

Australian Government

Australian Institute of Health and Welfare



Deaths among people with diabetes in Australia

2009–2014





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Australian Institute of Health and Welfare Canberra Cat. no. CVD 79

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Abbreviations

| ABS | Australian Bureau of Statistics |
|--------|--|
| AIHW | Australian Institute of Health and Welfare |
| APEG | Australasian Paediatric Endocrine Group |
| CHD | coronary heart disease |
| COPD | chronic obstructive pulmonary disease |
| CVD | cardiovascular disease |
| DALY | disability-adjusted life years |
| ERP | estimated resident population |
| ICD | International Statistical Classification of Diseases and Related Health Problems |
| ICD-10 | International Statistical Classification of Diseases and Related Health Problems 10th Revision |
| IDDM | insulin-dependent diabetes mellitus |
| IRSD | Index of Relative Socio-economic Disadvantage |
| NDI | National Death Index |
| NDSS | National Diabetes Services Scheme |
| NIDDM | non-insulin-dependent diabetes mellitus |
| NMD | National Mortality Database |
| PBS | Pharmaceutical Benefits Scheme |
| PYLL | potential years of life lost |

Summary

Diabetes and its complications are major causes of illness, disability and death in Australia. People with diabetes are more likely to die prematurely than people without diabetes.

This report examines the 156,000 deaths that occurred between 2009 and 2014 among 1.3 million Australians with diagnosed type 1 and type 2 diabetes. Specifically, data from the National Diabetes Services Scheme and the National Death Index were combined to look at causes of death and death rates for people with diabetes compared with the general population. Creating a comprehensive picture of diabetes-related deaths is important for population-based prevention strategies and could help to improve care for all people with diabetes.

Death rates for people with diabetes almost double that of other Australians

Compared with the Australian population, death rates for people with diabetes were nearly twice as high for those with type 1 diabetes in 2012–2014, and 1.6 times as high for those with type 2 diabetes in 2014. This higher mortality was apparent across sex, age, socioeconomic status and remoteness (for type 2 diabetes only) groups.

The disparity in death rates between people with diabetes and the general population was highest at younger ages—death rates were 4.5 times as high for people aged under 45 with type 1 diabetes and almost 6 times as high for those with type 2 diabetes, compared with the Australian population of the same age.

Death rates fell for people with type 1 diabetes but rose for those with type 2 diabetes

Between 2009 and 2014, death rates fell by 20% for people with type 1 diabetes but rose by 10% for those with type 2 diabetes. Death rates also fell in the general population over this period but not as steeply as among people with type 1 diabetes. This means that compared with the general population, the mortality gap widened for people with type 2 diabetes but reduced for those with type 1 diabetes.

Death rates increased with increasing socioeconomic disadvantage and remoteness

People with diabetes living in the lowest socioeconomic areas experienced higher death rates than those in the highest socioeconomic areas. Among people with type 2 diabetes, the highest death rates were in *Remote and very remote* areas.

Leading causes of death

Diabetes, coronary heart disease and cerebrovascular disease were the most common underlying causes of death among people with type 1 or type 2 diabetes. Kidney failure was also a leading cause of death for people with type 1 diabetes, while dementia (including Alzheimer disease) was also a leading cause of death among those with type 2 diabetes.

Cardiovascular disease death rates fell for people with type 1 diabetes but remain high

Between 2009 and 2014, at the disease group level, cardiovascular disease (CVD) was the second most common underlying cause of death among people with type 1 diabetes and the most common among those with type 2 diabetes. Over this period, CVD death rates among people with type 1 diabetes fell more sharply than in the general population but there was little change in rates among people with type 2 diabetes. This means that the mortality gap reduced for those with type 1 diabetes but widened for those with type 2 diabetes.

1 Introduction

Measuring deaths due to diabetes provides important information on the impact of diabetes and its complications in Australia—including how diabetes mortality has changed over time and differences between population groups. This information can assist policymakers to predict the impact of diabetes on future health system resources, build the evidence base for prevention programs and assess the success of diabetes-related health interventions. This study benefits from combining data from 2 registers of people with diagnosed diabetes: the National Diabetes Services Scheme (NDSS) and the Australasian Paediatric Endocrine Group (APEG) clinic-based state and territory diabetes registers. It links these data to the National Death Index (NDI), providing a more complete understanding of death rates and the causes of death among people with diagnosed diabetes than previous work in this area, which has focused on single unlinked data collections which are limited in their ability to integrate diagnosis and health outcome information.

1.1 What is diabetes?

Diabetes is a chronic condition marked by high levels of sugar (glucose) in the blood. It is caused by the body being unable to produce insulin (a hormone made by the pancreas to control blood glucose levels) or to use insulin effectively, or both. The main types of diabetes are:

- type 1 diabetes—an autoimmune disease that usually has an onset in childhood or early adulthood but can be diagnosed at any age
- type 2 diabetes—the most common form of diabetes, it is largely preventable and usually
 associated with lifestyle factors (such as physical inactivity, poor diet, overweight and
 obesity, tobacco smoking) and with a later onset
- gestational diabetes—when higher than normal blood glucose is diagnosed in pregnancy.

People with diabetes need to monitor and keep their blood glucose levels within an optimal range to avoid short- and long-term complications. Healthy eating, weight control and regular physical activity all assist people with diabetes to stay within the optimal range, and some may also require medications. All people with type 1 diabetes, and a proportion of people with other forms of diabetes, will require insulin replacement therapy to manage their condition. This involves multiple daily injections or continuous infusion using an insulin pump.

When diabetes is not managed well, consistently high blood glucose levels (hyperglycaemia) associated with diabetes can lead to serious health complications, including heart disease, kidney disease, blindness and lower limb amputation. People with diabetes are also at higher risk of developing chronic diseases, such as some cancers, depression and dementia (Badescu et al. 2016; Giovannucci et al. 2010; Saedi et al. 2016).

Complications due to diabetes are a major cause of disability and can have a significant impact on life expectancy and quality of life (IDF 2015; Matthews 1999). Life expectancy at birth for people with type 1 diabetes in Australia has been estimated to be about 12 years less than the general population (Huo et al. 2016). A study based on data from England and Wales found that, for people with type 2 diabetes, life expectancy at age 40 was around 8 years less than that for people without diabetes (Roper et al. 2001). In 2011, Australians lost 4.5 million disability-adjusted life years (DALY) due to premature death or living with disease or injury, and diabetes accounted for 2% (102,000 DALY) of this total, making it the

12th leading cause of total burden of disease in Australia (AIHW 2016a). Years of life lost due to premature mortality accounted for 53% of the total burden due to diabetes in 2011, and healthy years lost due to ill health accounted for the remaining 47%.

Diabetes and its complications are major causes of death in Australia. In 2015, diabetes was the sixth leading underlying cause of death in Australia, accounting for 4,662 deaths (3% of all deaths) (ABS 2016a). Of these, about 8% were due to type 1 diabetes, 47% were due to type 2 diabetes and for most of the remaining deaths the type of diabetes was not specified.

While diabetes has a substantial impact on mortality in Australia, it is not always diabetes itself that directly leads to death, but one of its many complications. As a result, the complication, and not diabetes, is commonly listed as the underlying cause of death on the death certificate (AIHW 2012a). In 2015, diabetes was reported as an associated cause of 11,758 deaths (7% of all deaths). Combined with deaths where diabetes was the underlying cause (4,662 deaths), there were 16,420 deaths (10% of all deaths) with diabetes mentioned on the death certificate (ABS 2016a). Where diabetes was an associated cause of death (72% of all diabetes deaths), the conditions most commonly listed as the underlying cause of death were cancer, coronary heart disease (CHD), dementia (including Alzheimer disease), stroke and chronic lower respiratory diseases (ABS 2016a).

Diabetes, however, is known to be under-reported on death certificates (IDF 2015; McEwen et al. 2011; Whittall et al. 1990), making it difficult to obtain a full picture of death rates and causes of death for people with diabetes from this source alone. One reason for this is that diabetes is often omitted from death certificates because diabetes itself may not directly lead to death; instead, as explained above, death may be due to one of the complications of diabetes. Therefore, examining cause of death using death certificate information only is likely to under-report the impact of diabetes on mortality. Linking data sets can tackle this issue by examining deaths among people with diagnosed diabetes.

1.2 Aims of this report

Previous data linkage studies have examined death rates in people with diagnosed type 1 or type 2 diabetes in Australia between 1997 and 2010 (Harding et al. 2014, 2016). This report extends this work for the period 2009–2014 and also uses linked data to examine deaths and causes of death among people with diagnosed diabetes. The main objectives of the report are to:

- estimate all-cause and cause-specific death rates among people with diagnosed type 1 and type 2 diabetes and compare these rates with those for the general population
- estimate all-cause death rates among people with diagnosed type 1 and type 2 diabetes by demographic and socioeconomic factors, and compare these rates with those for the general population
- compare trends over time for the main causes of death among people with diagnosed type 1 and type 2 diabetes with corresponding trends for the general population.

The report also presents information on all conditions reported on the death certificate (referred to as multiple causes of death) for people with diagnosed type 1 and type 2 diabetes, to reflect the full extent of diabetes and all its complications in causing the death. This adds new insights, as previous studies have examined only the disease or injury that initiated the train of events leading directly to death (the underlying cause of death), which are likely to underestimate deaths related to diabetes, cardiovascular disease (CVD) and kidney failure (AIHW 2012a, 2014a; Harding et al. 2014).

This report will contribute to improving the understanding of diabetes and its complications leading to death, including premature and/or preventable death in Australia. Identifying the true level of diabetes-related deaths, as well as causes of death for people with diabetes, is important to inform appropriate population-based prevention strategies for diabetes and its complications, and improving care for all people with diabetes.

As a result, this report will help to inform targeted programs to enable early detection and treatment of diabetes complications to reduce their burden, and potentially extend life for those with diabetes. It may also provide evidence to better manage diabetes and avoid the harmful effects of complications, such as kidney failure and peripheral neuropathy.

1.3 Structure of this report

This report is structured as follows:

- Chapter 2 describes the methodology, data sources, data limitations and populations used in the study.
- Chapter 3 focuses on people with type 1 diabetes, including all-cause, cause-specific and premature mortality by a range of demographic factors, and compares these with those for the general population.
- Chapter 4 presents results for people with type 2 diabetes, covering similar topics to those presented in Chapter 3.
- Chapter 5 discusses the report findings, implications and conclusions.
- The Appendix presents detailed information on the data sources and methods.
- Detailed statistical tables can be found in the accompanying Excel spreadsheet. Tables in this spreadsheet are identified by a 'B' in the table number, for example Table B1.

2 Methods

This chapter provides an overview of the project scope, statistical methods, data sources and populations used in the study. More detailed information about the methods can be found in 'Appendix: Methods and statistical notes'.

2.1 Overview of project and scope

This study uses data from 4 national data sources (Box 2.1). The NDSS and APEG clinic-based state and territory diabetes registers and the NDI were linked using a probabilistic data-linking process to determine vital status and, where relevant, cause of death for people diagnosed with type 1 or type 2 diabetes who were registered with the NDSS and/or APEG between 2009 and 2014 (including all those registered before 2009 and still alive on 1 January 2009). NDSS registrants with any other type of diabetes were excluded from the study.

People who had a diabetes-related death but were not registered with the NDSS were excluded as the focus of the study was examining death among people with diagnosed diabetes who were registered with the NDSS.

All-cause and cause-specific death rates for people with type 1 or type 2 diabetes were examined by diabetes type, age at death, sex, socioeconomic group and remoteness (for type 2 diabetes only). Analysis by Aboriginal and Torres Strait Islander status was not undertaken due to the lower coverage of Indigenous Australians in both data sources (see Appendix for further details).

The Australian Institute of Health and Welfare (AIHW) National Mortality Database (NMD) was used to estimate death rates in the general population.

Approval for this linkage study was obtained from the AIHW Ethics Committee. Further information regarding the data linkage process used for this project, including validation and data quality checks, can be found in the Appendix.

Box 2.1: Data sources

The study used the following data sets for analysis:

National Diabetes Services Scheme (NDSS) registrant and sales data

 The NDSS, an initiative of the Australian Government and administered by Diabetes Australia, provides subsidies for the supply of diabetes-related products to people who are registered with the scheme. A diagnosis of diabetes, that a health professional has substantiated, is required in order to register with, and purchase products through, the NDSS. The NDSS registrant data provide demographic information as well as basic clinical details, such as diabetes type, while the sales data can be used to assess insulin use.

Australasian Paediatric Endocrine Group (APEG) clinic-based state and territory diabetes registers

• The APEG is a professional body that represents health professionals involved in the management and research of disorders of the endocrine system, including diabetes, in children and adolescents. The APEG maintains clinic-based state and territory diabetes registers.

National Death Index (NDI)

• The NDI, a database housed at the AIHW, is a register of all the deaths that have occurred in Australia since 1980. It contains cause of death, classified according to the International Statistical Classification of Diseases and Related Health Problems (ICD) (since 1997, this has been using the 10th Revision; ICD-10), and identifying information (date of birth, name, sex, date of death and postcode).

AIHW National Mortality Database (NMD)

• The NMD holds records for deaths in Australia from 1964. At the time of the linkage, the most recent year of cause of death data available was preliminary data for deaths registered in 2015. The database comprises information about causes of death and other characteristics of the person, such as sex, age at death, area of usual residence and Indigenous status. The cause of death data are sourced from the Registrars of Births, Deaths and Marriages in each state and territory and the National Coronial Information System, and are compiled and coded to the ICD by the Australian Bureau of Statistics (ABS).

Further information about the scope and quality of these data sets is in the Appendix.

2.2 Identification of populations

Study population

The NDSS, combined with APEG data, was used as the data source to identify the prevalent population with diagnosed type 1 and type 2 diabetes. Not all people with type 1 and type 2 diabetes might register with the NDSS. However, given the incentives that the NDSS provides to people with diabetes, it is assumed that it captures a high proportion of the diabetes population in Australia. As most people with diabetes who are registered with APEG are also registered with the NDSS, the combined NDSS and APEG data will hereafter be referred to in this report as NDSS data. NDI data were linked to the NDSS data to establish vital status and, where relevant, date and cause of death of NDSS registrants.

Diabetes type is classified by a health practitioner at the time of NDSS registration; however, the recorded type might not always be correct as the symptoms of type 1 and type 2 diabetes may be similar, particularly in young adults (AIHW 2016b). Further, changes in the classification of diabetes type in the NDSS data in 2002–2003 may have resulted in people with insulin-treated type 2 diabetes being misclassified as having type 1 diabetes. Therefore, in this report, an algorithm proposed by Harding et al. (2016) was used to derive diabetes type. Based on this algorithm, NDSS registrants were classified as having type 1 diabetes if they were:

- recorded as having type 1 diabetes in the NDSS database and were diagnosed at under 45 years of age and were using insulin
 - or
- recorded as having type 2 diabetes in the NDSS database and were diagnosed at under 30 years of age and were using insulin, and the time between date of diagnosis and first insulin use was less than 1 year.

Note, diabetes type did not change for other NDSS registrants who were recorded as having type 2 diabetes (see Appendix for further information).

Although NDSS data are available from 1987, there are data quality issues with the diagnosis date variable, with a considerable proportion of registrants having missing data for this variable before 2009. This has a considerable impact on the derivation of diabetes type for older registrants and, as a result, the study period has been restricted to 2009–2014 (see Appendix).

The study population included all NDSS registrants with type 1 or type 2 diabetes who were registered with the NDSS between 2009 and 2014, including all those who registered before 2009 and were still alive on 1 January 2009. The total study population included 1,277,714 NDSS registrants with type 1 or type 2 diabetes (Figure 2.1). Of these, the majority (93%; 1,186,379 people) had type 2 diabetes, while 7% (91,335 people) had type 1 diabetes (see Appendix for further details on the characteristics of the study population).

It is important to note that the results presented in this report relate only to NDSS registrants with type 1 and type 2 diabetes. People with diabetes who were not registered with the NDSS were not included in the analysis.

Between 1 January 2009 and 31 December 2014, 12% of the study population died (156,123 deaths). Of these, the vast majority (98%; 152,634 people) had type 2 diabetes, while 2% (3,489 people) had type 1 diabetes (Figure 2.1).



General population

In this report, the general population is the total Australian population. Death rates between 2009 and 2014 for the general population were calculated using data from the AIHW NMD (see Box 2.1). The population used for the calculation of death rates was the Australian Bureau of Statistics (ABS) estimated resident population (ERP) estimates as at 30 June between 2009 and 2014 (ABS 2017). The ABS derives these ERPs from its Census of Population and Housing, and adjusts them for deaths, births and net migration. Between 2009 and 2014, the ERP as at 30 June increased from 21,691,653 to 23,460,694 persons (ABS 2017).

2.3 Mortality analysis

Cause of death

Cause of death data are important to understand the health profile of people with diabetes and to help set priorities for health policymakers. Often, cause-specific mortality data are reported based on underlying cause of death; that is, the disease or injury that initiated the train of events leading directly to death. However, diabetes is associated with multiple conditions that may cause or contribute to death. Therefore, it is necessary to examine all conditions reported on the death certificate (multiple cause of death, also referred to as 'any' cause) to capture diabetes and all its complications that played a role in causing the death. The death certification process in Australia allows for up to 20 diseases to be reported as causing or contributing to a death (AIHW 2012a). Box 2.2 outlines the definitions used to describe causes of death in this report.

Box 2.2: Describing causes of death

Death certificates document the diseases considered to be instrumental in causing a death. These are usually completed by a medical practitioner or coroner.

Key definitions used to describe causes of death include:

underlying cause of death: This is the condition, disease or injury listed on a death certificate that initiated the sequence of events leading directly to death; that is, the primary or main cause of death. For each death, only 1 underlying cause is selected from among all the conditions reported on the death certificate.

associated causes of death: All the causes listed on the death certificate, other than the underlying cause of death. They include the immediate cause, any intervening causes and conditions that contributed to the death but were not related to the disease or condition causing the death.

multiple causes of death: Defined as all causes listed on the death certificate. This includes the underlying cause of death and all associated causes of death. These may be referred to as 'any' cause of death.

Sources: ABS 2016a; AIHW 2014a.

Of the 156,123 people in the study population who died between 2009 and 2014, over half (56%) did not have diabetes recorded on the death certificate, 13% had diabetes recorded as the underlying cause of death and 34% had diabetes recorded as an associated cause of death. It should be noted that due to coding practices recently introduced to assist in the identification of an underlying cause of death, it is possible for a person to have diabetes recorded as both an underlying and associated cause of death (ABS 2016a). Among the 156,123 deaths, 44% had diabetes recorded as either an underlying or an associated cause of death (multiple cause), and 2% had it recorded as both an underlying and associated cause of death.

A higher percentage of people with type 1 diabetes than those with type 2 diabetes had diabetes recorded as the underlying cause (30% compared with 12%). However, the percentage of people with type 1 diabetes who had diabetes recorded as an associated cause was only slightly higher than that for people with type 2 diabetes (37% compared with 34%).

Details of the statistical methods used in this report are provided in the Appendix and a summary of the key statistical terms is given in Box 2.3.

Box 2.3: Key statistical terms used in this report

age-specific rate: A rate for a specific age group. The numerator and denominator relate to the same age group. The minimum age grouping for most age-specific death rates reported in this report is under 45 due to the small number of deaths among people with diabetes aged younger than this, especially for type 2 diabetes.

age-standardised rate: A method of removing the influence of age when comparing populations with different age structures. There are 2 methods commonly used to adjust for age—direct and indirect standardisation (see below). In this report, direct age-standardisation has been used to compare mortality rates over time and by remoteness and socioeconomic status, while indirect age-standardisation has been used to assess excess deaths in the study population compared with the general population.

crude rate: The number of events in a given period divided by the size of the population at risk in the specified time period.

direct age-standardisation: A directly age-standardised rate is derived by applying the age-specific rates in the study population to a single standard population (AIHW 2011). For the calculation of directly age-standardised rates in this report, the Australian ERP as at 30 June 2001 was used as the standard population.

excess deaths: Excess deaths were calculated by subtracting the observed number of deaths in the study population from the expected number of deaths based on age-specific mortality rates for the general population.

indirect age-standardisation: An indirectly age-standardised rate is calculated by applying the age-specific rates from a standard population to the age distribution of the study population. Therefore, the indirect method calculates how many events would be expected in each group in the study population if the age-specific rates of the standard population were applied (referred to as 'excess deaths' in this report).

mortality rate difference: Mortality rate differences provide a measure of the absolute gap in age-specific, crude and age-standardised rates between 2 populations. In this report, mortality rate differences were calculated as the mortality rate per 100,000 for the study population minus the mortality rate per 100,000 for the general population.

mortality rate ratio: Mortality rate ratios provide a measure of the relative gap in age-specific, crude and age-standardised rates between 2 populations. In this report, mortality rate ratios were calculated as the mortality rate per 100,000 for the study population divided by the mortality rate per 100,000 for the general population.

potential years of life lost (PYLL): PYLL measures the impact of premature or untimely death by counting the number of years between the age at death and a defined cut-off age for premature death. In this report, dying before the age of 75 is considered premature. Therefore, a person dying at age 45 has potentially lost 30 years of life, while a person dying at age 80 is deemed to have lost no years of life prematurely. This measure gives greater weight to deaths at younger ages, compared with measures that only count numbers of deaths which tend to be dominated by deaths of the elderly.

PYLL rate: PYLL rates are calculated by summing the individual PYLL for a population group and dividing by the number of people in the population group. In this report, PYLL rates are expressed per 10,000 population rather than 100,000 population which is used to express mortality rates.

(continued)

Box 2.3 (continued): Key statistical terms used in this report

PYLL rate difference: PYLL rate differences provide a measure of the absolute gap in PYLL rates between 2 populations. In this report, PYLL rate differences were calculated as the PYLL rate per 10,000 for the study population minus the PYLL rate per 10,000 for general population.

PYLL rate ratio: PYLL rate ratios provide a measure of the relative gap in PYLL rates between 2 populations. In this report, PYLL rate ratios were calculated as the PYLL rate per 10,000 for the study population divided by the PYLL rate per 10,000 for general population.

See the Appendix for further information.

2.4 Limitations of the study

In interpreting the results of this study, it is important to bear in mind the following limitations:

- Registration with the NDSS is voluntary, and not all people diagnosed with diabetes are on the scheme. However, coverage of people with diabetes on the NDSS is thought to be relatively high, especially where diabetes-related products are required for management purposes.
- The extent of missing data for some variables in the NDSS database, such as diagnosis date that is used in the derivation of diabetes is considerable although administrative processes around collecting information through the NDSS form have improved over time. For these reasons, the study period was restricted to 2009 to 2014.
- In 2014, the ABS introduced changes in mortality coding that have resulted in a small increase in deaths attributed to type 2 diabetes from 2013 onwards.
- As the population without diabetes is not known, the general population has been used as a proxy for comparison purposes.

Further information about these limitations is provided in the 'Chapter 5 Discussion' and the Appendix.

3 Type 1 diabetes

This chapter examines deaths that occurred between 2009 and 2014 among the 91,335 people in the study population with type 1 diabetes; that is, people with derived type 1 diabetes who were registered with the NDSS between 2009 and 2014, including those who registered before 2009 and were still alive on 1 January 2009. The aim of this chapter is to provide a greater understanding of the cause of death for people with diagnosed type 1 diabetes, including common complications of diabetes such as CVD. All-cause mortality and cause-specific mortality rates in people with type 1 diabetes are presented and, where appropriate, compared with those in the general population.

Due to the small number of deaths among people with type 1 diabetes, results in this chapter reported for the most recent period have been aggregated for the 3 years from 2012 to 2014 and 3-year rolling averages are presented for time trends. Analysis by remoteness was not undertaken due to the small number of deaths.

3.1 All-cause mortality

Over the entire study period from 2009 to 2014, there were 3,489 deaths among the study population with type 1 diabetes (4% of this population). In the most recent 3-year period from 2012 to 2014, there were 1,830 deaths among the study population with type 1 diabetes. The age-standardised all-cause mortality rate in 2012–2014 was nearly twice as high in the study population with type 1 diabetes compared with the general population (1,084 compared with 586 deaths per 100,000 population).

Over the 3-year period, there were 1,264 excess deaths among the study population with type 1 diabetes compared with the number expected based on the age-specific death rates of the general population (Table B3).

Age and sex

Nearly all deaths (97%) among the study population with type 1 diabetes were premature deaths (occurred before age 75)—22% died before age 45, and more than half (56%) died between ages 45 and 64 over the period 2012 to 2014.

Overall, all-cause mortality rates were similar for males and females (1,117 and 1,049 per 100,000, respectively). However, males aged 45 to 64 in the study population with type 1 diabetes had all-cause mortality rates that were around 1.5 times as high as their female counterparts.

Across all age groups under 75, mortality rates were much higher in the study population with type 1 diabetes compared with those in the general population, especially in the younger age groups (Figure 3.1). Mortality rate ratios (the relative difference in mortality rates between the study and general populations) ranged from 4.5 in those aged under 45 to 2.4 in those aged 65–74 (Figure 3.1; Table B4).

The mortality rate ratios were higher for females than males in each age group, with the highest rate ratio (5.6) observed for females aged under 45 (Figure 3.1; Table B4). For females in this age group, the all-cause mortality rate in the study population was 228 per 100,000 (based on 172 deaths) compared with 41 per 100,000 in the general population (based on 8,463 deaths). While the relative differences between mortality rates in the study population and the general population were highest for those aged under 45, the absolute



mortality rate difference between the 2 populations increased with age for those aged under 75 and was 1,798 per 100,000 for those aged 65–74 (Table B4).

Trends over time

The number of deaths among the study population with type 1 diabetes increased by around 19% between 2009 and 2014, from 533 to 632 deaths (Figure 3.2).

Between 2009 and 2014, the age-standardised all-cause mortality rate in the study population with type 1 diabetes remained around double that of the general population. However, the gap narrowed somewhat over the period, with the rate ratio reducing from 2.2 in 2009–2011 to 1.8 in 2012–2014. Over the period, the age-standardised all-cause mortality rate in the study population fell by 20% from 1,354 to 1,084 per 100,000 population (Figure 3.3). Among the general population, there was a 3% decline in the all-cause mortality rate over the same period, from 605 to 586 deaths per 100,000 population.





Sex and age

Between 2009 and 2014, mortality rates decreased by 23% in males with type 1 diabetes, from 1,447 to 1,117 deaths per 100,000 population, and by 16% among females with type 1 diabetes, from 1,248 to 1,049 deaths per 100,000 population (Figure 3.4; Table B5). Mortality rates in the general population decreased by 5% for males between 2009 and 2014 but there was little change in rates for females over this period (Table B5).

Among the study population with type 1 diabetes, all-cause mortality rates did not decline across all age groups. No change was observed for those aged under 45 but, over the same period, rates decreased by 7% in those aged 45–64 (from 1,286 to 1,196 deaths per 100,000) and by 13% in those aged 65 and over (from 3,764 to 3,280 deaths per 100,000) (Figure 3.4; Table B6).

All-cause mortality rates in the general population decreased across all age groups, by 7% for those aged under 45 (from 60 to 56 deaths per 100,000), by 3% for those aged 45–64 (from 366 to 355 deaths per 100,000) and by 5% for those aged 65 and over (from 3,856 to 3,662 deaths per 100,000) (Table B7).



Figure 3.4: Trends in all-cause mortality rates in the study population with type 1 diabetes, by sex and age at death, 2009–2014

Socioeconomic groups

In 2012–2014, socioeconomic disadvantage was associated with higher all-cause mortality rates among the study population with type 1 diabetes (Figure 3.5; Table B8). Compared with those in the highest socioeconomic group (758 deaths per 100,000 population), age-standardised all-cause mortality rates were 1.7 times as high in the lower socioeconomic groups (1,279 and 1,301 deaths per 100,000 in socioeconomic group 1 and group 2, respectively).

The socioeconomic gradient observed in the study population with type 1 diabetes was also apparent for the general population in 2012–2014. However, the age-standardised mortality rate in the study population with type 1 diabetes was about twice that of the general population across each of the socioeconomic groups (Figure 3.5).



Sources: AIHW analysis of NDSS-NDI linked data and the AIHW NMD.

Figure 3.5: All-cause mortality rates in the study population with type 1 diabetes compared with the general population, by socioeconomic group, 2012–2014

3.2 Premature death

Premature death refers to deaths that occur at a younger age than a selected cut-off. This report uses PYLL as a measure of the impact of premature death (see Box 2.3). PYLL are determined by age at death and only take into account deaths that occur before the age of 75.

Among the study population with type 1 diabetes aged under 75, there were 1,781 deaths between 2012 and 2014. These premature deaths amount to 37,759 PYLL over this 3-year period—an average annual PYLL rate of 1,259 per 10,000 population, which is almost 4 times as high as the rate in the general population (344 per 10,000 population). The mortality gap (the absolute difference in the PYLL rate) between the study population with type 1 diabetes and the general population was 915 per 10,000.

Compared with the general population, PYLL rates were higher in the study population with type 1 diabetes in all age groups and for both males and females (Figure 3.6). For males, the mortality gap (absolute difference) was highest in those aged 55–64 (2,341 PYLL per 10,000 population), while the rate ratio (relative difference) was highest (4.2) in those aged under 35–902 PYLL per 10,000 population in the study population compared with 214 PYLL per 10,000 in the general population (Figure 3.6; Table B9). For females, the mortality gap was highest in those aged 65–74 (1,762 PYLL per 10,000 population), while the rate ratio was highest (6.5) in those aged under 35–728 PYLL per 10,000 population in the study population in the study population in the study population in the study population.



Between 2009 and 2014, PYLL rates decreased by 8% in the study population with type 1 diabetes and by 6% in the general population, which resulted in no change in the rate ratio and little change in the mortality gap over this period (Table B10).

Figure 3.6: PYLL rates in the study population with type 1 diabetes compared with the general population, by sex and age, 2012–2014

3.3 Leading causes of death

Data for the leading causes of death among the study population with type 1 diabetes have been aggregated over the 6-year period from 2009 to 2014 to take account of small numbers of deaths for some causes.

Between 2009 and 2014, the 2 most common underlying causes of death among the study population with type 1 diabetes were diabetes (30% of deaths) and CHD (17%) (Table 3.1).

| Rank | Underlying cause of death (ICD-10 codes) | Number | % ^(a) |
|----------------------|---|--------|-------------------------|
| 1 | Diabetes (E10–E14) | 1,034 | 29.8 |
| 2 | Coronary heart disease (I20–I25) | 592 | 17.1 |
| 3 | Cerebrovascular disease (I60–I69) | 98 | 2.8 |
| 4 | Suicide (X60–X84) | 86 | 2.5 |
| 5 | Kidney failure (N17–N19) | 85 | 2.5 |
| 6 | Lung cancer (C33, C34) | 75 | 2.2 |
| 7 | Accidental poisoning (X40–X49) | 60 | 1.7 |
| 8 | Liver disease (K70–K76) | 57 | 1.6 |
| 9 | Selected metabolic disorders excl. dehydration (E70-E89 excl. E86, E87) | 51 | 1.5 |
| 10 | Septicaemia (A40–A41) | 51 | 1.5 |
| Total ^(b) | | 3,473 | 100.0 |

Table 3.1: Top 10 conditions reported as underlying causes of death in the study population with type 1 diabetes, 2009–2014

(a) Percentage of all deaths among the study population with type 1 diabetes, 2009–2014. Percentages do not sum to 100% as only the top 10 underlying causes of death are presented.

(b) Excludes deaths with no underlying cause recorded (16 deaths).

Source: AIHW analysis of NDSS-NDI linked data.

Age and sex

The percentage of deaths with diabetes as the underlying cause was higher in females than males in the study population with type 1 diabetes (32% compared with 28%) (Figure 3.7; Table B11) in 2009–2014. In contrast, the percentage of deaths with CHD as the underlying cause was higher in males than females (19% compared with 14%).

When examining the leading causes of death by 3 broad age groups (under 45, 45–64 and 65 and over), diabetes was still the most common underlying cause among the study population with type 1 diabetes in all the age groups, accounting for 28% to 34% of deaths (Figure 3.7; Table B12). The percentage of deaths with an underlying cause of diabetes was highest among those aged under 45, while for deaths with an underlying cause of CHD, cerebrovascular disease, kidney failure or lung cancer, the percentage of deaths was higher in the older age groups.



3.4 Diabetes-specific mortality

Almost two-thirds (60%; 2,099 people) of those in the study population with type 1 diabetes who died between 2009 and 2014 had diabetes coded as a multiple (any) cause of death; that is, it was listed as the underlying cause or at least 1 associated cause or both (Table B13). Thirty per cent had diabetes listed as the underlying cause of death and 37% had it listed as an associated cause of death (1,034 and 1,292 deaths, respectively).

In 2012–2014, the age-standardised mortality rate for diabetes as any cause was 740 deaths per 100,000 population among the study population with type 1 diabetes, which was 10% lower than the rate in 2009–2011 (820 per 100,000 population) (Figure 3.8; Table B14).



Mortality rates for diabetes as the underlying cause also fell by 10% over the same period, from 404 to 363 deaths per 100,000 population (Figure 3.8).

Diabetes as an underlying cause of death

In 2009–2014, among the 1,034 people in the study population with type 1 diabetes who died with diabetes as the underlying cause of death, 47% of the deaths were coded as diabetes without complication, 17% as diabetes with ketoacidosis and 15% as diabetes with kidney complication (Figure 3.9; Table B15).

For those aged under 45, diabetes with ketoacidosis accounted for a considerable percentage of deaths (38% of deaths where diabetes was the underlying cause; 13% of total deaths) (Table B16).



In 2009–2014, of the 1,034 deaths among the study population with type 1 diabetes where diabetes was coded as the underlying cause, the most common associated cause of death was CHD (41%), followed by kidney failure (35%) and hypertensive disease (19%) (Table 3.2).

CHD was more likely to be recorded as an associated cause of death when kidney complication (47%) and peripheral circulatory complication (51%) were the underlying causes of death. Kidney failure was the most common associated cause of death for deaths from diabetes with kidney complication (80%) and diabetes with multiple complications (64%).

| Diabetes as underlying cause of death | Most common associated causes of death (% of deaths) | | | | |
|---|--|------------------------------------|---|---|--|
| Rank | 1st | 2nd | 3rd | 4th | 5th |
| All diabetes (n = 1,034) | Coronary heart disease (41%) | Kidney failure (35%) | Hypertensive disease (19%) | Cerebrovascular disease (9%) | Heart failure and complications and ill-defined heart disease (9%) |
| With ketoacidosis (n = 178) | Coronary heart disease (17%) | Influenza and pneumonia (8%) | Mental and behavioural disorders due to psychoactive substance use (6%) | Other disorders of the nervous system (4%) | Disorders of fluid, electrolyte and acid-based balance (dehydration) (4%) |
| With kidney complication (n = 152) | Kidney failure (80%) | Coronary heart disease (47%) | Hypertensive disease (18%) | Heart failure and complications and ill-defined heart disease (15%) | Cerebrovascular disease (11%) |
| With peripheral circulatory complication (n = 89) | Coronary heart disease (51%) | Kidney failure (34%) | Hypertensive disease (26%) | Diseases of arteries, arterioles and capillaries excl. atherosclerosis, aortic aneurysm and dissection (24%) | Cerebrovascular disease (22%) |
| With multiple complications (n = 90) | Kidney failure (64%) | Coronary heart disease (36%) | Diseases of arteries, arterioles and capillaries excl. atherosclerosis, aortic aneurysm and dissection (30%) | Hypertensive disease (23%) | Septicaemia (14%) |
| Without complication (n = 489) | Coronary heart disease (49%) | Kidney failure (29%) | Hypertensive disease (23%) | Cerebrovascular disease (10%) | Selected metabolic disorders excl. dehydration (8%) |

Table 3.2: Most common associated causes of death where diabetes was the underlying cause of death in the study population with type 1 diabetes, by diabetes complication, 2009–2014

Notes

1. The rows do not sum to 100 as multiple associated causes can be assigned to deaths.

2. Underlying cause refers to deaths with the disease coded as the underlying cause of death, regardless of whether the disease was also coded as an associated cause of death. Associated cause refers to deaths with the disease coded only as an associated cause of death.

Source: AIHW analysis of NDSS-NDI linked data.

Diabetes as an associated cause of death

Between 2009 and 2014, 37% of the study population with type 1 diabetes who died had diabetes coded as an associated cause of death (1,292 people). When CHD, cerebrovascular disease, lung cancer or kidney failure were the underlying cause of death, diabetes was the most common associated cause of death (Table 3.3). However, the percentage of deaths with diabetes as an associated cause varied by the underlying cause of death. Diabetes was as an associated cause in more than half of the deaths where CHD (58%) and cerebrovascular disease (56%) were the underlying causes of death, and was an associated cause for 47% of deaths where lung cancer was the underlying cause of death. Around 1 in 3 people in the study population with type 1 diabetes who died with kidney failure as the underlying cause of death.

| Underlying cause of death | | Most common associated causes of death (% of deaths) | | | | |
|-------------------------------------|-------------------|--|---|---|--|--|
| Rank | 1st | 2nd | 3rd | 4th | 5th | |
| Coronary heart disease (n = 592) | Diabetes (58%) | Kidney failure (19%) | Hypertensive disease (16%) | Heart failure and complications and ill-defined heart disease (15%) | Cardiac arrhythmias (8%) | |
| Cerebrovascular disease (n = 98) | Diabetes (56%) | Hypertensive disease (30%) | Kidney failure (20%) | Coronary heart disease (10%) | Influenza and pneumonia (10%) | |
| Kidney failure (n = 85) | Diabetes (36%) | Coronary heart disease (29%) | Heart failure and complications and ill-defined heart disease (21%) | Septicaemia (19%) | Disorders of fluid, electrolyte and acid-based balance (dehydration) (9%) | |
| Lung cancer (n = 75) | Diabetes (47%) | Cancer, unknown, ill-defined (17%) | Chronic obstructive pulmonary disease (COPD) (15%) | Coronary heart disease (12%) | Influenza and pneumonia (9%) | |

Table 3.3: Most common associated causes of death in the study population with type 1diabetes, by underlying cause of death other than diabetes, 2009–2014

Notes

1. The rows do not sum to 100 as multiple associated causes can be assigned to deaths.

2. Underlying cause refers to deaths with the disease coded as the underlying cause of death, regardless of whether the disease was also coded as an associated cause of death. Associated cause refers to deaths with the disease coded only as an associated cause of death.

Source: AIHW analysis of NDSS-NDI linked data.

3.5 CVD-specific mortality

Between 2009 and 2014, CVD was the underlying cause of death for 25% of deaths among the study population with type 1 diabetes, while 49% of deaths had CVD as an associated cause of death and 58% as any cause of death (857, 1,708 and 2,032 deaths, respectively). Among the study population with type 1 diabetes, CVD was twice as likely to be coded as a multiple (any) cause of death than an underlying cause of death.

Over the same period, depending on whether CVD was the underlying cause or any cause of death, the age-standardised mortality rate in the study population with type 1 diabetes was around 2–3 times as high as the corresponding rate in the general population (Figure 3.10).

In 2009–2014, there were 650 excess deaths from CVD as the underlying cause among the study population with type 1 diabetes compared with the number expected based on the age-specific mortality rates for CVD as the underlying cause of death in the general population (Table B17).



Figure 3.10: Cardiovascular disease–specific mortality rates by cause of death in the study population with type 1 diabetes compared with the general population, 2009–2014

Coronary heart disease

A similar pattern was observed for mortality due to CHD. Between 2009 and 2014, CHD was the underlying cause of death for 17% of deaths among the study population with type 1 diabetes, while 25% of deaths had CHD as an associated cause of death and 37% as any cause of death (592, 866 and 1,288 deaths, respectively).

Between 2009 and 2014, depending on whether CHD was the underlying cause or any cause of death, the age-standardised mortality rate for CHD among the study population with type 1 diabetes was 2–3 times as high as the corresponding rate for the general population (Figure 3.10).

Cerebrovascular disease

Between 2009 and 2014, cerebrovascular disease was the underlying cause of death for 3% of deaths among the study population with type 1 diabetes, while 6% of deaths had cerebrovascular disease as an associated cause of death and 8% as any cause of death (98, 199 and 289 deaths, respectively).

In 2009–2014, the age-standardised mortality rate for cerebrovascular disease as the underlying cause of death in the study population with type 1 diabetes was 1.3 times as high as that of the general population; however, it should be noted that this is based on only 98 deaths from cerebrovascular disease as the underlying cause of death in the study population. The age-standardised rate for cerebrovascular disease as any cause of death was 2.0 times as high in the study population as the general population (Figure 3.10).

Trends

Among the study population with type 1 diabetes, the age-standardised mortality rate for CVD as either the underlying or multiple (any) cause of death decreased over the period from 2009 to 2014 (Figure 3.11; tables B18, B19).



Figure 3.11: Trends in cardiovascular disease–specific mortality rates in the study popu with type 1 diabetes compared with the general population, 2009–2014

When coded as the underlying cause, CVD mortality in the study population with type 1 diabetes declined by 43% between 2009 and 2014 (from 427 to 245 deaths per 100,000), which was a steeper decline than that observed in the general population over the same period (a 10% fall) (Figure 3.11; Table B18). When coded as a multiple (any) cause, the CVD mortality rate declined by 27% (from 971 to 706 deaths per 100,000) in the study population compared with a 6% decline in the general population over the same period (Figure 3.11;

Table B19). This has resulted in a narrowing of the gap in CVD mortality rates between people with type 1 diabetes and the general population since 2009.

3.6 Cancer-specific mortality

Between 2009 and 2014, cancer was the underlying cause of death for 16% of deaths among the study population with type 1 diabetes, while 5% of deaths had cancer as an associated cause of death and 18% as any cause of death (558, 179 and 624 deaths, respectively).

Over the same period, depending on whether cancer was the underlying cause or any cause of death, the rate ratio comparing the age-standardised mortality rate in the study population with type 1 diabetes with the corresponding rate in the general population was around 1, indicating no difference between the two populations (Figure 3.12; tables B20, B21).

Trends

Cancer mortality trends between 2009 and 2014 among the study population with type 1 diabetes should be interpreted with caution as the mortality rates are based on relatively small numbers of deaths.



When coded as the underlying cause, the cancer mortality rate in the study population with type 1 diabetes declined by 14% between 2009–2011 and 2011–2013 (from 187 to 161 deaths per 100,000) but then increased to 173 deaths per 100,000 in 2012–2014 (Figure 3.12; Table B20). Among the general population, mortality rates based on cancer as the underlying cause of death fell in each 3-year period between 2009 and 2014, with an

overall decline of 5%. Similar patterns were observed for cancer when coded as a multiple (any) cause, with the cancer mortality rate in the study population with type 1 diabetes declining by 17% between 2009–2011 and 2011–2013 (from 226 to 188 deaths per 100,000) but then increasing to 197 deaths per 100,000 in 2012–2014 (Table B21). In comparison, among the general population, mortality rates based on cancer as any cause of death fell by 4% between 2009 and 2014.

3.7 Cause-specific mortality by age group

Between 2009 and 2014, among the study population with type 1 diabetes (tables B22-B24):

- mortality rates for diabetes as the underlying cause increased by 9% in those aged under 45 but decreased by 6% and 4% in those aged 45–64 and 65 and over, respectively
- mortality rates for CVD as the underlying cause decreased by 18%, 19% and 25% for those aged under 45, 45–64 and 65 and over, respectively
- mortality rates for cancer increased by 7% for those aged 45–64 and decreased by 17% for those aged 65 and over, but there was virtually no change in rates for those aged under 45.
4 Type 2 diabetes

This chapter examines deaths that occurred between 2009 and 2014 among the 1,186,379 people in the study population with type 2 diabetes; that is, people with derived type 2 diabetes who were registered with the NDSS between 2009 and 2014, including those who registered before 2009 and were still alive on 1 January 2009. The chapter aims is to provide a greater understanding of the cause of death for people with diagnosed type 2 diabetes, including common complications of diabetes such as CVD and cancer. All-cause mortality and cause-specific mortality rates in people with type 2 diabetes are presented and, where appropriate, compared with those in the general population.

It is important to note that the results presented in this chapter only reflect the patterns among people with type 2 diabetes who were registered with the NDSS, and therefore the findings may not fully reflect the patterns of all people with type 2 diabetes.

Results in this chapter are presented for people with type 2 diabetes who died in 2014, as well as trends over time where appropriate.

4.1 All-cause mortality

Over the study period from 2009 to 2014, there were 152,634 deaths among the study population with type 2 diabetes (13% of this population) and, of these deaths, 29,468 occurred in 2014. The age-standardised all-cause mortality rate in 2014 was higher (1.6 times as high) in the study population with type 2 diabetes compared with the general population (883 deaths per 100,000 population compared with 547 deaths per 100,000 population).

In 2014, there were 7,094 excess deaths among the study population with type 2 diabetes compared with the number expected based on the age-specific death rates of the general population (Table B25).

Age and sex

Around two-thirds (68%) of deaths among the study population with type 2 diabetes in 2014 occurred in those aged 75 and over, 28% occurred in those aged 55–74 and 3% in those aged under 55 (Table B26).

Overall, all-cause mortality rates in the study population with type 2 diabetes were slightly higher in males than females (993 per 100,000 and 765 per 100,000, respectively). This was also observed for all age groups, with males in the study population having all-cause mortality rates that were around 1.3–1.4 times as high as their female counterparts for each age group below 85 and over.

Across most of the age groups examined, mortality rates were higher in the study population with type 2 diabetes compared with those for the general population, especially in the younger age groups. For those aged under 75, the mortality rate ratios ranged from 1.5 (males aged 65–74) to 6.6 (females aged under 45) (Figure 4.1). While the relative differences between the study population and the general population were highest for those aged under 45, the absolute rate differences between the 2 populations were largest for those aged 75–84 for both males and females (1,353 per 100,000 and 1,392 per 100,000, respectively).



Figure 4.1: All-cause mortality rates in the study population with type 2 diabetes compared with the general population, by sex and age at death, 2014

Trends over time

The number of deaths in the study population with type 2 diabetes increased by 35% between 2009 and 2014, from 21,899 to 29,468 deaths (Figure 4.2; Table B27).

Over the same period, the all-cause mortality rate in the study population with type 2 diabetes increased by 10% from 801 to 883 per 100,000 population (Figure 4.3). In contrast, the all-cause mortality rate in the general population decreased by 6% between 2009 and 2014, from 584 to 547 per 100,000. The relative gap between the study population with type 2 diabetes and the general population slightly widened over the study period, with the mortality rate ratio increasing from 1.4 in 2009 to 1.6 in 2014.





Sex and age

All-cause mortality rates in the study population with type 2 diabetes were consistently higher in males than females between 2009 and 2014, with a rate ratio of 1.3–1.5 over this period (Figure 4.4; Table B27). Mortality rates in females with type 2 diabetes increased by 18% between 2009 and 2014, from 647 to 766 deaths per 100,000 population. Over the same period, rates fluctuated for males, with the rate in 2014 being 2% higher than that in 2009 (993 compared with 972 deaths per 100,000 population). Among the general population, all-cause mortality rates decreased by 9% for males and 4% for females between 2009 and 2014 (Table B27).

Between 2009 and 2014, there were increases in all-cause mortality rates among the study population with type 2 diabetes in most age groups (Figure 4.4; Table B28). Rates increased by 23% for those aged 85 and over (from 11,292 to 13,842 per 100,000 population), by 4% among those aged 75–84 (from 5,059 to 5,257 per 100,000 population) and by 9% among those aged under 65 (685 compared with 748 per 100,000 population). These increases remained even after adjusting for age in each of the age groups. However, there was a small (2%) decline in rates among those aged 65–74 (from 2,049 to 2,004 per 100,000 population).

In contrast, all-cause mortality rates in the general population decreased for all 4 age groups during the same period—by 6%, 11%, 10% and 2% for those aged under 65, 65–74, 75–84 and 85 and over, respectively (Table B29).



Note: Sex-specific rates have been age-standardised to the Australian population as at 30 June 2001.

Sources: AIHW analysis of NDSS-NDI linked data and the AIHW NMD.

Figure 4.4: Trends in all-cause mortality rates in the study population with type 2, by sex, age at death and year of death, 2009–2014

Socioeconomic group

In 2014, socioeconomic disadvantage was associated with higher all-cause mortality rates among the study population with type 2 diabetes. Compared with those in the highest socioeconomic group, age-standardised all-cause mortality rates were 1.4 times as high in the lowest socioeconomic group (733 and 1,012 deaths per 100,000 population, respectively) (Figure 4.5; Table B30).

The age-standardised all-cause mortality rates in the study population with type 2 diabetes were 1.5–1.7 times as high as those of the general population (Figure 4.5). The socioeconomic gradient observed in the study population with type 2 diabetes was also apparent for the general population.



the general population, by socioeconomic group, 2014

Remoteness

In 2014, the age-standardised all-cause mortality rate in the study population with type 2 diabetes in *Remote and very remote* areas was 1.6 times as high as that in *Major cities* (1,278 per 100,000 compared with 822 per 100,000) (Figure 4.6; Table B31).

Compared with rates in the general population, age-standardised all-cause mortality rates were higher in the study population with type 2 diabetes in all remoteness areas, ranging from a rate ratio of 1.5 in *Inner regional* areas (866 compared with 584 per 100,000) to 1.9 in *Outer regional* areas (1,123 compared with 595 per 100,000) and *Remote and very remote* areas (1,278 compared with 658 per 100,000) (Figure 4.6).



4.2 Premature death

Premature death refers to deaths that occur at a younger age than a selected cut-off. This report uses PYLL as a measure of the impact of premature death (see Box 2.3). PYLL are determined by age at death and only take into account deaths that occur before the age of 75.

Among the study population with type 2 diabetes aged under 75 (referred as premature deaths; see 'Chapter 3 Type 1 diabetes' for further details), there were 9,364 deaths during 2014. These premature deaths amount to a total of 92,900 PYLL; an age-standardised rate of 1,110 PYLL per 10,000 population, which was 3.2 times as high as that of the general population (344 per 10,000 population). The mortality gap (the absolute difference in the PYLL rate) between the study population with type 2 diabetes and the general population was 766 PYLL per 10,000.

Compared with the general population, PYLL rates were higher in people with type 2 diabetes in all age groups for both males and females (Figure 4.7; Table B32). For males, the mortality gap (absolute difference) was highest in those aged 40–44 (972 PYLL per 10,000 population), and the rate ratio (relative difference) was highest (4.9) in those aged under 40 (1,155 PYLL per 10,000 population in the study population compared with 234 PYLL per 10,000 in the general population). For females, the mortality gap was also highest in those aged 40–44 (775 PYLL per 10,000 population), and the rate ratio was highest (6.9) in those aged under 40 (864 PYLL per 10,000 population in the study population compared with 126 PYLL per 10,000 in the general population).



Between 2009 and 2014, PYLL rates increased by 15% in the study population with type 2 diabetes and decreased by 9% in the general population (Table B33). Both the rate ratio and the mortality gap between the study population and general population increased over the study period—the rate ratio increased from 2.6 to 3.2 and the mortality gap from 589 to 766 PYLL per 10,000 (Table B33).

4.3 Leading causes of death

In 2014, among the study population with type 2 diabetes, the most common underlying cause of death was CHD (15% of deaths), followed by diabetes (12%), cerebrovascular disease (6%) and dementia and Alzheimer disease (6%) (Table 4.1).

| Table 4.1: Top 10 conditions reported as th | ne underlying cause of | death in the study | population |
|---|------------------------|--------------------|------------|
| with type 2 diabetes, 2014 | | | |

| Rank | Underlying cause of death (ICD-10 codes) | Number | % ^(a) |
|----------------------|---|--------|-------------------------|
| 1 | Coronary heart disease (I20–I25) | 4,400 | 15.0 |
| 2 | Diabetes (E10–E14) | 3,459 | 11.8 |
| 3 | Cerebrovascular disease (I60–I69) | 1,737 | 5.9 |
| 4 | Dementia and Alzheimer disease (F01, F03, G30) | 1,678 | 5.7 |
| 5 | Lung cancer (C33, C34) | 1,346 | 4.6 |
| 6 | Chronic obstructive pulmonary disease (COPD) (J40–J44) | 1,140 | 3.9 |
| 7 | Pancreatic cancer (C25) | 775 | 2.6 |
| 8 | Heart failure and complications and ill-defined heart disease (I50–I51) | 731 | 2.5 |
| 9 | Colorectal cancer (C18–C21) | 720 | 2.5 |
| 10 | Cancer, unknown, ill-defined (C26, C39, C76-C80) | 675 | 2.3 |
| Total ^(b) | | 29,376 | 100.0 |

(a) Percentage of all deaths among the study population with type 2 diabetes. Percentages do not sum to 100% as only the top 10 underlying causes of death are presented.

(b) Excludes deaths with no underlying cause recorded (92 deaths).

Source: AIHW analysis of NDSS-NDI linked data.

Sex and age

In 2014, the percentage of deaths with diabetes as the underlying cause among the study population with type 2 diabetes was relatively similar in males (11%) and females (13%) (Figure 4.8; Table B34). Where CHD was the underlying cause, 16% of deaths in the study population occurred in males and 13% in females, while for cerebrovascular disease and Dementia and Alzheimer disease as the underlying cause, 7% of deaths occurred in females and 5% in males, respectively.

When examining the leading underlying cause of death among the study population with type 2 diabetes by 3 broad age groups (under 65, 65–74 and 75 and over), CHD remained the most common cause in all age groups, accounting for 13%–16% of deaths, followed by diabetes 10%–13% (Figure 4.8; Table B35). For dementia and Alzheimer disease or cerebrovascular disease as the underlying cause, the percentage of deaths was highest in the 75 and over age group (7.8% and 7.2%, respectively). The percentage of those who died with lung cancer listed as the underlying cause was highest in those aged 65–74 at 8.6%.



When deaths among the study population with type 2 diabetes were examined by both age and sex, CHD was the most common underlying cause of death among males in all 3 age groups and among females aged under 65 and 75 and over (Table 4.2). For females aged 65–74, diabetes accounted for 11% of deaths and CHD for 9% (Table 4.2).

Diabetes was the second most common cause of death among males in the study population in each of the 3 age groups and among females aged under 65 and 75 and over.

Lung and pancreatic cancers were common underlying causes of death in males aged under 75, while breast and lung cancer were common in females in this age group. Dementia was the third leading underlying cause of death in men and women aged 75 and over in people with type 2 diabetes.

Table 4.2: Top 5 conditions reported as the underlying cause of death in the study population with type 2 diabetes, by sex and 3 broad age groups, 2014

| | | Males | | Females | | | |
|------|------------------------------------|--|---|------------------------------------|--|---|--|
| Rank | <65 | 65–74 | 75+ | <65 | 65–74 | 75+ | |
| 1st | Coronary heart disease (16%) | Coronary heart disease (16%) | Coronary heart disease (17%) | Coronary heart disease (10%) | Diabetes (11%) | Coronary heart disease (15%) | |
| 2nd | Diabetes (11%) | Diabetes (10%) | Diabetes (11%) | Diabetes (9%) | Coronary heart disease (9%) | Diabetes (14%) | |
| 3rd | Liver disease (6%) | Lung cancer (9%) | Dementia and Alzheimer disease (7%) | Breast cancer (8%) | Lung cancer (8%) | Dementia and Alzheimer disease (9%) | |
| 4th | Pancreatic cancer (5%) | Pancreatic cancer (4%) | Cerebrovascular disease (6%) | Lung cancer (6%) | Breast cancer (6%) | Cerebrovascular disease (8%) | |
| 5th | Lung cancer (4%) | Chronic obstructive pulmonary disease (COPD) (4%) | Chronic obstructive pulmonary disease (COPD) (5%) | Pancreatic cancer (4%) | Chronic obstructive pulmonary disease (COPD) (5%) | Chronic obstructive pulmonary disease (COPD) (3%) | |

Notes

1. The percentage relates to the percentage of people in each age group with the underlying cause of death.

2. Components do not sum to 100% as only the most common underlying causes of death are presented.

Source: AIHW analysis of NDSS-NDI linked data.

4.4 Diabetes-specific mortality

Among the study population with type 2 diabetes who died in 2014, 42% (12,365 people) had diabetes as a multiple (any) cause of death (Table B36). The majority had diabetes as an associated cause of death (36%, 10,601 people), while only a small percentage (12%, 3,459 people) had diabetes as the underlying cause of death.

In 2014, the age-standardised mortality rate for diabetes as any cause of death among the study population with type 2 diabetes was 340 deaths per 100,000 population, similar to the rate in 2009 (336 per 100,000 population) (Figure 4.9; Table B37). The mortality rate for diabetes as the underlying cause decreased between 2009 and 2014, by 9%, from 103 to 94 deaths per 100,000 population. In contrast, age-standardised mortality rates in the general population remained relatively flat between 2009 and 2014 both where diabetes was the underlying or multiple (any) cause of death (AIHW 2017a).



Diabetes as the underlying cause of death

Among the study population with type 2 diabetes, almost half (49%) of the 3,459 deaths in 2014 with diabetes as the underlying cause of death were coded as diabetes without complications (Figure 4.10; Table B38). Almost one-third (31%) were coded as diabetes with kidney complication, while 9% and 7% were coded as diabetes with multiple complications and diabetes with peripheral circulatory complications, respectively. Only a small percentage (1%) had diabetes with ketoacidosis coded as the underlying cause of death.



For all deaths among the study population with type 2 diabetes where diabetes was coded as the underlying cause, the most common associated cause of death was CHD (46%), followed by kidney failure (40%), hypertensive disease (33%), heart failure (23%) and cerebrovascular disease (18%) (Table 4.3).

CHD was more likely to be recorded as an associated cause of death when diabetes without complication was the underlying cause (53%). Kidney failure was the most common associated cause of death for deaths from diabetes with kidney complication (96%) and diabetes with multiple complications (91%).

| Diabetes as underlying cause of death | Most common associated causes of death (% of deaths) | | | | | | | |
|---|---|---|-------------------------------------|---|--|--|--|--|
| Rank | 1st | 2nd 3rd | | 4th | 5th | | | |
| All diabetes (n = 3,459) | Coronary heart disease (46%) | Kidney failure (40%) | Hypertensive disease (33%) | Heart failure and complications and ill-defined heart disease (23%) | Cerebrovascular disease (18%) | | | |
| With ketoacidosis (n = 43) | Disorders of fluid, electrolyte and acid-based balance (dehydration) (21%) | Coronary heart disease (19%) | Kidney failure (14%) | Dementia and Alzheimer disease (12%) | Heart failure and complications and ill-defined heart disease (7%) | | | |
| With kidney complication (n = 1,085) | Kidney failure (96%) | Coronary heart disease (40%) | Hypertensive disease (30%) | Heart failure and complications and ill-defined heart disease (28%) | Dementia and Alzheimer disease (11%) | | | |
| With peripheral circulatory complication (n = 227) | Diseases of arteries, arterioles and capillaries excl. atherosclerosis, aortic aneurysm and dissection (75%) | Coronary heart disease (36%) | Septicaemia (28%) | Heart failure and complications and ill-defined heart disease (24%) | Hypertensive disease (23%) | | | |
| With multiple complications (n = 314) | Kidney failure (91%) | Diseases of arteries, arterioles and capillaries excl. atherosclerosis, aortic aneurysm and dissection (46%) | Coronary heart disease (40%) | Hypertensive disease (30%) | Heart failure and complications and ill-defined heart disease (27%) | | | |
| Without complication (n = 1,705) | Coronary heart disease (53%) | Hypertensive disease (38%) | Cerebrovascular disease (25%) | Dementia and Alzheimer disease (21%) | Heart failure and complications and ill-defined heart disease (20%) | | | |

Table 4.3: Most common associated causes of death, where diabetes was the underlying cause of death among the study population with type 2 diabetes, by diabetes complication, 2014

Notes

1. The rows do not sum to 100 as multiple associated causes can be assigned to deaths.

2. Underlying cause refers to deaths with the disease coded as the underlying cause of death, regardless of whether the disease was also coded as an associated cause of death. Associated cause refers to deaths with the disease coded only as an associated cause of death.

Source: AIHW analysis of NDSS-NDI linked data.

Diabetes as an associated cause of death

In 2014, 36% of the study population with type 2 diabetes who died had diabetes as an associated cause of death (10,601 people).

For those who had CHD, cerebrovascular disease, dementia and Alzheimer disease, lung cancer or chronic obstructive pulmonary disease (COPD) as the underlying cause of death, diabetes was the most common associated cause of death (Table 4.4). The percentage of deaths with diabetes as an associated cause varied by the underlying cause of death. Diabetes was an associated cause in almost half of the deaths where CHD (47%) or dementia and Alzheimer disease (46%) were the underlying cause. Around 2 in 5 deaths in the study population with type 2 diabetes where cerebrovascular disease (39%) or COPD (38%) were the underlying cause of death, and diabetes was an associated cause of death in around 1 in 4 (27%) lung cancer deaths among the study population with type 2 diabetes.

| Underlying cause of death | Most common associated causes of death (% of deaths) | | | | | | | |
|---|--|---|--|-------------------------------------|---|--|--|--|
| Rank | 1st | 2nd | 3rd | 4th | 5th | | | |
| Coronary heart disease (n = 4,400) | Diabetes (47%) | Heart failure and complications and ill-defined heart disease (33%) | Hypertensive disease (22%) | Kidney failure (21%) | Cardiac arrhythmias (15%) | | | |
| Cerebrovascular disease (n = 1,737) | Diabetes (39%) | Hypertensive disease (28%) | Dementia and Alzheimer disease (15%) | Coronary heart disease (15%) | Lung diseases due to external agents (12%) | | | |
| Dementia and Alzheimer disease (n = 1,678) | Diabetes (46%) | Influenza and pneumonia (24%) | Hypertensive disease (15%) | Coronary heart disease (14%) | Lung diseases due to external agents (13%) | | | |
| Lung cancer (n = 1,346) | Diabetes (27%) | Cancer, unknown, ill-defined (17%) | Chronic obstructive pulmonary disease (COPD) (16%) | Coronary heart disease (13%) | Hypertensive disease (8%) | | | |
| Chronic obstructive pulmonary disease (COPD) (n = 1,140) | Diabetes (38%) | Heart failure and complications and ill-defined heart disease (29%) | Coronary heart disease (26%) | Influenza and pneumonia (25%) | Kidney failure (15%) | | | |

Table 4.4: Most common associated causes of death among the study population with type 2 diabetes, by underlying cause of death other than diabetes, 2014

Notes

1. The rows do not sum to 100 as multiple associated causes can be assigned to deaths.

2. Underlying cause refers to deaths with the disease coded as the underlying cause of death, regardless of whether the disease was also coded as an associated cause of death. Associated cause refers to deaths with the disease coded only as an associated cause of death.

Source: AIHW analysis of NDSS-NDI linked data.

4.5 CVD-specific mortality

In 2014, CVD was the underlying cause for 30% of deaths in the study population with type 2 diabetes, while 55% of deaths had CVD as an associated cause of death and 64% as any cause of death (8,716, 16,287 and 18,686 deaths, respectively) (Table B36). Among the study population with type 2 diabetes, CVD was 1.9 times as likely to be coded as an associated cause of death than an underlying cause of death.

CVD-specific mortality was higher in the study population with type 2 diabetes than in the general population in 2014. When CVD was the underlying cause of death, the age-standardised mortality rate in the study population was 1.6 times as high as the rate in the general population (244 and 154 deaths per 100,000 population, respectively) and 1.7 times as high when CVD was any cause of death (509 and 292 per 100,000, respectively) (Figure 4.11; Table B39).

In 2014, there were 1,768 excess deaths from CVD as the underlying cause among the study population with type 2 diabetes compared with the number expected based on the age-specific mortality rates for CVD as the underlying cause of death in the general population.



Sources: AIHW analysis of NDSS-NDI linked data and the AIHW NMD.

Figure 4.11: Cardiovascular disease–specific mortality rates in the study population with type 2 diabetes compared with the general population, by cause of death, 2014

Coronary heart disease

In 2014, CHD was the underlying cause for 15% of deaths in the study population with type 2 diabetes, while 21% of deaths had CHD as an associated cause of death and 31% as any cause of death (4,400, 6,186 and 9,183 deaths, respectively) (Table B36).

The mortality rate for CHD as the underlying cause in the study population with type 2 diabetes was 1.8 times as high as that for the general population in 2014 (123 deaths per 100,000 population compared with 69 deaths per 100,000). The mortality rate ratio was twice as high when CHD was recorded as any cause of death (246 per 100,000 in the study population compared with 125 per 100,000 in the general population; Figure 4.11; Table B39).

In 2014, there were 1,322 excess deaths from CHD as the underlying cause among the study population with type 2 diabetes compared with the number expected based on the age-specific mortality rates for CHD as the underlying cause of death in the general population.

Cerebrovascular disease

In 2014, cerebrovascular disease was the underlying cause for 6% of deaths in the study population with type 2 diabetes, while 9% of deaths had cerebrovascular disease as an associated cause of death and 13% as any cause of death (1,737, 2,498 and 3,896 deaths, respectively) (Table B36).

The mortality rate for cerebrovascular disease as the underlying cause of death in the study population was similar to that of the general population in 2014 (41 per 100,000 population compared with 37 per 100,000 population), while the mortality rate for cerebrovascular disease as any cause of death was 1.3 times as high in the study population (93 per 100,000) compared with the general population (69 per 100,000) (Figure 4.11; Table B39).

Trends

Between 2009 and 2013, there was little change in the mortality rate for CVD as either the underlying or any cause of death but there was a 7% increase in both rates between 2013 and 2014 (Figure 4.12; Table B40). In contrast, among the general population, mortality rates declined by 18% for CVD as the underlying cause of death and by 11% for CVD as any cause of death between 2009 and 2014 (tables B41, B42). This has resulted in a widening of the gap in CVD mortality rates between people with type 2 diabetes and the general population since 2009.



4.6 Cancer-specific mortality

In 2014, cancer was the underlying cause of death for 26% of deaths in the study population with type 2 diabetes, while 10% of deaths had cancer as an associated cause of death and 31% as any cause of death (7,773, 3,035 and 9,107 deaths, respectively) (Table B36). Unlike for CVD, cancer was far more likely (2.6 times as high) to be coded as the underlying cause of death than an associated cause of death among people with type 2 diabetes.

Between 2009 and 2014, there were large fluctuations in the age-standardised cancer mortality rate for the study population with type 2 diabetes for cancer as either the underlying or any cause of death but overall rates remained much the same (Figure 4.13; Table B43). In contrast, mortality rates for cancer as either the underlying or any cause in the general population decreased by 8% between 2009 and 2014 (tables B44, B45).



4.7 Cause-specific mortality for those aged 85 and over

The increase in all-cause mortality among the study population with type 2 diabetes was mainly driven by an increase in rates among those aged 85 and over between 2009 and 2014 (a 23% increase in age-specific rates; Table B28). Among the younger age groups, the changes in all-cause mortality rates between 2009 and 2014 were relatively small (9% and 4% increase for those aged under 65 and those aged 75–84, respectively, and a 2% decrease for those aged 65–74).

Trends in the age-specific mortality rates for the most common underlying causes have been examined for the study population with type 2 diabetes aged 85 and over to identify the causes of death contributing to the increases in mortality among these people.

Between 2009 and 2014, among the study population with type 2 diabetes aged 85 and over, the following patterns were observed for mortality rates based on underlying cause of death (Figure 4.14; Table B46):

- diabetes—mortality rates were fairly stable between 2009 and 2011, increased by 5% between 2011 and 2012 but then remained steady between 2012 and 2014
- CVD—mortality rates changed very little between 2009 and 2013 but then increased by 11% between 2013 and 2014
- cancer—mortality rates increased by 18%
- COPD—mortality rates increased by 58%
- dementia—mortality rates increased by 70%.

These results reflect the high prevalence of multimorbidities in the ageing population with type 2 diabetes.



Figure 4.14: Cause-specific mortality rates based on underlying cause of death in the study population with type 2 diabetes aged 85 and over, 2009–2014

5 Discussion

Chronic conditions, such as diabetes, are the leading cause of ill health, disability and death in Australia. They have a significant impact on individuals, the community and the health sector. Due to the escalating prevalence of chronic conditions, and a population that is living longer and often with more than 1 chronic condition, preventing and effectively managing these conditions is Australia's biggest health challenge.

Monitoring deaths of people with diabetes and diabetes-related complications can help to measure the impact of diabetes-related health interventions as well as those for a range of other serious chronic conditions—such as CVD, chronic kidney disease and dementia—which are associated with diabetes.

5.1 Main findings

Higher death rates among people with diabetes

This study found that all-cause death rates for people with diabetes were 1.6–1.8 times as high as those of the general population after accounting for age differences. This higher mortality was apparent across sex, age, socioeconomic status and remoteness (for type 2 diabetes only) groups.

The study also found considerable excess mortality among the study population, with 1,264 excess deaths among those with type 1 diabetes in 2012–2014 and 7,094 excess deaths among those with type 2 diabetes in 2014 compared with the numbers of deaths expected based on the age-specific death rates of the general population. Other studies have reported similar findings relating to excess mortality in people with type 1 and type 2 diabetes (Forbes et al. 2017; Gagnum et al. 2015, 2017; Harding et al. 2014; Lind et al. 2014).

Premature deaths more likely among people with diabetes

Nearly all people (97%) with type 1 diabetes who died in 2012–2014 and 1 in 3 people with type 2 diabetes who died in 2014 were aged under 75.

Between 2009 and 2014, PYLL rates fell in the general population and among those with type 1 diabetes but increased in people with type 2 diabetes. Therefore, over this period, compared with the general population, the mortality gap did not change for those with type 1 diabetes but worsened for those with type 2 diabetes.

The high rate of premature death among people with type 1 diabetes is reflected in their lower life expectancy. Other research has shown that life expectancy is around 12 years less for people with type 1 diabetes compared with the general population (Huo et al. 2016; Livingstone et al. 2015). Early onset of type 1 diabetes has been shown to be a predictor of premature mortality (Huo et al. 2016). Research has also shown that CVD, diabetic coma and diabetic ketoacidosis, especially in younger people, are large contributors to the lower life expectancy among people with type 1 diabetes (Livingstone et al. 2015). This suggests that to reduce premature deaths, it is important to focus both on the acute metabolic complications and the chronic cardiovascular complications of type 1 diabetes (Huo et al. 2016).

Studies have also shown that life expectancy is lower among people with type 2 diabetes, by around 5 to 12 years, compared with the general population (Franco et al. 2007; Manuel & Schultz 2004; Roper et al. 2001), with research suggesting that this is due both to a higher incidence of potentially fatal complications and a higher risk of death following these complications (Almdal et al. 2004).

Gap in all-cause death rates narrowed for people with type 1 diabetes but widened for people with type 2 diabetes

Between 2009 and 2014, all-cause death rates for the general population fell slightly. Over the same period, death rates for people with type 1 diabetes fell more steeply than in the general population, but they rose for people with type 2 diabetes. This means that the relative gap narrowed for people with type 1 diabetes but widened for people with type 2 diabetes.

Among those with type 1 diabetes, death rates fell for both males and females between 2009 and 2014, but did not decline across all age groups. Death rates fell in those aged 45 and over, but did not change for younger people.

The fall in death rates among people with type 1 diabetes is likely due to improvements in management and care, particularly clinical guidelines emphasising the importance of keeping blood sugar levels within the target range, as well as other measures to prevent the development of, and treat, chronic complications of diabetes (Harding et al. 2014, 2016; Secrest et al. 2010b). There is also some evidence that improvements in diabetes care have delayed the progression of chronic kidney disease (Hahr & Molitch 2015).

The increase in death rates for people with type 2 diabetes between 2009 and 2014 was higher for females than males, and occurred across all age groups, except 65–74. The largest increase was among those aged 85 and over.

For the study population with type 2 diabetes, the increase in all-cause death rates was mainly driven by a 23% increase among those aged 85 and over. This may relate to better management of the disease and its complications, which could be causing a shift to an older age at death over time (Muschik et al. 2017). Death rates from cancer, COPD and dementia all increased markedly between 2009 and 2014 for people aged 85 and over with type 2 diabetes, reflecting the high prevalence of coexisting conditions in the ageing population with type 2 diabetes. In contrast, over this period, there was very little change in death rates for COPD and dementia did increase among the general population aged 85 and over, the increases were much smaller than those for people with type 2 diabetes of the same age (AIHW 2017b, 2017c, 2017d). The most dramatic change was for dementia, for which mortality rates increased by 70% over the study period. Note that dementia mortality for the total Australian population aged 85 and over also increased between 2009 and 2014 but to a lower degree by 24%.

Type 2 diabetes is associated with an increased incidence of dementia as well as onset of dementia at a younger age (Davis et al. 2017). In 2011, diabetes was responsible for 5% of the dementia burden or 8,000 DALY (AIHW 2016c). Dementia poses more challenges for management of diabetes in older people, as it impacts on their ability to understand and self-manage their condition and also puts them at greater risk of hypoglycaemia than older people without dementia (Bunn et al. 2016).

Death rates increased with socioeconomic disadvantage and remoteness

The study found that all-cause death rates for people with diabetes were higher than in the general population across all 5 socioeconomic groups. Further, socioeconomic disadvantage was associated with higher all-cause mortality rates in both people with type 1 and type 2 diabetes. This is consistent with studies in Sweden and Scotland that reported that socioeconomic disadvantage was associated with higher risk for all-cause mortality in people with type 1 or type 2 diabetes (Rawshani et al. 2015, 2016; Walker et al. 2016).

In combination, socioeconomic disadvantage and diabetes may further heighten all-cause mortality risk (Kim et al. 2016). Many factors might contribute to higher mortality in people with diabetes and socioeconomic disadvantage, such as disparities in health behaviours (Pampel et al. 2010), higher rates of cardiovascular risk factors (Bihan et al. 2016) and inequality in accessing health services (Korda et al. 2009).

Death rates by remoteness were not reported for people with type 1 diabetes, due to small numbers. Death rates for people with type 2 diabetes were 1.5–1.9 times as high as the general population across all geographical areas, with the highest rate experienced in *Remote and very remote* areas. These findings are consistent with other Australian studies showing higher death rates for people in remote areas (AIHW 2014b; Chondur et al. 2014; Magliano et al. 2015). People living in rural and remote areas may find it difficult to access services and maintain continuity of care (ABS 2016b). Rural and remote communities are also associated with socioeconomic disadvantage and have a higher proportion of Indigenous Australians, and the complex interaction between these factors has been shown to lead to substantial variation in access to, and use of, health services (AIHW 2015).

Leading causes of death

Diabetes, CHD and cerebrovascular disease were the most common underlying causes of death among people with type 1 and type 2 diabetes. Kidney failure was also a common underlying cause of death for people with type 1 diabetes, while dementia (including Alzheimer disease) was also a leading underlying cause among those with type 2 diabetes. Diabetes was recorded as an associated cause of death in around 50% of deaths where CVD or dementia was the underlying cause, compared with 30%–40% of COPD and kidney failure deaths. Previous studies have similarly found that diabetes is most frequently co-reported with cardiovascular causes of death (Cheng et al. 2008; McEwen et al. 2011; Thomason et al. 2005). This association has been linked to glycaemic control, with 1 study finding that in people with diabetes who had very poor glycaemic control, the risk of death from cardiovascular causes was 10 times as high as that of the general population (Lind et al. 2014).

Diabetes with ketoacidosis was also a common cause of death in people with type 1 diabetes, and, in those under 45, accounted for almost 2 in 5 deaths where diabetes was the underlying cause. Other studies have also found that excess mortality in young people with type 1 diabetes is predominately due to acute diabetic complications such as ketoacidosis (Lind et al. 2014; Secrest et al. 2010a).

Improvement in diabetes death rates among people with type 1 and type 2 diabetes but CVD death rates fell only for those with type 1 diabetes

Between 2009 and 2014, death rates from diabetes as the underlying cause of death fell by around 10% among both people with type 1 and type 2 diabetes. In contrast, age-standardised diabetes death rates in the general population remained relatively flat over the same period (AIHW 2017a).

Death rates from CVD fell markedly among the general population from 2009 to 2014. In people with type 1 diabetes, CVD death rates fell even more sharply than in the general population but there was little change in rates among people with type 2 diabetes.

The fall in CVD death rates among those with type 1 diabetes is consistent with a previous Australian study based on the same diabetes population (Harding et al. 2016) and with a contemporary Swedish study (Petrie et al. 2016). The results in our study may also help to explain the findings from other research which has suggested that the life expectancy of people with type 1 diabetes has improved by around 2 years, given that CVD has been shown to be the largest contributor to their lower life expectancy (Huo et al. 2016; Petrie et al. 2016).

The fall in CVD death rates in people with type 1 diabetes occurred across all age groups and was largest in those aged 65 and over. This may be partly due to improvements in diabetes management and care over time. More widespread use of blood lipid lowering and blood pressure lowering medicines in the past 2 decades may have helped to reduce CVD risk factors in people with type 1 diabetes (AIHW 2007). Despite the fall in CVD death rates for people with type 1 diabetes, the rate is still around twice as high as in the general population.

Studies have shown that CVD and chronic kidney disease contribute to excess mortality in people with diabetes, especially after 10 years from the onset of diabetes (Groop et al. 2009; Livingstone et al. 2012; Secrest et al. 2010a). In these studies, excess mortality in people with diabetes was found to be substantially higher with worsening control of blood sugar levels, impaired kidney function and severe renal complications. However, people with diabetes with well-controlled blood sugar levels and normal kidney function still had a higher risk of death than those without diabetes (Lind et al. 2014; Tancredi et al. 2015). These findings may partly explain why our study found that the death rate from CVD among people with type 2 diabetes was considerably higher than in the general population and that the trend in the CVD death rate over time had not followed the same improvement as that experienced in the general population. This has resulted in the CVD mortality gap widening for people with type 2 diabetes between 2009 and 2014.

5.2 Value of linked data studies

Mortality is an important population health measure. While it is possible to examine mortality from diabetes in Australia using deaths data, it is not possible to determine how many people with diabetes die. One reason for this is that diabetes is often omitted from death certificates, either because diabetes itself may not be involved in the death or it was not listed by the certifying doctor.

A strength of this study is that it examines causes of death and death rates among a cohort of people with diagnosed diabetes—rather than relying solely on cause of death information on death certificates—therefore providing a more comprehensive picture of diabetes-related deaths in Australia. Accurately estimating mortality due to particular diseases, such as

diabetes, can assist to guide health interventions and clinical care, and to inform health policy and service planning.

Between 2009 and 2014, there were 90,047 deaths where the death certificate had diabetes coded as the underlying or associated cause of death (based on the NMD). In contrast, this study (using linked data) found there were 156,123 deaths of people with type 1 or type 2 diabetes who were registered with the NDSS over the same period. Even though diabetes would not be involved in all of the latter deaths (56% had diabetes recorded on the death certificate), it is evident that the data from death certificates only do not provide a complete picture of deaths among people with diabetes. Using linked data was also able to highlight that diabetes was recorded on the death certificate more commonly among people with diagnosed type 1 diabetes than those with diagnosed type 2 diabetes (60% and 42%, respectively).

5.3 Limitations of mortality data

Cause of death data in Australia are of very high quality. Each death is certified by a doctor or coroner and the information is provided to the ABS through the Registrar of Births, Deaths and Marriages in each state and territory. The National Coronial Information System provides information for deaths certified by a coroner. The information is then processed, coded to an international standard and validated (ABS 2016a).

However, there are some issues with the reliability and validity of cause of death data for people with diabetes. These problems can stem from inaccuracy of diagnosis, changing perceptions of the causal role of diseases, improper completion of death certificates and variation in interpreting causal sequences leading to death (Harriss et al. 2011; Lu et al. 2005, 2006, 2010; Sington & Cottrell 2002; Tierney et al. 2001). Reporting the cause of death can be especially difficult in people who have multiple chronic conditions because the cause of death may not be due to a single disease. Further, not everyone with diabetes dies from diabetes. To address this, the study has examined multiple causes of death, as well as underlying cause of death, among people with diabetes.

It should be noted that reporting of diabetes on death certificates may have improved over the study period because of its increasing prevalence has resulted in a greater focus on diabetes in Australia, as has occurred overseas (McEwen et al. 2011). Further, changes in mortality coding by the ABS resulted in a small increase in deaths attributed to type 2 diabetes that occurred towards the end of the study period, affecting deaths registered from 2013 onwards (ABS 2015). These coding changes aim to reveal in mortality data the link between diabetes and conditions that are complications of diabetes, and that are often recorded as underlying causes of death, such as chronic kidney disease. Consequently, mortality data should now provide a more accurate measure of the impact of diabetes than previously.

5.4 Conclusion

This study found that people with diagnosed type 1 or type 2 diabetes in Australia have higher all-cause mortality rates than the general population. Premature deaths are also more likely among people with diabetes. Although death rates fell for people with type 1 diabetes over 2009–2014, they rose for people with type 2 diabetes.

These findings indicate there is much room for improvement. The International Diabetes Federation has stated that a substantial proportion of diabetes-related deaths could be potentially avoided or delayed through public health action directed at preventing diabetes and its complications, early detection of diabetes and improvements in care for people with diabetes (IDF 2015).

The combination of Australia's ageing population and increasing diabetes prevalence means the number of older people with type 2 diabetes will continue to rise. The complexities of diabetes care associated with ageing are a big challenge for the health system. This study provides evidence that can help plan for the care of the older population with type 2 diabetes, many of whom have coexisting conditions that add to the complexity of care.

This study also illustrates how linked data can provide a more comprehensive picture of diabetes-related deaths than routine deaths data alone.

Appendix: Methods and statistical notes

Data sources

National Diabetes Services Scheme

The National Diabetes Services Scheme (NDSS) was established in 1987 and is administered by Diabetes Australia. It is an initiative of the Australian Government to subsidise the supply of diabetes-related products—such as pens and needles to administer insulin, blood glucose test strips and insulin pump consumables—to people who are registered with the scheme. A diagnosis of diabetes, that a health professional has substantiated, is required in order to register with, and purchase products through, the NDSS.

The NDSS was used to identify the population with diagnosed diabetes. Not all people with type 1 and type 2 diabetes may register with the NDSS. However, given the benefits that the NDSS provides to people with diabetes, it is assumed that it captures a high proportion of the diabetes population in Australia and therefore it has been used in this report as the denominator population for calculating death rates for the study period from 2009 to 2014.

NDSS registrant data

The NDSS registrant data are held by Diabetes Australia, under the custodianship of the Department of Health. The NDSS records include demographic and diabetes information for all people with diagnosed diabetes who are registered. Diabetes diagnosis is confirmed by a general practitioner, endocrinologist, other specialist or a credentialed diabetes educator. Information on the type of diabetes diagnosed is provided by a doctor or a certified diabetes educator, while the date of diagnosis is provided by the registrant at the time of first registration with the scheme.

NDSS sales data

These data provide information about diabetes-related products—such as pens and needles to administer insulin, blood glucose test strips and insulin pump consumables—that are subsidised by the scheme and purchased by NDSS registrants.

For this project, NDSS sales data were used to determine diabetes type and insulin use among NDSS registrants.

Limitations of NDSS data

The coverage of the Australian population with diabetes registered with the NDSS is unknown, although it is thought to be relatively high, especially where diabetes-related products are required for management purposes. Based on linked data from the NDSS and Pharmaceutical Benefit Scheme (PBS) insulin claims data, the Australian Institute of Health and Welfare (AIHW) found that between 1 July 2002 and 30 June 2012 around 8% of people who purchased insulin through the PBS were not registered on the NDSS (AIHW 2016b). The NDSS will not be able to capture those who have undiagnosed diabetes, which is estimated by the Australian Bureau of Statistics (ABS) to be 1 in every 4 people with diagnosed diabetes (ABS 2013). The NDSS may also underestimate those who manage their diabetes primarily by regulating their diet and with an adequate level of physical activity (AIHW 2009). Coverage of the NDSS may also be lower in remote areas of Australia as other programs are available in these areas to assist with the purchase of diabetes-related products (see below) (AIHW 2016b).

The NDSS is an administrative database and undergoes changes to improve the quality of the service, which may impact on the trend analysis in this study (AIHW 2016b). The system has undergone 2 major known structural changes: in 2002 a new system improved the collection of data fields; and in 2010 there was a change to the retention of historical information so that any change to information was not permanently overwritten, which resulted in an improved level of checking and information retention.

There were changes in classification of diabetes type in 2002–2003 from insulin-dependent diabetes mellitus (IDDM) and non-insulin-dependent diabetes mellitus (NIDDM) to type 1 and type 2 diabetes in the NDSS database that impact on the number of registrants with insulin-treated type 2 diabetes. All registrants that were registered as IDDM before this date were classified as type 1 diabetes, resulting in people with insulin-treated type 2 diabetes being misclassified as having type 1 diabetes. Some records may remain misclassified, despite efforts to correct them, which may inflate the number of registrants with type 1 diabetes and subsequently reduce the number of registrants with insulin-treated type 2 diabetes before 2002–2003.

Another limitation is the extent of missing data for some variables in the NDSS database, such as diagnosis date (AIHW 2014c), although administrative processes around collecting information through the NDSS form have improved over time. Further, in the case of missing information for date variables, the AIHW can use proxy variables to ensure the data set is as complete as possible. For example, in this study, where date of diagnosis was missing, NDSS registration date was used as a proxy (see the 'Data quality checks' section below for more information).

One variable for which the extent of missing data has a considerable impact is diagnosis date, which is used in the derivation of diabetes type in this study. Although NDSS data are available from 1987, a considerable proportion of registrants who registered with the NDSS in its early years of operation have a missing diagnosis date. In particular, this has a major impact on the derivation of diabetes type for older registrants with reported type 1 diabetes who may have been diagnosed a long time before registering with the NDSS but whose date of diagnosis is missing in the NDSS database. An examination of the number of people aged 65 and over who were registered with the NDSS, and still alive on or before 30 June of each year from 2003 to 2014, showed that the percentage with a missing date of diagnosis decreased from 45% to 30% between 2003 and 2009 and then continued to fall to 22% by 2014. Therefore, to minimise misclassification of derived diabetes type, it was decided to restrict the study period to the period from 2009 to 2014.

Taking these limitations into account, the NDSS data were considered to be of good quality from 2009 onwards and, as data for 2014 were the latest available at the time of analysis, the study period for the analysis was restricted to the period from 2009 to 2014.

Coverage in remote areas

NDSS Access Points assist in delivering support services and products to people with diabetes in all states and territories. These Access Points may be limited in rural Australia and unavailable in remote communities, with other programs being available in these areas to assist with the purchase of diabetes-related products. As a result, the coverage of the NDSS may be lower in remote and very remote areas or across states and territories with large remote communities.

Coverage of Indigenous Australians

Analysis by Aboriginal and Torres Strait Islander status was not undertaken for this study as the NDSS may underestimate the number of Aboriginal and Torres Strait Islander registrants for several reasons:

- Aboriginal and Torres Strait Islander status—identifying as being of Indigenous origin when registering with the NDSS is voluntary.
- There were changes in the recording of Indigenous status in 2005 for new registrants to the NDSS (AIHW 2014c). Before 2005, the default for no response was non-Indigenous, but from 2005 onwards, the default became 'not stated'.
- Accessing diabetes-related products through programs other than the NDSS—the existence of other programs that provide Indigenous Australians access to diabetes-related products—may result in low registration rates for the NDSS among Aboriginal and Torres Strait Islander people. For example, programs operating under Section 100 of the *National Health Act 1953*—such as Aboriginal Medical Services and the National Aboriginal Community Controlled Health Organisation—provide Indigenous Australians access to free and subsidised products that people with insulin-treated diabetes need. In addition, NDSS Access Points are not always available in remote areas, limiting the access of many Australians to NDSS services.

Australasian Paediatric Endocrine Group clinic-based state and territory diabetes registers

The Australasian Paediatric Endocrine Group (APEG) is a professional body that represents health professionals involved in the management and research of disorders of the endocrine system, including diabetes, in children and adolescents. The APEG maintains clinic-based state and territory diabetes registers.

APEG data were combined with NDSS data in this study, to ensure that the prevalent population with diagnosed type 1 and type 2 diabetes was a complete as possible.

National Death Index

The National Death Index (NDI) is an Australian Government database that contains records of deaths registered in Australia since 1980. Data come from Registrars of Births, Deaths and Marriages in each jurisdiction, the National Coronial Information System and the ABS. The NDI is designed to facilitate the conduct of epidemiological studies and its use is strictly confined to medical research (AIHW 2012b). Ethics approval is required for the NDI to be used for any particular research project.

The NDI database comprises the following variables for each deceased person: surname (including maiden names, where appropriate), given names (up to 3), sex, date of birth, address at time of death, date of death, state/territory where death was registered, year of death registration, underlying and other causes of death (based on the International Statistical Classification of Diseases and Related Health Problems, 10th Revision (ICD-10) since 1997), Indigenous status (only data for New South Wales, Queensland, Western Australia, South Australia and the Northern Territory are considered by the ABS to be of sufficient quality for analysis of deaths data by Indigenous status), marital status and region of address at time of death (AIHW 2017e).

The NDI data used for this report are based on year of death rather than year of death registration but cover deaths registered from 2009 to the end of 2015. Causes of death data for deaths registered in 2012 and earlier are based on the final data; deaths registered in

2013 and 2014 are based on revised and preliminary data, respectively, and are subject to further revision by the ABS.

Records from the NDSS, combined with APEG data, were linked to the NDI and used to calculate the mortality data presented in this report.

Note that the AIHW is not able to confirm the correctness or completeness of the death registration data provided for the NDI; however, it is expected that some death registration details may contain errors and some information that is critical might be missing (AIHW 2012b). The AIHW uses a probabilistic data-linking technique to link researchers' data to the NDI. Consequently, the linkage result is an indication or index of death, rather than an absolute fact of death. Incorrect linkages can result because of errors or incorrect details in personal information supplied when deaths are registered.

The Data Quality Statement underpinning the NDI can be found at (AIHW 2012b) http://meteor.aihw.gov.au/content/index.phtml/itemId/480010>.

National Mortality Database

The National Mortality Database (NMD) holds records for deaths in Australia from 1964 to 2014. The database comprises information about causes of death and other characteristics of the person, such as sex, age at death, area of usual residence and Indigenous status (only data for New South Wales, Queensland, Western Australia, South Australia and the Northern Territory from 1998 onwards are considered by the ABS to be of sufficient quality for analysis of deaths data by Indigenous status). The cause of death data are sourced from the Registrars of Births, Deaths and Marriages in each state and territory, and the National Coronial Information System, and compiled and coded by the ABS. The NMD data were used in this report to estimate mortality rates in the general population, whereas the linked NDSS–NDI data were used to estimate mortality rates in the study population.

The Data Quality Statements underpinning the AIHW NMD can be found in the following ABS publications:

- ABS quality declaration summary for Deaths, Australia (ABS cat. no. 3302.0)
 http://www.abs.gov.au/Ausstats/abs@.nsf/0/9FD0E6AAA0BB3388CA25750B000E3CF5;
 OpenDocument>.
- ABS quality declaration summary for Causes of death, Australia (ABS cat. no. 3303.0) http://www.abs.gov.au/Ausstats/abs@.nsf/0/D4A300EE1E04AA43CA2576E800156A24 ?OpenDocument>.

For more information on the AIHW NMD see *National Mortality Database (NMD)* https://www.aihw.gov.au/about-our-data/our-data-collections/national-mortality-database>.

The mortality data used for this report are based on year of death rather than year of death registration but cover deaths registered from 2003 to the end of 2014. As some deaths that occurred in 2014 may not have been registered that year, the results for 2014 presented in this report are likely to be an underestimate for that year. Causes of death data for deaths registered in 2012 and earlier are based on the final data; deaths registered in 2013 and 2014 are based on revised and preliminary data, respectively and are subject to further revision by the ABS.

In 2014, the ABS implemented Iris, a software program which automatically assigns codes from the ICD-10 to the diseases and conditions listed on the death certificate and then applies decision tables to select the underlying cause of death. This has resulted in a greater number of conditions that link to type 2 diabetes to form a combination code for underlying cause of death output (ABS 2015). Combination codes occur when 2 or more conditions on

the death certificate link and combine to form 1 code. For example, an increased number of kidney disease codes are linking with type 2 diabetes code E11 to output as E11.2 *Type 2 diabetes mellitus with renal complications*, which has resulted in an increased number of deaths assigned to an underlying cause of E11.2 (ABS 2015). These changes apply to deaths registered from 2013 onwards.

While cause of death data in Australia are of very high quality, various studies have shown that that diabetes may not always be listed on death certificates of people known to have diabetes (McEwen et al. 2011; Roper et al. 2002; Tseng 2004). There are several reasons for this, including that diabetes itself may not directly lead to death; instead, death may be due to a complication of diabetes. Further issues around inaccuracy of diagnosis, changing perceptions of the causal role of diseases, improper completion of death certificates, variation in interpreting causal sequences leading to death, and identifying a single disease among those with multiple chronic conditions may lead to diabetes being omitted from death certificates. As a result, the findings presented in this report may underestimate diabetes-related deaths.

Data linkage

There are 2 methods commonly used in the data linkage process: deterministic and probabilistic linkage. Deterministic linkage is applied when there is 1 or several identifiers, such as Medicare numbers, that match completely between data sets. Probabilistic linkage involves the matching of partially identifying variables, such as name, age and sex. It is used when a unique identifier is not available. Agreement and disagreement weights for each variable are calculated according to standardised formulas. Links are accepted as true matches, or rejected based on predetermined weights thresholds. The probabilistic linkage method was used in this report.

The AIHW Ethics Committee approved this project for linkage.

Data quality checks

The AIHW undertook data validation and data quality checks with the NDSS–NDI linked data set before analysis. Data cleaning tasks included:

- checking data consistency between NDI and NDSS data. When discrepancies between the data sets were found on variables such as sex and state of usual residence, demographic information from the NDI was used as it is believed to be updated more regularly than the NDSS database
- classifying underlying cause of death and associated cause of death using an AIHW-modified version of the classification recommended by the World Health Organization for deriving leading cause of death (Becker et al. 2006)
- checking the diabetes diagnosis date variable from the NDSS data for missing values. Analysis of the linked NDSS data showed that between 2009 and 2014, the percentage of NDSS registrants who were missing a diagnosis date fell from 26% to 20%. Missing data mostly occurred among older NDSS registrants who potentially were diagnosed before the register was established and therefore were more likely to have a missing diagnosis date. The percentage of NDSS registrants aged 65 and over with a missing diagnosis date fell from 30% to 22% between 2009 and 2014, while for those aged under 65 the percentage fell from 22% to 18%. For people with a missing diagnosis date, the NDSS registration date was used as a proxy

 checking the date of death variable against dates of birth/diagnosis/registration/insulin injection/insulin product purchase. Those who had any of these dates after the date of death were deemed as invalid and excluded from analysis (less than 1% of all the NDSS registrants who died between 2009 and 2014).

Data issues

Determining insulin use

Insulin users were identified based on NDSS sales data. NDSS registrants who had records for insulin pens/needles purchase or insulin pump consumables purchase and those who had a first insulin purchase date or injection date recorded in the NDSS database were deemed insulin users. The first insulin injection date recorded in the NDSS database was compared with the first insulin products purchase date and the earliest date was used as the date for the first insulin use.

Derivation of diabetes type

Diabetes type is classified by a health practitioner at the time of NDSS registration; however, the recorded type might not always be correct as the symptoms of type 1 and type 2 diabetes may be similar, particularly in young adults (AIHW 2016b). In addition, there were changes in classification of diabetes type in 2002–2003 from insulin-dependent diabetes mellitus (IDDM) and non-insulin-dependent diabetes mellitus (NIDDM) to type 1 and type 2 diabetes in the NDSS database that impact on the number of registrants with insulin-treated type 2 diabetes. Therefore, in this report, diabetes type was derived based on an algorithm proposed by Harding et al. (2016). The algorithm was applied to the NDSS data set before calculating the NDSS population.

First, NDSS registrants with a missing diabetes diagnosis date were allocated a proxy diagnosis date based on their date of registration with the NDSS. However, while this is probably reasonable for younger people with recorded type 1 diabetes, it may not be for older people with recorded type 1 diabetes (see below) or for people with type 2 diabetes who may not register with the NDSS until they have more complex care requirements later in the course of the disease.

Type 1 diabetes was then assigned to NDSS registrants who satisfied all 3 of the following conditions:

- recorded as having type 1 diabetes in the NDSS database
- diagnosed aged under 45
- using insulin.

In addition, NDSS registrants were reclassified as having type 1 diabetes if they met all 4 of the following criteria:

- recorded as having type 2 diabetes in the NDSS database
- diagnosed aged under 30
- using insulin
- the time between diagnosis and first insulin use was less than 1 year.

Diabetes type did not change for other NDSS registrants who were recorded as having type 2 diabetes.

The age cut-offs in the algorithm were chosen to minimise the misclassification of type 1 diabetes. But, it is possible that some people with late-onset type 1 diabetes were misclassified as having type 2 diabetes. However, the proportion of misclassification is expected to be small.

As noted above, the derived diabetes type algorithm uses date of registration as a proxy for diagnosis date for NDSS registrants for whom date of diagnosis is missing. One group in the study population for which the use of this proxy date has a major impact is those with recorded type 1 diabetes who would have been aged 45 and over in 1987, the year the NDSS was established, as this group is likely to represent a significant proportion of the type 1 diabetes population at that time. Between 2003 and 2008, the percentage of NDSS registrants with reported type 1 diabetes who had a missing date of diagnosis and were aged 45 and over in 1987 fell from 42% to 30%. Between 2009 and 2014, this percentage had fallen further from 28% to 17%. This suggests that the extent of misclassification of derived diabetes type for people with reported type 1 diabetes has probably reduced in recent years, and therefore the study period for analysis was restricted to the period from 2009 to 2014.

To estimate the level of misclassification of the algorithm, derived diabetes type was checked against the diabetes type reported in the NDI data for deaths among the study population where diabetes was the underlying cause of death. Between 2009 and 2014, there were 20,098 deaths among the study population with derived type 1 or type 2 diabetes with an underlying cause of death of diabetes on the NDI (Table A1). Of these deaths, 48% had unspecified diabetes coded as the underlying cause of death. Eight per cent of deaths among persons with derived type 2 diabetes were coded as having type 1 diabetes as the underlying cause of death on the NDI, and 14% of deaths among those with derived type 1 diabetes were coded as having type 1 diabetes type 1 diabetes were coded as having type 1 diabetes type 1 diabetes were coded as having type 1 diabetes type 1 diabetes were coded as having type 2 diabetes.

| | | | | Unde | rlying cause | of deat | h on the NDI | | | |
|--------------------------|----------|-----|-----------|------|-------------------|---------|-------------------|-----|--------|-----|
| | Type 1(E | 10) | Type 2 (E | 11) | Other (E12, E1 | 3) | Unspecif (E14) | ied | Tota | I |
| Derived diabetes type | Number | % | Number | % | Number | % | Number | % | Number | % |
| Type 1 | 390 | 38 | 144 | 14 | 0 | 0 | 500 | 48 | 1,034 | 100 |
| Type 2 | 1,610 | 8 | 8,313 | 44 | 5 | 0 | 9,136 | 48 | 19,064 | 100 |
| Total | 2,000 | 10 | 8,457 | 42 | 5 | 0 | 9,636 | 48 | 20,098 | 100 |

Table A1: Deaths with an underlying cause of diabetes among the study population by derived type of diabetes and underlying cause of death, 2009–2014

Source: AIHW analysis of NDSS-NDI linked data.

Identification of populations

Study population

The NDSS, combined with APEG data, was used as the data source to identify the prevalent population with diagnosed type 1 and type 2 diabetes. As most people with diabetes who are registered with the APEG are also registered with the NDSS, the combined NDSS and APEG data are referred to in this report as NDSS data. NDI data were linked to the NDSS data to establish vital status and, where relevant, date and cause of death of NDSS registrants.

The study population included all NDSS registrants with derived type 1 or type 2 diabetes who were registered with the NDSS between 2009 and 2014, including all those who registered before 2009 and were still alive on 1 January 2009.

Between 2009 and 2014, the study population with type 1 diabetes increased by 12%, from 77,438 to 86,936 people (Figure A1; Table B49). Over the same period, there was an 18% increase in the study population with type 2 diabetes, from 867,631 to 1,026,333 people.



Characteristics of the study population in 2014

As at 30 June 2014, the study population included 86,936 people with derived type 1 diabetes (8%) and 1,026,333 people with type 2 diabetes (92%). Among those with type 1 diabetes, 52% were male and 48% were female, while among those with type 2 diabetes, 54% were male and 46% were female.

The age distribution of the study population in 2014 differed substantially by diabetes type. Among those with type 1 diabetes, 32% were aged under 30, 63% were aged 30–64 and only 6% were aged 65 and over (Figure A2). In contrast, among those with type 2 diabetes, a very small percentage (1%) were aged under 30, while more than half were aged 65 and over (55%) (Figure A2).



General population

In this report, the general population is the total Australian population. Death rates between 2009 and 2014 for the general population were calculated using data from the AIHW NMD (see Box 2.1). The population used for the calculation of death rates was the ABS estimated resident population (ERP) estimates as at 30 June between 2009 and 2014, which were sourced from ABS Australian demographic statistics (ABS cat. no. 3101.0) as at December 2016 (ABS 2017). The ABS derives these ERPs from its Census of Population and Housing,

and adjusts them for deaths, births and net migration. Between 2009 and 2014, the ERP as at 30 June increased from 21,691,653 to 23,460,694 persons (ABS 2017).

Classifications

Disease classifications

Causes of death data presented in this report have been classified using an AIHW-modified version of the method described by Becker et al. (2006). The relevant codes for deaths during the period covered by the report are provided in Table A2.

 Table A2: ICD-10 codes used to define conditions recorded as the underlying or associated cause of death

| Conditions | ICD-10 codes |
|---|-------------------|
| Cardiovascular disease | 100–199 |
| Coronary heart disease | 120–125 |
| Cerebrovascular disease ^(a) | 160–169 |
| Heart failure and complications and ill-defined heart disease | I50–I51 |
| Hypertensive disease | I10–I15 |
| Cancer | C00–C97 |
| Lung cancer | C33, C34 |
| Pancreatic cancer | C25 |
| Colorectal cancer | C18–C21 |
| Cancer, unknown, ill-defined | C26, C39, C76–C80 |
| Diabetes | E10–E14 |
| Kidney failure | N17–N19 |
| Chronic obstructive pulmonary disease (COPD) | J40–J44 |
| Dementia and Alzheimer disease ^(a) | F01, F03, G30 |
| Septicaemia | A40–A41 |
| Liver disease | K70–K76 |
| Accidental poisoning | X40–X49 |
| Suicide | X60–X84 |

(a) There have been updates to the ICD-10 coding instructions resulting in deaths that may have previously been coded as cerebrovascular diseases (which include stroke) being coded as vascular dementia (ABS 2016a).

Socioeconomic group

The Index of Relative Socio-economic Disadvantage (IRSD) is 1 of 4 Socio-Economic Indexes for Areas developed by the ABS. This index is derived from social and economic characteristics of the local area, such as low income, low educational attainment, high levels of public-sector housing, high unemployment and jobs in relatively unskilled occupations. Because the IRSD summarises variables that indicate disadvantage, a low score indicates that an area has many low-income families, many people with little training and many people working in unskilled occupations, and this area may be considered as disadvantaged relative to other areas. It is important to understand that a high score reflects a relative lack of disadvantage rather than advantage. The IRSD is not a person-based measure; rather, it is an area-based measure of socioeconomic disadvantage that relates to the average disadvantage of all people living in the geographical area. This information is used as a proxy for the socioeconomic disadvantage of people living in those areas and may not be correct for each person in that area.

In this report, the first socioeconomic group corresponds to geographical areas containing the 20% of the population with the greatest socioeconomic disadvantage according to the IRSD, and the fifth group corresponds to the 20% of the population with the least socioeconomic disadvantage.

For all populations in this report, socioeconomic groups were assigned to deaths according to the postcode of residence at the time of death.

Remoteness areas

The remoteness areas divide Australia for statistical purposes into broad geographical regions that share common characteristics of remoteness. The Remoteness Structure, which divides each state and territory into several regions on the basis of their relative access to services, has 6 classes of remoteness area: *Major cities, Inner regional, Outer regional, Remote, Very remote* and *Migratory.* The category *Major cities* includes Australia's capital cities, except for Hobart and Darwin, which are classified as *Inner regional.* Remoteness areas are based on the Accessibility and Remoteness Index of Australia, produced by the Australian Population and Migration Research Centre at the University of Adelaide.

For the study population, mortality rates by remoteness area were calculated using the remoteness category for each deceased registrant on the linked NDSS–NDI data set. The remoteness categories of *Remote* and *Very remote* were combined into the 1 category of *Remote and very remote*, and registrants with a remoteness category of *Migratory* were excluded from the remoteness areas analysis. For the NDSS population and general population, mortality rates by remoteness area were calculated by applying a correspondence from the 2011 Statistical Areas Level 2 to the 2011 remoteness areas.

Statistical methods

Age-specific rates

Age-specific rates provide information on the incidence of a particular event in an age group relative to the total number of people at risk of that event in the same age group. It is calculated by dividing the number of events occurring in each specified age group by the corresponding 'at-risk' population in the same age group and then multiplying the result by a constant (for example, 100,000) to derive the rate. All age-specific rates in this report are presented as the number of cases per 100,000 population.

Age-standardised rates

A crude rate provides information on the number of, for example, deaths in the NDSS population in a specified period. No age adjustments are made when calculating a crude rate.

Age-standardisation is a method used to eliminate the effect of differences in population age structures when comparing populations with different age structures, and where age affects the variable being compared. Age-standardisation is used in this report when comparing rates across different periods of time, different geographical areas, different socioeconomic groups, or other populations.

The direct method of age-standardisation is used throughout this report, and the standard population used is the Australian ERP as at 30 June 2001.

Mortality and potential years of life lost (PYLL) rate ratios

Mortality rate ratios provide a measure of the relative gap in age-specific, crude and age-standardised rates between 2 populations. In this report, mortality rate ratios were calculated as the mortality rate for the study population divided by the mortality rate for general population. PYLL rate ratios were calculated using a similar method.

A mortality rate ratio of 1 indicates no difference in mortality rates between the study and general populations, while a mortality rate ratio greater than 1 indicates proportionally how much higher the mortality rate in the study population is compared with the general population. For example, a mortality rate ratio of 2 indicates that the rate in the study population is 2 times as high as that in the general population.

Mortality and PYLL rate differences (mortality gap)

A rate difference is a measure of the absolute difference in rates between 2 populations. In this report, mortality rate differences were calculated as the mortality rate for the study population minus the mortality rate for general population. Similarly, PYLL rate differences were calculated as the PYLL rate for the study population minus the PYLL rate for the study population minus the PYLL rate for the study population.

A mortality rate difference of 0 per 100,000 indicates that the mortality rate for the study population is the same as the mortality rate for the general population. A mortality rate difference of greater than 0 per 100,000 indicates that the rate for the study population is higher than the rate for the general population. For example, a mortality rate difference of 200 per 100,000 indicates that there were an additional 200 deaths per 100,000 in the study population compared with the general population.

PYLL rate differences are interpreted in the same way as mortality rate differences but are expressed per 10,000 population rather than per 100,000 population.

Excess deaths

Excess deaths were calculated as the observed number of deaths in the study population minus the number of deaths expected if the age-specific death rates of the general population were applied to the study population.

Calculation of death rates

Study population with type 1 diabetes

Due to the small number of deaths among the study population with type 1 diabetes, mortality rates were calculated based on 3-year rolling averages for 2009–2011, 2010–2012, 2011–2013 and 2012–2014. For each 3-year period, rates were based on the number of deaths and the total number of people in the study population with type 1 diabetes during the 3-year period.

Study population with type 2 diabetes

The number of deaths among the study population with type 2 diabetes was large enough to calculate annual age-standardised death rates. For each year, rates were based on the number of deaths and the total number of people in the study population with type 2 diabetes in that year.
General population

When comparing mortality rates in the general population with those for the study population with type 1 diabetes, mortality rates in the general population were calculated for the corresponding 3-year rolling averages and were based on the number of deaths in the general population and the total ERP for each 3-year period.

When comparing mortality rates in the general population with those for the study population with type 2 diabetes, mortality rates in the general population were based on the number of deaths in the general population and the total ERP for each year.

It should be noted that because a different method was used to calculate mortality rates in the general population for comparison with the study population with type 1 diabetes to that used for comparison with mortality rates in the study population with type 2 diabetes, the overall percentage change in rates over time in the general population will differ depending on which study population is being compared. For example, the overall percentage decrease in all-cause mortality rates in the general population from 2009–2011 to 2012–2014 is 3% while the overall percentage decrease from 2009 to 2014 is 6%.

Glossary

age-specific rate: A rate for a specific age group. The numerator and denominator relate to the same age group.

age-standardisation: A method of removing the influence of age when comparing populations with different age structures. This is usually necessary because the rates of many diseases vary strongly (usually increasing) with age. The age structures of the different populations are converted to the same 'standard' structure and then the disease rates that would have occurred with that structure are calculated and compared.

angina: Temporary chest pain or discomfort when the heart's own blood supply is inadequate to meet extra needs, as can occur during exercise. See also cardiovascular disease and coronary heart disease.

associated cause(s) of death: All causes listed on the death certificate other than the **underlying cause of death**. They include the immediate cause, any intervening causes and conditions that contributed to the death but were not related to the disease or condition causing the death. See also **cause of death**.

cancer: Cancer, also called malignancy, is a term for diseases in which abnormal cells divide without control and can invade nearby tissues. Cancer cells can also spread to other parts of the body through the blood and lymph systems.

cardiovascular disease (CVD): Any disease of the circulatory system; namely, the heart (cardio) or blood vessels (vascular). Includes heart attack, angina, stroke, heart failure and peripheral vascular disease. CVD is also known as circulatory disease.

cause of death: The causes of death entered on the Medical Certificate of Cause of Death are all diseases, morbid conditions or injuries that either resulted in, or contributed to, death, and the circumstances of the accident or violence that produced any such injuries. Causes of death are commonly reported by the underlying cause of death. See also associated cause(s) of death and multiple causes of death.

cerebrovascular disease: Any disorder of the blood vessels supplying the brain or its covering membranes. A notable and major form of cerebrovascular disease is **stroke**.

coronary heart disease (CHD): Disease due to blockages in the heart's own (coronary) arteries, expressed as **angina** or a **heart attack**. Also known as ischaemic heart disease.

data linkage: Data linkage is a statistical procedure in which identifying information contained in 2 or more data sets is compared to determine matching records; for example, the same individual or the same institution. This can provide more information about the entity and in certain cases provide a time sequence, helping to 'tell a story', show 'pathways' and perhaps unravel cause and effect. The term is used synonymously with 'record linkage' and 'data integration'.

dementia: A general term for disorders that are characterised by worsening mental processes (such as Alzheimer disease or vascular dementia). Symptoms include impaired memory, understanding, reasoning and physical functioning.

diabetes (diabetes mellitus): A chronic condition in which the body cannot properly use its main energy source, the sugar glucose. This is due to a relative or absolute deficiency in insulin, a hormone that is produced by the pancreas and helps glucose enter the body's cells from the bloodstream and then be processed by them. Diabetes is marked by an abnormal build-up of glucose in the blood, and it can have serious short- and long-term effects. For the 3 main types of diabetes, see **type 1 diabetes**, **type 2 diabetes** and **gestational diabetes**.

diabetic ketoacidosis: Diabetic ketoacidosis is a complication of diabetes, caused by a lack of insulin. Without enough insulin, the body's cells cannot use glucose for energy and, to compensate, the body burns fat for energy. This leads to the production of high levels of blood acids, known as ketones, which are also present in the urine.

diabetic nephropathy: Disease of the capillaries of the glomeruli resulting from diabetes.

heart attack: Life-threatening emergency that occurs when a vessel supplying blood to the heart muscle is suddenly blocked completely by a blood clot. The medical term commonly used for a heart attack is **acute myocardial infarction**.

heart failure: When the heart functions less effectively in pumping blood around the body. It can result from a wide variety of diseases and conditions that can impair or overload the heart, such as **heart attack**, other conditions that damage the heart muscle directly, or a damaged heart valve.

gestational diabetes: A form of diabetes that is first diagnosed during pregnancy (gestation). It may disappear after pregnancy but signals a high risk of diabetes occurring later on.

hypertensive disease: Occurs when high blood pressure (hypertension) is severe or prolonged enough to cause damage to the heart, brain or kidneys.

hypoglycaemia: Occurs when the blood glucose level is below the normal range. If not treated quickly, it can progress to confusion, loss of consciousness and, in very rare cases, to death. Hypoglycaemia is not directly caused by diabetes, but a consequence of treatment with insulin or with sulfonylurea tablets (an oral medication that controls blood sugar levels in people with type 2 diabetes).

insulin: A hormone produced in the pancreas that helps glucose to enter body cells for energy metabolism.

International Statistical Classification of Diseases and Related Health Problems: The World Health Organization's internationally accepted classification of death and disease. The 10th Revision (ICD-10) is currently in use.

kidney disease: Kidney disease is caused by damage to small blood vessels in the kidneys leading to the kidneys becoming less efficient or failing altogether. Kidney disease is much more common in people with diabetes than in those without diabetes. The disease is caused by damage to small blood vessels, which can cause the kidneys to be less efficient, or to fail altogether. See also **diabetic nephropathy**.

mortality: Death.

multiple causes of death: All causes listed on a death certificate. This includes the underlying cause of death and all associated cause(s) of death. See also cause of death.

potential years of life lost (PYLL): Number of potential years of life lost in a population as a result of premature death. For example, if dying before the age of 75 is considered premature, then a person dying at age 40 would have lost 35 potential years of life.

stroke: When an artery supplying blood to the brain suddenly becomes blocked or bleeds. Often causes paralysis of parts of the body normally controlled by that area of the brain, or speech problems and other symptoms.

type 1 diabetes: A form of **diabetes** mostly arising among children or younger adults, marked by a complete lack of insulin and needing insulin replacement for survival.

type 2 diabetes: The most common form of **diabetes**, occurring mostly in people aged 40 and over, and marked by reduced or less effective insulin.

underlying cause of death: The disease or injury that initiated the train of events leading directly to death, or the circumstances of the accident or violence that produced the fatal injury. See also **cause of death** and **associated cause(s) of death**.

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Related publications

The following Australian Institute of Health and Welfare (AIHW) publications relating to diabetes might also be of interest:

- AIHW 2016. Incidence of insulin-treated diabetes in Australia 2014. Diabetes series no. 25. Cat. no. CVD 75. Canberra: AIHW.
- AIHW 2016. Use of medicines by older people with type 2 diabetes. Cat. no. CVD 76. Canberra: AIHW.
- AIHW 2015. Cardiovascular disease, diabetes and chronic kidney disease—Australian facts: Aboriginal and Torres Strait Islander people. Cardiovascular, diabetes and chronic kidney disease series no. 5. Cat. no. CDK 5. Canberra: AIHW.
- AIHW 2015. Cardiovascular disease, diabetes and chronic kidney disease—Australian facts: risk factors. Cardiovascular, diabetes and chronic kidney disease series no. 4. Cat. no. CDK 4. Canberra: AIHW.
- AIHW 2015. Prevalence of type 1 diabetes among children aged 0–14 in Australia 2013. Diabetes series no. 24. Cat. no. CVD 70. Canberra: AIHW.
- AIHW 2014. Cardiovascular disease, diabetes and chronic kidney disease—Australian facts: morbidity: hospital care. Cardiovascular, diabetes and chronic kidney disease series no. 3. Cat. no. CDK 3. Canberra: AIHW.
- AIHW 2014. Cardiovascular disease, diabetes and chronic kidney disease—Australian facts: prevalence and incidence. Cardiovascular, diabetes and chronic kidney disease series no. 2. Cat. no. CDK 2. Canberra: AIHW.
- AIHW 2014. Cardiovascular disease, diabetes and chronic kidney disease—Australian facts: mortality. Cardiovascular, diabetes and chronic kidney disease series no. 1. Cat. no. CDK 1. Canberra: AIHW.



This report uses linked data to provide a more complete understanding of deaths among people with diagnosed diabetes. It highlights that death rates for people with diabetes are almost double those of other Australians and that people with diabetes are more likely to die prematurely. Between 2009 and 2014, death rates fell by 20% for people with type 1 diabetes but rose by 10% for those with type 2 diabetes.

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