Department of Veterans' Affairs National Treatment Account; or services provided in public hospitals to public patients, services provided in outpatient clinics, emergency departments or other publicly funded programs of public hospitals; or services provided by doctors who are not registered Medicare providers. Also, people who self-manage their diabetes without medical supervision will not be captured.

The MBS data can be limited by item 'coning', a process where the Health Insurance Pathology Services Table Regulations limit the entitlement to Medicare benefits for pathology services. Under the coning rule, where four or more MBS items of pathology testing services are ordered for a particular patient on the same day, the Medicare benefits will only be paid for the three items with the highest schedule fees. The effect of this is that the MBS pathology data include only those tests billed to the MBS after interpretation of the order by the pathologist and after selection of the three most expensive tests. This effect will not be random. For example, in an order of four tests to review the status of a patient with diabetes, it is likely that the HbA1c test will be the least expensive and will 'drop off' the billing process due to coning. This results in an underestimate of the number of HbA1c tests ordered by GPs (AIHW: Britt et al. 2005). Coning only applies to GP ordered pathology tests outside hospitals.

Anecdotal evidence suggests that in Australia, the HbA1c test is used increasingly as a screening tool to diagnose diabetes, and also in the assessment of cardiovascular risk in people without diabetes (NDDWG 2008). Research from the United States has shown that HbA1c increases the sensitivity of screening in high-risk patients (Perry et al. 2001). If the HbA1c test is being used in Australia for screening and assessment purposes, then it is possible the MBS estimate of diabetes prevalence includes people who do not have diagnosed diabetes.

It is also possible that the estimate may include some cases of gestational diabetes, as it is not possible to determine diabetes type from these data.

# Pharmaceutical Benefits Scheme database

## Currency and frequency of estimates

The Australian Government subsidises diabetes medicines and blood glucose testing strips under the Pharmaceutical Benefits Scheme (PBS). Patients using diabetes medicines and testing strips can be identified to estimate a proportion of diabetes prevalence. This will be an underestimate as not all people with diabetes require diabetes-specific medicines. Some people will get products they need (for example, blood glucose testing strips) from other sources such as the NDSS and some will not use these products. As an administrative database the PBS is updated regularly. Comparable data on medicines and products for diabetes management are available from 2002 onwards, by both calendar and financial year.

In 2004–05, the prevalence of implied diabetes was 3.0% of the Australian resident population (at 31 December 2004).

Data are also available to calculate diabetes prevalence for 2005–06, 2006–07 and 2007–08.

## Coverage of the diabetes population

The use of diabetes medicines and/or blood glucose testing strips for diabetes implies an individual is being treated for diabetes.

Medicines to treat diabetes and blood glucose indicator strips to monitor diabetes that were used to count people with diabetes accessing PBS services are shown in Table 2.3. People who accessed PBS services to obtain at least one of these items in each year were considered to have diabetes.

**Table 2.3: PBS items used to count patients receiving treatment for diabetes mellitus**

<b>Medicine class</b>	<b>PBS item number</b>
<b>Insulin</b>	
Fast acting insulin	8571D, 8435Y, 8084L, 8212F, 1713E, 1531N, 1762R
Intermediate acting insulin	1711C, 1533Q, 1761Q, 1718K
Combined fast & intermediate	8609D, 8390N, 1426C, 1425B, 8006J, 1763T, 2062M
Long acting insulin	1722P
<b>Oral hypoglycaemic agents</b>	
Metformin	2430X, 1801T, 8607B
Glibenclamide	2939Q
Gliclazide	8535F, 2449X
Glimepride	8450R, 8451T, 8533D, 8452W
Glipizide	2440K
Pioglitazone	8691K, 8692L, 8693M, 8694N, 8695P, 8696Q
Rosiglitazone	8687F, 8688G, 8689H, 8690J
Acarbose	8188Y, 8189B
<b>Blood glucose indicator strips</b>	
Disc electrode sensor	8176H
Electrode strips	2926B, 8522M, 8573F, 8608C, 2891E, 8557J, 8634K, 8723D, 8766J, 8749L
Reagent strips	2890D, 2914J, 2917M, 2919P, 8053W, 8190C, 8739Y, 8759B

Source: DoHA 2008.

The information held on the PBS database is restricted to subsidised prescriptions where the cost of a pharmaceutical item is greater than the patient contribution level and where a pharmacist required reimbursement and made a claim. Box 2.5 details the criteria applied to diabetes medicines for inclusion in the PBS. The statistics used in this report do not include medicines supplied by private prescriptions or medicines supplied under the Repatriation Pharmaceutical Benefits Scheme (RPBS) – a separate scheme run for veterans in Australia.

### **Box 2.5: Medicines for diabetes covered by the PBS**

*The Pharmaceutical Benefits Scheme (PBS) subsidises the cost of a wide range of prescription medications, providing Australians with access to necessary and cost-effective medicines at an affordable price.*

*Patients are grouped into two classes: general and concessional. As at 1 January 2009, general patients paid the first \$32.90 for each PBS prescription item. For concessional patients (people with low incomes and sickness beneficiaries who hold a Health Care Card), the payment was \$5.30 per prescription item. These copayments are increased on 1 January each year, generally in line with Consumer Price Index increases.*

*Individuals and families are protected from large overall expenses for PBS-listed medicines by safety nets. For the calendar year to 2009, once a general patient and/or immediate family had spent \$1,264.90, the patient copayment per item decreased to the concessional rate of \$5.30. For concessional patients, the \$5.30 copayment was not required once their expenditure on PBS items exceeded \$318.00.*

*Patients may pay more than the standard copayment where a PBS item is priced above the benchmark price for different brands of the same drug or the benchmark price for a particular therapeutic group of drugs. These additional payments do not count towards safety nets.*

*The PBS data only capture dispensed medicines that are subsidised by the scheme. All insulin preparations are subsidised and therefore are captured, however the rules vary for oral glucose-lowering medicines. Most older oral glucose-lowering medicines are priced below the patient copayment level and therefore only those scripts dispensed to concessional patients or to general patients who reach the safety net will be subsidised and consequently recorded on the PBS database. There are special conditions for subsidy of newer oral glucose-lowering medicines and therefore only those that meet the criteria will be subsidised and recorded on the database.*

*Source: DoHA 2009.*

A significant limitation of this data set is that not all diabetes is managed with medicines, and that other diabetes management products available through the PBS can also be sourced from the NDSS at a reduced cost (see Table A1, Table A2). Therefore the PBS database covers only a subset of patients with diagnosed diabetes. Additionally, it is possible that some PBS medicines prescribed for the treatment of diabetes are also used to treat other conditions, such as polycystic ovary syndrome, or to prevent diabetes developing in people at high risk (Slama 2003). As diagnostic information is not available on the PBS data set it is not possible to separate these cases from true cases of diagnosed diabetes.

There may be some incidental cases of gestational diabetes included in the PBS estimate, as this type of diabetes is managed with similar products to Type 2 diabetes and it is not possible to identify pregnancy status from these data.

## Chapter summary

This chapter described the advantages and limitations of each of the five sources of diagnosed diabetes data. An evaluation of these data sources against the key criteria of coverage, currency and frequency, are summarised in Table 2.4, below.

**Table 2.4: Summary of data source advantages and limitations, against three evaluation criteria**

Data source	Criterion	Advantages	Limitations
AusDiab study	Coverage	Measured diabetes status	Low response rate
	Currency	Most recent available data on total diabetes prevalence	10 years old (1999–2000)
	Frequency		One-off cross-sectional study
National Health Surveys	Coverage	Representative population survey	Self-reported diabetes status, excludes institutionalised population
	Currency	2004–05 available, 2007–08 anticipated release in late 2009	
	Frequency	3–5 year survey cycle, from 1977–78 to 2007–08	
National Diabetes Services Scheme	Coverage	Certified diabetes status	Dependent on service use, voluntary registration
	Currency	2007–08 available	
	Frequency	From 1987, by calendar and financial year	
Medicare Benefits Schedule	Coverage		Dependent on service use, implied diabetes status, subset of treated diabetes population, over-counting may occur
	Currency	2007–08 available	
	Frequency	From 2001, by calendar and financial year	
Pharmaceutical Benefits Scheme	Coverage		Dependent on service/medicines use, implied diabetes status, subset of treated diabetes population, over-counting may occur
	Currency	2007–08 available	
	Frequency	From 2001, by calendar and financial year	

While the AusDiab study provides the most recent estimate of total diabetes prevalence in Australia, this is outweighed by the limitations of a low response rate and restricted population (25 years and over), lack of currency and low frequency. And although the MBS and PBS are current and have good frequency, this is outweighed by the limitations of restricted coverage and lack of diagnosis information. Based on this evaluation, the AusDiab study, MBS and PBS data are not analysed further.

Of the remaining two data sources – the NHS and the NDSS – both provide reasonable coverage of the diabetes population, are current and have reasonable frequency. The

evaluation of these two data sources continues in Chapter 3 where analyses of these data are compared over two time periods (2001 and 2004–05), by age and sex.

### **3 Diagnosed diabetes prevalence: a comparison of the NHS and NDSS**

In Chapter 2, five sources of national data on diagnosed diabetes prevalence were described and evaluated against three criteria: coverage of the diabetes population, currency and frequency of available data. Three data sources, the AusDiab study, the MBS and PBS, had significant limitations in some or all of the criteria. The remaining two data sources, the NHS and the NDSS, fulfilled all the criteria to a reasonable standard and were found to be preferred sources of diagnosed diabetes prevalence estimates for routine monitoring in Australia.

In order to make an informed decision on the preferred source of diagnosed diabetes prevalence estimates for diabetes monitoring in Australia, the NHS and NDSS are compared in this chapter by overall diagnosed diabetes prevalence and by age and sex. Two time periods, 2001 and 2004–05, were chosen to enable comparison with the two most recent National Health Surveys with complete data available.

Only long-term cases of diabetes (that is, cases expected to last more than 6 months) have been included in the prevalence estimates. This excludes all known cases of gestational diabetes. As a result of the data limitations discussed in Chapter 2, analyses by diabetes subtypes are not presented.

#### **The preferred data sources**

The NHS is a self-reported population-based survey that is reliably representative of the Australian population who do not live in institutions or very remote areas. Data from self-reported surveys can introduce bias into the estimate of diagnosed diabetes prevalence. An estimation of self-reporting bias was made from the 1999–2000 AusDiab study, in which approximately 9% of participants who self-reported having diabetes were found not to have blood glucose levels in the diabetes range. Diabetes prevalence data are available from the 2001 and 2004–05 NHS.

The NDSS is an administrative database and provides counts of people known to have diabetes (through certification of diagnosis by a doctor or diabetes educator) who access NDSS services. While diagnosis is certified, and a self-reporting bias does not exist, the NDSS is based on voluntary registration and service use and it is estimated that 10%–15% of people with diabetes do not access diabetes services through the NDSS (Diabetes Australia 2008b). Diabetes prevalence data based on the NDSS data set from 2001 and 2004–05 are presented here for comparison with the survey data, and are available from 1987.

#### **Diagnosed diabetes prevalence, 2001**

##### **Overall**

The NHS estimated both a higher number and higher proportion of Australians with diagnosed diabetes in 2001, compared to the count of registrants on the NDSS database

(Table 3.1). In 2001, it was estimated from NHS self-reports that around 615,200 (3.3%) Australians had been told by a doctor or nurse that they had diabetes. In the same period, just over 607,000 (3.1%) Australians with a certified diagnosis of diabetes were registered with the NDSS. Males and females had similar rates in the NHS and males had a higher rate of diabetes compared to females in the NDSS.

**Table 3.1: Prevalence of diagnosed diabetes, NHS and NDSS, 2001**

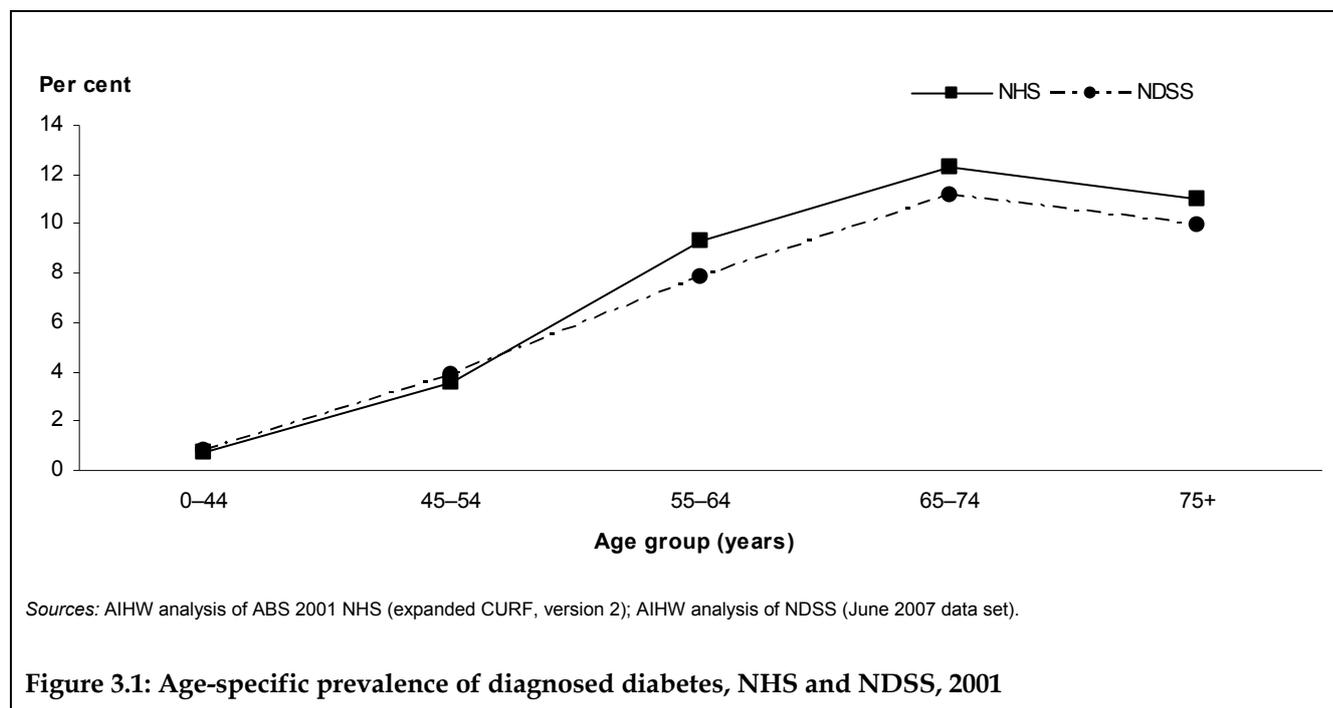
	People with diabetes	Population	Prevalence (per cent)		
			Males	Females	Persons
NHS <sup>(a)</sup>	615,202	18,915,642	3.2	3.3	3.3
NDSS <sup>(b)</sup>	607,242	19,413,240	3.3	3.0	3.1

(a) Prevalence estimate is based on the 2001 NHS population.

(b) Prevalence estimate is based on the 30 June 2001 Australian population.

Sources: AIHW analysis of ABS 2001 NHS (expanded CURF, version 2); AIHW analysis of NDSS (June 2007 data set).

In 2001, the age-distribution of diabetes among all people was similar in the NHS and NDSS—rising to age 65–74 years and declining at age 75 years and over (Figure 3.1, Table A3). The rates of diabetes were similar in both data sources among people aged 0–44 years and 45–54 years, and the NHS had higher rates of diabetes compared to the NDSS for all other age groups. The difference between age-specific rates in each data source ranged from 0.1 to 1.5 percentage points.



## By age and sex

In 2001, both the NHS and NDSS showed a general pattern of increasing prevalence with age for both males and females, followed by a decline among older females in the NHS and

NDSS and older males in the NDSS (Figure 3.2, Table A3). In general, both sources showed higher rates of diabetes among males compared to females.

In the 2001 NHS:

- The rate of diabetes generally increased with age for both males and females, though it declined among females aged 75 years and over.
- Males had higher rates of diabetes than females at ages 45–54 years, 55–64 years and 75 years and over.
- Females had a higher rate of diabetes at ages 65–74 years, and were similar to males at ages 0–44 years.

In the 2001 NDSS:

- The rate of diabetes increased to ages 65–74 years for both males and females and then declined among males and females aged 75 years and over.
- Males had higher rates of diabetes than females in all age groups, except at ages 0–44 years where the male and female rates were similar.

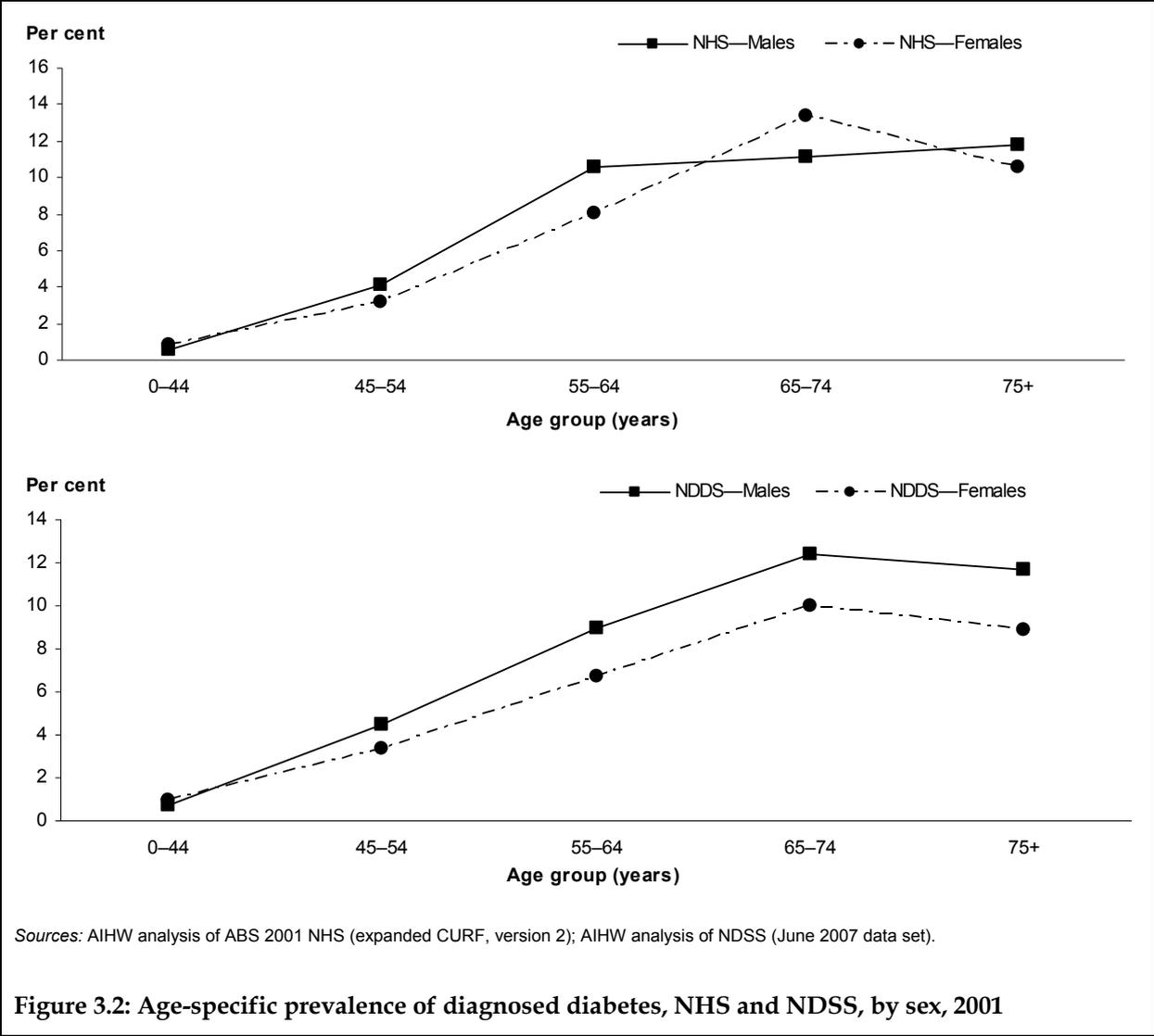


Figure 3.2: Age-specific prevalence of diagnosed diabetes, NHS and NDSS, by sex, 2001

# Diagnosed diabetes prevalence, 2004–05

## Overall

In 2004–05, the estimated proportion of Australians with diagnosed diabetes is the same from both the NHS and NDSS. The number of registrants on the NDSS in 2004–05 is higher than the estimate of Australians with diagnosed diabetes from the NHS (Table 3.2). In 2004–05, it was estimated from NHS self-reports that just over 700,000 (3.6%) Australians had been told by a doctor or nurse that they had diabetes. In the same period, just over 733,000 (3.6%) Australians with a certified diagnosis of diabetes were registered with the NDSS. Males had higher rates of diabetes than females in both data sources.

**Table 3.2: Prevalence of diagnosed diabetes, NHS and NDSS, 2004–05**

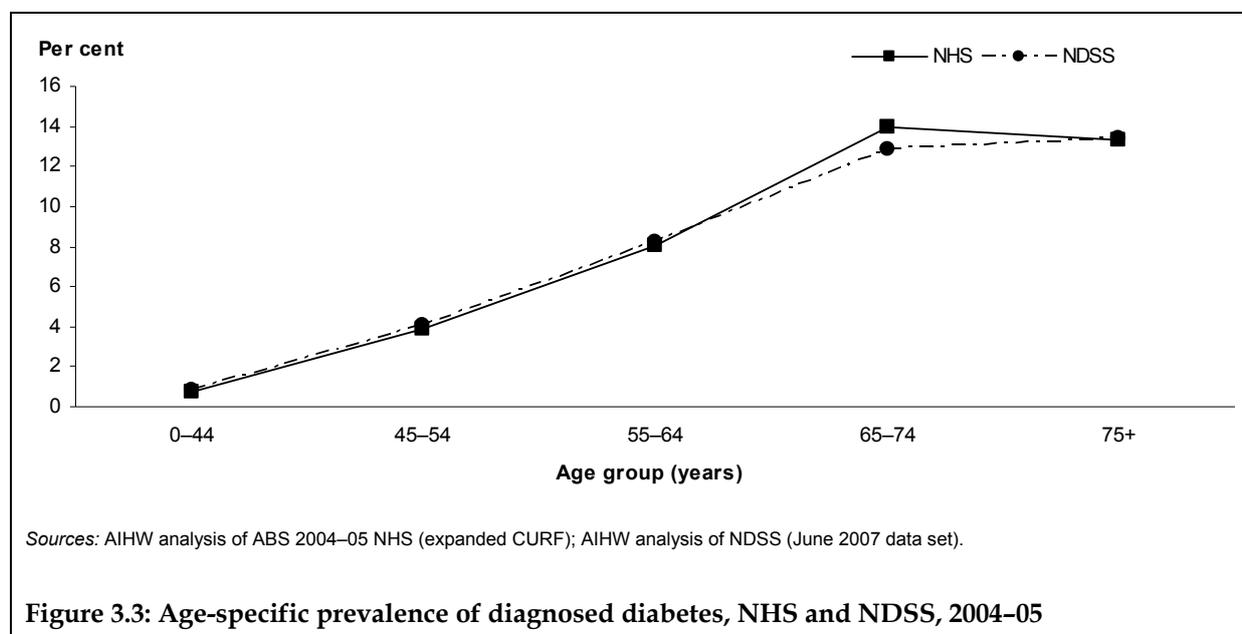
	People with diabetes	Population	Prevalence (per cent)		
			Males	Females	Persons
NHS <sup>(a)</sup>	700,183	19,681,538	4.0	3.2	3.6
NDSS <sup>(b)</sup>	733,345	20,252,132	3.8	3.4	3.6

(a) Estimate is based on the 2004–05 NHS population.

(b) Estimate is based on the 31 December 2004 estimated resident population.

Sources: AIHW analysis of ABS 2004–05 NHS (expanded CURF); AIHW analysis of NDSS (June 2007 data set).

In 2004–05, the age distribution of people with diabetes was very similar in the NHS and NDSS. While the rate of diagnosed diabetes was highest at age 75 years and over in the NDSS, there was a decline from the 65–74 year age-group in the NHS (Figure 3.3, Table A4).



**Figure 3.3: Age-specific prevalence of diagnosed diabetes, NHS and NDSS, 2004–05**

## By age and sex

In 2004–05, there is a pattern of increasing prevalence with increasing age in both the NHS and NDSS. Both sources show generally higher rates of diabetes among males compared with females aged 45 years and over (Figure 3.4, Table A4).

In the 2004–05 NHS:

- The rate of diabetes generally increased with age for both males and females, though it declined slightly for both sexes at age 75 years and over.
- Males had higher rates of diabetes than females at ages 45–54 years, 65–74 years and 75 years and over, and ranged from 0.8% (0–44 years) to 16.3% (65–74 years).
- The rate of diagnosed diabetes among females ranged from 0.7% (0–44 years) to 11.7% (65–74 years).

In the 2004–05 NDSS:

- The rate of diabetes increased with age among both males and females.
- Similar to 2001, males had higher rates of diabetes than females in all age groups, except 0–44 years (0.7% compared to 0.9%).

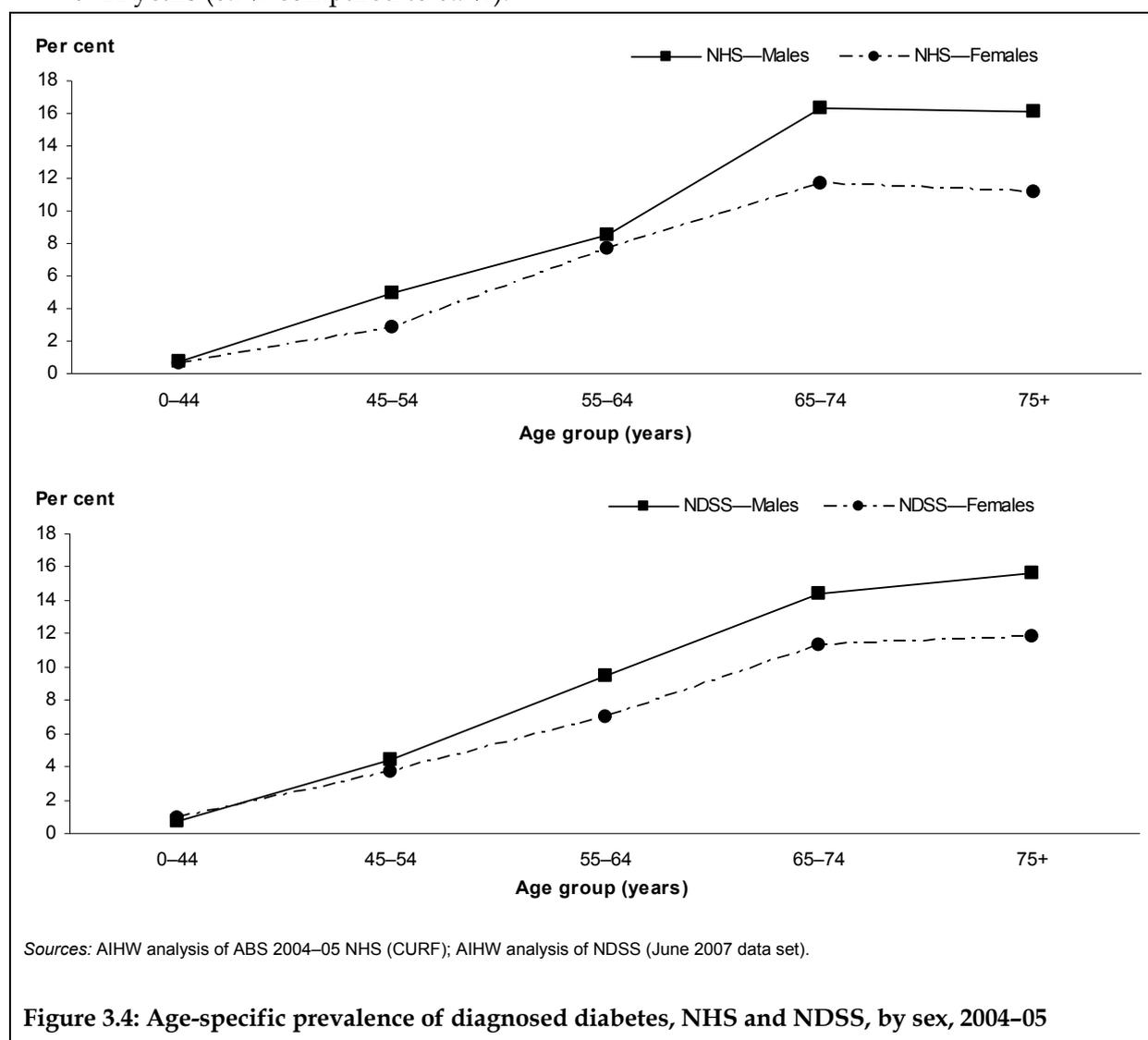


Figure 3.4: Age-specific prevalence of diagnosed diabetes, NHS and NDSS, by sex, 2004–05

## 4 Discussion

The most accurate estimate of the prevalence of total diabetes (diagnosed and undiagnosed) can only be obtained by taking a blood sample from the whole population or a representative sample of the population. This method identifies the undiagnosed population that is lacking in other methods. Other methods of collecting data on diabetes prevalence may incur errors such as recall bias, under-representation of patients, misunderstanding of questions by persons being surveyed, or be influenced by access to health services. Service data for diabetes can be incomplete for reasons such as self-management of diabetes and lack of availability of local services.

### What are the preferred sources of diagnosed diabetes prevalence data?

In this report we described and evaluated five national sources of diagnosed diabetes prevalence data in Australia: the 1999–2000 Australian Diabetes, Obesity and Lifestyle Study (AusDiab), the 2001 and 2004–05 National Health Surveys (NHSs), National Diabetes Services Scheme (NDSS), the Medicare Benefits Schedule (MBS) and the Pharmaceutical Benefits Scheme (PBS). In Chapter 2, the strengths and limitations of these data sources were evaluated against three criteria: accuracy of coverage, currency of data and frequency of new estimates.

Based on these criteria, three data sources (AusDiab, MBS, PBS) were excluded from further analysis in Chapter 3, for reasons summarised below:

- The AusDiab study gives the most recent national estimate of total diabetes prevalence (diagnosed and undiagnosed). However, caution must be used when comparing these data with other sources presented in this report, due to the low response rate to the study and the limited age range (25 years and over). These data are now quite dated, being almost 10 years old.
- The MBS and PBS databases capture a subset of people being managed or receiving treatment for diabetes and allow nationwide counts of individuals. The data are current (2007–08 data are available) and comparable time series analyses of diabetes specific services and medicines are possible from 2001 (MBS) and 2002 (PBS), for both calendar and financial years. However, these databases do not carry diagnostic information and rely on the availability and use of diabetes-related clinical care and medicines. The implied diagnosis is fraught with error as it may include people who have not been diagnosed with diabetes and are using medicines to treat other conditions, such as polycystic ovary syndrome, or who are accessing diabetes clinical services, such as HbA1c testing, because they are at high risk of the condition. In addition, changes to MBS items make time series analyses complex.

Based on the evaluation in Chapter 2, the NHS and the NDSS were found to have reasonable coverage, currency and frequency of diagnosed diabetes in Australia and, following further analysis in Chapter 3, both are assessed as being the preferred sources of diagnosed diabetes prevalence data in Australia.

In 2004–05 the estimated prevalence of diagnosed diabetes in Australia was 3.6% for both the NHS and the NDSS. When analysed by sex, the NHS showed 4.0% of males and 3.2% of females had diagnosed diabetes, while estimates from the NDSS showed 3.8% of males and 3.4% of females had diagnosed diabetes in 2004–05.

## **How can the preferred estimates of diagnosed diabetes prevalence be improved?**

The analysis in Chapter 3 shows that although the NHS and NDSS were evaluated as the preferred sources of diagnosed diabetes prevalence and provide the highest estimates of diagnosed diabetes in 2004–05, they do not capture all people with diabetes (total diabetes prevalence). Each data source assessed in this report has the potential to capture cases of diagnosed diabetes not covered by others, and some overlaps are also expected between these populations although the extent is unknown. However, the proportion of people who do not register for NDSS services, do not self-report their diagnosis in survey data and do not access medical care or medicines for the treatment of their diabetes is unknown. There is also a population of unknown size with undiagnosed diabetes. The limitations in coverage of the preferred data sources are summarised below:

- The NHS is a cross-sectional population survey. The estimate of self-reported diabetes does not rely on individuals accessing services for diabetes management and may therefore provide a measure of people who do not appear in the service-based MBS, PBS or NDSS data sets. In 2004–05 the NHS estimated 3.6% (700,183) of the Australian population in scope for the survey (all ages) had diagnosed diabetes. However, the survey methodology excludes people living in institutions and in very remote areas of Australia, and therefore excludes some populations at high risk for diabetes – the elderly and those living in very remote areas – from the prevalence estimate. In 2004–05, the NHS excluded 2.8% of the Australian population.
- The NDSS captures the population with diagnosed diabetes accessing subsidised products through the scheme. In 2004–05 this was 3.6% (733,345) of the total Australian population (all ages). There is an unknown population who do not register with the NDSS. While estimates suggest this is around 10%–15% of all people with diabetes, it is not currently possible to determine the exact number, given that the number of people registered with the NDSS exceeds the estimate of people with diabetes from all other data sources.

One way to establish a better measure of diagnosed diabetes prevalence in Australia would be to link the three service-based data sources examined here, the NDSS, the PBS and the MBS databases. These databases all record the Medicare number of the recipient of the service. This number could be used to link the databases at the unit (person) record level. Linking these data sources would help to estimate how many people with diabetes are not being captured by the NDSS, because they are using other medical services to manage their diabetes, and therefore enhance the estimate of diagnosed diabetes prevalence. However, there are issues with using Medicare numbers over time, as an individual may have more than one number in their lifetime as they move from their parents' card to their own and as they marry and divorce.

A nationally representative biomedical survey with blood samples taken would provide reliable measures of the prevalence of diabetes and would help validate the approach taken

in this report to determine the prevalence of diagnosed diabetes from existing data. In the absence of such a survey, data linkage between the NDSS, MBS and PBS data sets would assist in identifying the unknown 'non-registrant' population in the NDSS data set and contribute to a more complete enumeration of the diagnosed diabetes population in Australia.

## **Conclusion**

- Our analysis shows that the NHS and NDSS are preferred sources of data for deriving regular estimates of the prevalence of diagnosed diabetes in Australia.
- The NHS and NDSS provide estimates of diagnosed diabetes prevalence that have good (although incomplete) coverage of the diabetes population, are current and are updated frequently.
- In 2004-05, the prevalence of diagnosed diabetes among Australians was 3.6% according to self-reports from the NHS and the medically certified diabetes status of registrants on the NDSS database.

# Appendix: Supplementary tables

**Table A1: Cost of diabetes products available through National Diabetes Services Scheme (NDSS), at 2 April 2009**

Product (no. per pack)	Beneficiary				
	General	Health Care Card <sup>(a)</sup>	Pension <sup>(b)</sup> / DVA <sup>(c)</sup>	Safety net concession <sup>(d)</sup>	Safety net entitlement <sup>(e)</sup>
	<b>Price per pack</b>				
Blood test strips (50–100)	\$7.10–\$14.10	\$1.10–\$2.20	\$0.60–\$1.10	\$0.60–\$1.10	Free
Urine test strips (50)	\$3.60	\$0.60	\$0.30	\$0.30	Free
Diagnostic compound tablets (36)	\$2.60	\$0.40	\$0.20	\$0.20	Free
Syringes and needles (100)	Free	Free	Free	Free	Free
Insulin pump consumables (10–24)	\$13.90–\$33.40	\$13.90–\$33.40	\$13.90–\$33.40	\$13.90–\$33.40	\$13.90–\$33.40

(a) Includes Health Care Card holders: unemployed, New Start Allowance, Low Income, Disability Allowances.

(b) Includes Pensioner Concession Card holders: Full Pension, Commonwealth Seniors' Health Card.

(c) Includes all Department of Veteran Affairs (DVA) card holders.

(d) Includes those who have reached the general patient safety net threshold, currently \$1264.90 in a calendar year.

(e) Includes those who have reached the concessional safety net threshold, currently \$318.00 for patients with a concession card.

Source: Diabetes Australia 2008a.

**Table A2: Cost of diabetes products available through the Pharmaceutical Benefits Scheme (PBS), at 1 January 2009**

Product (no. per pack)	Beneficiary			
	General <sup>(a)</sup>	Concession card holder <sup>(b)</sup>	Safety net concession <sup>(b)</sup>	Safety net entitlement <sup>(c)</sup>
	<b>Price per pack</b>			
Blood test strips (50–100)	\$32.90	\$5.30	\$5.30	Free
Urine test strips (50)	\$21.69–\$24.21	\$5.30	\$5.30	Free
Diagnostic compound tablets (36)	\$32.90	\$5.30	\$5.30	Free
Syringes and needles		Not covered		
Insulin pump consumables		Not covered		

(a) General cost to consumers without concession cards, who have not reached the safety net threshold for PBS items.

(b) Cost to consumers on a concession card (Pensioner Concession Card, Commonwealth Senior Card, Repatriation Health Card For All Conditions (gold), Specific Conditions (white) and Repatriation Pharmaceutical Card (orange, concessional patients under RPBS) or those who have reached the general patient safety net threshold, currently \$1264.90 in a calendar year.

(c) Cost to consumers who have reached the concessional safety net threshold, currently \$318.00 for patients with a concession card (Pensioner Concession Card, Commonwealth Senior Card, Repatriation Health Card For All Conditions (gold), Specific Conditions (white) and Repatriation Pharmaceutical Card (orange, concessional patients under RPBS).

Source: DoHA 2009.

**Table A3: Age-specific prevalence of diagnosed diabetes, NHS and NDSS, 2001**

Age (years)	NHS			NDSS		
	Males	Females	Persons	Males	Females	Persons
	<b>Per cent</b>					
0–44	0.6	0.8	0.7	0.7	0.9	0.8
45–54	4.1	3.1	3.6	4.5	3.4	3.9
55–64	10.6	8.1	9.3	8.9	6.7	7.8
65–74	11.1	13.4	12.3	12.4	10.0	11.1
75+	11.8	10.5	11.0	11.7	8.9	10.0

Sources: AIHW analysis of ABS 2001 NHS (expanded CURF, version 2); AIHW analysis of NDSS (June 2007 data set).

**Table A4: Age-specific prevalence of diagnosed diabetes, NHS and NDSS, 2004–05**

Age (years)	NHS			NDSS		
	Males	Females	Persons	Males	Females	Persons
	<b>Per cent</b>					
0–44	0.8	0.7	0.7	0.7	0.9	0.8
45–54	4.9	2.9	3.9	4.5	3.7	4.1
55–64	8.5	7.6	8.1	9.5	7.0	8.2
65–74	16.3	11.7	13.9	14.4	11.3	12.8
75+	16.1	11.2	13.3	15.6	11.9	13.4

Sources: AIHW analysis of ABS 2004–05 NHS (expanded CURF); AIHW analysis of NDSS (June 2007 data set).

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