



**Australian Government**  
**Australian Institute of  
Health and Welfare**



# Australia's health 2020

## data insights



**AIHW**

Stronger evidence,  
better decisions,  
improved health and welfare



The background features several overlapping, semi-transparent geometric shapes in various colors: a large green shape at the top left, a blue shape to its right, a purple shape below the blue one, a large green shape at the bottom right, and an orange shape at the very bottom right. The shapes have rounded corners and are arranged in a dynamic, overlapping pattern.

Australia's  
health **2020**  
data insights

The Australian Institute of Health and Welfare is a major national agency whose purpose is to create authoritative and accessible information and statistics that inform decisions and improve the health and wellbeing of all Australians.

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Australian Government  
Australian Institute of  
Health and Welfare

AIHW



The Hon Greg Hunt MP  
Minister for Health  
Parliament House  
Canberra ACT 2600

Dear Minister

On behalf of the Board of the Australian Institute of Health and Welfare, I am pleased to present to you *Australia's health 2020*, as required under Subsection 31(1) of the *Australian Institute of Health and Welfare Act 1987*.


This edition continues the AIHW tradition of delivering high quality evidence and value-added analysis on health in Australia, and it continues the multi-format report introduced in *Australia's welfare 2019*. The report provides comprehensive coverage of topics in statistical snapshots (online) and explores new insights into topical issues, in narrative articles (print and online). This report discusses health data in Australia and includes an article on what is known about COVID-19 in Australia four months on from the first confirmed case. This report also explores how more timely data could better meet the needs of policy makers, service providers, researchers and the public.

I commend this report to you as a significant contribution to national information on health-related issues and to the development and evaluation of health systems and programs in Australia. The relevance of this report is heightened by the fact that we are in a time when it is acknowledged that availability of data and evidence is more important than ever.

Yours sincerely,

Mrs Louise Markus  
Chair  
AIHW Board  
9 June 2020

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# About *Australia's health 2020*

This edition of the AIHW's biennial flagship report on health introduces a new format and an expanded product suite:



## ***Australia's health 2020: data insights***

This is a collection of topical, in-depth articles on selected health issues, including a picture of health data in Australia. It is available online and as a print report.



## ***Australia's health snapshots***

These are web pages that present key information and data on the health system, health of Australians and factors that can influence our health. The 71 snapshots are available online in HTML and as a PDF.



## ***Australia's health 2020: in brief***

This is a short, visual report summarising key findings and concepts from the snapshots to provide a holistic picture of health in Australia. It is available online and as a print report.

All products can be viewed or downloaded at [www.aihw.gov.au/australias-health](http://www.aihw.gov.au/australias-health)

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# Preface

*Australia's health 2020* is the 17th biennial flagship report on health released by the Australian Institute of Health and Welfare (AIHW) since it was established in 1987.

The AIHW's flagship reports, *Australia's health* and *Australia's welfare*, are highly regarded by policy makers, service providers, researchers and the public as sources of independent, authoritative and accessible information. They are compiled from multiple data sources and explore different perspectives on topical and ongoing issues. By exploring how we are faring as a nation, they also serve as 'report cards' on the health and welfare of Australians.

*Australia's health 2020* continues the trend of providing independent and trusted information to the wide range of Australians who use it. It reports on our health status and health system, and takes an in-depth look at a number of topical health issues—including the links between the environment and health, and the complex role that socioeconomic factors play in our health.

Global and national events over the past year have placed health at the forefront of our minds—for individuals, families, communities, and nations. In particular, the novel coronavirus (COVID-19) continues to pose a great potential threat to health and to Australia's health system. Australian governments and the Australian community have responded well to this crisis and, as a result, it appears that Australia may have avoided some of the large adverse impacts that have been seen in some other countries. Nevertheless, COVID-19 has changed most aspects of our lives, including social, cultural and economic activities. More than any other event in recent history, this pandemic has illustrated how integral our health is to the effective functioning of society and of its support systems, including the health system.

The AIHW's core purpose—to produce authoritative and accessible information and statistics—is now more relevant than ever. Every day, data on the number of new cases and on the number of deaths related to COVID-19 have been reported in the media, and governments have needed up-to-date, timely and reliable data on health-system capacity and on the potential indirect effects of COVID-19, such as on employment, mental health and family violence. The AIHW has helped meet this immediate need by seconding staff to assist the Department of Health with its response to the crisis and by helping compile timely data for governments on Australians' use of a range of health services. (To read more on how the AIHW is assisting governments in responding to the COVID-19 crisis, see the AIHW website at <https://www.aihw.gov.au/news-media/news/2020-1/march/covid-19>).



Because of the availability of data at the time of writing, much of *Australia's health 2020* reflects 'pre-COVID Australia'. However, to present what we do know about the disease in Australia, this report includes a special article on COVID-19 prepared by the AIHW in collaboration with Associate Professor Sanjaya Senanayake, an infectious disease specialist at the Australian National University. This article draws on data and information from the 4 months since Australia's first reported case. In future publications, the AIHW will continue to incorporate information about the impact of COVID-19 on relevant health and welfare issues.

The broad scope of Australia's response measures—and their swift implementation to suppress COVID-19—have required unprecedented cooperation and data-sharing between Australian, state and territory governments. The pandemic has also emphasised the need for the AIHW, the Australian Bureau of Statistics (ABS) and other government agencies to consider how well the Australian statistical system supports the planning and delivery of health services.

Many current developments and opportunities for improving our data evidence base are explored in *Australia's health 2020*. Lessons learnt from the timely provision of data in a crisis can help improve the breadth, depth and timeliness of existing data collection and analysis. This is of particular importance when considering acute, time-sensitive issues such as mental health, suicide and intentional self-harm.

In recent years, the AIHW has also dedicated itself to improving the accessibility of its information and is continuing to move from large hard-copy publications towards more diverse and accessible formats. *Australia's health 2020* builds on the new multi-product format, first introduced in *Australia's welfare 2019*.

The *Australia's health 2020* product suite comprises: online snapshots (statistical and contextual information); *Australia's health 2020: in brief* report (key findings from the snapshots); and this report, *Australia's health 2020: data insights* (a collection of articles on timely issues). In addition, updates to the Australian Health Performance Framework (AHPF) indicators provide the latest trends in health. This new format is consistent with global moves away from large print publications towards more diverse and accessible formats.

The new print publication—*Australia's health 2020: data insights*—contains original articles on selected health issues and presents an overview of health data in Australia. The common theme across all the articles is the importance of data, and of building the evidence base for achieving long-term, sustainable improvements in health and health care for all Australians. *Australia's health 2020: data insights* presents information on how to fill data gaps and build the evidence for addressing these inequalities.

*Australia's health* includes 71 online snapshots, presenting statistical, easily digestible and interactive information on health status, determinants of health, health systems, health of population groups and the health of Aboriginal and Torres Strait Islander people. The statistical and contextual information presented in snapshots are from a number of sources—reflecting the many organisations involved in collecting and producing health data in Australia.

Australia's health snapshots are accompanied by *Australia's health 2020: in brief*, a print and online product that summarises the key concepts and findings from the snapshots. *Australia's health 2020: in brief* is accessible and visually appealing, and is for all audiences to gain an understanding of the holistic picture of health in Australia.

The AIHW manages a number of national health information assets, and works with state and territory governments, the ABS, other independent bodies and the non-government sector, to ensure the data included in *Australia's health 2020* are comprehensive, accurate and informative.

The new format and expanded suite of products for *Australia's health 2020* showcases the AIHW's commitment to its 5 strategic goals: to be leaders in health and welfare data; drivers of data improvements; expert sources of value-added analysis; champions of open and accessible data and information; and trusted strategic partners.

I would like to thank everyone involved in producing this report and to acknowledge the valuable advice provided by the many experts who reviewed draft material. We are committed to improving the usefulness and relevance of our flagship reports and we would welcome your feedback via [flagships@aihw.gov.au](mailto:flagships@aihw.gov.au).

**Barry Sandison**

CEO



# Introduction

Health is ‘a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity’ (WHO 1946).

Health influences, and is influenced by, how we feel and how we interact with the world around us. Health is broader than just the presence or absence of disease, it reflects the complex interactions of an individual’s genetics, lifestyle and environment. Generally, a person’s health depends on determinants (factors that influence health) and on interventions (actions taken to improve health, and the resources required for those interventions). These determinants can strengthen or undermine the health of individuals and communities.

Health outcomes and experiences of health are not the same for everyone and are often shaped by the distribution of wealth and resources at national and local levels (WHO 2020). Income, education, conditions of employment and social support (often known as ‘social determinants’ of health) are known contributors to health inequalities between population groups.

Compared with their more advantaged counterparts, some population groups within the community—such as Aboriginal and Torres Strait Islander people; people with disability; and people from rural and remote Australia—may experience poorer health and/or have difficulty accessing health care. These inequalities are a major focus for research and are important for monitoring population health risks and outcomes. (For example, 34% of the gap in health between Indigenous and non-Indigenous Australians is due to social determinants.)

Health systems play a crucial role in health and can help to reduce the burden that ill health places on the community. Australia’s health system is considered one of the best in the world, with many services funded and delivered by Australian, state and territory governments. Australia’s health system includes public and private hospitals; primary health care services (such as general practitioners and allied health services); and referred medical services (including many specialists).

In the past year, Australia has faced several major public health crises that have required large-scale government intervention—crises that have further highlighted how important health is to our quality of life and overall wellbeing.

The coronavirus disease (COVID-19) pandemic is a major health threat; it is highly infectious and has a higher death rate than many other infectious diseases. Since the World Health Organization (WHO) classified COVID-19 as a pandemic in March 2020, the Australian community has implemented many changes to reduce the spread of the disease. The health benefits of ‘social distancing’ measures are clear, and have resulted in a slowed spread of infection and reduced pressure on health services—but the long-term impacts of the pandemic are not yet known.

Australia has dealt with the potential threat of COVID-19 comparatively well and as a result, discussions are now focusing more on other critical aspects of overall health, including mental health. Isolation from family, friends and other support networks can negatively affect mental health and may also lead to a reduction in physical activity or to increased use of alcohol and other drugs (FARE 2020). Large-scale loss of employment, broad economic downturn and general uncertainty add to these stressors (Frasquilho et al. 2015). The social and economic impacts of COVID-19 may have a range of flow-on effects—for example, an increased incidence of family, domestic and sexual violence and a greater burden of mental health issues. In May 2020, to address some of these concerns, the Australian Government appointed the first Deputy Chief Medical Officer for Mental Health to focus on strengthening the coordinated medical and mental health response, including delivery of system reforms.

Natural disasters (such as bushfires) are known contributors to post-traumatic stress disorder, other mental health conditions and other longer-term health outcomes—adding to the immediate effects of death and trauma from the fire (Clemens et al. 2013). The unprecedented 2019–20 Australian bushfires, for example, saw intense smoke and air pollution hit areas of Australia. While the immediate threat to life has passed, the long-term impacts on our health are not yet fully known.

In the aftermath of the 2019–20 bushfires, and for the ongoing management of COVID-19, governments and policymakers need accurate, relevant and timely data to develop and implement evidence-based policies. The articles in *Australia's health 2020: data insights* illustrate how health data are crucial to improving the health of Australians and ensuring that health systems respond effectively to current and changing needs.

As a health and welfare statistical agency, the AIHW recognises that health data are crucially important for improving health for individuals and populations, as well as for monitoring trends and planning for future health needs. To understand health needs at individual and population levels, we need to be able to measure health status and to collect health data; to understand people’s interactions with multiple parts of the system—and with multiple systems—we also need to be able to link relevant data.

Box 1 summarises how Australia was faring across a range of measures before the emergence of COVID-19. While the full impact of COVID-19 on the health of Australians will not be known for some time, it is expected that COVID-19 will affect many of the statistics in Box 1, particularly elective surgery wait times and emergency department presentations.

## **Box 1: Measuring health performance: how are we faring?**

In general, Australians enjoy good health and have an effective health system. How do we know this? We use the Australian Health Performance Framework (the Framework) to describe and assess the health of our population and health system and to compare Australia with other Organisation for Economic Co-operation and Development (OECD) countries.

The Framework includes an initial set of health indicators that describe specific aspects of our health and our health system's performance. It also compares data for different population groups and different degrees of remoteness from essential services.

### **International comparisons**

Comparing Australia with other OECD countries on a range of health measures, we find that:

- Australian males have the ninth highest life expectancy at birth, and females have the seventh highest
- Australia has lower rates of deaths due to coronary heart disease than the average for OECD countries
- the obesity rate in Australia remains higher than most other OECD member countries—Australia has the fifth highest rate of obesity among the OECD countries
- Australians consumed 9.4 litres of pure alcohol per year for each person aged 15 and over. This is higher than the OECD average of 8.9 litres per person.

International comparison for selected health indicators are summarised in 'International comparisons of health data' <https://www.aihw.gov.au/reports/australias-health/international-comparisons-of-health-data>

### **Australian Health Performance Framework**

Based on the health indicators in the Framework, Australians are improving on many aspects of their health:

- **People are living longer.** In 2015–2017, life expectancy at birth (for males and females combined) was 82.5 years. This is up from 81.9 years in 2009–2011.
- **Infant and child mortality rates are down.** In 2018, the infant (aged under 1) mortality rate was 3.1 deaths per 1,000 live births—down from 4.2 deaths per 1,000 in 2009—and the child (aged 0–4) mortality rate was 72.9 deaths per 100,000 population—down from 104.6 deaths per 100,000 in 2009.
- **Decrease in potentially avoidable deaths.** In 2015–2017, there were 104 potentially avoidable deaths per 100,000 population (age-standardised rate). (These were deaths among people aged under 75 that were potentially preventable through individualised care and/or treatable through existing primary or hospital care.) This was down from 116 deaths per 100,000 in 2009–2011.

*continued:*

## **Box 1: (continued) Measuring health performance: how are we faring?**

- **Smoking rates are down.** In 2017–18, 13.8% of people aged 18 and over were daily smokers. This was down from 18.9% in 2007–08, but has remained relatively stable since 2014–15, at around 14%.
- **Fewer children are exposed to tobacco smoke in the home.** In 2019, 2.1% of households with children aged 14 and under had someone who smoked inside the home. This is down from 19.7% in 2001 and 2.8% in 2016.
- **Fewer adults are drinking alcohol at risky levels.** In 2017–18, 16.1% of people aged 18 and over consumed (on average) more than 2 standard drinks per day—exceeding the lifetime risk guideline. This is down from 20.9% in 2007–08.

A few things warrant attention:

- **More people are overweight and obese.** In 2017–18, 66.4% of people aged 18 and over were overweight or obese (age-standardised rate). This is up from 61.1% in 2007–08.
- **Elective surgery waiting times are increasing.** In 2018–19, before COVID-19, 50% of patients waited at least 41 days for admission from elective surgery waiting lists. This is up from 33 days in 2008–09.
- **Fewer emergency department presentations seen on time.** In 2018–19, before COVID-19, 71% of emergency department presentations were ‘seen on time’. This is down from 75% in 2013–14.

Health indicators in the Framework also show notable patterns for:

- **Immunisation.** In 2018–19, 94.2% of children aged 1, 91.4% of children aged 2 and 94.8% of children aged 5 had received all the scheduled vaccinations appropriate for their age.
- **Cancer survival.** In 2012–2016, 5-year relative survival for all cancers combined was 69%. (This means that people diagnosed with cancer had a 69% chance of surviving for at least 5 years, compared with their counterparts in the general population.) This was an increase from a 5-year survival rate of 51% in 1987–1991.
- **Heart attacks.** In 2017, there were 324.9 acute coronary events in the form of a heart attack or unstable angina per 100,000 people aged 25 and over (age-standardised rate). This compares with 379.2 such events per 100,000 in 2013.
- **Diabetes.** In 2017–18, 4.8% of people aged 18 and over had diabetes (age-standardised rate). This is similar to the rate in 2014–15.
- **Suicide.** In 2018, there were 12.1 deaths by suicide per 100,000 population (age-standardised rate). This compares with 10.7 deaths per 100,000 in 2009.

See <https://www.aihw.gov.au/reports-data/australias-health-performance/australias-health-performance-framework> to explore data for all indicators.

## Current focus in Australia's health:

*Australia's health 2020: data insights* examines issues related to health and health systems. It underscores both the importance of data, and of building the evidence base, in achieving long-term, sustainable improvements in health and health care for all Australians. The 10 chapters that follow present focused discussions, analyses and evidence on current issues in health data and evidence.

The report begins with **Chapter 1 'Health data in Australia'**, an overview of what the health data landscape currently looks like, and key issues and challenges faced. Robust and consistent health data practices—in terms of the availability, collection, collation and analysis of health data—are important for the planning and delivery of appropriate health care and for assessing the health system as a whole.

We have opportunities to improve the ways in which data are collected, accessed and analysed to inform how we respond to many existing or emerging challenges—including the health impacts of the recent bushfires across Australia; the emergence of COVID-19; and existing issues such as the rate of suicide in Australia. Increased use of data linkage methods may provide opportunities to better understand and address these challenges. The article also discusses data gaps and limitations; developments in health data; the AIHW's work; and the future of health data.

During crises, there is a strong need to obtain data as quickly as possible to allow for an informed, immediate response to manage the situation. Timely data, and innovative uses of data, has been vital in informing Australia's response to the challenges posed by COVID-19. **Chapter 2 'Four months in: what we know about the new coronavirus disease in Australia'**, is a point in time article that summarises what is known about the epidemic in Australia so far. While we remain in the middle of an evolving situation, with many facets of the epidemic not yet fully understood, it is apparent that Australia, at least so far, has been able to contain the epidemic when compared with many other countries. As at 7 June 2020, Australia had recorded 7,277 cases and 102 deaths. Analysis within the chapter reveals that, if Australia had experienced the same COVID-19 case and death rates as Canada, Sweden or the UK, it is estimated Australia would have had between 8 and 14 times the number of cases and around 5,000 to 14,000 extra deaths.

There are a number of potential indirect effects from changes within the health system and changes in wider society due to interventions put in place to manage the spread and impact of COVID-19. For example, the need for as many people to stay at home as possible to increase physical distancing meant that many people were isolated from family, friends and other support networks. The widespread interventions have a number of longer-term potential adverse health and welfare effects, although interventions can be put in place to reduce the risk of these. The large-scale loss of employment and the general economic downturn is a large challenge, and the longer-term effects will need to be monitored into the future.

Understanding the broad contextual factors that influence our health is important because our health is not immune to social and environmental influences. **Chapter 3 ‘Social determinants of health in Australia’** looks at how health is affected by social and economic conditions of everyday life, such as family circumstances, housing, working conditions, livelihood and education. The connections between these social factors and health outcomes are complex and occur over many years. There is now a strong evidence base to help us understand the social determinants of health and the relationships between social determinants and biological mechanisms. In many cases, it is the social determinants that contribute to inequalities in health between population groups.

There is no particular level of poverty that indicates poorer health (though absolute poverty remains important). Instead, social factors affect population health across all levels of society: the relationship between socioeconomic position and health follows a ‘gradient’, with health status improving as socioeconomic circumstances rise. Social determinants can increase or decrease a person’s risk of subsequent health outcomes: not everyone from a low-income family will necessarily have poor health, but their risk will be higher than others.

Further, those with multiple unfavourable social determinants over a lifetime will be at even higher risk—and will be most vulnerable when another life challenge occurs. Social influences on an individual’s health and wellbeing occur in combination and cumulatively across their lives and the impacts from earlier in life are apparent over many years, and potentially for generations. (Disadvantage in early childhood, for example, can reduce social and health opportunities in the future, and this pattern can continue and accumulate over an individual’s life.) Further, the length of time in disadvantage increases the risk of ill health.

Despite substantial improvements in the health of Aboriginal and Torres Strait Islander people over the past 30 years, there are disparities in health outcomes between Indigenous Australians and non-Indigenous Australians. The reasons for these disparities are complex, and include the lasting impact of colonisation and separation from Country. It is also recognised that, for Indigenous Australians, social determinants of health result in differences in risks, exposures, access to services and outcomes throughout life.



**Chapter 4 'Housing conditions and key challenges in Indigenous health'** examines social determinants that have a substantial impact on Indigenous health. Diseases including chronic kidney disease, rheumatic heart disease, and certain eye and ear diseases, disproportionately affect Indigenous Australians. Some of the common factors underlying these health conditions are housing, living conditions and access to services. For example, Indigenous Australians have among the highest recorded rates of acute rheumatic fever and rheumatic heart disease in the world. These diseases are preventable and treatable, and common in low- and middle-income countries—both linked to overcrowding, socioeconomic deprivation, and inadequate access to health hardware and health resources. Lack of access to health services also affects health outcomes for Indigenous Australians, as access to primary health care services is critical for timely management of acute and relatively minor illnesses such as infections.

Two critical factors connecting housing conditions to health are the state of domestic health hardware (the physical equipment and infrastructure needed to support good health) and the impact of overcrowding. Housing not only provides shelter and safety, but also supports family, culture and cultural practices—while the lack of available and adequate health hardware can lead to illness or injury. Compared with non-Indigenous Australians, Indigenous Australians have less access to adequate, affordable or secure housing and are more likely to live in overcrowded conditions or to experience homelessness. Dwellings that are inadequate for the number of residents, including long-term visitors, may result in premature failure of health hardware and lead to poor health outcomes.

Meeting these health challenges requires a multi-sectoral approach that addresses the basic needs of adequate housing and access to health services, including maintaining and fixing health hardware. Data about housing adequacy; service-access issues; and the incidence and prevalence of various health conditions; and evidence for what achieves improvement, are key to reducing the disparities.

The issues of health inequity and preventive measures are further explored in **Chapter 5 'Potentially preventable hospitalisations—an opportunity for greater exploration of health inequity'**. The concept of 'equity' in health is that, ideally, everyone should have a fair opportunity to attain their full health potential and that disadvantage should not prevent them from achieving this potential. Understanding health equity is a core component of the Australian Health Performance Framework, and potentially preventable hospitalisation (PPH) statistics provide a useful measure for examining this issue. In Australia, and other countries, PPH data are used to assess timely, effective and appropriate primary health care.

PPH are grouped into 3 categories: vaccine-preventable conditions; acute conditions; and chronic conditions. In 2017–18, 1 in every 15 (6.6%) hospitalisations were classified as potentially preventable. New analyses quantifying the economic costs of PPH to the hospital sector found that expenditure varied by PPH condition, patient age and sex—but that, overall, PPH conditions cost the hospital sector \$4.5 billion in 2015–16. Three of the most common chronic PPH conditions—Congestive cardiac failure, Chronic obstructive pulmonary disease (COPD) and Diabetes complications—had the highest expenditure, with more than \$1.5 billion spent on these hospitalisations in 2015–16.

Interpretation of PPH statistics over time is complex, because PPH is influenced by many factors, including individual circumstances, patient characteristics and health-system factors. However, PPH statistics remain a valuable tool for exploring health disparities between different populations. For example, a case study on PPH for diabetes complications explores who is most at risk, comparing trends in PPH for specific groups within the Australian population—Indigenous Australians; people living in remote and socioeconomically disadvantaged areas; the very young; and older Australians.

The article discusses the importance of exploring and understanding patient-care pathways that result in PPH. A number of studies using linked patient data are underway across Australia to determine the true preventability of these hospitalisations, and for example, to explore broader social factors influencing PPH in Indigenous children. The future use of health data linkage presents opportunities for a more nuanced understanding of patient-care pathways that result in, and follow on from, PPH.

Data relating to health expenditure and funding are shaped both by health system activity and by health funding mechanisms. Australia's health system is a complex mix of government and privately funded services delivered in a variety of settings. **Chapter 6 'Funding health care in Australia'** provides an overview of the funding arrangements in place to fund Australia's health system and provides some comparisons with other OECD countries.

There have been changes to the funding of the Australian health system over time, including to the relative contribution of different funders across different areas of health expenditure. Across the OECD there are also differences in how countries fund their health systems. The Australian health system is financed through a hybrid model—a mix of both welfare state and market models—in which governments provide universal public insurance for access to health services but individuals can choose to pay for private health insurance in addition to their public insurance.

Managing the rising costs of health care is a challenge facing many OECD countries. Over the past 2 decades health expenditure in Australia has grown faster than either inflation or population growth. In the 20-year period to 2017–18, total health expenditure in Australia increased from \$77.5 billion to \$185.4 billion in real terms, and spending per person increased from \$4,189 to \$7,485. As a proportion of Gross Domestic Product (GDP), health expenditure increased from 7.6% in 1997–98 to 10% in 2017–18 (current prices). In the context of increasing health expenditure, different approaches to health care financing are being explored, including value-based health care models, capitation-based funding, and bundled and blended payments. Finding alternative mechanisms is especially important for increasingly complex and long-term health care needs.

Meeting complex and long-term health care needs is critical, especially with Australia's ageing population, and necessitates even greater interaction between the health and welfare systems. An example of this intersection is found in the aged-care sector, where an individual's need for a higher level of care can be the result of various factors including chronic and complex health issues or cognitive and/or physical decline. As people's abilities decline, everyday self-care activities become increasingly difficult to manage and, for some older people, this can mean moving into residential aged-care facilities.

Not only is this a transition in living situation, but it can also prompt a transition in the use of selected health services and medications. **Chapter 7 'Changes in people's health service use around the time of entering permanent residential care'** explores people's use of health services in the 6 months before and after entry into permanent residential aged care. Using original analysis, it provides insights into the nature of health-service use during this transition, which may help us to understand the context for change. The analysis focused on 3 groups of people who first entered permanent residential aged care in a selected 3-month period in 2014, 2015 or 2016. Using linked administrative data from aged care, Medicare Benefits Schedule claims and Pharmaceutical Benefits Scheme dispensing data, the analysis focuses on general practitioner (GP) and specialist attendances and on prescriptions dispensed for selected medicines.

Access to care and services is influenced by the interactions aged-care services have with health care services; the availability of health care professionals in the local area; the workforce available within residential aged care; and prescribing practices within facilities. GPs play a central role in prescribing medicines for older people in residential aged care and access to medicines can be relatively straightforward.

Medicines that act on the central nervous system have been of particular interest due to their effects on older people, and many are prescribed at high rates in residential aged care. Through the proceedings of the recent Royal Commission into Aged Care Quality and Safety, there has been a focus on how people living in such facilities are able to access health care services and how medicines are used within residential aged care. The interim report of the Royal Commission highlighted workforce issues, and potentially problematic use of certain medicines (particularly antipsychotics), and recommended immediate action to reduce their use as a chemical restraint.

People living with dementia also experience the intersection of health services and aged-care services. The Royal Commission found systemic issues in the aged-care sector and has called for fundamental reforms to address failures in providing appropriate care for older people—including the growing number with dementia. Over half of those in residential aged-care facilities have dementia, and a large proportion of people with dementia are living at home.

Dementia is a major health issue in Australia, causing substantial illness, high levels of dependency, and death. The number of Australians living with dementia is estimated to be between 400,000 and 459,000 in 2020, but the exact number is unknown. In 2018, dementia was the second leading cause of death in Australia and the leading cause of death for women. It has also been a leading contributor to the burden of disease and injury, requiring \$428 million in direct health expenditure in 2015–16.

Without a significant breakthrough in treatment, the number of people with dementia is expected to double by 2050, placing a greater demand on Australia's health and aged-care systems. **Chapter 8 'Dementia data in Australia—understanding the gaps and opportunities'** examines current issues and gaps in Australia's dementia data and how this affects our understanding of—and response to—dementia in Australia. It also looks at opportunities for data development to ensure Australia has sufficient data to inform dementia policy and service planning.

Monitoring dementia—and its impact on individuals and their carers and on Australia's health and aged-care systems—is essential for the development of evidence-based health, aged-care and social policy and for associated service planning. Gaps in the data include a lack of dementia diagnosis in GP and other specialist care data; inconsistent reporting of dementia across different datasets and over time; and ad-hoc and limited data on groups of interest and across different health care types. The progression of dementia is also complex and each person with dementia has different needs and experiences.

However, national monitoring of dementia has been irregular and inconsistent, limiting its ability to inform policy development and service planning. To address some of these gaps and data limitations, the Australian Government has committed to improve national dementia data assets and capabilities. The AIHW recently used linked administrative data to understand the health service use pathway of people with dementia in their last year of life, finding that people with dementia used fewer health services than people without dementia.

Another area with a national public focus—one for which timely data, monitoring, and evidence-based information are crucial—is suicide and intentional self-harm. Suicide prevention in Australia is a complex area of policy, with governments, policymakers and service providers all having a role in reducing suicides and cases of intentional self-harm. The reasons for suicide are also complex and are different for each individual, and the prevalence, characteristics and methods of suicidal behaviour vary between different communities, demographic groups and over time. Effective suicide prevention thus requires a multi-sector approach, including health, education; employment; welfare and law-enforcement agencies; housing providers; and non-government organisations.

Australian governments have also agreed to take a national approach to mental health planning and service delivery, including improving the quality and timeliness of data collection on suicide, suicide attempts and intentional self-harm in Australia. A National Suicide Prevention Adviser was recently appointed and a National Suicide Prevention Taskforce has been established to coordinate activities between government agencies and across different levels of government.

**Chapter 9 'Improving suicide and intentional self-harm monitoring in Australia'** provides an overview of the policy context for intentional self-harm and suicide monitoring and examines existing national sources of data currently used for this purpose. It discusses the limitations of these data sources, current data gaps and potential new sources of data that may strengthen the evidence base. There is also a particular focus on Indigenous Australians and on serving and ex-serving Australian Defence Force personnel.

Collection of data on suicide and intentional self-harm is essential to establish the extent of the problem; to highlight trends and emerging areas of concern; and to identify vulnerable populations. Data underpins the appropriate targeting of prevention strategies or research, and it is therefore important that monitoring of both suicide and intentional self-harm is as comprehensive and informative as possible. The National Suicide and Self-harm Monitoring System has been established to collate and coordinate data and information on suicide and intentional self-harm in Australia to improve their coherence, accessibility, quality and timeliness. This will better inform the development of suicide and intentional self-harm prevention policies and service planning. The AIHW will receive funding of \$5 million per year for 3 years (2019–20 to 2021–22) to deliver the monitoring system.

Picking up on some of the threads in the other articles—ageing population, health status, inequality/health inequity—the report ends with a fundamental question about our understanding of health and wellbeing, and how to measure them. Life expectancy is often used as a key indicator of the health of a population and of overall progress in health and wellbeing over time. In Australia, life expectancy has increased substantially over many decades, and in 2018 it was 80.7 years for males and 84.9 years for females.

But what does our increasing life expectancy mean for individuals, and for the health system, in a country like Australia? Our longer lives have implications, not only for the quality of life of individuals, but also for health care planning, demand and need for health and welfare services, as well as health-system costs. Does living a longer life mean that people are also living healthier lives—or are we enduring poor health for longer at the end of our lives? (In 2015, Australians aged 65 and over represented 15% of the population—but experienced one-third (33%) of the burden of ill health.)

**Chapter ‘10 Longer lives, healthier lives?’** looks at this important distinction—between years lived in full or in ill health—in the years of life we have gained.

There is ongoing debate about whether there has been an increase in the amount of ill health experienced by older Australians. Burden of disease analyses—particularly health-adjusted life expectancy (HALE) which combines the health-related quality of life and life expectancy into a single measure—assists health planning and the assessment of health in Australia. To highlight trends in the health of Australia’s ageing population, the article focuses on HALE at age 65, and also explores differences in HALE for Australians from different socioeconomic areas.

At a national level for people aged 65—while life expectancy continues to increase—the proportion of their lifetime spent in ill health has remained constant. However, this does not apply to all population groups. There is a clear gradient: life expectancy and years lived in full health increase as socioeconomic status increases.

The 10 articles in this report discuss issues covering health inequity; health indicators and measures; data linkage; data gaps and limitations; interactions between different parts of the health system and the welfare sector; and the external influences on our health. Data can facilitate greater understanding about how differences in personal circumstances and behaviours may lead to different health outcomes over time—and can be used to provide an overview of the functioning of the health care sector and the health of Australians.

What is evident from these articles is the vital importance of data in supporting better understanding and planning for current and future health needs.

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## List of Australia's health snapshots

Australia's health snapshots are web pages that present key information and data on the health system, health of Australians and factors that can influence our health. The full list of snapshots is provided here and can be viewed at [www.aihw.gov.au/australias-health/snapshots](http://www.aihw.gov.au/australias-health/snapshots).

### Health status

Bone and joint health  
Burden of disease  
Cancer  
Causes of death  
Chronic conditions and multimorbidity  
Chronic kidney disease  
Chronic respiratory conditions  
Coronary heart disease  
Dementia  
Diabetes  
Health impacts of family, domestic and sexual violence  
Health of people experiencing homelessness  
How healthy are Australians?  
Infectious and communicable diseases  
Injury  
International comparisons of health data  
Mental health  
Physical health of people with mental illness  
Stroke  
Suicide and intentional self-harm  
What is health?

### Determinants of health

Alcohol risk and harm  
Biomedical risk factors  
Built environment and health  
Diet  
Health literacy  
Illicit drug use  
Insufficient physical activity  
Natural environment and health  
Overweight and obesity  
Social determinants of health  
Stress and trauma  
Tobacco smoking

### Health system

Alcohol and other drug treatment services  
Allied health and dental services  
Cancer screening and treatment  
Clinical quality registries  
Digital health  
Health and medical research  
Health expenditure  
Health promotion  
Health system overview



Health workforce

Hospital care

Immunisation and vaccination

Medicines in the health system

Mental health services

Palliative care services

Patient experience of health care

Primary health care

Private health insurance

Safety and quality of health care

Specialist, pathology and other diagnostic services

Workers' compensation

## **Indigenous health**

Culturally safe health care for Indigenous Australians

Health risk factors among Indigenous Australians

Indigenous Australians' use of health services

Indigenous health and wellbeing

Indigenous hearing health

Indigenous life expectancy and deaths

Profile of Indigenous Australians

Social determinants and Indigenous health

## **Health of population groups**

Health across socioeconomic groups

Health of children

Health of mothers and babies

Health of older people

Health of people with disability

Health of prisoners

Health of veterans

Health of young people

Rural and remote health





# Health data in Australia

1

'Health' is not simply the presence or absence of disease or injury but should be considered as a state of wellbeing (WHO 1946). As the nation's health and welfare statistics agency, the AIHW knows that decisions that can improve the health of Australians require good health data. Policymakers, service providers and researchers—and the Australian community—also have high expectations that data will be available to inform them.

Health can influence, and be influenced by, the world around us, as events over the past year have shown. The novel coronavirus disease (COVID-19) pandemic—characterised as a 'human, economic and social crisis' by the United Nations (UN 2020)—continues to pose a very large potential threat to health and to the health system. Fortunately, early responses to the pandemic in Australia have been positive and thus far Australia's health services have been able to manage the challenges posed by the virus well. While the long-term health effects of COVID-19 are largely unknown at present, health data—in particular, linked data—will be critical to understanding its impact on health, society and the economy.

Data have been central to the COVID-19 response because governments have needed immediate data to make swift, evidence-based decisions. They also have a need for data to quantify the impact of COVID-19 on various other matters, for example, employment, mental health, and family violence. Data from Australia and overseas have featured heavily in media reporting of the pandemic, highlighting the community's appetite for current and accessible data and the important role of data in coordinating measures to slow the spread of disease. The AIHW is among the many government departments and agencies that provided practical assistance and expertise to assist the government with its immediate data needs. For example, in addition to seconding staff to the Department of Health to assist with responding to the COVID-19 crisis, the AIHW compiled data on the use of hospital, mental health, and homelessness services, as well as data from various crisis help lines

Beyond such public health crises, health data are crucial to the planning, delivery, responsiveness and effectiveness of health care services and the health system as a whole. This article provides an overview of health data in Australia and discusses data gaps and limitations; recent and emerging developments in health data; and the future of health data in Australia.

# The health data landscape

The Australian health data landscape includes a range of information about the health of Australians and the functioning of the health system, including:

- the determinants of health: the links between a person's behaviours and circumstances and their lifetime risks and health outcomes
- the health status of a person—their health conditions, functioning ability and general wellbeing
- the health system, including information to support health-service provision, funding and planning: the system's effectiveness, efficiency and appropriateness; its safety and accessibility; and the sustainability of health care
- the broader area of societal impacts (contextual information)—the changing demographics of the Australian population, the advancements in research, economic circumstances impacting workforce and infrastructure, and the expansion and improvements in the collection of data (AIHW 2020b).

Measuring health status at a population level involves analysis of trends and patterns in risk factors; disease frequency and impact; and health-service use. Data used in population health monitoring in Australia include surveys, disease-specific registries and disease-surveillance systems.

Australia has well established national health reporting systems, which enable identification of emerging health issues. One of these national reporting networks, the Communicable Diseases Network Australia (CDNA), delivers state and territory notifiable diseases data into the National Notifiable Diseases Surveillance System (NNDSS). The work of the CDNA has been essential to Australia's national response to the COVID-19 pandemic. See Chapter 2 'Four months in: what we know about the new coronavirus disease in Australia' for more information.

Population health monitoring is supported by a variety of data sources, including clinical trials and other research; cross-sectoral data from, for example, mental health, disability and aged care services; new consumer sources (such as banking and supermarket data); and emerging data sets (genomic data, electronic health records and enduring multi-source linked datasets).

Health-services data are commonly used in population health monitoring, and measures of population health may act as indicators of health-system efficacy. Health system data provide information on the equity, efficiency and effectiveness of a range of health services in delivery of health care in Australia. This includes data on the health workforce; health services; safety and quality in health care settings; and electronic health records. Health-services data are collected from episodes of service use, such as hospital admissions, pharmaceutical dispensing and general practitioner visits. These data are used in health system planning and administration, including in activity-based hospital funding arrangements and Medicare Benefits Schedule (MBS) claims for doctor visits.

Health data are also integral to support and prioritise effective health research. The work of the National Health and Medical Research Council and the Medical Research Future Fund (MRFF), in addition to countless research institutes and universities across Australia is underpinned by the evidence base that arises from these varied data sources. They depend on the proper management and curation of data as well as the synthesis of health information to inform decision making about projects and their interpretation of findings.

## Using data to monitor health outcomes and services and inform responses

Robust and accessible health data can inform decisions and policies, service planning and resource allocation—which is particularly important in areas where there are disparities in health status or outcomes, or in health-service access. Data also inform responses during crises, as seen during the COVID-19 pandemic and the 2019–20 Australian bushfires. Box 1 describes the role of data in responding to, and understanding the health impacts of, natural disasters—such as the widespread 2019–20 bushfires.

## Box 1: How we can better use data to understand the impact of natural disasters

Extreme weather events and natural disasters such as heat waves, drought, bushfires and floods can affect health. Data can assist with monitoring health impacts and planning responses—including action to minimise the effect of future natural disasters, such as, targeting vulnerable populations with precautionary measures or improving warning systems. For example, during the 2019–20 Australian bushfires, up to date low-level geographical data enabled effective fire management through critical responses, such as text messaging, to order residents to evacuate at-risk areas. Frequently updated air quality data and forecasts also enabled individuals to manage their exposure to hazardous environmental conditions.

The AIHW is currently using a variety of data sources—including bushfire burn-area mapping and air-quality, pharmaceutical, Medicare and hospital emergency department data—to assess the impact of the 2019–20 bushfires on health and on the health system in some affected areas. See *A burning issue: The short-term health impacts of the 2019–20 Australian bushfires* (AIHW forthcoming 2020).

While timely data are important, there are likely to be a range of long-term health effects from the 2019–20 bushfires that will not be evident for some time. Studies of firefighters after a fire season show reduced lung function can return to baseline over a long follow-up period, however cumulative and repeat effects are unknown (Black et al. 2017).

Long-term mental health can be affected by natural disasters. For example, for those with any exposure to bushfires in the 2009 Victorian ‘Black Saturday’ bushfires, levels of post-traumatic stress disorder (PTSD) were markedly higher than for the general population. The same longitudinal study showed that, while the majority of people affected showed great resilience in the face of the disaster experience and its aftermath, those who suffered bereavement or severe property loss have later shown signs of impaired resilience and of deteriorating mental health. These types of data are critical in focusing recovery efforts (Bryant et al. 2018).

The MRFF is funding a large-scale research project to look at the medium-term health impacts of smoke and ash exposure, including mental health, for frontline responders and affected communities (Department of Health 2020).

Measures which summarise information can be used to inform decision making and may be structured and analysed using a framework. For example, Australia's Health Ministers have agreed to the Australian Health Performance Framework (AHPF) (NHIPPC 2017), which includes domains for the determinants of health; health systems; health status; and the health system context, with consideration of equity. More information can be found at <https://www.aihw.gov.au/reports-data/australias-health-performance>.

Other national examples of frameworks include the National Aboriginal and Torres Strait Islander Health Performance Framework and the National Strategic Framework for Chronic Conditions. Typically, indicator frameworks:

- allow different population groups, regions and countries to be compared over time and with each other
- provide information on the effect of changes to policies, practices and programs
- support accountability and transparency of service provision
- support service improvement activities.

## Data gaps and limitations

There are parts of the health system, and aspects of health of Australians, where information is not adequate for population and system monitoring or reporting purposes.

Data gaps can exist where data are not collected or recorded; where the data are collected but are not in a suitable format for easy collation, processing or reporting; or where the data are collected in isolated systems that are either not easily accessible or not comparable. In addition to data gaps, analysis gaps exist where data may be available but are not currently brought together efficiently.

Some notable gaps in Australian health data and analysis—relating to health status; patient pathways and health service use; and health system activity and performance—are:

- incidence and prevalence data for some conditions, such as dementia
- data on the contribution of some health determinants
- links between public health interventions and health outcomes
- information on some population groups, including people with disability; culturally and linguistically diverse populations; refugees; and lesbian, gay, bisexual, transgender, queer and intersex populations
- data for smaller geographical areas to identify variations in health status and care by location



- environmental data for understanding links between the natural and built environments and human health
- person-centred data including social and economic factors that affect health and patient pathways through the health system, across jurisdictional boundaries and between sectors
- measures of health system efficiency and cost-effectiveness
- national, comparable and reportable data on primary health care activity and outcomes
- indicators of health system safety and quality, including outcomes of interventions and patient rated outcome and experience measures (all of which are available only for a limited range of health services).

## Developments in health data

Australian health data are undergoing rapid change. Increasing digitisation of health information means more data are being collected at a more detailed level, and this expands the possibilities for analysing and reporting. There is increasing demand for accurate and secure health information that is available in real time and at small geographic levels for service planning and delivery; easily accessible, flexible and interactive for a variety of uses and users; comparable at national and sub-national levels; and which maintains privacy and confidentiality.

These requirements present challenges and opportunities for using health data to improve the health of Australians.

### Digital health

One of the most substantial drivers of change in health data is the rise of digital technology in health care (ADHA 2017). Digital health is the use of technology by individuals (through digital access to health services, wearable devices) and by clinicians and administrators (through clinical information systems and patient administration systems) to collect and share a person's health information.

Digital health technology has the potential to:

- remove barriers to service access, for example through the use of telemedicine to provide specialist care to remote or isolated communities
- improve continuity in patient care through the use of electronic health records (such as My Health Record)
- enhance clinical decision making and system-wide responses with real-time access to health information between services, sectors and jurisdictions.

For individuals, digital health technology can enable people to understand and take control of their own health and health information. For clinicians, this technology can support improved interactions with patients, continuity of care and improved effectiveness, efficiency and delivery of health services. Secondary use of data from digital health information can also improve understanding of health-service use and patient pathways through the health system. See 'Digital health' <https://www.aihw.gov.au/reports/australias-health/digital-health> for further information.

The scope and use of digital health technologies are growing and changing rapidly in Australia, enabling real-time information to be available to patients and health care providers. However, the rate of this change is not consistent or coordinated across the health system (ADHA 2017). There can also be a disconnect between information collected in digital information systems and the need to have data available for statistical reporting systems. The lack of systematic, standardised collection of data from primary care data, relative to other areas of health, poses a particular challenge. This also affects our ability to share information within and between systems and sectors to inform good patient care. There is a need to ensure that enabling infrastructure is put in place for the capture, analysis and reporting of these data, including governance arrangements to maintain the privacy and security of individuals.

Secondary use of data from digital health information also allows understanding of health service use and patient pathways through the health system.

Connecting different parts of the health system (for example primary care to allied health and hospitals) through interoperable technology and complementary governance arrangements, will be an important underpinning for an integrated health system, for patient journey analysis and for supporting the continuity and quality of patient-centred care.

## Person-centred data

A significant proportion of data on the health system in Australia are organised around individual services. While these data are useful for managing individual parts of the system, they are not ideally placed to help us understand how people interact with a range of services and they do not always provide useful information on health and other outcomes. By linking data across the health system (while preserving privacy), and with other data including data from surveys, it is possible to gain a much richer understanding of how people interact with services and their health outcomes.

The importance of 'person-centred data' has emerged due to a number of factors. These include:

- the link between health and wellbeing
- developments in personalised medicine
- the importance of continuity and coordinated health care for positive outcomes and the potential for value-based rather than activity-based management of health service provision.

Following a cohort of individuals from diagnosis, through interactions with the health system, to recovery, deterioration or death improves our ability to analyse the development and trajectory of disease; the interaction of determinants and interventions; and the role and performance of the health system in managing, treating and preventing disease. This is achieved in 2 ways: through longitudinal analysis of a single data set, or through the integration (linkage) of two or more datasets. The most noteworthy developments in recent times are in relation to building and managing large-scale data linkage.

## Data linkage

Data linkage, also known as data integration, is a process that brings together information from more than one source. Linked datasets can provide more detailed information than could be gained from each individual dataset, by matching disparate pieces of information together. This can fill gaps in our knowledge on specific diseases, service use, specific population groups and across the health and welfare sectors.

An example is the use of different types of data to understand participation in cervical cancer screening. Combining health services data (cervical screening program participation, human papillomavirus (HPV) vaccination data) and population health data (cancer incidence, deaths data) has shown the links between HPV vaccination, increased participation in cervical cancer screening, and decreased incidence of high grade cervical abnormalities (AIHW 2019a).

In Australia, our health and welfare sectors and their associated evidence bases are largely disconnected. Recent developments in person-centred data have included cross-sector data linkage and analyses, such as a study on the interface of aged care and health (see Chapter 7 'Changes in people's health service use around the time of entering permanent residential aged care').

Multi-source Enduring Linked Data Assets (MELDAs)—such as the National Integrated Health Services Information Analysis Asset (NIHSI AA or the Asset) developed by the AIHW—are a standout example of this development in health data. The Asset is deidentified and links multiple health data sources (including hospital admitted, non-admitted and emergency department care; residential aged care; mortality; the MBS and the Pharmaceutical Benefits Scheme) from multiple jurisdictions, as an enduring asset, for the first time. While the Asset is currently available for analysis by Australian Government and state and territory health authorities, the AIHW continues to work with stakeholders to support access for other potential users of data from the Asset. At least 27 analysis projects are currently approved to use this national health information resource. Examples of NIHSI projects include exploring patterns of service use in the last year of life, and the quality of care and outcomes following hospitalisation for hip fracture.

Another example of a MELDA is the Multi-Agency Data Integration Project (MADIP) developed by the Australian Bureau of Statistics (ABS). This project is a partnership among Australian Government agencies to develop a secure and enduring approach for combining information on topics including health care, education, government payments, personal income tax, and population demographics (including the Census of Population and Housing) to create a comprehensive picture of conditions in Australia over time. More than 260 government and academic users are drawing from 10 available MADIP datasets for a large number of research projects to help inform future government policies and services (ABS 2019a, 2019b).

## Developments in the broader data context

These MELDAs are examples of the improved use of the significant data assets held by governments across Australia. The AIHW is a national Accredited Integrating Authority authorised to perform data linkage within and between Australian Government, state and territory data collections.

This work is part of a broader reform agenda for the use of data in Australia. The Office of the National Data Commissioner (ONDC) has recently been established and is currently developing a simpler data sharing framework for public sector data in Australia. The ONDC is responsible for progressing new legislation—to be known as the *Data Availability and Transparency Act (DATA)*—to support better sharing of government-held data. This proposed legislative framework will help overcome barriers which prevent efficient use and reuse of public sector data, while maintaining the strong security and privacy protections that the community expects (ONDC 2019).

The safekeeping of data assets and individual privacy, with data access and availability for a wide range of uses, is critical to ongoing development and innovation in the use of health data. This is particularly relevant in building and maintaining public trust in relation to the use of person-centred and digital data.

## On the horizon

Substantial gains have already been made to address some of the longstanding gaps in health data and to overcome the disconnectedness of health information. Wellbeing, digital transformation and genomics are areas in which health data are undergoing change, and are providing challenges for data collection, analysis and reporting.

### Wellbeing

‘Wellbeing’ is a term describing quality of life and living conditions. It combines the more commonly reported domains of health and welfare (education and skills; housing; employment; income and finance; social support; justice and safety), and includes contextual factors (environment, community engagement) and subjective measures (life satisfaction and work-life balance) (AIHW 2019b; OECD 2013).

In Australia and internationally, the concept of wellbeing as an indicator (or set of indicators) is increasingly being used as a more holistic measure of, and benchmark for, economic and social development. Examples are the Organisation for Economic Co-operation and Development’s (OECD) Better Life Initiative (OECD 2017), the New Zealand Government’s Wellbeing Budget (NZ Government 2019) and the Australian Capital Territory Government’s planned ACT Wellbeing Framework (ACT Government 2019).

### Digital transformation

Substantial developments in digital technologies for health are not being holistically or consistently adopted and integrated into the Australian health system (ADHA 2017). However, there are emerging developments in the systems for defining, classifying, storing, transmitting and analysing health information that could, if adopted, lead to true interoperability and integration between acute, primary and allied care systems and their data.

For example:

- The Australian Digital Health Agency’s Framework for Action outlines priority activities and opportunities, including the development of the National Health Interoperability Framework, to overcome barriers to sharing clinical information between services and systems (AHDA 2018).
- The digitally enabled health classification system, the International Classification of Diseases 11th Revision (ICD-11) (WHO 2019), represents an opportunity to bridge the digital divide between clinical systems and statistical systems for the acute and primary care sectors, and to facilitate data availability for statistical reporting in services such as ambulance and community health (AIHW 2020a).

## Genomics

Genomics is a data-rich field of research and a rapidly developing area with potential for improving risk detection, diagnosis, treatment and patient outcomes. Australia has agreed on a national approach to genomic policy, data collection, storage, analysis and clinical application, laid out in the National Health Genomics Policy Framework (Department of Health 2017) and its implementation plan (Department of Health 2018). Incorporating genomic information—and the precision and personalised medicine it facilitates—into population and health system data is an emerging and challenging area for Australian health data.

## AIHW and the future of health data

The AIHW produces independent and authoritative health and welfare information and statistics. Nationally and internationally, the AIHW works with other organisations to:

- maintain and enhance the health evidence base
- facilitate approved access to health data
- provide leadership, partnership and advice in relation to improving data quality and availability
- provide data governance, technology and analysis capability.

These roles, and the work of other agencies in the health data landscape, are fundamental to ensuring stronger evidence for better decisions in relation to health.

## Responding to the changing landscape

The changing shape of health data defines the environment in which AIHW operates. The AIHW is engaged in a variety of activities to help it to better understand and meet Australian health information needs; to support the further digitisation of health information; to improve data utility and accessibility; and to create the enabling infrastructure to meet future health data needs. The COVID-19 pandemic has demonstrated the AIHW's responsiveness to changing data needs and will be a focus for future data development and reporting (Box 2).

## Box 2: Data opportunities resulting from the COVID-19 response

More than any other recent event COVID-19 has highlighted the need for timely data. The AIHW provided immediate assistance to help the Department of Health meet their data needs, such as compiling up to date data on mental health services and crisis help line use to support the COVID-19 response. While many AIHW data collections and associated releases have established schedules for collection, analysis and reporting, AIHW activity associated with the COVID-19 response used a flexible approach to data collection and analysis, giving decision makers access to comparable, credible and up-to-date data for monitoring change. It is expected there will be increased demand for near real time data as a result of COVID-19, and the AIHW's future planning will consider its capacity to deliver information more quickly, while maintaining quality and accuracy.

Australia's COVID-19 response has resulted in new data sources and opportunities for data improvements to, or integration with, existing sources to enable more nuanced information. These new sources and linkage opportunities will enable analysis of longer-term outcomes associated with COVID-19. For example, at time of writing, the AIHW has been assisting the Department of Health by compiling data on mental health on a weekly basis. It has also worked with the Australian National University to develop a survey (conducted in May 2020), using the Life in Australia Panel (a national probability-based online panel). This survey had a focus on mental health, loneliness, housing and alcohol consumption.

The AIHW's future reporting will incorporate information about the impact of COVID-19 on health and welfare issues relevant to Australians.

The AIHW continues to play a valued role in data linkage by providing researchers with access to deidentified data in secure environments. The AIHW is also building enduring assets such as the NIHSI AA and is working closely with the ABS and states and territories to facilitate more efficient and effective data linkage while preserving privacy.

Integration of digital health data with existing data sources will improve the cohesiveness of the Australian health information system. The AIHW, in partnership with the Australian Digital Health Agency and the Department of Health, is exploring the interoperability of digital and other health data standards, governance and reporting, and developing the governance and analysis capability for the secondary use of My Health Record data. As discussed above, this work has overlaps with a national review to inform decision making on the implementation of the ICD-11 as a potential replacement for ICD-10 and ICD-10-AM in our health and vital statistics systems.

## Closing data gaps

The AIHW, in collaboration with other organisations, engages in initiatives to fill identified information gaps.

Projects underway to fill longstanding disease and sector-specific gaps are covered in Chapter 8 ‘Dementia data in Australia—understanding gaps and opportunities’ and Chapter 9 ‘Improving suicide and intentional self-harm monitoring in Australia’. To improve understanding of inter-sectoral pathways, Chapter 7 ‘Changes in people’s health service use around the time of entering permanent residential aged care’, covers the interfaces between the aged care and health systems. Further work is underway to build a new disability data asset. Much of this work relies on the use of MELDAs and other linked data.

The AIHW is working to establish the National Suicide and Self-harm Monitoring System in collaboration with the National Mental Health Commission and the Department of Health. An important role for the system will be to provide more timely data on suspected deaths by suicide and to improve data on risk factors. The AIHW has been compiling data on suspected deaths by suicide that are already available from suicide registers in some jurisdictions. These data have been extremely valuable to governments in monitoring the impact of the pandemic.

The AIHW also has an integral role in improving data governance for health data in Australia, including by:

- exploring options to improve the efficiency of data linkage and the handling of our large integrated datasets through improved data architecture and high performance computing capabilities
- playing a leadership role in national health data governance in Australia, supported by legislation and by the AIHW Ethics Committee; a longstanding role as custodian of national health datasets; and expanding and emerging roles as custodians of multi-source and multi-use integrated data assets and of secondary use of My Health Record data
- continuing management of health metadata on behalf of Australian Health Ministers’ Advisory Council (AHMAC)
- management of national health metadata in METeOR (the AIHW’s Metadata Online Registry)
- investing in partnerships with governments, non-government bodies and research agencies, in Australia and internationally—recognising that developments in the health data landscape to date, and those on the horizon, are built on collaboration between agencies, researchers and sectors.



## Improved access to and value of data

The AIHW is working to improve access to our data holdings, and to the analysis and reports we produce—for example, by publishing more regional data and by making data available in a more interactive form. We are also developing processes and improving systems to allow quicker secure access to AIHW data, by approved researchers.

The AIHW is continuing to make more of its data available using interactive displays online. Compared with static data displays, which illustrate specific findings, interactive displays are flexible and enable users to answer their own questions of the data, which in turn supports data-driven decision making. For example, users can focus on specific parts of the Australian population, for a given time period, or in some cases select relevant levels of geography—all in much greater detail than has been available previously.

The AIHW also brings together, and regularly updates, diverse data on a single topic for easy access and use. The AIHW web report *Alcohol, tobacco & other drugs in Australia* is an example. The Australian Health Performance Framework ‘national front door’ also provides a high-level overview of health indicators.

As noted earlier, the COVID-19 pandemic required a rapid and innovative response from AIHW researchers to help meet the health information needs of Australian governments in formulating a response to the COVID-19 crisis. Some administrative collections were used to report to policy and decision makers on the changing situation at a much higher cadence than previously (sometimes daily) while ensuring that the highest quality research standards were maintained. Collaboration and coordination between data providers, governments and other stakeholders were key to establish the effects of the COVID-19 pandemic on the Australian population. Innovative presentation techniques were needed so that decision makers could assimilate detailed information from diverse data sources quickly. Extensive use was made of business intelligence software for rapid analysis and trend identification; key insights were presented in easy to understand data visualisations.

Going forward the AIHW will harness these learnings to improve the timeliness, accessibility and presentation of its health and welfare statistics to better inform policy and service delivery decisions.

## Taking a strategic approach to future data needs

There is a need to develop data to better measure the health impacts of recent global and local events on the health of Australians, immediately and in the long term. This has implications for national approaches to collecting, managing and using health data.

The AIHW is working to use data to better understand the links between the natural and built environments on health—building on and complementing the work of experts in environmental, respiratory and mental health, other research bodies, and Australian Government, state and territory agencies.

Improvements to health outcomes for all Australians—and to the efficiency and effectiveness of the health system—will require a strategic approach to managing health system data. Recently, AHMAC has agreed that an independent expert panel will develop a National Health Information Strategy, in consultation with stakeholders, for consideration in 2021. The AIHW supports the work of this panel. The Strategy will provide a framework for ongoing improvement of national health information resources for the next 10–15 years, and provide a basis for shorter investment plans including specific improvement activities for 3–4 year periods. The framework may incorporate principles to shape the Strategy and associated activities, and to outline a vision for the future.

The Strategy may form the basis for a revised National Health Information Agreement (the current agreement was formed in 2013), setting out national arrangements governing national health data assets in a contemporary health data environment. Another example of the AIHW's work in addressing emerging health data needs is its work with the World Health Organization to develop appropriate data coding for COVID-19. This will assist with research into the impact of the pandemic. Addressing existing gaps and limitations, enhancing data assets and planning for developments in health data collection, analysis and reporting, builds our capacity and capability to respond to the health information needs of the Australian population. This includes those arising during, and following, future health crises.

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Please practice  
social distancing



# Four months in: what we know about the new coronavirus disease in Australia

2

The information and data provided in this chapter were accurate at the time of writing. However, given the dynamic nature of the pandemic there may be changes or revisions to the underlying data and/or information as more is learnt about the disease. This chapter focuses on the first 4 months of the disease in Australia, covering 25 January 2020 (when the first Australian cases were confirmed) to the end of May. Analyses in this chapter are also preliminary and in some instances less complex than would normally be the case, reflecting the limited amount of detailed data available at this stage of the epidemic.

COVID-19 is a disease caused by the new coronavirus SARS-CoV-2. It is a major health threat and international crisis, which has led to substantial disruption to almost all parts of society worldwide. The outbreak first came to international notice through a cluster of unexplained pneumonia cases in Wuhan, China, in late December 2019. The COVID-19 epidemic was declared a pandemic (the worldwide spread of a new infectious disease) by the World Health Organization (WHO) on 11 March, and by 31 May there had been over 5.9 million confirmed cases and over 360,000 deaths worldwide (WHO 2020g).

There are several reasons why COVID-19 has become such a major crisis. Briefly, being caused by a virus not previously seen in humans, there is no immunity in the population and currently no vaccine or specific treatments. It is also highly infectious and affects some people severely. It was therefore important to protect the health of vulnerable people and prevent the health system from being overwhelmed with many severe cases presenting to hospital at once. The only practical way to contain its spread at this stage is by travel bans, strong physical distancing policies and practices (such as through closure of non-essential services and keeping a minimum distance from others) and personal hygiene. These restrictions have had a serious impact on economies and societies across the world, with travel, trade and people's ability to work, attend school and socialise, all affected.

Most countries have not had recent experience with similar epidemics, making the adjustment to new ways of living challenging. However, the threat of a pandemic was recognised internationally prior to the emergence of the virus (Ziegler et al. 2018) and Australia had its own well-developed system of public health response to communicable diseases (WHO 2018). The Australian Government developed an emergency response plan specifically for COVID-19, which was released on 27 February (Department of Health 2020a).

The Communicable Diseases Network Australia (CDNA) coordinates communicable disease surveillance and investigation across jurisdictions. Part of their work is to bring together the data collected by states and territories on notifiable diseases into a de-identified national dataset—the National Notifiable Diseases Surveillance System (NNDSS). These data are an important component of this chapter, and are described further below. In addition, the Public Health Laboratory Network is a collaborative group of laboratory representatives that contributes laboratory-level expertise to the response to infections of public health importance (Department of Health 2020j). There are also Centres of Research Excellence that can provide valuable real-time clinical research which contributes to both the national and international efforts to combat the pandemic (Doherty Institute 2020).

To date, Australia has fortunately avoided the severe health impacts seen in many other countries, where there have been large numbers of severe cases and deaths, putting a huge strain on the health system (MacIntyre & Heslop 2020). While we do not yet have detailed knowledge of which specific factors may have contributed to the favourable situation in Australia, the early implementation of international travel restrictions and physical distancing measures in combination with one of the highest testing rates in the world have played a key role (Cheng & Williamson 2020). It is difficult, at least at this stage, to know definitively what may have happened in Australia without these measures. Also, as with all prevention, it can be challenging for the community to fully appreciate the value of the preventive actions undertaken (Hemenway 2010). It is not possible to predict what may happen in the future, and the infectious nature of the virus means there could still be further outbreaks in Australia.

We remain in the middle of an evolving situation, with many facets of the epidemic not yet fully understood, though research continues to become available to fill some of the gaps in knowledge. Similarly, due to the rapid development and applied nature of the data collections currently available, the completeness and accuracy of the data may improve over time; therefore, data in this chapter are preliminary. There are also a number of areas where national data are not yet available.

This chapter is a point in time article that reviews the first 4 months of the epidemic in Australia using currently available data. The areas covered are outlined in Box 2.1.

### Box 2.1: Chapter focus and outline

This chapter takes a broad ‘monitoring’ approach to provide an overview of the epidemic so far in Australia. This is in contrast to ‘surveillance’ data collection and analyses done by the federal, state and territory governments specifically to take action to manage the epidemic (see the glossary for relevant definitions of terms used in this chapter).

The main focus of this chapter is on the short-term situation given the stage of the epidemic we are at. Sections of the chapter cover:

- key characteristics of the disease, and its prevention, control and treatment
- available information on the number of cases and deaths in Australia—including variation across the country and population
- data and analysis on age at death and severity of the disease
- a focus on particular at-risk populations
- comparison to previous epidemics
- comparison to the situation in other countries
- an overview of the indirect effects, including impact on the health system and broader health and welfare
- discussion of the use of data in epidemics and how the current epidemic has extended these.

## About the disease

This section is intended to give broad background on the key characteristics of COVID-19, and the current prevention and treatment available. It does not aim to provide detail on these topics, but rather is provided as background for the sections that follow.

### Disease characteristics

COVID-19 is predominantly a disease of the respiratory system, particularly in the early stages of the illness, caused by the coronavirus SARS-CoV-2 (Box 2.2). Common early symptoms are similar to other respiratory illnesses such as fever, cough, sore throat, runny nose and shortness of breath. However, the infection can have a wide variety of manifestations, including diarrhoea, loss of smell and loss of taste (CDNA 2020a). In some people the infection can progress to become a more severe disease, with the immune system overreacting, resulting in inflammation and lack of oxygen to many



parts of the body. This can lead to multiple organ failure and death. Severe symptoms tend to develop in the second week of the disease.

### **Box 2.2: What are coronaviruses?**

Coronaviruses are RNA viruses that are mainly found in animals. Under an electron microscope, they give the appearance of the corona of the sun; hence, the name 'coronavirus'. Seven coronaviruses have occurred in the human population. Four of these (OC43, HKU1, NL63, 229E) have been circulating for many years, and account for about 20% of the cases of common cold. The remaining 3 coronaviruses cause more serious illnesses, namely Middle East Respiratory Syndrome (MERS), Severe Acute Respiratory Syndrome (SARS) and now the Coronavirus Disease 2019 (COVID-19). SARS-CoV-2 is the virus that causes COVID-19. This virus is 96% genetically similar to a bat virus. It is therefore likely that SARS-CoV-2 originated in bats before moving to humans through an intermediate animal host (Andersen et al. 2020). The pangolin has been nominated as a possible intermediate host since its own coronavirus is very similar to SARS-CoV-2 (Zhang et al. 2020).

In the Northern Hemisphere, clusters of an unusual condition have occurred in children, the majority of whom have had positive antibody tests for SARS-CoV-2. This has been called a multisystem inflammatory syndrome. Its association with COVID-19 is still unclear and is being investigated (WHO 2020j). Despite this, COVID-19 appears to be an uncommon infection in children (WHO 2020n) but research is not yet definitive on whether the low rates of confirmed cases in children are driven by lower chances of children catching the disease or lower rates of symptoms and therefore less testing (Vogel & Couzin-Frankel 2020). In addition, children do not appear to transmit COVID-19 easily (NCIRS 2020). This is quite unusual as children are often major sources of community transmission of respiratory infections, such as influenza.

Another emerging unusual feature of the COVID-19 illness is a propensity to form blood clots. This appears to be more common in critically ill patients, can involve both the arteries and veins, and lead to life-threatening complications such as stroke and pulmonary embolism (Willyard 2020).

COVID-19 is a highly infectious disease with a wide spectrum of severity. Many people experience mild to moderate disease, but unfortunately some develop very serious illnesses and it has a higher death rate than many common infectious diseases. The severity spectrum ranges from asymptomatic (no symptoms), to mild/moderate disease (symptoms confined to the upper respiratory system, or flu-like symptoms serious enough to keep someone off work), to severe (with pneumonia, respiratory

failure, septic shock, organ failure and potentially death). Early in the epidemic using data on cases in China, it was estimated that 81% of cases had relatively mild to moderate disease and 14% severe disease requiring hospitalisation. At the most severe end, around 5% of cases required intensive care unit (ICU) admission (Wu & McGoogan 2020). Current estimates of the proportion of infections that are asymptomatic range from 18–43% (Gudbjartsson et al. 2020; Mizumoto & Chowell 2020; Nishiura et al. 2020a).

An estimate of case-fatality (the percentage of known cases that are fatal) from the early epidemic was 1.4%, based on data from cases in China, adjusted for demographic factors and potential missed cases (Verity et al. 2020). However, the rates differ substantially across age groups, from less than 0.3% for all age groups under 50 years, then steadily increasing with age to 13.4% for those over 80 years. Accurate case-fatality rates require full counts of both those dying from the disease (the numerator) and the number of cases (the denominator), otherwise adjustments need to be made for under-counting.

South Korea had an earlier epidemic than many other countries, and had good levels of testing, making it likely that the denominator included a high proportion of cases. The crude case-fatality in South Korea up to 10 March was 0.7% (KSID & KCDCP 2020). The age pattern was similar to the Chinese estimates but with lower rates: 0.1% or less for all age groups under 50 years, then steadily increasing to 6.8% for those over 80 years. Given the strong age effect, case-fatality rates are highly influenced by the age profile of people contracting the disease within a population. High-quality care contributes to lower case-fatality rates, and thus an important aim of epidemic management is to contain the spread of the disease to ensure intensive care units (ICUs) are not overwhelmed with too many cases at once, which would compromise their ability to provide care to everyone who could benefit.

As well as age, there are other factors that increase the risk of severe disease. At this stage, these appear to include smoking (WHO 2020o), obesity (Simonnet et al. 2020), and having chronic conditions such as heart or respiratory disease, diabetes or cancer (Department of Health 2020c). Even more at risk are those with multiple comorbidities or who are immunocompromised due to disease or therapy (Liang et al. 2020). Disadvantaged groups are at increased risk for a range of reasons, including their higher rates of these risk factors and overcrowded housing (PHE 2020).

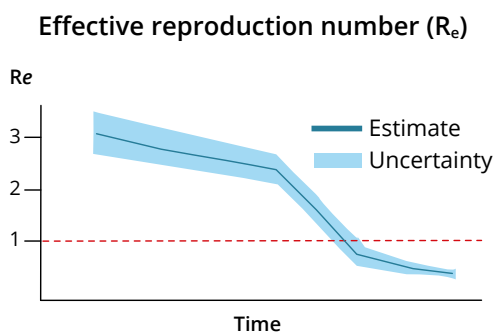
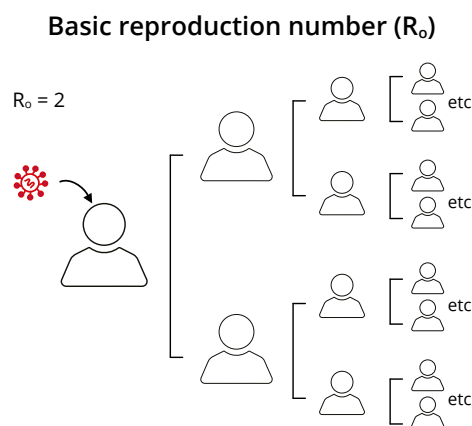
The primary reasons COVID-19 has become a worldwide crisis are its severity in combination with high transmission rates. These high transmission rates are driven by a number of factors: it is a new virus and thus there was no immunity in the population; there is currently no vaccine; and it can be transmitted by people who are not very ill (such as those with no or very mild symptoms), allowing it to spread throughout the community 'under the radar' (MacIntyre & Heslop 2020). In addition,

peak infectiousness appears to occur prior to or just after symptoms develop (He et al. 2020). This contrasts to the SARS outbreak of 2003, where cases only became infectious after they became unwell, and where the peak infectiousness occurred later in the illness. In other words, it was easier for SARS cases to be identified and isolated as soon as they developed symptoms, reducing the risk of further transmission significantly. COVID-19 also spread very quickly around the world due to high levels of international travel prior to travel bans.

The measures used for estimating and monitoring the spread of the virus are outlined in Box 2.3. The median incubation period of 5–6 days (though ranging from 1–14 days; WHO 2020e) and high transmission rates results in rapid growth in the spread of the infection if measures are not in place to stop the chains of transmission.

### Box 2.3: Measuring spread of the disease

The basic reproduction number ( $R_0$ ) quantifies, at the start of the epidemic (when there are no public health interventions and no immunity), the average number of people each case infects (see diagram below showing an  $R_0$  of 2; Delamater et al. 2019). For SARS-CoV-2, the estimated  $R_0$  is around 2.5 (WHO 2020n). As the epidemic continues, and the impact of the public health interventions are seen, the effective reproduction number ( $R_e$ ) can be estimated. It is expected to fall as a result of these interventions, and when under 1 for a sustained period of time, the epidemic is in decay. However, unless the  $R_e$  is close to 0, any change to the public health measures in place mean it could quickly increase again to over 1 (Pan et al. 2020).



If  $R_e$  is **greater than 1**, cases will increase, but if it is **less than 1**, the outbreak will spread more slowly and eventually end.

(continued)

**Box 2.3: (continued) Measuring spread of the disease**

An  $R_0$  of 2.5 with an average incubation period of 5 days would result in 1 case leading to 406 new infections within 30 days. With 50% less exposure to other people following public health interventions (an  $R_e$  of 1.25), 1 person would infect 15 people within 30 days. With 75% less exposure, only 2.5 other people would be infected within 30 days.

Four factors determine the value of  $R$ : the duration of infectiousness, the number of opportunities for transmission (for example, how many close contacts the infectious person has), how likely the virus is to be transmitted when the opportunity arises, and the susceptibility of the population (Kucharski 2020). Addressing any of these factors has the potential to reduce the value of  $R$ . For example, physical distancing measures reduce the opportunities for transmission, and a vaccine would decrease the proportion of the population that were susceptible.

Another measure of spread of infection is the 'serial interval'. This measures the time between a case becoming unwell and someone they have infected becoming unwell. For COVID-19, the median serial interval has been estimated at 4.6 days—shorter than the average incubation period—which is evidence for transmission of infection before cases become ill (Nishiura et al. 2020b).

Some infections lead to lifelong immunity—they can never be contracted again. However, this is not the case for all infections. It is currently unclear into which category COVID-19 falls. Some people with COVID-19 have been shown to develop a strong immune response to the virus, suggesting that they will be immune to further infection (Thevarajan et al. 2020); however, the duration of that immunity is unclear. Further research will be needed to answer this question (Senanayake 2020).

## Prevention, control and treatment

### Public health response

The aim of public health interventions is to stop or slow transmission of the virus. Unlike some other infectious diseases in Australia, there is currently no vaccine for the SARS-CoV-2 virus. There are a number in development but they are not expected to be available before 2021 (Graham 2020). This means that more traditional public health interventions are the focus of prevention measures.

There are 3 major groups of prevention actions instigated or undertaken by the public health workforce: policies aimed at the population level; actions that can be taken by individuals; and case isolation and contact tracing/quarantine. In the absence of a vaccine, these measures are vital and effective in reducing the spread of disease (Chang et al. 2020).

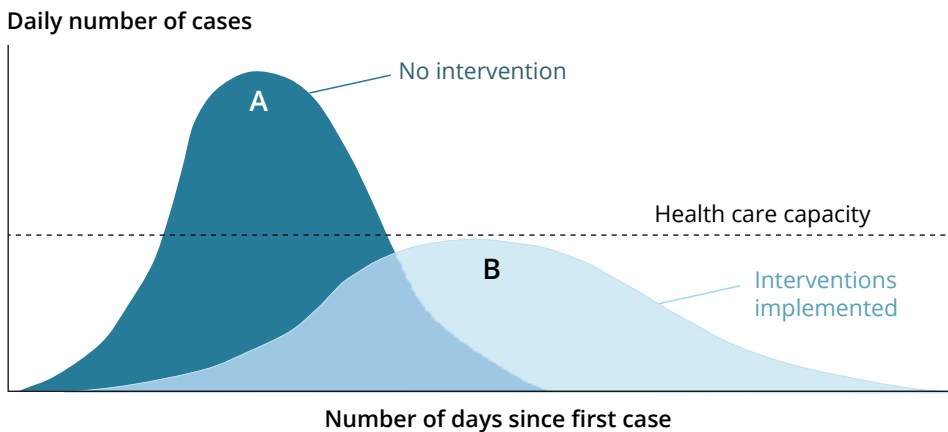
### Population-level actions

A range of population-wide interventions are possible, aiming to stop the chain of transmission of the virus. These focus on reducing the number of interactions between individuals and ensuring physical distancing measures are used when interactions are unavoidable. These interventions can be mandated using laws or fines, or advisory notices. Examples of interventions Australia has used include travel bans, bans on social gatherings of a certain size, closing pubs and clubs, and encouraging people to work or educate from home. These measures, some of which are expected to be in place for a long period, have a substantial impact on people's lives. Governments have needed to mitigate the income, employment and social isolation effects with a range of substantial policies and programs.

The concept of 'flattening the curve' has been used extensively during the pandemic. It is explained in Box 2.4.

## Box 2.4: Flattening the curve

During the early stages of the epidemic, community discussion occurred on the concept of ‘flattening the curve’. This refers to the epidemic curve, which shows the number of new infections over time. Without any vaccine or public health interventions, the expected shape is quite steep (line A in the figure below). In an epidemic like the current one where a proportion of cases will be severe enough to require hospitalisation, this large peak can result in the health system being overwhelmed and the health workforce being put at significant risk of infection and death themselves. The concept of flattening the curve is to use various public health interventions to push this distribution of cases down, so that the peak is much lower, though the total period of the epidemic is extended (line B). As well as flattening the curve, prevention activities can also reduce the total number of infections (Churches & Jorm 2020).



By controlling the number of cases requiring hospital treatment at any point in time to within the capacity of the health system to manage them, the chances of better outcomes are increased for patients, which is likely to save lives. If the curve is not flattened, the risk is there will not be enough resources (for example, personal protective equipment (PPE) for health workers; ventilators in ICU) to treat everyone safely and effectively, as was the case in countries such as Italy, Spain, the UK and the US (Ranney et al. 2020).

Additionally, if the number of cases is not controlled, the impact on the health system itself would be large. The likelihood of many more infections amongst the health workforce is increased, as demonstrated in Spain where 20% of infections were amongst health care workers (ECDC 2020a). A health system overwhelmed by COVID-19 is also less likely to serve other functions and treat other patients.

Flattening of the curve also buys time: for the health system to better prepare for the extra cases needing treatment and to develop systems for prevention of transmission through contact tracing and other public health measures; for treatments of cases to be refined as research evidence accumulates on effectiveness; and potentially for a vaccine to be developed.

## Individual-level actions

As well as encouraging individuals to follow the population-wide measures outlined above, there are other behaviours individuals can follow to reduce their risk of contracting or spreading the virus. These focus on regular handwashing or sanitising, not touching the face, good respiratory hygiene, staying home when unwell and getting tested for SARS-CoV-2 (Department of Health 2020h). In addition, individuals are encouraged to follow physical distancing measures including working from home when possible. During this pandemic, the issue of 'presenteeism' has also come to the forefront, which refers to people coming into work when they are unwell. They might do this for a variety of reasons, such as concerns over letting their colleagues down by not turning up, fear of losing their job, or worries about not being paid. However, given the risk of an infected worker introducing COVID-19 into the workplace, presenteeism is now being actively discouraged. The various measures are communicated to the public in a variety of ways, including large-scale information campaigns through the main media platforms.

## Isolation of cases, and contact tracing and quarantine

Alongside prevention measures, a vital component of the public health response is isolation of cases and quarantine of cases' contacts or others at high risk, to stop transmission of the virus. The first step aims to find as many cases as possible, which relies on high levels of testing of suspected COVID-19 cases, and to then isolate them from other people until they are considered to be no longer infectious. The second step is contact tracing which aims to identify all people who had close interactions with the cases while they were infectious. Quarantine is then required for those considered to have been potentially exposed to a case, including returning travellers, and they are monitored to see if they develop symptoms. The detailed requirements for each of these steps are updated in the National Guidelines, as new information becomes available (CDNA 2020b).

## Diagnosis and treatment

Acute COVID-19 is currently diagnosed by taking a swab of the nose/throat or of sputum (mucus from the respiratory tract). A blood test can identify those with an immune response from past infection, which may have been asymptomatic or undiagnosed, but has no current role in diagnosing acute infections (CDNA 2020b).

Unlike other viral diseases, which may benefit from treatments such as antivirals, there is currently no specific pharmaceutical treatment for COVID-19. A number of trials are underway, which may identify drugs that reduce severity and possibly infectiousness (Davis et al. 2020). In the absence of specific treatments, supportive

care is provided to keep the body functioning as well as possible while it fights the infection. For mild-moderate cases, this is likely to include common symptom relievers such as paracetamol. For more severe cases, treatment in hospital and supplemental oxygen therapy may be required. For critical cases, this supportive care would require admission to ICUs, often with various advanced technology treatments such as mechanical ventilation.

## Vaccine development

A vaccine is the best way to rapidly build immunity against the virus and protect the population from developing disease. Scientists across the world are working on developing and testing candidates for vaccines at a rapid rate using a number of different technologies. However, vaccine development is a lengthy and costly process, with many challenges to overcome. The development of SARS and MERS vaccines raised concerns about adverse reactions (such as worsening of lung disease) so rigorous testing in animal models and safety monitoring in clinical trials in humans will be important (Luri et al. 2020).

## The epidemic in Australia so far

When this chapter was finalised, it had been around 4 months since the first case of COVID-19 was diagnosed in Australia. This section outlines what is known so far about how the disease has affected the health of the Australian population. While relying on early data, which may not be as comprehensive or refined as data that will become available later, the need for data to be available quickly to manage the epidemic has meant that enough information was available to paint a picture of the key, short-term impacts.

Data for this section primarily come from the NNDSS which contains de-identified, official notification data from each of the states and territories. The NNDSS was established in 1990 and contains national surveillance data for more than 60 communicable diseases or disease groups (Department of Health 2015). NNDSS data presented here cover the period to the end of May and early June, sourced from published reports containing NNDSS data, and from data supplied directly from the NNDSS. Due to the dynamic nature of the NNDSS, data in this extract are subject to retrospective revision and may vary from data in published NNDSS reports and reports of notification data by states and territories. Note that 'confirmed cases' in this section essentially refer to laboratory-confirmed cases of COVID-19 notified to the NNDSS; it may also include a small number of probable cases.



The deaths data provided here from the NNDSS may differ from counts of deaths that will be available from death certificate data in coming months. This issue is discussed further in the 'Use of data in epidemics and pandemics' section below.

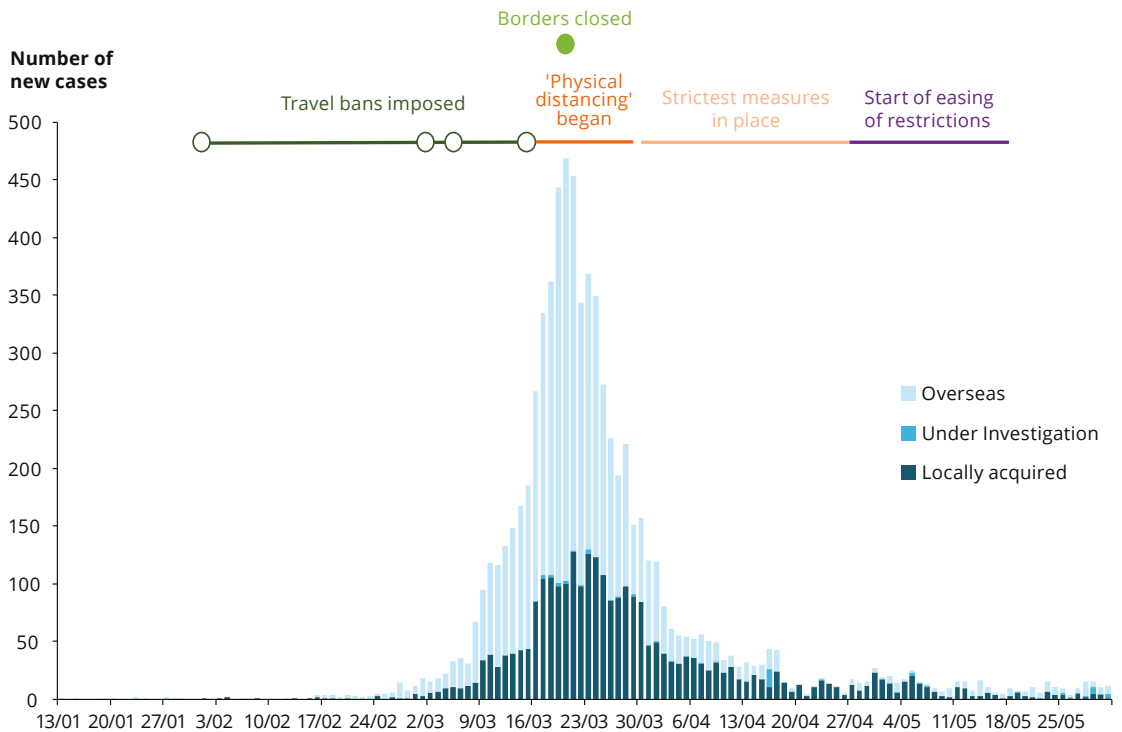
## Confirmed cases

Australia's first cases were diagnosed on 25 January amongst a group that had travelled from Wuhan, China. There were then sporadic cases, with either zero or small numbers of cases diagnosed each day until early March, when the numbers diagnosed started to accelerate and clusters of cases started to emerge. Particular groups at risk were those who returned from overseas, lived with a person who had caught the virus overseas, or those in a residential care facility. The 100th case was diagnosed on 10 March, the 200th on 15 March, the 400th on 18 March and the 800th on 21 March (ECDC 2020b). This shows that cases were doubling every 3–4 days in these early days of the epidemic. The peak (to date) was reached on 23 March, when 611 cases were diagnosed in one day, after which the rate of growth started to slow substantially.

In terms of date of illness onset, the peak day was 20 March with 468 new illnesses (Figure 2.1). The large drop in daily cases at the end of March and into April coincided with the various mitigation measures introduced (national actions are summarised in Figure 2.1).

By 7 June, there had been 7,277 laboratory confirmed cases in Australia, and 102 of these people had died (COVID-19 NIRST 2020e). During the epidemic, cumulative case counts have also been provided by states and territories daily for national reporting. Those data indicate that, by 9 June, the vast majority of cases had recovered and only 6% were still active cases (Department of Health 2020d).

**Figure 2.1: Number of confirmed cases of COVID-19 in Australia, by date of illness onset and source of infection**



**Notes**

1. Data to 31 May 2020.
2. Where date of illness onset was not available, the earliest of the specimen collection date, the notification creation date, or the notification received date has been used.

Source: NNDSS, Australian Government Department of Health.

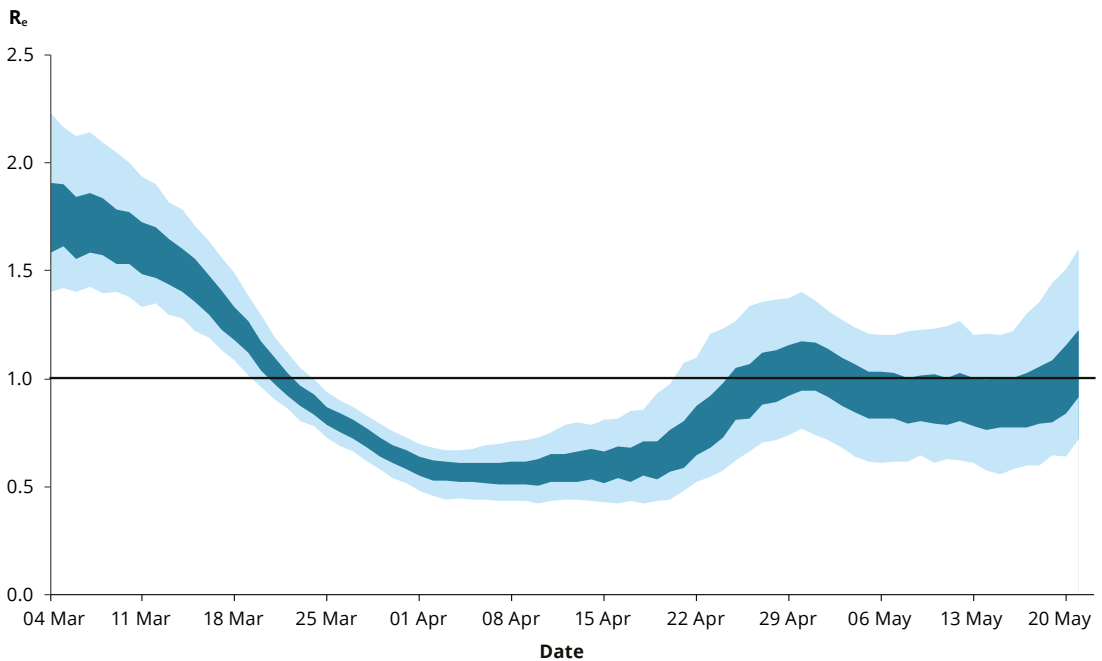
At the start of the epidemic, a substantial number of infections were acquired overseas. This included visitors to Australia until travel bans began, as well as Australians returning home during the pandemic. This continued to a lesser extent during April and May as further Australians returned home. The largest proportion of cases in Australia were in people who were infected overseas (Figure 2.1), and this remained the case to early June with 62.2% of cases being acquired overseas (Department of Health 2020e). Without these overseas-acquired cases, the transmission within Australia has been relatively small, with the peak day being 21 March with 128 new illnesses on that day. Even within the locally-acquired infections, nearly three-quarters were among people who were a close contact of a case, and thus only 10% of all cases were in people without a known contact (Department of Health 2020e).

High rates of testing for the virus are needed within a population to ensure that cases and contacts are not missed, and to enable isolation and quarantine to reduce the chance of transmission within the community. High testing rates are also required for notification data to be accurate. In the early days of the epidemic in Australia, only certain groups were eligible for testing. At the end of March, the eligible groups were those who had returned from overseas or had been in close contact with a confirmed case in the last 14 days; had severe, unexplained pneumonia; or were a health care worker or from certain other high-risk groups and had symptoms consistent with COVID-19 (ABC News 2020c; MacIntyre 2020). The groups eligible for testing were expanded over time, and by 12 May, anyone with symptoms of respiratory illness was eligible for testing in many states and territories, and were being actively encouraged to be tested (Department of Health 2020l; NSW Health 2020a; Queensland Government 2020; Victoria State Government 2020).

Australia has had high levels of testing, as reflected in the number of tests per capita (34 per 1,000) and a low percentage of tests found to be positive (0.5%) (Department of Health 2020d). Studies also suggest Australia is unlikely to be undercounting cases (Russell et al. 2020), reflecting the high testing rates.

The  $R_e$  in Australia was estimated to have been between 1.5 and 2.0 in the first week of March (Figure 2.2). The initial high values reflect infections in Australians returning from overseas, rather than high levels of transmission within Australia. The  $R_e$  then fell sharply over the next 10 days, and was estimated to be under 1.0 in the last week of March. These trends reflect the travel bans and physical distancing measures implemented during this period. In the most recent period, it remained around 1.0 due to contained outbreaks in New South Wales and Victoria. Note that the  $R_e$  becomes increasingly unstable when the number of cases becomes very low, which is the current situation in Australia (Golding et al. 2020).

**Figure 2.2: Time-varying estimate of the effective reproduction number ( $R_e$ ) for COVID-19, Australia, 4 March to 21 May 2020**



Note: Light ribbon = 90% credible interval; dark ribbon = 50% credible interval.

Source: Centre for the Mathematical Modelling of Infectious Diseases, London School of Hygiene and Tropical Medicine; <https://epiforecasts.io/covid/posts/national/australia/>.

## Variation across the country

Using the WHO definition of stages of the epidemic, Australia continued with 'clusters of cases' (WHO 2020d) until the end of May (WHO 2020h). These clusters resulted in variation in the number of cases across the country, although there were cases in every state and territory (Table 2.1). New South Wales had the most cases, with 3,117 diagnosed by 24 May, followed by Victoria (1,616) and Queensland (1,058). Taking into account the size of the population, Tasmania had the highest rate by that date, followed by New South Wales.

**Table 2.1: Total confirmed cases of COVID-19, by state and territory**

	Number of cases	Rate (per 100,000)
NSW	3,117	38.5
Vic	1,616	24.5
Qld	1,058	20.8
WA	541	20.6
SA	439	25.1
Tas	228	42.7
NT	29	11.8
ACT	107	25.1
Australia	7,135	28.1

Note: Data to 24 May 2020.

Source: COVID-19 NIRST 2020d.

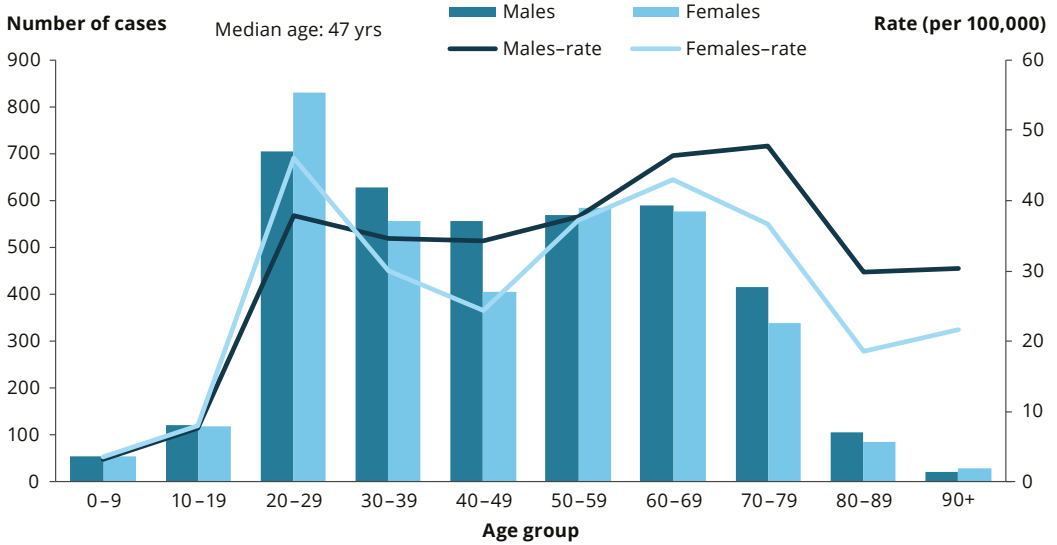
## Variation by age and sex

By the end of May, there was little difference in the total number of cases between males and females. However, there was variation in the number of cases in each age group (Figure 2.3a). The 20–29 age group accounted for the highest number of cases, with age groups up to 70 years having lower numbers. The highest rates for females were in the 20–29 and 60–69 age groups, while for males the highest rates were for the 60–69 and 70–79 age groups.

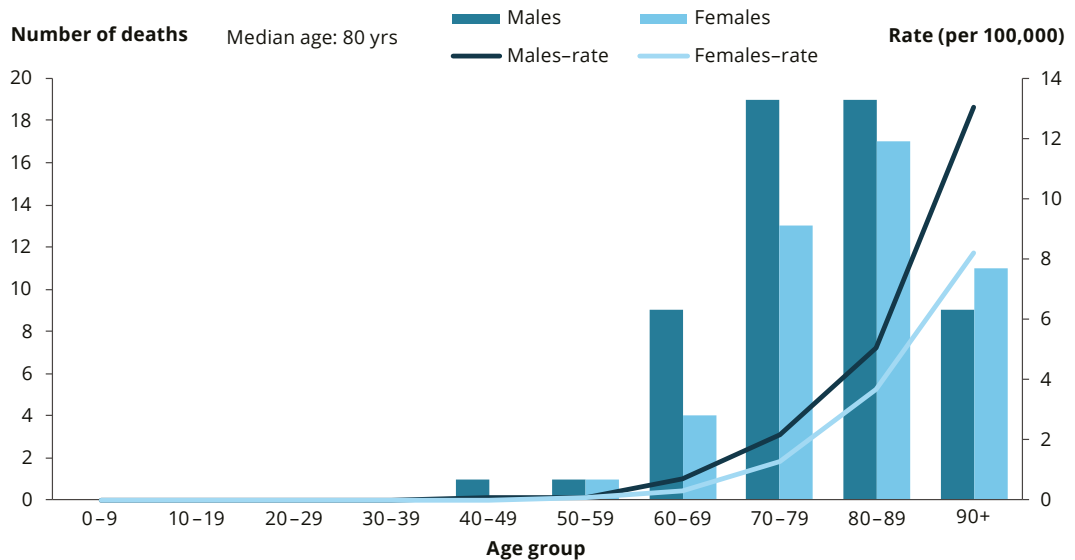
In contrast, there was more variation by age and sex for reported deaths (Figure 2.3b). The majority of deaths were in the older age groups, with the 80–89 age group having the most deaths. There are steep increases in death rates across the age groups and higher rates for males than females, particularly in the oldest age groups. Similar patterns in the distribution of deaths have been observed in other countries (ONS 2020; Salje et al. 2020).

**Figure 2.3: Number and rate of confirmed cases of COVID-19 and associated deaths in Australia, by age and sex**

**a) Confirmed cases**



**b) Deaths**



Note: Data to 31 May 2020.

Source: NNDSS, Australian Government Department of Health; Department of Health 2020e.

## Age at death

The median age at death for COVID-19 was 80 years, which is slightly lower than that for all causes of death in 2018 (81 years). It is also somewhat lower than many other leading causes of death that commonly occur in older age. Compared with the top 7 leading causes of death occurring in 2018, as well as suicide (12th), pneumonia (14th) and influenza (90th) (Table S2.1), the median age at death for COVID-19 was:

- lower than the 3 leading causes of death—coronary heart disease (CHD) (84 years), dementia (88) and stroke (86)—and pneumonia (89) and influenza (82)
- similar to diabetes (81) and chronic obstructive pulmonary disease (COPD) (80)
- higher than bowel cancer (77), lung cancer (73) and suicide (44).

Another way to examine the impact of age at death is to measure years of life lost (YLL), which counts the number of years between the age at death and life expectancy at that age. There has been speculation that YLL are low for COVID-19, which would indicate that some people dying from the disease did not have a long life expectancy prior to developing COVID-19, largely due to being older or having comorbidities that put them at higher risk of the severe effects of disease. A study using Italian and UK data shed some light on this, showing that average YLL per person was 14 for men and 12 for women (Hanlon et al. 2020). The authors also produced modelled estimates adjusting for comorbidities, which showed that the presence of comorbidities did not greatly decrease the estimates, reducing average YLL to 13 for men and 11 for women.

Preliminary calculations for Australia (not adjusted for comorbidity) using similar methods to the European paper shows average YLL per person was 17 years for men and 14 for women (including deaths up to 31 May). These higher estimates in Australia indicate a lower proportion of deaths in older people, possibly due to fewer outbreaks in aged care facilities than have occurred in other countries (COVID-19 NIRSTd). Using methods similar to Australia's usual approach for calculating YLL (which uses a different reference life table) results in preliminary estimates of average YLL per person of 14 and 11 for males and females respectively. Corresponding estimates for 2015 for the 5 leading causes of death in Australia are: CHD (14 for males, 8 for females), dementia (9 and 7), stroke (11 and 8), lung cancer (17 and 18) and COPD (13 and 12) (AIHW 2019). This shows that those dying from COVID-19 lost more years of their expected life span than most other major causes of death. This suggests there is a strong possibility that the COVID-19 deaths were among people that, on average, would not have been expected to die soon, particularly when taken alongside the Hanlon et al. (2020) finding that comorbidity did not greatly reduce YLL.

## Severity

The vast majority of cases were mild-moderate in severity and were managed at home. However, a small proportion of people developed more severe disease. By 24 May, 13% of diagnosed cases had been admitted to hospital (Table 2.2). Hospitalisation usually indicates more severe disease, though in the early stages of the epidemic in Australia, some mild cases were admitted to hospital to enhance isolation procedures in order to minimise the chance of further transmission. The median age for hospitalised cases was older than for all cases (61 years compared with 47 years).

**Table 2.2: Characteristics of confirmed cases, hospitalisations and deaths**

	All cases	Hospitalisations	Deaths
Number	7,135	947	102
Per cent of all cases	100	13	1.4
Median age (years)	47	61	80
Age interquartile range (years)	29–62	42–72	74–86

Note: Data to 24 May 2020.

Source: COVID-19 NIRST 2020d.

The more severe cases were admitted to ICU—202 cases, which is 2.8% of all diagnosed cases up to 24 May (COVID-19 NIRST 2020d). Over one-quarter (28%) of those in ICU received mechanical ventilation.

In terms of the crude case-fatality rates, 1.4% of cases had died by 24 May—102 deaths. As noted above, these mostly occurred in the older age groups, and the median age at death was 80 years (COVID-19 NIRST 2020d). As observed in other countries the case-fatality rates in Australia increase with age, being 0.1% or lower up to age 50, then 0.4% for those aged 50–64, 3.1% for the 65–79 age group and 22.7% for those 80 and over. The case-fatality rate for males (1.6%) was higher than for females (1.3%). Possible reasons for this difference include more chronic conditions in older men and a stronger immune system in women (Lawton 2020).

## At-risk populations

There are a number of population groups that are at increased risk of infection or severe disease if infected. This section focusses on 4 important high-risk population groups: health care workers, people in aged care, Aboriginal and Torres Strait Islander people and cruise ship passengers. People who live in shared residential settings, such as correctional facilities, military bases, and residential disability care facilities are also at increased risk of infection from outbreaks in these settings.



## Health care workers

Members of the health workforce are at higher risk of catching COVID-19 as they may be treating (and therefore in close contact with) people with the disease. This is why the availability of PPE and being competent in both putting on (“donning”) and removing (“doffing”) the PPE is so important.

Outbreaks in the Alfred Hospital in Melbourne and the North West Regional and North West Private hospitals in Tasmania demonstrate how hospitals can become focal points for outbreaks. The outbreak of COVID-19 in hospitals in northwest Tasmania began in late March 2020. Cases occurred among health care workers, patients and household contacts. As of 27 April 2020, there were 125 persons associated with the outbreak, including 78 staff members (COVID-19 NIRST 2020a). Outbreaks in aged care facilities (see the next section) also demonstrate the risk for health care workers in those settings. Ongoing monitoring of health care workers will be an important part of the response to COVID-19.

The importance of PPE in protecting the health workforce from infection has been an ongoing worldwide challenge in the management of COVID-19 due to supply chain issues (WHO 2020m).

## People in aged care

Given that people aged 60 and over are at greater risk of poorer outcomes due to COVID-19 than people aged less than 60 years (WHO 2020k), and that aged care residents often live in close proximity to each other, the aged care sector is a high risk setting. Residential aged care facilities often deal with infectious disease outbreaks, such as influenza and gastrointestinal illness (Kirk et al. 2010), and have procedures in place to respond to and manage them (CDNA 2017). As of 24 May, there had been 129 confirmed cases of COVID-19 in residential aged care facilities in Australia (66 residents and 63 staff), with 27 associated deaths (and 72 recovered cases). In addition, there were 42 cases in ‘in home care’ settings, 31 of which occurred in care recipients and 11 in care staff (with 37 recoveries), and 3 deaths (COVID-19 NIRST 2020d). A large outbreak in an aged care facility in New South Wales, resulting in 16 associated deaths by 6 May, was challenging to contain and highlights the risk to aged care residents (Aged Care Quality and Safety Commission 2020).

In the early stages of the epidemic, the Australian and state and territory governments put restrictions in place to protect older Australians in residential aged care facilities, including limiting the number of visitors to 2 people per resident and not permitting children aged 16 and under to visit (Department of Health 2020g). The CDNA released the *National Guidelines for the Prevention, Control and Public Health Management of COVID-19 Outbreaks in Residential Care Facilities in Australia* (CDNA 2020c).

## Aboriginal and Torres Strait Islander people and communities

Aboriginal and Torres Strait Islander people and their communities are at high risk of COVID-19 outbreaks and severe outcomes for a number of reasons. They are a mobile population and remote communities have frequent visitors (including fly-in fly-out health care workers), increasing the chances of disease importation. They often have reduced access to health services either due to physical distance for those in remote areas or due to other barriers related to institutional racism, and mistrust of mainstream health services (CDNA 2020b). In addition, Indigenous Australians experience a burden of disease 2.3 times the rate of non-Indigenous Australians, with 64% of the burden due to chronic diseases such as diabetes and CHD (AIHW 2016). Overcrowding in homes and lack of infrastructure to support personal hygiene in remote areas can promote disease transmission and make physical distancing and efforts to self-quarantine challenging.

To protect remote communities from COVID-19, governments working in collaboration with Aboriginal and Torres Strait Islander organisations and communities began restricting the movement of people in and out of remote areas and began setting up respiratory clinics to support Indigenous Australians (Hunt & Wyatt 2020). *The National Management Plan for Aboriginal and Torres Strait Islander Peoples* has been developed by the Aboriginal and Torres Strait Islander Advisory Group on COVID-19 and endorsed by the Australian Health Protection Principal Committee, and was released on 30 March 2020.

As of 24 May, less than 1% of notified cases had been reported in Indigenous Australians (59 cases; with 95% Indigenous identification completeness for notified cases), who represent 3.3% of the Australian population. Ten per cent of these cases were acquired in *Outer Regional* areas, and none in *Remote* or *Very Remote* areas; 47% were acquired overseas (COVID-19 NIRST 2020d).

While the number of cases in Australian Indigenous communities has been low, there have been outbreaks in Indigenous populations in Brazil and in Navajo Native Americans in the USA (SBS 2020, The Guardian 2020).

## Cruise ship passengers

The number of people travelling on cruise ships globally has increased in recent years. An estimated 30 million passengers travelled on cruise ships in 2019, an increase from 17.8 million in 2009 (Cruise Lines International Association 2019), and 1.35 million Australians took a cruise in 2018 (Cruise Lines International Association Australasia 2020). Disease outbreaks can occur on cruise ships due to the large numbers of people confined in close proximity on board (Kak 2015). Large outbreaks of COVID-19 on cruise ships have been a feature of the early part of the pandemic. On one cruise ship, the virus seemed to be so transmissible that the  $R_0$  onboard was calculated to be as high as 11—4 times the basic  $R_0$  of COVID-19 (Mizumoto et al. 2020). In early February 2020, the largest cluster of COVID-19 cases outside Mainland China occurred on the *Diamond Princess* cruise ship docked in Yokohama Japan with 2,666 passengers (including 223 Australians) and 1,045 crew on board (Moriarty et al. 2020). The ship was quarantined on 5 February with passengers confined to their cabins, but the crew continued to work throughout the ship. By the end of quarantine, there were approximately 700 confirmed cases of COVID-19 among passengers and crew (Kakimoto et al. 2020). On 20 February, 164 Australians who were COVID-19 negative and not displaying symptoms were repatriated by air to Darwin to undergo further quarantine (Department of Health 2020k). A small number subsequently developed symptoms and tested positive for SARS-CoV-2.

A number of other cruise ships around the world have recorded COVID-19 cases, including some in Australian waters. On 19 March, around 2,600 passengers disembarked from the *Ruby Princess* cruise ship in Sydney and either returned to their homes across Australia, or returned to their home countries. On 20 March, 3 passengers and 1 crew member tested positive for SARS-CoV-2 (NSW Health 2020c). Subsequently, a number of cases and deaths across Australia were linked to the *Ruby Princess* (ABC News 2020a).

As at 17 May, of those cases with place of acquisition recorded, 1,126 were acquired at sea on a cruise ship, representing around 18% of these cases, and there were 26 associated deaths (COVID-19 NIRST 2020c).

# Comparison to previous epidemics

## SARS, MERS and swine flu

It is possible to compare COVID-19 to other recent epidemics, including SARS and MERS which were also coronaviruses, and the last pandemic influenza (commonly referred to as swine flu). Some key characteristics are outlined in Table 2.3.

**Table 2.3: Comparison of the characteristics of COVID-19, SARS, MERS and 'swine flu' epidemics**

	COVID-19	SARS	MERS	Influenza A(H1N1) pdm09 ('swine flu')
Median incubation period	5–6 days	4–5 days	5 days	3–4 days
Modes of transmission	Respiratory droplet, close contact, fomites	Respiratory droplet, close contact, fomites	Respiratory droplet, close contact, possibly fomites	Respiratory droplet, close contact, fomites
Pandemic	Yes (2020)	No	No	Yes (2009)
Year(s)	2019 to present	2003–2004	2012–2020 sporadic outbreaks	Emerged in 2009, with seasonal outbreaks each year
Regions affected	Global (ongoing pandemic)	Mainland China, Hong Kong SAR, Taiwan, Canada, Singapore	Saudi Arabia (2012–current) Republic of Korea (2015)	Global (Seasonal outbreaks)
Number of global cases (during pandemic period)	5.93 million <sup>(a)</sup> (by 31 May 2020)	8,098	2,494	491,382 <sup>(a)</sup> (laboratory-confirmed April 2009–Aug 2010))
Number of global deaths (during pandemic period)	367,200 <sup>(a)</sup> (by 31 May 2020)	774	858	18,631 <sup>(a)</sup> in laboratory-confirmed cases
Estimated case-fatality rate (based on latest data)	1.38% <sup>(c)</sup> 0.7% <sup>(d)</sup>	9.6%	34%	0.03% <sup>(b)</sup>
Basic reproduction number ( $R_0$ )	2–2.5 (initial estimate based on data from China)	2–4 (initial estimates)	<1	1.7 (initial estimate)
Vaccine now available	No (candidates being tested)	No	No (candidate being trialled)	Yes
Transmission by pre-symptomatic/asymptomatic cases	Yes	No	No	Yes

(a) Laboratory-confirmed cases/deaths reported by WHO during the epidemic—likely to be an underestimate of true numbers.

(b) Estimate by Donaldson et al. 2009 using data from England.

(c) Data from China adjusted for censoring, demography, and under-ascertainment by Verity et al. 2020.

(d) Estimate from South Korea (KSID & KCDCP 2020).

By 31 May, the number of COVID-19 cases and deaths worldwide had surpassed all of these other epidemics, with over 5.9 million cases and more than 367,000 deaths. Swine flu had the next highest number of cases (nearly 500,000) and deaths (over 18,000) during the epidemic period. It is important to note that the number of cases and deaths reported during epidemic periods is often an underestimate of the true number in the community. For example, a modelling study carried out after the swine flu pandemic estimated there were 123,000–203,000 pandemic respiratory deaths worldwide, substantially higher than the estimate available at the time of the pandemic (Simonsen et al. 2013). As a result, case-fatality rates cannot be calculated directly from the estimates in Table 2.3.

Comparing with the other coronaviruses first, the  $R_0$  for COVID-19 is in the same range as SARS but higher than it was for MERS. However, the case-fatality rate for COVID-19 is much lower than either, reflecting the higher proportion of people with mild–moderate disease. This also increases the spread of the disease, as people with milder disease do not require treatment in hospital—they can still go about their daily lives making it more likely they could spread the infection to others. Further, COVID-19 can also be spread prior to symptoms developing, and perhaps when no symptoms are present (Arons et al. 2020).

Of the 3 epidemics, swine flu is the only other one with locally-acquired cases in Australia. Compared with the most recent pandemic of swine flu, COVID-19 has a much higher case-fatality rate and higher transmissibility ( $R_0$ ). In other words, it is much more likely to spread and is also a much more severe disease for many people. The swine flu pandemic was able to be controlled following the development of the vaccine, however the strain still exists and is responsible for seasonal outbreaks each year.

## 1918–1919 pneumonic influenza

Looking even further back takes us to the very large epidemic of pneumonic influenza in 1918–1919, also known as the ‘Spanish flu’ (as it was first widely reported in Spain, rather than originating there). The most detailed data are the deaths data. Information from death registrations is used in this section, which is different to the data above on death notifications made through the infectious disease process (see discussion in the ‘Use of data in epidemics and pandemics’ section below).

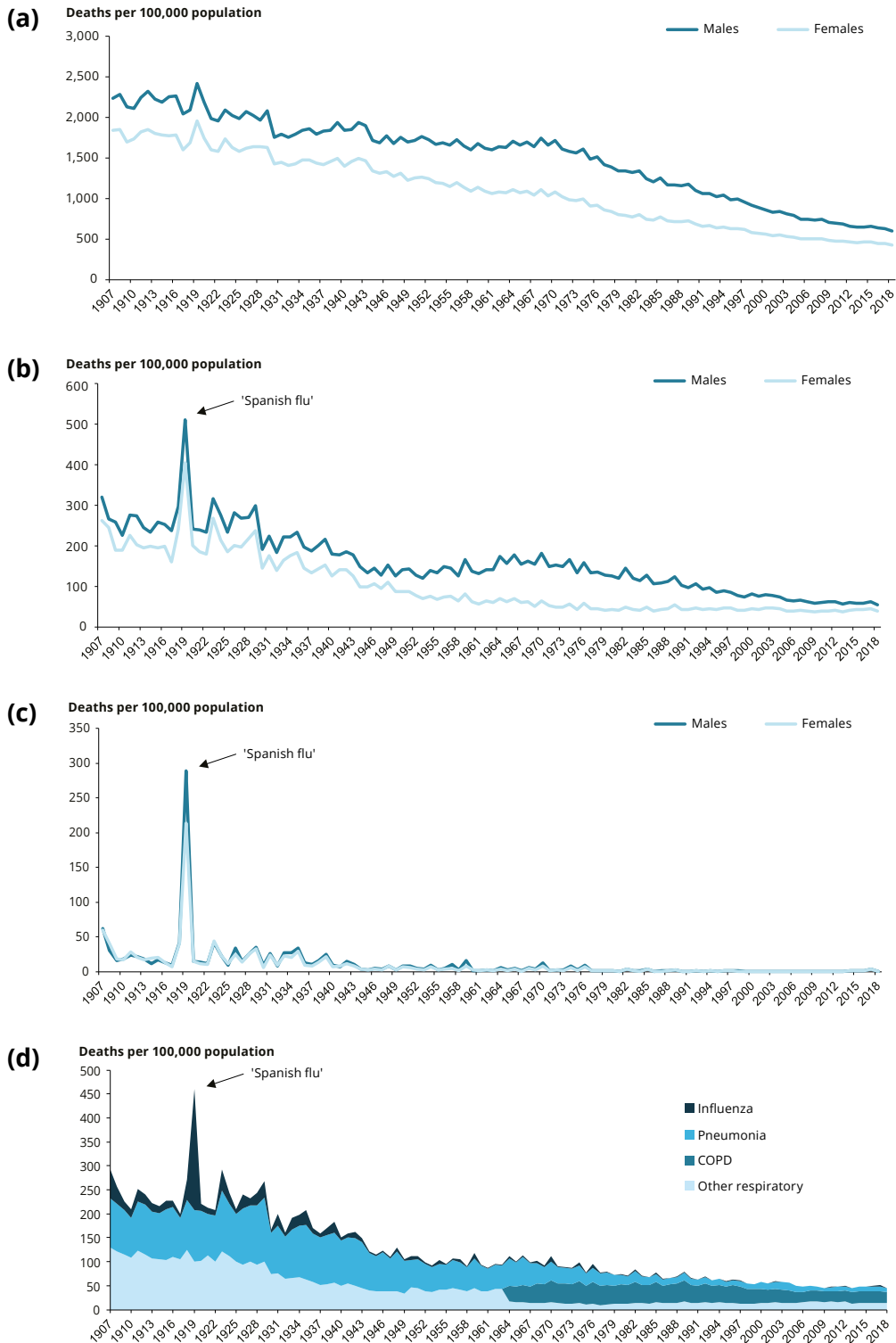
The Spanish flu caused approximately 12,000 deaths in Australia in 1919 making it the most common cause of death in Australia that year (Cumpston 1989). In the previous 5 years, there were an average of 400 influenza deaths each year (AIHW 2020b). The 1919 figure corresponds to a crude rate of 220 deaths per 100,000 people, which is much higher than the current death rate for COVID-19 of approximately 0.4 per 100,000.

The Spanish flu deaths led to a large spike in influenza death rates, as well as the broader respiratory death rate (Figure 2.4b and c). Despite this, it did not have a large impact on overall death rates (Figure 2.4a). Figure 2.4d also shows the relative impact of influenza compared with other respiratory diseases. Australia's death rate was one of the lowest in the world, though in some Aboriginal communities, mortality rates of 50% were recorded (National Museum of Australia 2020).

It is estimated that the Spanish flu pandemic killed at least 20 million people worldwide, although some estimates range to 50 and 100 million (Hobbs 2019). Similar to COVID-19, higher death rates were recorded for older people. However, unusually for respiratory epidemics, younger, healthy adults also had high death rates (CDC 2020b; Cumpston 1989). A vaccine was developed in Australia, which was later evaluated to have been partially effective (National Museum of Australia 2020).

There are many reasons why the world is in a better position to control viral epidemics today than 100 years ago. There is much more knowledge on all aspects of viruses now, including how they spread. Health care has advanced enormously, enabling advanced supportive care and antibiotics for secondary infections, even in the absence of specific treatments or vaccines for a particular virus. Scientific methods have developed substantially—for instance, the invention of the electronic microscope in the late 1930s enabled viruses to be visualised and their structure understood. The health of the population has improved, and communication methods mean that international cooperation is much more possible now. Nevertheless, at this stage, successful control of COVID-19 spread still relies on similar public health approaches to those used in 1919 such as quarantine, isolation and physical distancing.

**Figure 2.4: Deaths due to all causes (a), respiratory diseases (b), influenza (c) and respiratory diseases by more detailed cause (d), Australia, 1907–2018**



Source: AIHW National Mortality Database.

## Comparison with other countries

The first confirmed cases of COVID-19 outside China were in Thailand, Japan and South Korea, which all had a small number of identified cases by 20 January (WHO 2020a). At the start of February, the virus had already spread to 23 countries other than China, including Australia, with the highest numbers of cases of COVID-19 in Thailand, Japan and Singapore (WHO 2020b). By March it was in 58 countries (WHO 2020c), by April in 175 (WHO 2020d), and 182 by the start of May (WHO 2020f), indicating that very few countries had no detected cases. At this stage, Australia has been able to manage the epidemic very well compared with many other countries.

It is always challenging to obtain comparable data across countries to enable these types of assessments, and even more so in the midst of a crisis. Nevertheless, due to the importance of data in managing the pandemic, countries have been reporting on 2 main aspects: the number of confirmed cases and the number of deaths among that group. While there have been specifications produced to enhance comparability (WHO 2020h), some differences remain. These are outlined in the relevant sections below.

Data compiled by the European Centre for Disease Prevention and Control (ECDC) are used in this section. This dataset was chosen because it contained consistent information on cases and deaths, was updated daily, and was available in an easily accessible machine-readable format. Box 2.5 outlines some concepts for interpreting the figures presented below containing international data.

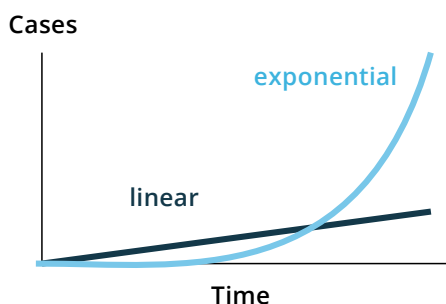


### Box 2.5: Interpreting the international data in figures 2.5 and 2.6

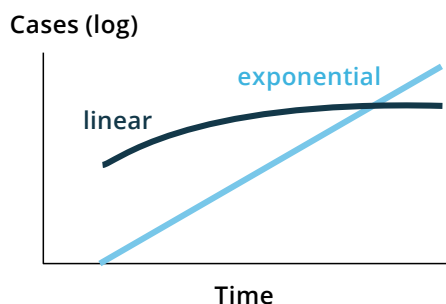
To compare the situation in various countries, a particular presentation of the data is used in figures 2.5 and 2.6. The following are important in interpreting these graphs:

- The data are presented on a log scale. This is particularly useful when data are following an exponential rather than a linear path (see Figure A below). When the number of cases or deaths is increasing exponentially, it quickly becomes difficult to examine the patterns in the data, as the rate of increase is so steep. By using a log scale, the exponential curve becomes linear (see Figure B below) with increments in multiples of 10s (1, 10, 100, 1,000 etc.) rather than 1s (1, 2, 3, 4 etc.). The steeper the line, the more quickly the numbers are increasing. The log scale also helps comparisons between countries with very different population sizes.

**Figure A**



**Figure B**



- 7-day moving averages are used to reduce the volatility in the trend lines. This makes it clearer to see the underlying trends, rather than them being dominated by unusual daily counts (for example, from different testing or reporting rates over weekends or holidays). It is also very useful when the numbers are small in some countries (small numbers are often associated with much more volatility in the data).
- The trends are presented as the number of weeks since a certain threshold in the number of cases or deaths was reached. Thus, comparisons are made across countries over the trajectory of the epidemic rather than by calendar day/week, as the epidemic took off at different times across the world. The threshold is also used so that the focus is on when the epidemic was well established, as there was variation in how quickly initial cases were found through testing, or spread.

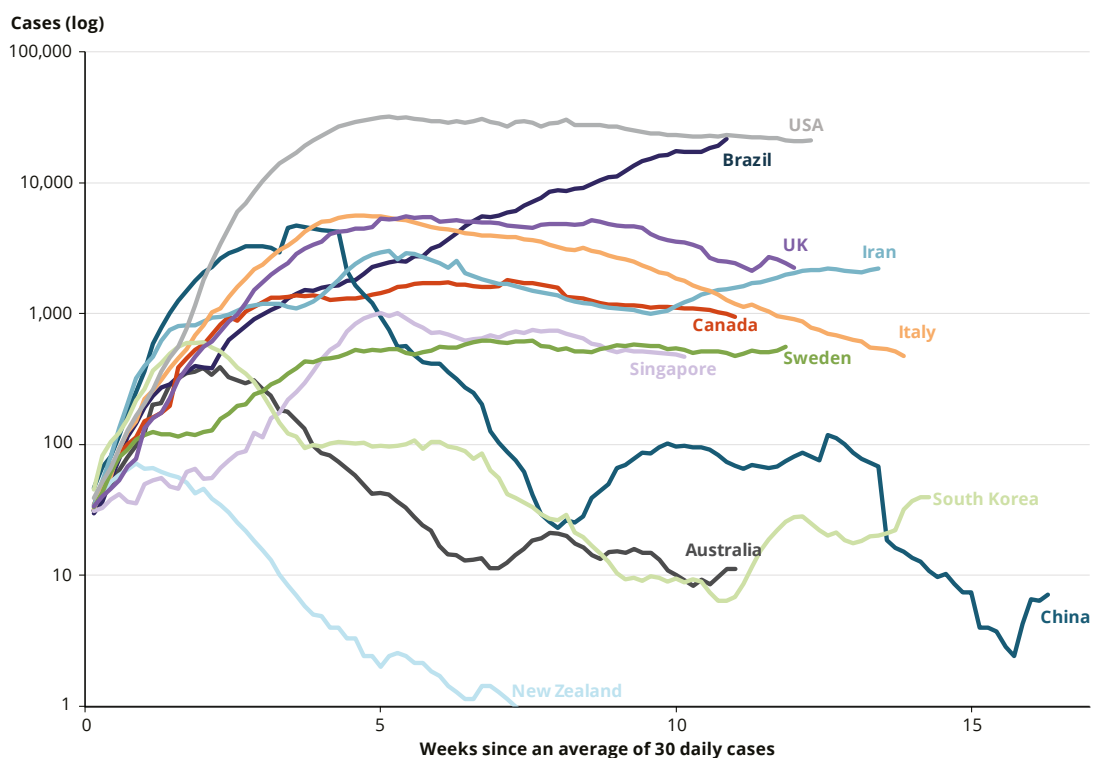
## Number of cases

It is important to recognise that the completeness of testing for SARS-CoV-2 in each country—both in terms of the testing rates and the scope of testing (who is being tested)—can have a large impact on the absolute number of cases. As mentioned above, the testing rates varied substantially across countries (Russell et al. 2020), and therefore care needs to be taken when comparing the number of cases in each country. However, it is likely that the trends within a country are still fairly reliable unless there are major changes in testing regimes within a country.

Despite the challenges in comparing the situation across countries, some broad patterns can be seen. The number of cases over the course of the epidemic for selected countries is shown in Figure 2.5, over the weeks since they experienced an average of 30 daily cases.

For nearly all these selected countries, there was a similar trajectory in the initial days after 30 cases had occurred. There was then variation around the peaks in the number of cases per day (based on the 7-day moving averages) and subsequent declines where they have occurred. One group had peaks around 500 cases per day or less (Australia, New Zealand and South Korea), and another around 5,000 per day (such as China, Italy and the UK). The US has had the highest peak so far at over 30,000 per day, and have since plateaued at that level rather than declining. Other countries that have not yet commenced a clear decline include Canada, Singapore and Sweden, and it is notable that most countries are experiencing a very gradual decline. Brazil continues to have very large increases, currently with over 20,000 cases per day on average. Some countries also had further upturns (such as China, South Korea and Iran).

**Figure 2.5: Number of confirmed cases of COVID-19 per day in selected countries from date when an average of 30 cases reported daily**



Note: Data shown are for 7-day moving averages using data to 31 May.

Source: ECDC.

So far, Australia has kept case numbers down to the level of other countries that have managed to contain their epidemics and prevent the health system from being overwhelmed. Across the countries compared here, those with the lowest rate of confirmed cases (per 100,000 population) by 31 May were Australia (29), New Zealand (24), South Korea (22), Japan (13) and China (6) (Table S2.2). Countries with much higher rates (>300) were Italy, Singapore, Sweden, the UK and the US.

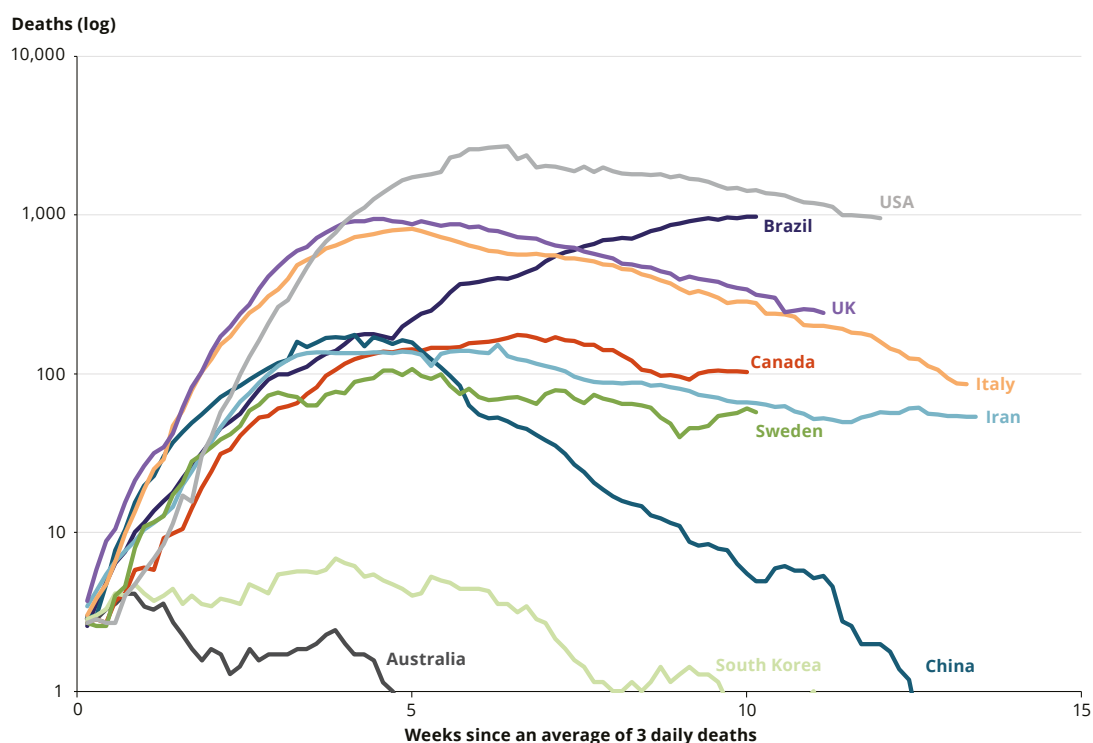
A country with an even lower rate of cases is Taiwan, where there is only a slightly smaller population size than Australia. By 31 May they had 442 confirmed cases in the country (based on ECDC data) which translates to a rate of 1.9 per 100,000. They also did not meet the threshold of daily cases to be included in Figure 2.5. Some of the reasons cited as to why Taiwan have been so successful in containing the virus include experience from the 2003 SARS epidemic, acting very early (in early January they were screening flights from Wuhan), widespread testing and contact tracing, and the use of linked data to assist in finding suspected cases (Le Thu 2020; Wang et al. 2020).

## Number of deaths

Differences in detection rates across countries are compounded further in the deaths data. Some countries focussed on deaths in hospital particularly in the earlier phases of the pandemic, while others also included deaths in nursing homes and in the community (Caul 2020; CDC 2020a). In addition, a higher proportion of older people and those with particular chronic diseases in the population are important risk factors for higher death rates. Despite these differences, it is still useful to compare the trajectories across countries, and the number of deaths may be a better indicator of the size of the epidemic in a country where testing rates are lower.

Figure 2.6 shows the number of daily deaths for a selected group of countries that had at least 3 deaths per day on average. Australia and South Korea had notably lower numbers of deaths and have been able to maintain these levels. Countries with the highest numbers included Italy, the UK and the US, while the number of deaths in Brazil continues to rapidly increase. It is notable that some countries are experiencing a plateauing of the number of daily deaths, rather than a decline. Singapore and New Zealand are not shown here as they have been able to keep their daily deaths lower than the cut-off of 3 deaths per day on average.

**Figure 2.6: Number of deaths among confirmed cases of COVID-19 per day in selected countries from date when an average of 3 daily deaths was reported**



#### Notes

1. A large number of deaths in China were reported on 17 April that reflected reclassification of deaths from the preceding period. These deaths have been redistributed to earlier dates in the same proportion as existing deaths.
2. The y-axis commences at 1 rather than 0, to aid in presenting the key components of the trends. This means that once the average number of deaths per day goes below 1, the trends are not shown on this figure (the case for Australia, South Korea and China).
3. Data shown are for 7-day moving averages using data to 31 May.

Source: ECDC.

When these numbers of deaths are expressed as a rate to account for differences in population size, Australia was in the group of countries with lower rates. Australia (0.41), New Zealand (0.45), and all the Asian countries in the group being compared had crude death rates lower than 1 per 100,000 (Table S2.2). Notably, while Singapore had a relatively high case rate as indicated above, the death rate there has remained very low (0.41 per 100,000). Italy, Sweden and the UK all had death rates over 40 per 100,000. Taiwan had an exceptionally low rate of 0.03 per 100,000 (from 7 deaths). Box 2.6 examines the scenarios if Australia had experienced the same crude death rates as 3 comparable countries who have had larger epidemics than Australia: Canada, Sweden and the UK. Under these scenarios, Australia would have had between 4,800 and 14,400 deaths.

## Box 2.6: 'What-if' scenarios: if Australia had not fared as well over the first 4 months

It is not possible to precisely estimate what the situation in Australia would have been if the epidemic had not been as well contained, as we do not yet know all the factors that influence the number of cases and deaths. However, it is of interest to look at what did happen in other countries and then estimate what the situation would have been in Australia if the same rates (which account for the different sizes of populations) had applied. The simple scenarios provide some broad context, at this early stage, of the order of magnitude of what might have been. It is expected that more detailed research and analysis will be undertaken in the future, taking into account more factors than is possible at this time.

A small set of countries have been chosen for this comparison—Canada, Sweden and the UK. These countries did apply some level of travel bans or physical distancing, though to varying degrees. However, the estimates provided here are not an analysis of the impact of these interventions—a much more detailed analysis would be required for that. The 3 countries are all comparable to Australia in ways relevant to the analysis: they have similar proportions of people over 65 (which will partly account for different population age structures), similar health as summarised by life expectancy at birth, and similar health systems and expenditure on health care (Table S2.2).

By the end of the first 4 months, Canada, Sweden and the UK had increasingly higher case and death rates compared with Australia (Table S2.2):

- case rates (per 100,000) were 243 in Canada, 364 in Sweden and 410 in the UK, while in Australia it was 29
- death rates (per 100,000) were 19, 43 and 58 in Canada, Sweden and the UK respectively; in Australia it was 0.4.

When the rates for the other 3 countries are applied to the Australian population, it can clearly be seen how fortunate Australia has been (Table 2.4). If those rates had applied, Australia would have had between 8 and 14 times the number of cases. The number of deaths under these scenarios would have also been much higher—from around 4,800 to 14,400 deaths. These volumes of cases, and in particular severe cases as indicated by the number of deaths, would have put substantial pressure on the health system. Until a vaccine or specific treatment is developed, rates in this order could still happen in Australia if exhaustive testing, contact tracing and isolation of new cases, and the carefully considered application of physical distancing measures do not continue (Grattan 2020).

*(continued)*

## Box 2.6: (continued) 'What-if' scenarios: if Australia had not fared as well over the first 4 months

**Table 2.4: Scenarios in Australia if rates in Canada, Sweden and the UK had applied**

Country	Confirmed cases			Deaths		
	Number	Extra cases	Ratio scenario: observed	Number	Extra deaths	Ratio scenario: observed
Australia (observed)	7,277			102		
Canada rates	60,816	53,539	8.4	4,770	4,668	46.8
Sweden rates	91,086	83,809	12.5	10,787	10,685	105.8
UK rates	102,552	95,275	14.1	14,425	14,323	141.4

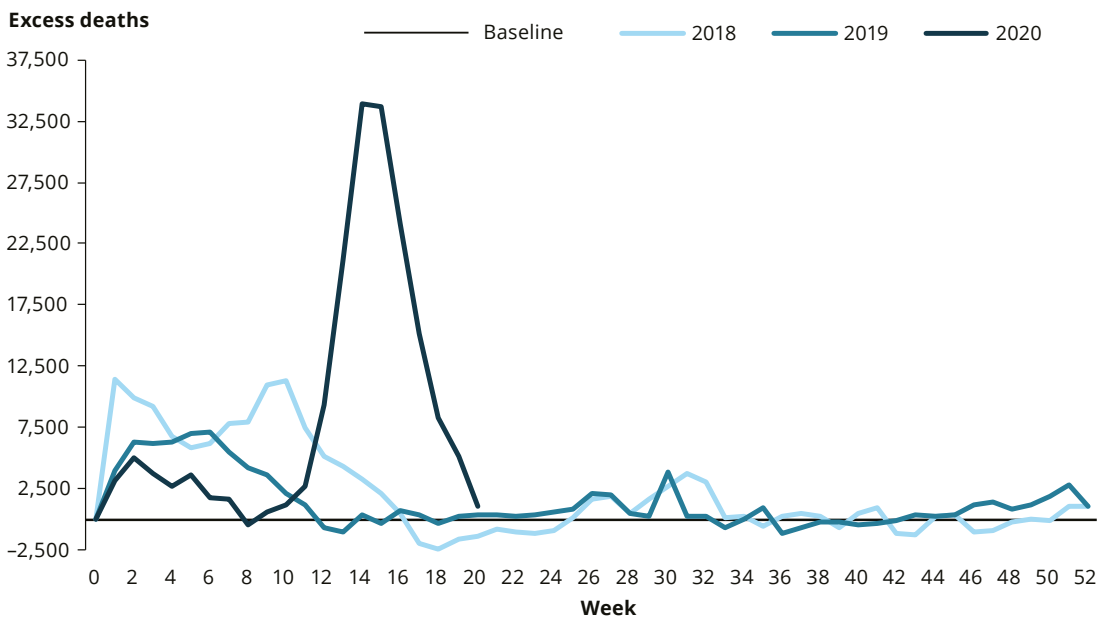
*Note:* Australian data to 7 June 2020, rates from other countries to 31 May 2020.

*Source:* Table S2.2.

If any of these country's death rates had applied in Australia, the deaths from COVID-19 would have been similar in magnitude to the leading causes of death in Australia in 2018 (Table S2.1). The Swedish and UK death rates would have resulted in more deaths than from CHD—the leading cause of death in Australia in 2018. Using a more direct comparison of the current situation in the UK, the age-standardised death rate from COVID-19 in April 2020 was nearly 3 times as high as the next cause of death, dementia, based on all deaths that occurred in England and Wales in that month (ONS 2020).

One way to manage the problem of some deaths not being classified as due to COVID—leading to potential undercounts of deaths in some countries—is to undertake analysis of ‘excess deaths’ (Leon et al. 2020). This compares the counts of all deaths observed in the country to the expected counts based on patterns from previous non-pandemic years. As an illustration, the EuroMOMO (European mortality monitoring) network has been monitoring excess deaths for 24 participating European countries and has observed an increase in weekly excess deaths since week 12 of 2020, compared with 2018 and 2019, for people of all ages (Figure 2.7). The number of excess deaths declined back towards the baseline by week 20. Similar analysis for Australia is not likely to show a significant impact at this stage due to the small number of deaths, though there may be interest in whether or how the measures put in place in response to the epidemic have affected mortality rates.

**Figure 2.7: Weekly excess deaths for the EuroMOMO network of countries, all ages, 2018–2020**



Note: Participating countries include: Austria, Belgium, Denmark, Estonia, Finland, France, Germany (Berlin), Germany (Hesse), Greece, Hungary, Ireland, Italy, Luxembourg, Malta, Netherlands, Norway, Portugal, Spain, Sweden, Switzerland, UK (England), UK (Northern Ireland), UK (Scotland), UK (Wales).

Source: EuroMOMO.



## Indirect effects

The information above on the epidemic so far in Australia covers the direct, short-term effects of COVID-19. However, there are also a number of potential indirect effects from changes within the health system and changes in wider society due to interventions put in place (Douglas et al. 2020). This section seeks to outline some of these effects, but not to provide full detail.

### Impacts on the health system

Key aims of the measures taken to control the COVID-19 epidemic were to protect all parts of the health system from being overwhelmed and to protect health care workers from infection as much as possible. Areas of particular concern were the public health sector, general practitioners (GPs), ICUs and other parts of the hospital system. In particular, overseas experience had shown the importance of controlling the number of people requiring ICU care by reducing the number of infections (Remuzzi & Remuzzi, 2020). Overseas experience had also shown the vulnerability of health care workers to being infected by the virus (ECDC 2020a). Due to the success in delaying and containing the virus in Australia, the impact on hospitals and health care workers has been managed and preparations made for any future increase in cases.

A number of changes have been made to the Australian health system during the epidemic. Some were to treat the initial COVID-19 cases and to prevent transmission of the virus to other people, including new types of health care settings such as respiratory clinics and drive-through testing clinics. Other changes aimed to prepare for a potential surge in the number of COVID-19 patients, such as sourcing many more ventilators and establishing agreements with private hospitals for support if required. While the number of COVID-19 cases requiring health care has remained manageable to date, including in ICUs, if the need increases, it is not known whether this will reduce available resources for the care of people with other diseases. There were also other considerations in the changes made, such as reducing the chance of exposing people to infection from the virus through elective surgery.

There have been changes in people's use of other types of health care. Initially, lower priority elective surgery was cancelled, and it is not yet known what the impact of the consequential delay will be for the health of the population. There has also been concern that people may delay their usual care (such as management of chronic conditions (WHO 2020l) to avoid exposure to the virus. It is encouraging that, for the period 1 January to 30 April, total GP visits (including telehealth services) were in fact higher than the same period last year: they had increased by 3.9% (AIHW analysis of Medicare Benefits Schedule (MBS) data on 3 June, adjusted for working days).

This is larger than the annual population increase to the end of September 2019 of 1.5% (ABS 2019) While this indicates there has not been a decline for this key component of primary care provision—though there may have been variation across the population or parts of the country—there were declines in elective surgery due to the enforced bans and it is possible that other parts of the health system have had declines in use as well.

The changes made to increase the availability of telehealth services (PM&C 2020), aimed to protect patients and health care workers from potential infection. These services have been used in large numbers to date. During March and April 2020, 1 in 5 (20%) MBS-subsidised GP visits used telehealth methods compared with less than 1% of GP visits in the same period in 2019 (AIHW analysis of MBS data on 3 June).

## Broader effects on health and welfare

The large scale changes to society that were required to contain this virus also have a number of potential adverse health and welfare effects, although there are interventions that can be put in place to reduce the risk of these. At this stage we are still likely to be experiencing the earlier effects of the COVID-19 epidemic, but clearly these longer-term effects will need to be monitored into the future.

### Loneliness and mental health effects

The need for as many people to stay at home as possible to increase physical distancing meant that many people were isolated from family, friends and other support networks. By mid-April, based on self-reported information in the Australian Bureau of Statistics (ABS) household impact of COVID-19 survey, one-third of Australian adults had reduced the frequency of contact with family and friends since the start of the COVID-19 epidemic, and the most commonly reported personal stressor was loneliness—reported by 22% of people (ABS 2020c). A longitudinal survey showed that, in April 2020, 41% of male and 50% of female respondents felt lonely at some time, but those percentages decreased to 31% and 40% respectively in May (Biddle et al. 2020b).

The initial impacts of the epidemic in Australia appear to have increased levels of psychological distress. This was particularly the case for those in age groups in the range 18–44 years, where there were statistically significant increases in levels of distress using the Kessler (K6) scale when comparing April 2020 estimates with those from February 2017 (Biddle et al. 2020b).

To provide more information on the broader effects of the COVID-19 epidemic, the AIHW is compiling data on the use of mental health services and from the various crisis help lines, as well as data on the use of homelessness services.

## Changes to health risk factors

The large changes in society may have other effects such as changes to diet, a reduction in incidental physical activity or increases in alcohol use. During the period April and early May, based on self-reported information, 22% of adults increased their intake of unhealthy snack foods and 20% decreased physical activity (although 25% increased it) (ABS 2020c). Around 1 in 5 reported they had increased their alcohol consumption since the spread of COVID-19 (17.9% of males, 22.8% of females), and a little more than 1 in 4 said they had decreased their consumption (27.5% for males, 26.7% for females) (Biddle et al. 2020a). For those who increased their consumption, 45.8% said the increase was 1–2 standard drinks per week, and 27.8% reported an increase of 3–4 standard drinks per week.

## Labour force and income changes

The large-scale loss of employment and the general economic downturn added to the challenges mentioned above, and we know that these and other social determinants are important for an individual's health and wellbeing.

By April, 31% of Australian adults' household finances had worsened due to COVID-19, based on self-reported data (ABS 2020b). Further, longitudinal data show that per person after-tax income decreased by 8.2% between February and May. However, this decline occurred prior to May as there was an increase in after-tax income of 1% between April and May (Biddle et al. 2020c).

Behind these numbers are dramatic changes in the labour market. During April, employment fell by 594,300 people which was nearly 5% of total employment (ABS 2020e). In addition, average hours worked for those employed fell by 9.2%. Together, these figures meant that around 20% of those employed in March either left their employment or had their work hours reduced in April.

A number of government programs were put in place aiming to reduce the impact of these labour market changes. Two of the largest were the doubling of the JobSeeker (unemployment) payment and the introduction of the JobKeeper program, which provides wage subsidies to eligible businesses for payment to their employees. Overall, between 28 February and 22 May 2020, the number of recipients receiving unemployment payments (including JobSeeker, Bereavement Allowance, Sickness Allowance and Youth Allowance (Other)) doubled—an increase of nearly 825,000 recipients over this period (Commonwealth of Australia 2020; Services Australia 2020). As at 20 May 2020, around 2.9 million employees from nearly 760,000 businesses had received benefits under the JobKeeper program, totalling \$8.7 billion in approved payments (The Treasury 2020).

As mentioned earlier, evidence from other countries shows marked inequalities in direct COVID-19 impacts (PHE 2020) and it is expected that there will also be inequalities in the indirect effects which will not be apparent for some time. However, in the early stages of the epidemic in Australia, people whose incomes were lower prior to the epidemic generally experienced an increase in income due to government support measures. On the other hand, people whose incomes were higher before the epidemic experienced a fall in income (Biddle et al. 2020c).

## Children and families

All parts of society have been affected by the short-term impacts of the response to COVID-19, including children and families. A large proportion of children were schooled or cared for at home—76% of Australians with children in their household kept them at home from school or childcare (ABS 2020d)—potentially putting pressure on families and their workplaces to accommodate this, and on children academically and socially.

In times of major crisis, such as natural disasters and disease epidemics, the risk of family and domestic violence can also increase (Peterman et al. 2020; van Gelder et al. 2020). Early evidence of increases in family and domestic violence in Australia are mixed and subject to the complexities in detecting these forms of violence. For example, the number of domestic violence assaults reported to or detected by NSW Police in March and April 2020 was similar (March), or lower (April) than the corresponding months in 2019 (Freeman 2020a; Freeman 2020b). However, Freeman (2020a) notes ‘it is possible that an increase has been masked by isolation strategies affecting victim willingness or ability to seek assistance from police’. International literature suggests that children are at increased risk of abuse and neglect during the COVID-19 crisis (UNICEF 2020). As for domestic violence, it may be difficult to detect and respond to such abuse in the short term, particularly in light of the fact that school personnel are the second most likely profession to draw suspected child abuse to the attention of authorities (behind police) (AIHW 2020a). Finally, the number of calls to the Men’s Referral Service (a family violence telephone counselling, information and referral service) increased by 37% in the last week of April compared with the same period in 2019 (ABC News 2020d), which may indicate an underlying issue not yet apparent in other data.

Evidence on the early impact of the COVID-19 epidemic on older adult victims specifically is limited. However, as COVID-19 has had substantial economic impact and people who commit elder abuse are more likely to be financially dependent on the older victim, an increased risk of elder abuse has been noted (Storey & Rogers 2020).

## Potential positive effects

Despite the challenges outlined above, the changes to society during the epidemic may have some positive health effects. An early example is the reduction in influenza cases. In April, the number of laboratory-confirmed cases of influenza was 98.4% lower than in April 2019, and 85% lower than in April 2018 (Department of Health 2020i). It is plausible that the dramatic reduction in influenza cases reflects measures taken to address COVID-19, such as physical distancing and the closure of schools (as children are major drivers of influenza transmission in the community). These findings are also supported by broader tracking of respiratory illnesses in New South Wales where low positive rates for influenza testing, decreased pneumonia presentations at hospital and a decrease in flu-like symptoms for this time of year were linked to the community restrictions and physical distancing in place (NSW Health 2020b). It is also possible that the increased uptake of influenza immunisation has played a role—although it may be too early to see the beneficial effect of increased vaccination uptake—or that there was reduced influenza testing during part of the period. Other potential positive health effects include reduction in mortality from traffic accidents and air pollution, particularly CHD and stroke deaths (Chen et al. 2020; Shilling & Waetjen 2020; Toffolutti & Suhrcke 2014). It is very complex to weigh the positive and negative effects against each other (Holden & Preston 2020).

## Use of data in epidemics and pandemics

Different types of data are being used in a number of new ways during the response to COVID-19 in order to gain insight and an understanding of how the SARS-CoV-2 virus is spreading across the world and the impact it is having on populations. During this and other crises, there is a strong need to obtain data as quickly as possible. These data may not be perfect but they are needed immediately to be able to manage the situation.

### Current data systems expanded

When the first cases of COVID-19 were confirmed in Australia, there was rapid development and rollout of enhanced data fields for COVID-19 in the NNDSS data supplied daily by the states and territories for collation into the national dataset. This shows adaption of the passive surveillance dataset in the current critical situation. CDNA set up a COVID-19 Working Group who developed a COVID-19 National Surveillance Plan to guide surveillance activities and provide critical evidence to inform public health responses (Department of Health 2020b).

A range of existing complementary infectious disease surveillance systems have also been expanded or used differently during this crisis. Many of these were part of the National Influenza Surveillance Scheme, which monitors and reports on aspects of influenza severity, incidence and virology (Sullivan et al. 2020). An example is the Influenza Complications Alert Network (FluCAN-PAEDS), which is a sentinel hospital surveillance system for people with confirmed influenza who require hospitalisation. It has been expanded to also capture information on hospitalised cases of COVID-19, and has increased its coverage of participating hospitals. Similarly, the Australian Sentinel Practices Research Network, a network of sentinel general practitioners that collects information on influenza-like illness (ILI) presentations in general practice, including test positivity, was also expanded to include COVID-19 cases. In addition, FluTracking, an online health surveillance system which collects information on ILI in the community during the influenza season, began its survey early and expanded its list of questions to capture the impact of COVID-19 and provide early warning of increased respiratory illness in the community.

Other data collections were established in response to COVID-19. Some of these related to the urgent need for timely data on hospital capacity and activity to assess health system capacity to respond to the pandemic. For example, the AIHW has worked with the states and territories to collect daily data on emergency departments, admitted patients and elective surgery, as well as data from the newly created Critical Health Resource Information System (CHRIS). The CHRIS was developed in response to COVID-19 by the Australian and New Zealand Intensive Care Society, Ambulance Victoria and Telstra Purple and covers ICU capacity and activity (Hunt 2020).

## Developments and innovations since previous epidemics

There has been a notable increase in the amount of data provided to the public during this epidemic compared with previous ones. The Australian, state and territory governments have all used tools to keep the public informed of the situation in near real time. For example, many have used some type of summary infographic or dashboard to communicate the daily situation (DHHS Victoria 2020; NSW Health 2020d) and to engage the public in the efforts to contain the virus. There has also been more use of innovative data presentations by the media and research institutions (ABC News 2020b; Dong et al. 2020; Financial Times 2020). Sophisticated modelling of the epidemic and potential future progression have been important for informing governments and the public (Costantino et al. 2020; Moss et al. 2020).

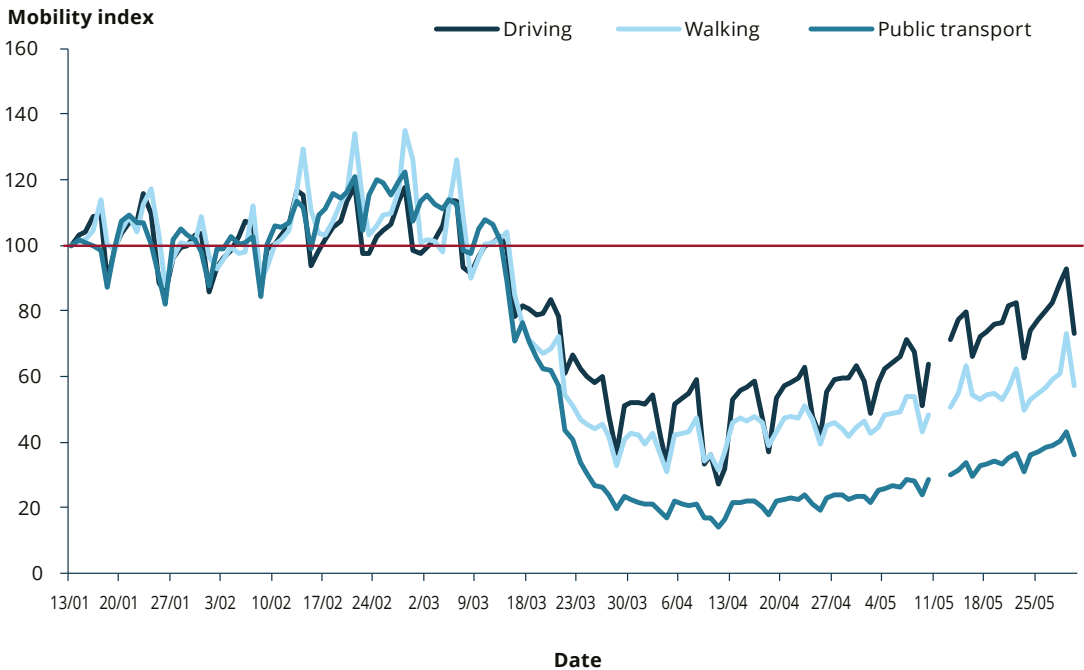
## Genomic sequencing data

Recent developments in scientific knowledge have supported enhanced management of this epidemic. Very soon after the cluster of novel coronavirus cases was reported to the WHO, China shared the genomic sequence (WHO 2020k), and the virus was found to be closely related to 2 bat-derived SARS-like coronaviruses (Lu et al. 2020). Genomic sequencing is being used more routinely in disease outbreak investigations, as it is now cheaper and easier to perform. During the COVID-19 pandemic an open source online resource called NextStrain ([www.nextstrain.org](http://www.nextstrain.org)) is tracking SARS-CoV-2 genomes in real-time as they are released. The information provided by sequence data can assist in determining the origins of a viral outbreak and allows monitoring of virus mutations. Keeping track of how a virus changes can help public health officials contain the spread and can also assist with drug and treatment development. Understanding where mutations occur in the virus is also important to inform the development of vaccines.

## Mobile phone data

Innovative use of mobile phone data has also been a feature of this pandemic. Most countries have introduced measures to reduce movement within and between countries and interaction between people ('physical distancing') to reduce the spread of the SARS-CoV-2 virus. Some countries have put these measures in rapidly and strictly to substantially reduce transmission (for example, mainland China and New Zealand), while others have not implemented them as strictly (for example, Japan and Sweden). Data from mobile phones have been used to track the movement of populations in response to public health interventions, for instance in Wuhan, China, to assess the effectiveness of quarantine measures (Jia et al. 2020).

The large technology companies Google and Apple have publically released aggregated, anonymised mobility data from their mapping products to provide insight into movement trends over time in response to public health measures introduced during the COVID-19 pandemic. The mobility data released by Apple for Australia shows a substantial decrease in mobility in the categories of driving, walking and public transport from early March as public health measures were introduced to reduce transmission of the virus in the community (Figure 2.8).

**Figure 2.8: Apple mobility index, Australia, 13 Jan to 30 May 2020**

*Note:* The data represent daily changes in requests for directions in Apple Maps by transportation type (driving, walking or public transport), compared to a baseline volume on 13 January 2020. The baseline is shown as a red line at 100. No data were available for 11 and 12 May.

*Source:* Apple Mobility Trends; <https://www.apple.com/covid19/mobility>.

A number of countries have introduced mobile phone applications to assist in the contact tracing work needed as part of this epidemic, including South Korea, Singapore and the UK. Australia introduced its own voluntary application, COVIDSafe, in late April (Department of Health 2020f). By 17 May, there had been around 5.7 million downloads of the application (COVID-19 NIRST 2020c). These applications use various features of people's phones so that their interactions with other people can be traced if either they, or one of the people they have been in contact with, contract the virus. This can complement an individual's recall of contacts (they may not remember or know all people they were in contact with) and also speed up the notification of potential exposure to these contacts.

## Linked data

Some countries have been able to use linked administrative data sets to assist with their response to COVID-19 (Park et al. 2020). Taiwan, for example, integrated their national health insurance database with immigration and customs data to develop real-time alerts to aid case identification (Wang et al. 2020).



There is the potential to use de-identified linked administrative data in Australia to enhance disease surveillance, monitoring and research. This could also include linkage between health and welfare (social) data sets, providing information on risk factors, vulnerable populations, outcomes and treatment/vaccination efficacy. For example, linked data (such as Medicare and pharmaceutical data) could allow analysis of longer-term patient outcomes after they have recovered from COVID-19 and their use of the health system.

This could provide important evidence to inform future planning, particularly if there are further waves of disease and if a vaccine is developed and administered to protect the population. The use of data linkage has been increasing in Australia and is recognised as a cost-effective method for filling data gaps and enhancing the value of health data (Rowe et al. 2019).

## Data during crisis may differ to final data

During a crisis, having data quickly is important. This can mean some usual quality checks and processes cannot be completed. For example, deaths data used in this chapter may differ compared with the final death registration data, which will be available in the future for official cause of death reporting. The deaths data reported here are those notified as part of the NNDSS. While the NNDSS is currently receiving reliable information on COVID-19 associated deaths, it may not capture instances where COVID-19 is a contributing factor to the death that occurs after the case has recovered from their initial infection. This is because cases are discharged from public health monitoring once they have recovered. It is also not possible from these data to determine whether COVID-19 was the main (underlying) or an associated cause of death (the terminology used in the official deaths data).

In contrast, deaths data collected through the death registration process takes time to prepare as deaths must be certified by a doctor, registered and processed to ensure the data are as accurate as possible. These data cover all deaths occurring in Australia, and include causes of death information coded using the International Classification of Diseases (ICD) 10th Revision (ABS 2020a). There have been specific emergency ICD codes developed by the WHO for COVID-19, which allows a death to be coded as a confirmed or suspected COVID-19 case (WHO 2020i). Notably, from these data it will be possible to determine whether COVID-19 was the underlying cause of death or an associated cause.

In Australia, the full registration based cause of death dataset is typically released by the ABS approximately 9 months after the end of a particular reference period. In 2020, the ABS has brought forward coding of data (using ICD codes) to enable the release of provisional mortality data on a monthly basis. These interim reports are designed to enable early detection of changes in patterns of mortality by key causes of death and bring forward the reporting of deaths substantially. Data contained in these reports can still lag by several weeks, reflecting both the legislative requirements around death registration in Australia and the need to enable meaningful comparison with historic data.

The first publication of the provisional deaths data (excluding coroner-certified deaths) was released on 24 June (ABS 2020f). There had been 89 death registrations received by the ABS by the end of May—less than the number reported through the NNDSS (102)—though further registrations are still expected for this period. The release also included provisional data for the period 1 January to 31 March on all deaths (to enable excess mortality analysis) and selected causes of death. More detailed analysis will be important as further data become available, enhancing the evidence base on the direct and indirect effects of the epidemic

## Next steps

As a continually evolving situation, there are many things we still do not fully understand about COVID-19. Data are continuing to be collected and will be analysed to provide further clarity in the coming months.

As well as continuing to monitor the various aspects outlined in this chapter, there are many other aspects of the COVID-19 epidemic that will still need further analysis. Some of the unknown characteristics of the virus and disease are outlined in Box 2.7.

### Box 2.7 Some remaining questions about COVID-19

- What proportion of cases are truly asymptomatic throughout the course of their infection?
- Are asymptomatic cases more likely, less likely or just as likely to generate secondary cases compared with cases who are unwell?
- Why do children appear to be less susceptible to contract and transmit COVID-19 compared with other respiratory tract infections, such as influenza?
- Is the multisystem inflammatory disorder seen in children in the Northern Hemisphere caused by SARS-CoV-2?
- Can a person get COVID-19 twice? Is immunity developed and how long does it last?
- Will clinical trials show that certain medications or antibody-derived therapy improve the outcome of COVID-19?
- Will a vaccine be developed for SARS-CoV-2?
- Will there be a second wave of infections?

As well as health data mentioned throughout this chapter, there are other datasets that will help us understand the broader health and social impacts. These include data on homelessness, mental health, employment and Centrelink payments. The AIHW are planning to produce further reports using relevant new data as they become available.

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# Social determinants of health in Australia

3

It is well known that certain biomedical factors and health behaviours are risk factors for ill health. However, there are social features that influence these risk factors—the ‘causes of the causes’—as well as impacting on health directly. Known as ‘social determinants’ of health, these are the social and economic conditions of everyday life that impact on health, such as family circumstances, housing, working conditions, income and education (Lucyk 2017; Marmot & Wilkinson 1999).

The pathways and interactions between these social factors and health outcomes are typically complex, involving mechanisms with uneven distribution (differential exposure) and effect (differential vulnerability); with causal factors that vary by socioeconomic position; and which may occur over many years (Diderichsen et al. 2019). The complexity of these relationships makes it unlikely that any one research study would be able to fully demonstrate the links between social determinants and health. However, there is now a very strong evidence base built up from many studies showing the direct and indirect associations between social determinants and health, the pathways between them and the biological mechanisms involved (Braveman et al. 2011). This chapter uses this evidence to outline relationships between these determinants and health and uses specific Australian data to illustrate the patterns (Box 3.1).



### Box 3.1: Chapter focus and key issues

This chapter provides an overview of the important relationship between the social and economic conditions of everyday life and health outcomes, based on the current strong international evidence base. Australian data are provided to illustrate these relationships, and how these factors should be monitored into the future is outlined.

The key contemporary review of the international evidence around social determinants of health is the final report of the World Health Organization's Commission on Social Determinants of Health (WHO CSDH) (Friel & Marmot 2011; WHO CSDH 2008). The 3 years' work of the Commission synthesised global evidence on social determinants and their impact on health and health inequalities. Some of the findings of the review are included in sections of this chapter.

The large body of research available, taken as a whole, provides strong evidence of the link between social determinants and health outcomes. This chapter cites just some of this evidence, largely drawn from large-scale reviews or various longitudinal studies showing relationships between social factors and health outcomes over time. It also uses analyses from the Australian Burden of Disease Study (ABDS) that quantifies the health impact of a number of social determinants at the population level, by bringing together high-quality research on the links between specific risk factors and health outcomes (AIHW 2019b).

In addition, this chapter provides other Australian data that illustrate the sometimes complex causal links between social determinants and individual or population health outcomes. While these illustrations often show the relationship between 2 factors only, the actual pathways may also involve other factors.

In many cases, social determinants contribute to inequalities in health between population groups that have been defined according to criteria such as socioeconomic position; gender; race or ethnicity; or location. Thus, these inequalities are a major focus for research on social determinants of health and for monitoring population health risks and outcomes. Socially determined inequalities in health that are deemed to be remediable and unfair are referred to as 'health inequities' (Lucyk 2017; Whitehead 1992; WHO 2019; Wilkinson & Pickett 2009).

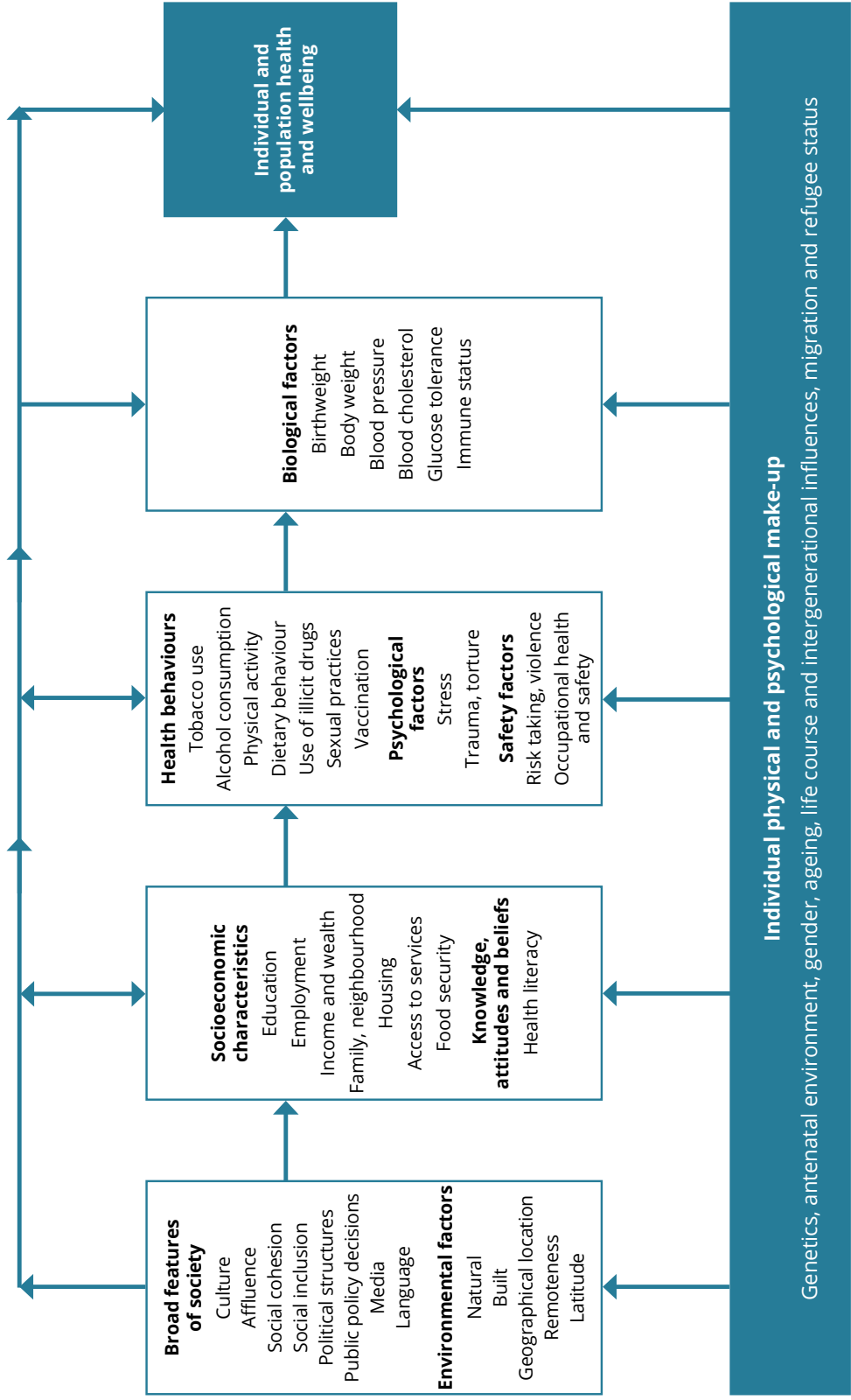
## What are social determinants of health?

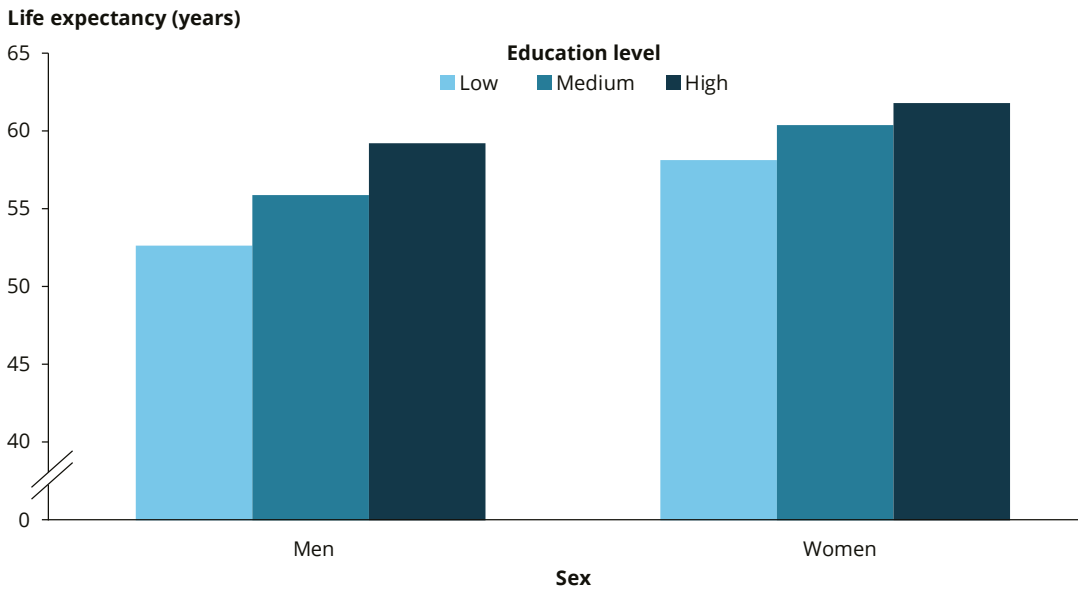
Evidence around the social determinants of health has increased dramatically in recent decades (Honjo 2004). However, the interest in social and related environmental causes of ill health has a much longer history. Some well-known examples are the seminal work of John Snow in the mid-1800s identifying the source of a cholera outbreak in London as a contaminated water source and William Farr's ground-breaking work in the same period, using statistics to examine social inequalities in health in England and Wales (Whitehead 2000). Broader social causes of ill health started to receive much more attention towards the end of the 20th century. An example is the findings of the UK Whitehall studies, commenced in the 1970s and continuing today, which have examined the relationship between various occupational and social factors and health outcomes across employment grades in the relatively homogenous group of British civil servants (Marmot et al. 1984; Marmot et al. 1991; Marmot et al. 1997). Much further research on social determinants of health has since been undertaken, and the WHO CSDH (described further below) brought these findings together in a major report in 2008, leading to the Rio Political Declaration on Social Determinants of Health in October 2011.

Social determinants have been represented in a number of ways, including through conceptual diagrams or as a list of various social and economic factors that have an impact on health (Lucyk 2017). Some conceptual diagrams illustrate the various factors that influence the health of an individual, from their own biology and behaviour, through to family, school and working conditions, to community and societal factors (Dahlgren & Whitehead 2006; Krieger 2008). The framework in Figure 3.1 depicts risk factors from 'downstream' behavioural and biomedical factors to 'upstream' risk factors (further away in the causal chain from the health outcome), which include broad features of society such as culture and affluence. It is the socioeconomic characteristics in the framework that are the main focus of this chapter—including education; employment; income; family circumstances and early childhood; housing; working conditions; and social support. While these social determinants have each been shown to affect health outcomes, there are overlaps between them: for example, people with higher education are more likely to earn higher incomes. Due to the long lead time between exposure to these risk factors and subsequent effects on health outcomes, it is often the downstream factors that receive the most attention—potentially missing opportunities to address the more fundamental, socioeconomic causes of population health and illness (Braveman et al. 2011).

To illustrate the magnitude of the association between 1 social determinant—education level—and health, Figure 3.2 shows life expectancy at age 25 across 3 broad education groups in Australia. For men aged 25, those with higher levels of education (diploma or degree) can expect to have around 59 years left to live, while those with lower levels of education (an attainment less than Year 12, Certificate I, or Certificate II) can expect to have nearly 53 more years—a gap of over 6 years. For women, the gap is nearly 4 years.

**Figure 3.1: Framework for determinants of health**



**Figure 3.2: Life expectancy at age 25, by education level, 2011**

Note: Education levels at age 25: 'Low' = less than Year 12, Certificate I or II; 'Medium' = Year 11 or 12, Certificate III or IV; 'High' = diploma, degree or higher.

Source: Australian data included in Murtin et al. 2017.

## How do social determinants affect population health?

The mechanisms and pathways between the various social determinants and health outcomes are complex and typically take effect over a long period of time. Social factors may affect health because they may reduce access to health care or increase exposure to unhealthy living or working conditions. Stress is viewed as another common pathway between social determinants and downstream risk factors and health outcomes. The chronic anxiety and lack of control arising from unfavourable family, work or other circumstances can have both biological and psychological outcomes, through neuroendocrine, inflammatory, immune and vascular processes (Braveman et al. 2011; Fisher & Baum 2010; Wilkinson & Marmot 2003). Chronic stress can increase people's dispositions to adopt unhealthy behaviours such as smoking, over-eating or alcohol use as forms of relief-seeking (Krueger & Chang 2008).

As noted earlier, social determinants have a direct influence on health outcomes as well as indirect effects by influencing downstream behavioural and biomedical risk factors. Various research studies have demonstrated the direct role of social determinants by separating their impact from that of other determinants (Moor et al. 2017; Walker et al. 2015). An Australian example showed that 34% of the gap in health between Aboriginal and Torres Strait Islander people and Other Australians could be attributed to social determinants and another 19% to health risk factors (with the remaining portion unexplained). These factors do not work in isolation, and an estimated 11% of the gap was attributed to the combined effect of social determinants and health risk factors. The remaining 47% of the gap—the unexplained portion—may include factors for which measurement is more difficult, such as access to health services; the cumulative effects of early life events; or the effect of marginalisation (AIHW 2018a).

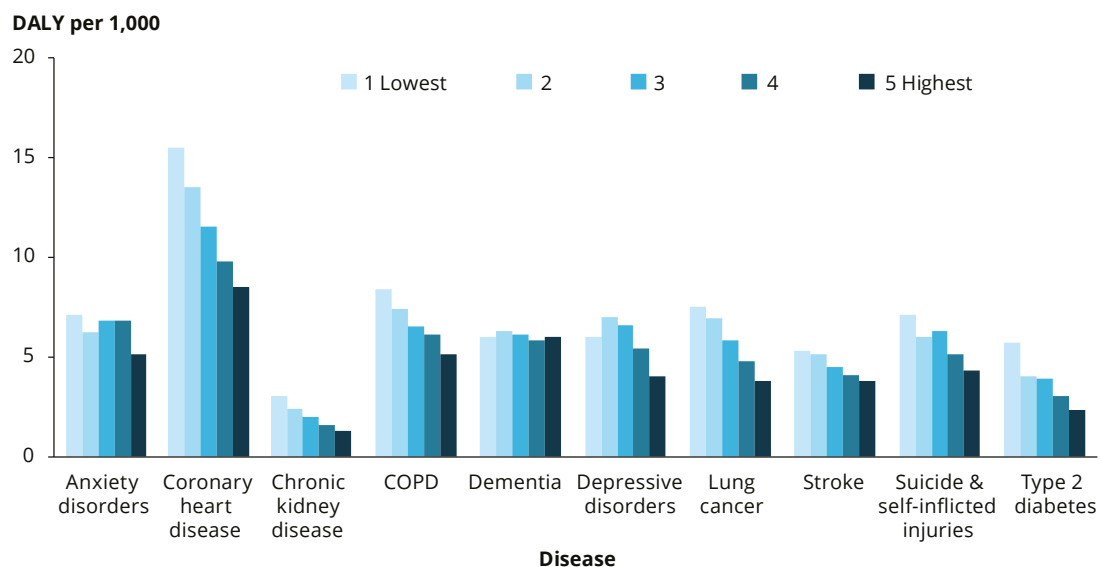
As with any risk factor, social determinants can increase or decrease a person's risk of subsequent health outcomes: in other words, not everyone from a low-income family will necessarily have poor health, it is just that their risk is higher than others. Further, those with multiple unfavourable social determinants over their life will be at even higher risk and be most vulnerable when another life challenge occurs (Braveman et al. 2011).

The relationship between socioeconomic position and health typically follows a 'gradient' pattern, with stepwise increases in health status across each successive increase in socioeconomic circumstances (Lucyk 2017; WHO CSDH 2008; Wilkinson & Marmot 2003). This shows that there is no particular level of poverty that necessarily entails poorer health (though absolute poverty remains important)—but rather, on average, social factors affect population health across all levels of society.

A comprehensive measure of population health is provided by burden of disease analyses, which quantify the health loss from virtually all diseases and injuries in the population using the disability-adjusted life year (DALY) measure. (See 'Burden of disease' webpage <https://www.aihw.gov.au/reports/australias-health/burden-of-disease>). As reflected in Figure 3.3, analysis across socioeconomic groups (based on the socioeconomic status of individuals' area of usual residence) illustrates the social gradient described above for many major diseases, with the burden of disease decreasing as socioeconomic status increases.

The total inequality across all diseases is substantial: 20% of the disease burden in 2015 could have been avoided if there had been no difference in burden across the 5 socioeconomic groups analysed (AIHW 2019a).

**Figure 3.3: Total disease burden for selected diseases, by socioeconomic area, 2015**



*Notes*

1. DALY = Disability-adjusted life year.
2. COPD = Chronic obstructive pulmonary disease.
3. Socioeconomic areas are based on the ABS Index of Relative Socio-economic Disadvantage (IRSD). The 5 groups represent the most disadvantaged 20% of the population to the least disadvantaged 20%, based on the individual's area of residence.
4. Rates were age-standardised to the 2001 Australian Standard population.
5. Prevalence estimates and deaths with insufficient geographic detail to align to a socioeconomic area are excluded from the analysis.

Source: AIHW ABDS 2015.

The next sections provide details on a number of particular social determinants and illustrate the magnitude of the effects on population health in Australia. This list of social determinants is not intended to be exhaustive and there are related sections later in *Australia's health 2020* that provide further detail (Box 3.2).

**Box 3.2: Australia's health 2020 content relevant to social determinants**

*Australia's health 2020* includes significant content relevant to the social determinants of health or health inequalities, as listed below.

Chapters in this report:

Chapter 4: Housing conditions and key challenges in Indigenous health

Chapter 5: Potentially preventable hospitalisations—an opportunity for greater exploration of health inequity

Chapter 10: Longer lives, healthier lives?

*Australia's health* snapshots include:

'Social determinants of health' webpage <https://www.aihw.gov.au/reports/australias-health/social-determinants-of-health>

'Health across socioeconomic groups' webpage <https://www.aihw.gov.au/reports/australias-health/health-across-socioeconomic-groups>

'Built environment and health' webpage <https://www.aihw.gov.au/reports/australias-health/built-environment-and-health>

'Social determinants and Indigenous health' webpage <https://www.aihw.gov.au/reports/australias-health/social-determinants-and-indigenous-health>

## Socioeconomic position

The concept of socioeconomic position describes the social and economic circumstances of an individual, household or area. It can be measured using either 1 specific indicator—such as levels of education, occupation or income—or a composite measure (Dutton et al. 2005), such as the Australian Bureau of Statistics (ABS) Socio-Economic Indexes for Areas (SEIFA), which brings data together on a range of factors. When constrained by data availability, area-based measures (which reflect the average socioeconomic circumstances of people living within a particular area) are often used in routine reporting of inequalities in health outcomes in Australia. This corresponding index is often used as a proxy for an individual's socioeconomic position, as people of similar circumstances often live in the same area (Dutton et al. 2005). It may also reflect aspects of the local area that impact on an individual's health. While the average level is used as a measure of the socioeconomic position of the area, there is also variation in socioeconomic circumstances between individuals within the area.

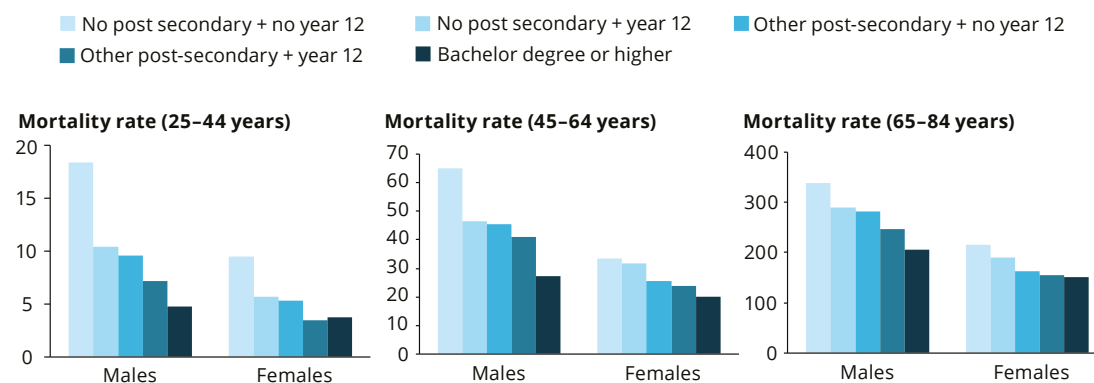
In general, an individual's socioeconomic position indicates their status relative to others in the population, and it has been found that related aspects—such as control over life choices and prestige—may have an impact on downstream risk factors and health outcomes (Marmot et al. 2012). While health can also have an impact on socioeconomic position (as being unwell may reduce earning capacity, for example), it is accepted that the main direction of causation is from socioeconomic position to health outcomes (Braveman et al. 2011). The 3 commonly used components of socioeconomic position—education; employment and occupation; and income—are examined in more detail in the following sections.

## Education

The education level of an individual has a number of fairly direct influences on their health. These include having the knowledge and skills to increase their material resources and ultimately their general socioeconomic position, through higher skilled jobs or higher income. More directly, higher levels of education can assist in understanding and implementing health messages, and health literacy is higher in those with higher education (WHO CSDH 2008). People with higher levels of education are also more likely to participate in society—such as through the political process—that can lead to improvements in living standards for that group, and they are more likely to be able to adapt to changes in the labour market than groups with less education (Mikkonen & Raphael 2010).

Mortality rates show a clear gradient across differing levels of education, with the probability of dying in 2011 decreasing as education levels increase (Figure 3.4). Relative gradients are steeper at younger ages. This possibly reflects the fact that more non-preventable causes of death occur at older ages and that—for a fair proportion of the population—education levels have increased across generations, making disadvantage now more concentrated in the lower education groups (Korda et al. 2019).



**Figure 3.4: Mortality rates by education level, by age and sex, 2011****Notes**

1. Rates presented as deaths per 10,000 person years.
2. Y-axis scale differs for the 3 age groups, and these cannot be directly compared.

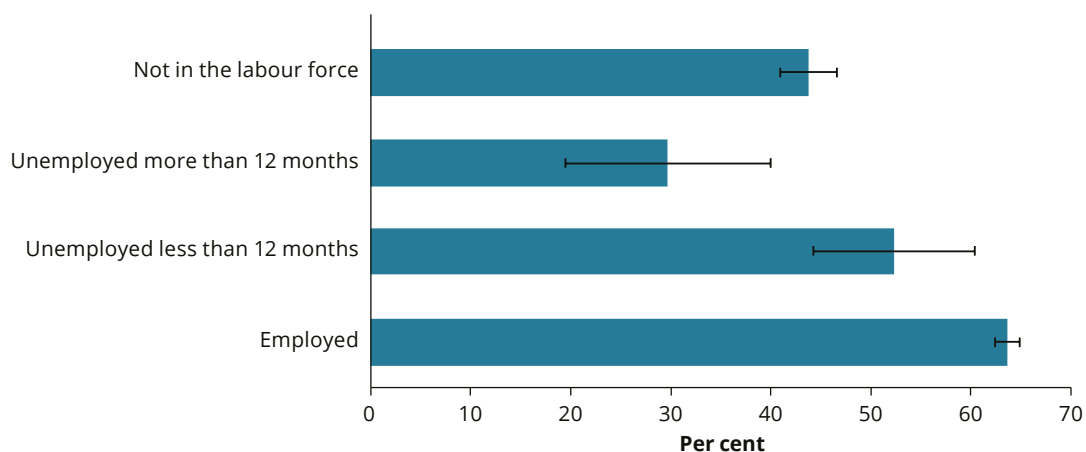
Source: Korda et al. 2019.

## Employment and occupation

Whether someone is able to obtain a job—and the nature of that occupation—is an important component of socioeconomic position. Unemployment leads to reduced income, and potentially to social isolation, psychological stress and unhealthy behaviours, and this can then lead to poor physical and mental health (Kasl & Jones 2000; Wilkinson & Marmot 2003). In Australia, the unemployment rate was around 5% in 2019 (average annual 2019 rate) but the rate is much higher for younger people, at around 10% (AIHW 2019d). Even for those who are employed, around 10% are classed as ‘underemployed’, which means they are willing and able to work more hours than they currently do.

The health of those in and out of the workforce is known to vary. In 2017–18, 64% of those aged 18–64 years who were employed rated their health as ‘excellent’ or ‘very good’ (Figure 3.5). This percentage was lower for those who were ‘unemployed’ (45%) or ‘not in the labour force’ (44%) (a diverse group that includes students, stay-at-home parents, carers, retirees and those who have given up looking for a job). Further, there was substantial difference in reported health among the unemployed, depending on their length of unemployment: 52% of those unemployed for less than 12 months rated their health as ‘excellent’ or ‘very good’, whereas only 30% of those unemployed for over 12 months did so. While it is not clear from these data whether the unemployment caused lower health or whether ill health contributed to being unemployed, other studies have demonstrated that unemployment does increase the risk of ill health (Montgomery et al. 1999; Wilkinson & Marmot 2003).

**Figure 3.5: Self-reported 'Excellent' or 'Very good' health among people aged 18–64, by labour force status, 2017–18**



*Notes*

1. Excludes those for whom labour force status is not applicable.
2. Percentage is age-standardised to the 2001 Australian Standard Population.
3. Bars represent 95% confidence intervals.

*Source:* ABS 2019.

For those who are able to find work when they want to, advantages include income and other benefits such as a sense of purpose (Marmot & Friel 2008). As with education levels, some occupations are higher in status than others, which has its own impact on socioeconomic position (that is, occupational status is not dependent solely on the income received).

Further information on occupational risks and job security are provided in the section on working conditions below.

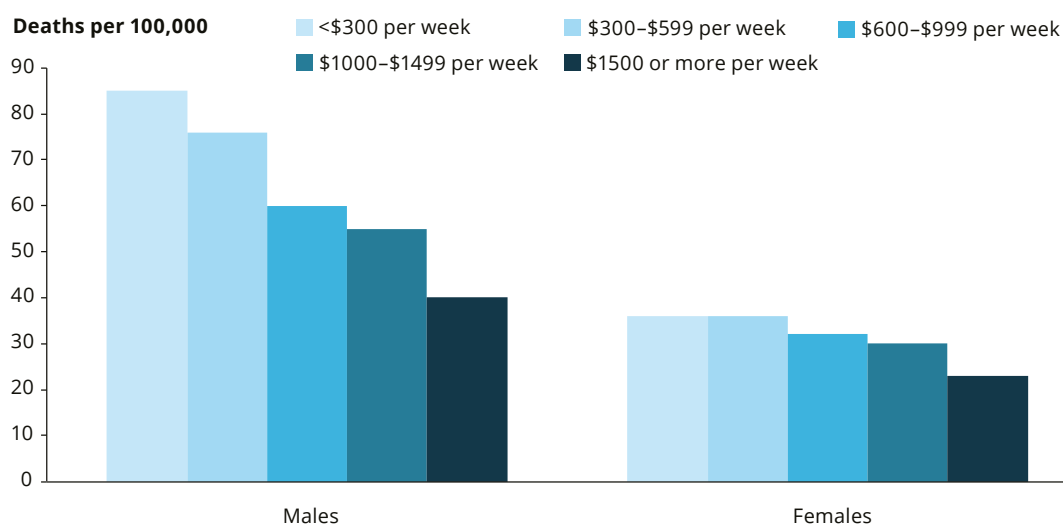
## Income

The final key component of socioeconomic position considered here is income, which most obviously impacts on the financial resources available to the individual or family, directly influencing their standard of living. Higher income levels provide more choices in relation to food availability and quality, housing, physical activity, social participation and health care, which can lead to better health outcomes (Braveman et al. 2011).

In addition, higher levels of income are likely to result in less stress in meeting the demands of everyday life. As with other social determinants, there is the potential for reverse causality, with ill health leading to loss of income.

In developed countries like Australia, important aspects in understanding the relationship between income and health are whether an individual's income can provide the necessities of life, and their relative income level compared to others (Mikkonen & Raphael 2010). Figure 3.6 illustrates the relationship between household income levels and death rates from diabetes in 2011–12: death rates for those in the lowest income bracket (less than \$300 per week) were more than double those seen in the highest income bracket (\$1,500 or more per week) for males, while for females in the lowest income bracket, the rate was nearly 60% higher than for females in the highest bracket.

**Figure 3.6: Diabetes mortality by equivalised household income, 2011–12**



*Notes*

1. Rates are age-standardised to the 2001 Australian population.
2. Includes diabetes as either an underlying or associated cause of death.
3. Includes persons living in occupied private dwelling only.

Source: AIHW 2019f.

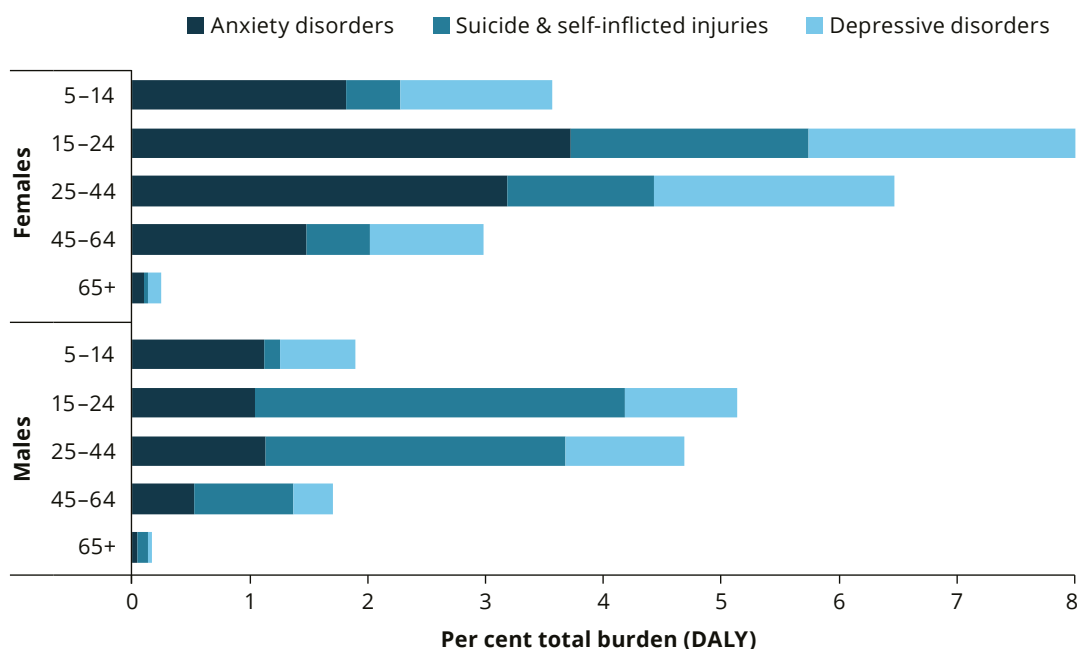
## Family situation

An individual's family functioning and situation has a large influence on their health. All members of an immediate family usually share the same social and economic resources and the influence of those on their health. The influence of the family on health—from parents, siblings, partners and other family members—continues through childhood, young adulthood, adulthood and older age. As with other health determinants, this follows a continuum from large potential benefit for those in high-functioning, cohesive and supportive relationships, to substantial potential disadvantage in families experiencing violence, abuse, interaction with the justice system or other significant challenges (AIHW 2019g).

Two examples of situations which put substantial stress on families are child abuse and neglect, and intimate partner violence. These are included as risk factors in the ABDS, and therefore the impact of these risk factors on disease burden in Australia can be estimated. These estimates take into account the subsequent increased risk of developing and/or dying from diseases known to be linked to the risk factor, based on high-quality research studies relevant to Australia.

Child abuse and neglect increases the risk of anxiety disorders, depressive disorders and suicide/self-inflicted injuries and the effects occur both during childhood and later in life (AIHW 2019b). In terms of the proportion of disease burden attributed to this risk factor, the largest impacts in 2015 were during young adulthood (15–24 years; 8.0% of disease burden for females and 5.1% for males) and the earlier working years (25–44 years; 6.5% for females and 4.7% for males) (Figure 3.7). These are large health impacts: child abuse and neglect was the leading risk factor (that is, causing the most disease burden) for all children aged 5–14, and for females aged 15–24 and 25–44, and the third leading risk factor for males aged 15–24 and 25–44.

**Figure 3.7: Burden of disease attributed to child abuse and neglect, by sex and age, 2015**

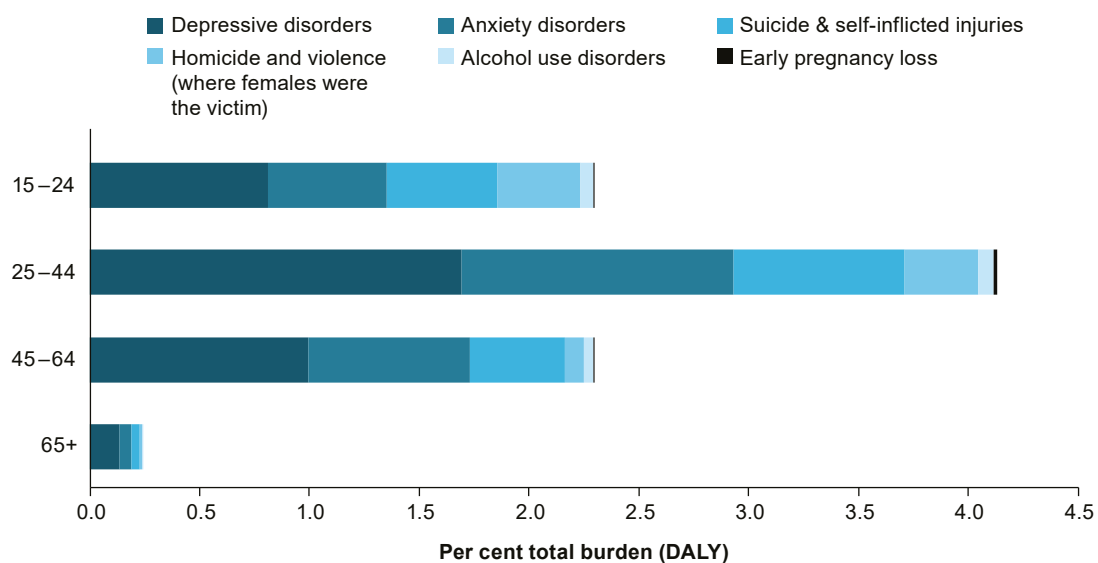


Note: DALY = Disability-adjusted life year.

Source: AIHW ABDS 2015.

Similar data for intimate partner violence among women also shows the large impact on health that results from partner violence, including emotional, physical or sexual violence. As shown for child abuse and neglect, anxiety disorders, depressive disorders and suicide/self-inflicted injuries were also linked to intimate partner violence, along with 3 other factors: alcohol use disorders, homicide/violence, and early pregnancy loss. Again, the impacts were large and occurred across all age groups (Figure 3.8). Intimate partner violence accounted for 2.3% of burden in 15–24 year olds (ranked the fourth leading risk factor for this age group), 4.1% for 25–44 year olds (ranked third) and 2.3% for 35–64 year olds (ranked eighth).

**Figure 3.8: Burden of disease attributed to intimate partner violence for females, by age, 2015**



Note: DALY = Disability-adjusted life year.

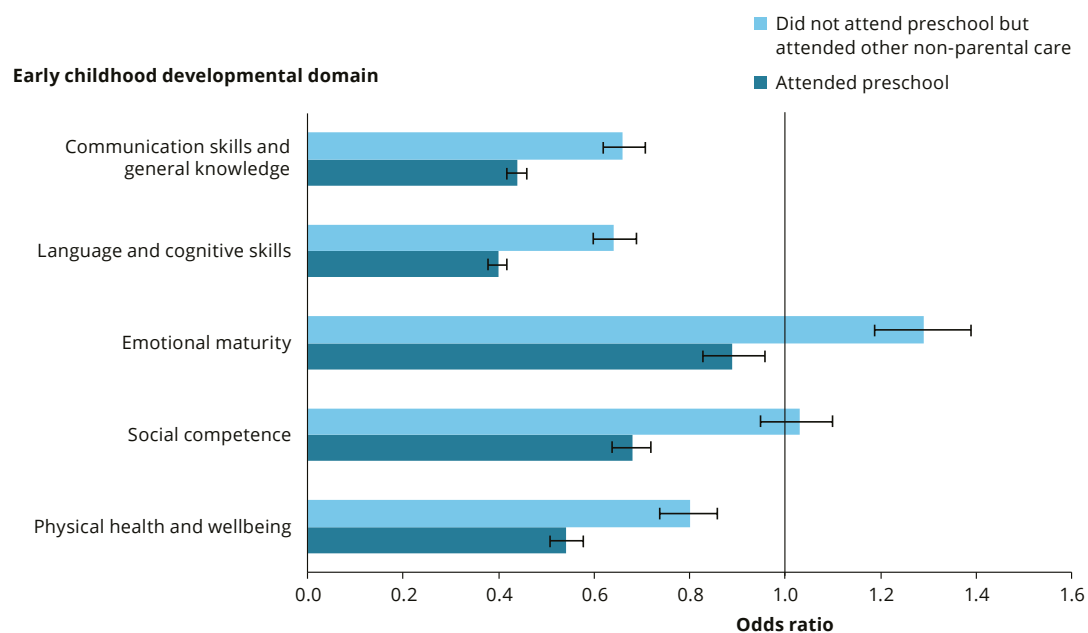
Source: AIHW ABDS 2015.

## Early childhood

Early childhood circumstances have been shown to have a large impact on a child's current and future health. This life stage is often viewed as one of the best times to intervene to reduce health inequities stemming from inequalities in family's socioeconomic circumstances (Marmot 2015). Early childhood development lays the critical foundation for the child's future health and wellbeing, and it has been shown that brain development is highly sensitive to the early life situation (WHO CSDH 2008). This development begins before birth, when the mother's health and diet are particularly important, and continues in the early years of life when material, emotional and social circumstances are highly influential. The impacts may be through various pathways: for example, having a lower readiness to learn when entering school can have an impact on longer-term education outcomes, or more directly through unhealthy learned behaviours. There is also the potential for cumulative effects: for example, the longer a child lives under deprivation, the more likely they are to have health effects from it (Aber et al. 2007).

Early childhood and preschool education has been shown to provide substantial advantages for child development outside the family (AIHW 2019c, 2019i; Elliott 2006; WHO CSDH 2008). As an illustration of this, Australian data from developmental checks on school entry show an association between preschool programs and development (Figure 3.9). In this study (Goldfeld et al. 2016), 'vulnerability' is defined as being in the bottom 10% of children in a particular domain, covering aspects such as language and communication skills; emotional and social competence; and physical health and wellbeing. In almost all cases, the risk of being at the vulnerable end of the spectrum was lower for those children who attended preschool programs, compared with those who attended other types of non-family care or were cared for by their parents only. The effect was greatest in the domains of communication skills and general knowledge, and of language and cognitive skills: children who attended preschool were around 60% less likely to be considered vulnerable in those domains, compared with children who were in their parents' care only (odds ratio = 0.4). It is also important to note that this pattern was also found regardless of socioeconomic group: the advantages obtained from preschool education were apparent for children from both well-off and less well-off groups.

**Figure 3.9: Likelihood of vulnerability across developmental domains in first year of schooling, by preschool attendance compared with parental care only, 2009**



#### Notes

1. All models are adjusted for gender; Language Backgrounds Other Than English; Aboriginal and Torres Strait Islander status; socioeconomic status of area of usual habitation; and state or territory.
2. 'Developmental vulnerability' is defined as being in the bottom 10% of children in a particular early childhood development domain.
3. Odds ratios represent the likelihood of a child being developmentally vulnerable, compared with children who received care from their parents only (reference group, indicated by the vertical line passing through 1). Compared with a child who received care from their parents only, an odds ratio of less than 1 means a child is less likely to be developmentally vulnerable in a developmental domain, and an odds ratio of more than 1 means a child is more likely to be developmentally vulnerable in a developmental domain.
4. Horizontal bars indicate 95% confidence intervals (CIs). CIs not overlapping with the reference group line usually indicate statistically significant differences. The exception is emotional maturity, where 'attended pre-school group' is not significantly different to the reference group.

Source: Goldfeld et al. 2016.



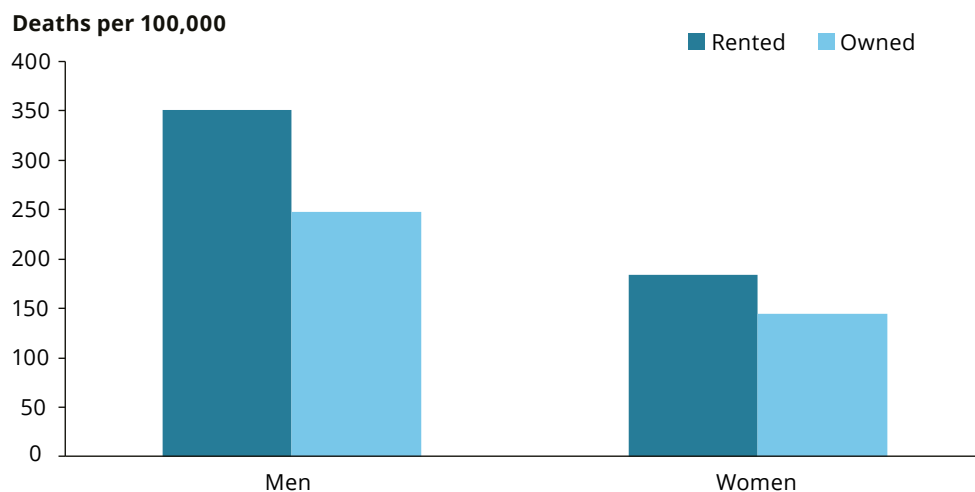
## Housing

It has been shown that a number of aspects of housing can have an impact on health outcomes (Mikkonen & Raphael 2010) and that housing improvements, when needed, can lead to improved health (Thomson et al. 2013). There are direct, more physical effects, such as the level of overcrowding (which can increase the spread of infectious diseases); the quality of the infrastructure within the house; and the ability of the structure to protect the inhabitants from excessive temperatures, storms, insects and various types of pollution.

There are also a number of characteristics of housing that can have a less direct impact on health. Insecure housing (where there is no guarantee of long-term occupancy); unaffordable housing; or, in extreme cases, homelessness can result in stress, substance abuse, or the need to relocate often, which can impact on schooling, employment and family and social support (Sandel et al. 2018). Homelessness and insecure housing can present barriers to accessing health care (ABS 2015), and high housing costs also reduce the resources available for other health-promoting purchases, including quality food. Health problems, including mental illness and substance abuse, can in turn lead to housing challenges.

Home ownership is viewed as the most stable form of housing, whereas renting can range from stable long-term arrangements to short-term, precarious arrangements. Even with this variability in renting arrangements, a difference in health outcomes is seen. For example, cardiovascular disease mortality rates are clearly higher for those renting, compared with rates for home owners (Figure 3.10). The proportion of the population who are renters has increased steadily over time, with 30% of the population renting in 2017–18 (AIHW 2019e).

**Figure 3.10: Cardiovascular disease mortality, persons aged 25 and over, by housing tenure and sex, 2011–12**



*Notes*

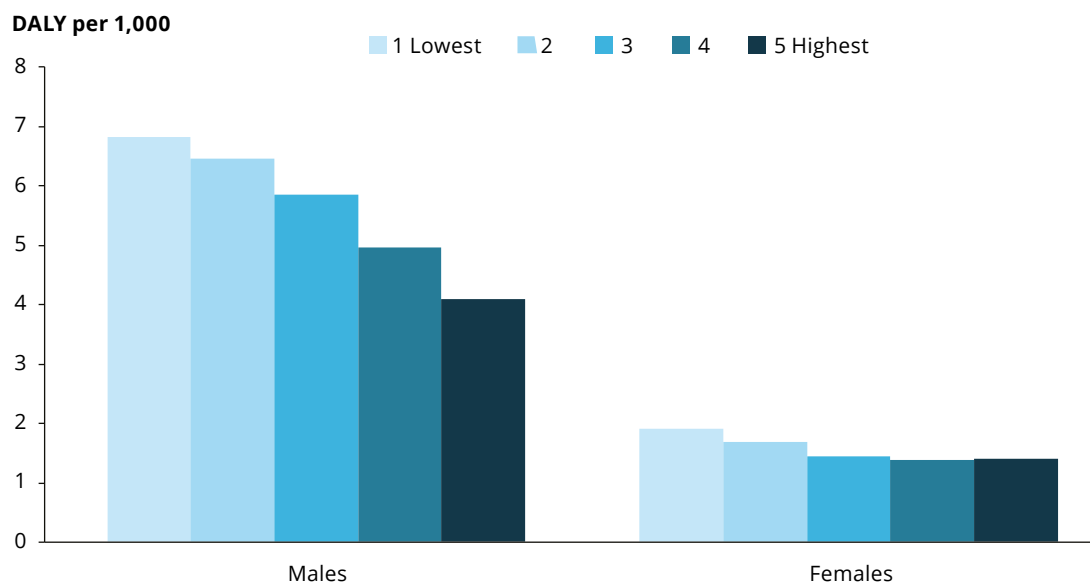
1. Age-standardised to the 2001 Australian population.
2. Includes persons living in occupied private dwellings only.
3. Excludes 'Tenure type not stated' and 'Tenure type not applicable'.

Source: AIHW 2019f.

## Working conditions

An individual's workplace and employment conditions are another social determinant of health, and again there are direct and less direct pathways between this social determinant and health outcomes. Direct impacts include exposure to harmful substances and injury risks, resulting in higher rates of a range of conditions including some cancers (such as mesothelioma) (AIHW 2018b); certain respiratory diseases; back pain; hearing loss; and a number of injuries. The impact of these occupationally-linked diseases is quantified as part of the ABDS in a similar way to other risk factors described above. It shows that these are important causes of disease burden for both males and females, ranking in the top 5 leading risk factors for males aged 15–24 and 25–44 and for females aged 15–24 (AIHW 2019b)—though the rate for males is considerably higher than for females. The occupational disease burden also shows a strong social gradient, with much higher attributed burden for the lower socioeconomic groups compared with the higher ones (Figure 3.11).

**Figure 3.11: Burden of disease from occupational exposures and hazards, by socioeconomic area and sex, 2015**



*Notes*

1. DALY = Disability-adjusted life year.
2. Rates are age-standardised and presented as DALY per 1,000 population.
3. Socioeconomic areas are based on the ABS Index of Relative Socio-economic Disadvantage (IRSD). The 5 groups represent the most disadvantaged 20% of the population to the least disadvantaged 20%, based on the individual's area of residence.

Source: AIHW ABDS 2015.

There are also indirect adverse impacts related to employment conditions, including being in more insecure work such as temporary or casual arrangements (WHO CSDH 2008) or being underemployed (where an individual can obtain some work but not as much as they would like) (Milner & LaMontagne 2017). Working excessively long hours or being in a job with high demands but little control have also been demonstrated to be more stressful and to have subsequent adverse health effects, while social connections at work have been shown to have health benefits (Braveman et al. 2011; Stansfeld & Candy 2006).

## Social support and participation

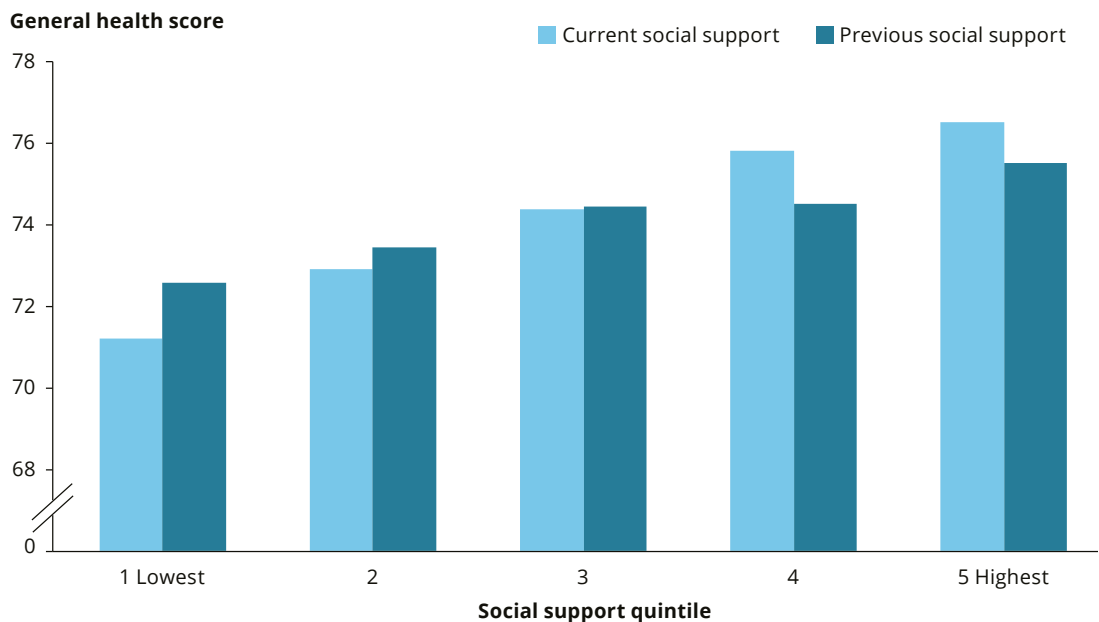
Having strong social networks outside the family has been shown to be very beneficial for physical and mental health (Holt-Lunstad et al. 2010; Wilkinson & Marmot 2003). These networks are able to provide practical and emotional help and support, particularly during challenging periods, and can encourage healthy lifestyles (Berkman & Glass 2000;

Cockerham et al. 2007). Conversely, lack of support and loneliness are detrimental to an individual's health and have been shown to increase rates of various risk factors, stress, depression and the risk of premature death (AIHW 2019h; Holden et al. 2015; Wilkinson & Marmot 2003).

A meta-analysis which combined results from 148 research studies showed a 50% survival benefit among those with stronger social relationships, which the authors note is comparable to other well-established risk factors for mortality (Holt-Lunstad et al. 2010).

An Australian study using data on young women (aged from 22–27 to 35–39 years) from the Australian Longitudinal Study on Women's Health (Holden et al. 2015) showed a strong gradient in general health scores across 5 levels of social support, after adjusting for demographic and behavioural characteristics (Figure 3.12). This gradient held for both current and previous social support levels (that is, when social support was measured prior to the subsequent health score). Note that, in this figure, the taller bars indicate better health outcomes.

**Figure 3.12: General health scores, by social support levels in Australian women aged 22–39, 2012**



*Notes*

1. Scores are adjusted for psychological distress; area of residence; education; ability to manage on available income; alcohol consumption; smoking status; and physical activity.
2. Social support levels were measured using the 6-item Medical Outcomes Study Social Support Scale (MOS-SSS-6) (Holden et al. 2014).

Source: Holden et al. 2015.

Social exclusion occurs when an individual or groups of the population do not have the opportunity to participate in community life and decision making (Saunders et al. 2008). Social exclusion may result from people being excluded from certain services such as housing or education; geographically isolated from others; or unable to participate in social and cultural activities due to lack of income (Mathieson et al. 2008). Some groups are more likely to experience social exclusion, including those living in poverty; the unemployed; older people; immigrants from non-English speaking countries; Indigenous Australians; people with disability or a long-term health condition; and single-person and lone-parent households (Brotherhood of St Laurence & MIAESR 2018; Wilkinson & Marmot 2003). Social exclusion reduces opportunities for education and employment, and adversely affects mental health, with rates of depression being shown to be higher among those experiencing social exclusion (Mikkonen & Raphael 2010).

## Life course and intergenerational impacts

The sections above describe the role of the key individual social factors; however, these factors do not occur in isolation. Social influences on an individual's health and wellbeing occur in combination and cumulatively across life, and the impacts from earlier life are apparent over many years and potentially for generations (Singh-Manoux & Marmot 2005). As discussed earlier in the context of early childhood, disadvantage at that stage of life can reduce social and health opportunities in the future, and this pattern can continue and accumulate over an individual's life (Braveman et al. 2011; Marmot 2012). Further, the length of time in disadvantage increases the risk of ill health in later life (Wilkinson & Marmot 2003).

There are many research studies and reviews that have demonstrated the role of lifetime social and economic conditions on health. For example, in the context of early life, accumulation of disadvantage during childhood was highlighted in an Australian evidence review as having a negative impact on children's development, health and wellbeing, and also their health in later life (Moore et al. 2014). Another Australian study demonstrated that those who had been in manual occupations for longer had an increased risk of being a smoker in mid-life, compared with those who consistently reported being in non-manual occupations (Tian et al. 2019).

Other examples drawn from studies in the UK include 2 from the Whitehall study of civil servants. The first of these showed that men with the highest accumulation of disadvantage had higher risk of coronary heart disease, poor physical functioning and poor mental functioning, and for women this was found for coronary heart disease and physical functioning (Singh-Manoux 2004). The second study showed that the likelihood of adult overweight and obesity increased with accumulation of social disadvantage (Heraclides & Brunner 2009).

Wealth, as a measure of accumulated socioeconomic position over the life course, was found to be strongly associated with all-cause mortality in an English longitudinal study of adults aged 50 and over (Demakakos et al. 2016; Siegrist 2016). The study used repeated measures of wealth and various risk factors, and wealth was found to be more strongly associated with lower mortality than were other socioeconomic variables.

As well as the impact over an individual's lifetime, there are also impacts across generations. Children of socially disadvantaged parents have a higher risk of being socially disadvantaged themselves (Braveman et al. 2011; Cobb-Clark 2019). These impacts start from conception and continue throughout childhood and into adulthood (Aizer & Currie 2014; Assink et al. 2018; Bowers & Yehuda 2016; Elhakeem et al. 2016).

The impact of social determinants over a lifetime and across generations results in a number of population groups that are particularly vulnerable to adverse health effects. Social exclusion (discussed earlier) has been noted to have negative effects particularly in combination with vulnerability and resilience (Marmot et al. 2012). Groups at high risk include those with a high accumulation of social disadvantage, such as Indigenous Australians, those with mental health illness or disabilities, and older people.

## Need for ongoing monitoring

The WHO CSDH highlighted the importance of ongoing monitoring of the social determinants of health and health inequalities: the need to measure and understand the problem (including routine monitoring) was 1 of the 3 overarching recommendations of the Commission (WHO CSDH 2008), and other commentators have echoed this call (Braveman et al. 2011; Donkin et al. 2017). More recently, the United National Sustainable Development Goals and associated indicators include many social determinants of health (UN 2020).

In the WHO report, measuring and monitoring was 1 of the 3 primary recommendations, aiming to ensure routine monitoring of 2 aspects: the social determinants themselves (such as income, education, housing) and the distribution of health across population groups (inequality and inequity). The goal is to assess the magnitude of the problem; who is most affected; and whether the situation is changing over time (MEKN 2007). The need for more longitudinal research to track individuals' experiences over time and across generations is also highlighted.

In *Australia's health 2020*, through 2 corresponding 'snapshots', we have established a mechanism for core ongoing monitoring of the 2 aspects called for in the international literature: one to monitor the social determinants themselves 'Social determinants of health', and another to monitor health inequality 'Health across socioeconomic groups'. There is also potential for more detailed monitoring outside these core components. The AIHW also continues to include related analysis in many of its other reports on health and welfare, including detailed analysis at the small geographic area level.

## Further reading

Social determinants of health are explored further in the 2 *Australia's health 2020* data insights chapters: *Housing conditions and key challenges in Indigenous health* and *Longer lives, healthier lives?*

There are also a number of web pages included in the online components of *Australia's health 2020* that provide data on the social determinants, including comparisons over time and across population groups. These snapshots include 'Social determinants of health', 'Health across socioeconomic groups', 'Health of people experiencing homelessness', 'Built environment and health' and 'Social determinants of Indigenous health', and are available at [www.aihw.gov.au/australias-health/snapshots](http://www.aihw.gov.au/australias-health/snapshots).

Equitable and safe access to health and social services are both important social determinants of health and wellbeing. Further information on access to health services can be found in snapshots relating to the health system in *Australia's health 2020*, including 'Safety and quality of health care', 'Private health insurance', and 'Cancer screening and treatment'. Access to social services is addressed in *Australia's welfare 2019* [www.aihw.gov.au/reports-data/health-welfare-overview/australias-welfare/overview](http://www.aihw.gov.au/reports-data/health-welfare-overview/australias-welfare/overview).

There are a number of reports that have followed the WHO's Commission on the Social Determinants which reviewed the situation in Europe, England and Australia and potential approaches to continue to address the social determinants of health (Marmot et al. 2010; Marmot et al. 2012; Senate Community Affairs Reference Committee 2013).

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# Housing conditions and key challenges in Indigenous health

'Without fundamental things like access to water, the ability to wash, ... the ability to get rid of waste, the ability to live in a house that is safe ... to try and improve health is impossible.'

— Dr Lilon Bandler, Sydney Medical School.  
*The importance of living conditions to health.*  
[www.housingforhealth.com](http://www.housingforhealth.com).

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There have been substantial improvements in Aboriginal and Torres Strait Islander health over the past 30 years, with decreases in cardiovascular death rates and infant mortality, and increases in life expectancy and in the number of people accessing preventive or health monitoring services (such as health checks, chronic disease management plans, and antenatal care) (AHMAC 2017). However, Indigenous Australians as a group still experience poorer health outcomes compared with non-Indigenous Australians. The reasons for this disparity are complex, and key among these is the impact of colonisation and separation from Country on the wellbeing of Indigenous Australians (Osborne et al. 2013). It is also well recognised that disparities in upstream factors—the social determinants of health—result in differences in risks, exposures, access to services and in outcomes throughout life. One social determinant having a substantial impact on Indigenous health is housing conditions.

This article considers common factors underlying a number of diseases prevalent in the Indigenous Australian population, particularly those in remote areas, but less commonly or even rarely seen among non-Indigenous Australians: chronic kidney disease, rheumatic heart disease, and certain eye and ear diseases. Bringing together the available information, and highlighting data gaps, can help us to draw out critical issues and to identify potential points of intervention that would produce benefits across multiple areas. Given that many of the social determinants, including housing, lie outside of the health system, the efforts of a range of systems, government departments and other organisations will be needed to support and drive interventions. Establishing agreed indicators across the main domains of interest, and regularly monitoring these, can also help to ensure that all parties, both within and outside the health system, are able to gauge progress and to make sure their efforts are having the desired impact.

## Social determinants of health and Indigenous Australians

The World Health Organization (WHO) describes social determinants of health as ‘the structural determinants and conditions of daily life’—that is, the conditions of work or leisure; people’s homes, communities and environments; and their access to education and health care (WHO CSDH 2008). People’s opportunities and circumstances are shaped by the distribution of power, income, goods and services, which are in turn affected by policy choices, and are a major component of health inequities between and within countries.

Commonly recognised social determinants of health include housing, education, employment, income, and social networks and connections. For Indigenous Australians and other Indigenous peoples across the world, cultural factors—including connection with land and waters, identity, and language, as well as the ongoing effects of dispossession, marginalisation, racism, and discrimination—also play a key role in influencing health outcomes (Figure 4.1).

Other important social determinants affecting health outcomes include:

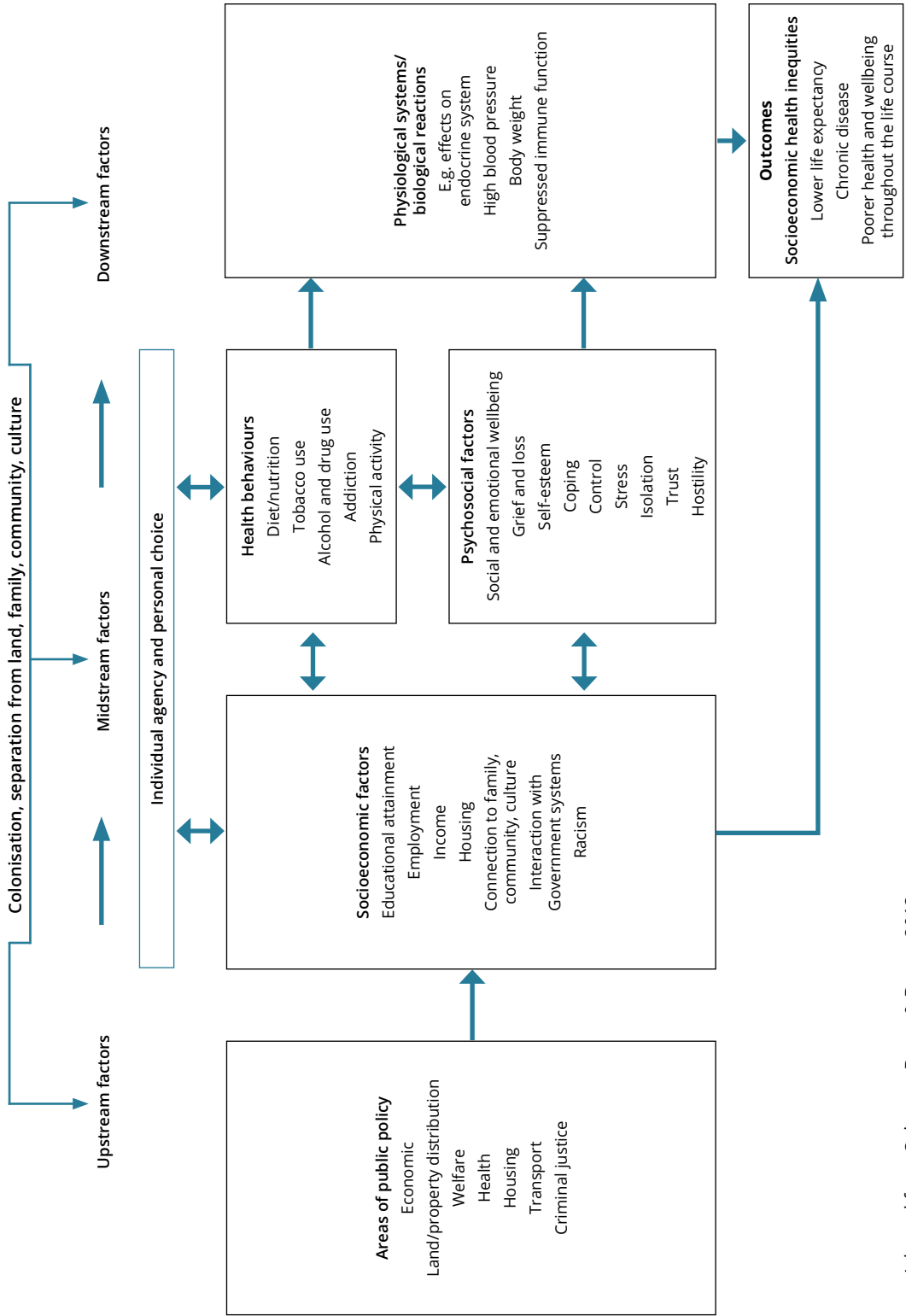
- health literacy (the ability to obtain, read, understand and use health-related information to make appropriate health decisions), and
- availability of health resources (the funds, equipment, facilities, personnel and other items such as medicines and medical supplies) needed to provide health services.

The social determinants of health act through complex and multidirectional pathways, and underlie a broad range of poor health and welfare outcomes. A combination of factors may act at the community and the individual level to influence health. For example, an individual's level of education and household income may influence their food choices, while the area in which they live may affect the availability and cost of various foods.

Other articles in this report and the *Australia's health 2020* snapshots (for example, 'Social determinants of health' <https://www.aihw.gov.au/reports/australias-health/social-determinants-of-health> and 'Social determinants and Indigenous health' <https://www.aihw.gov.au/reports/australias-health/social-determinants-and-indigenous-health>) detail the range of social determinants and how they relate to health; their impact throughout life; and their contribution to the gap in health outcomes between Indigenous and non-Indigenous Australians. This article examines key health conditions disproportionately impacting Indigenous Australians, which are affected by housing conditions and access to services.

Two of the critical factors connecting housing conditions to health are the impact of overcrowding and the state of domestic health hardware. 'Health hardware' refers to the physical equipment needed to support good health. This includes safe electrical systems; access to water; working taps, showers, and sinks with plugs; toilets; waste and wastewater removal systems; and facilities needed for the safe storage and preparation of food. If any of these facilities are unavailable, not working, or inadequate to support the number of residents, illness or injury can occur. Also implicit in this is that local infrastructure should minimise environmental health risks, by providing access to safe drinking water, and by supporting sanitation and waste management services.

**Figure 4.1: Conceptual model for social determinants of Indigenous health and health inequities**



Source: Adapted from Osborne, Baum & Brown 2013.



## Key challenges in Indigenous health

Although the social determinants of health—in particular the housing conditions in which people live and their access to relevant health services—affect the incidence and prevalence of many health conditions, there are several conditions which have been identified by governments, health organisations and Aboriginal and Torres Strait Islander communities as being key challenges in Indigenous health. These are kidney disease; acute rheumatic fever (ARF) and rheumatic heart disease (RHD); eye health; and hearing health. Each of these conditions cause considerable burden to individuals, communities and health services, and can lead to hospitalisations that are potentially preventable. ‘Roadmaps’ outlining a framework to deliver programs and services have been, or are being, developed for each of these conditions (Hearing Health Sector Committee 2019; Taylor et al. 2012) and were presented to the Council of Australian Governments (COAG) Health Council in late 2019.

### Kidney disease

Chronic kidney disease (CKD) is common among Indigenous Australians, with around 1 in 6 (18%) Indigenous adults showing signs of kidney problems in 2012–13—more than twice the rate among non-Indigenous adults, after adjusting for age (ABS 2014). If left undiagnosed or untreated, kidney problems can progress to end-stage kidney disease (ESKD), requiring dialysis or kidney transplant for survival (see Box 4.1). CKD may develop as a complication of diabetes or heart disease, or occur independently of these conditions. Although making up only 3.3% of the total Australian population, Indigenous Australians accounted for 12% of new patients beginning ESKD treatment in Australia in 2017, and 8.9% of all Australians either on dialysis or who had a functioning kidney transplant at the end of that year (ANZDATA Registry 2018).

### Box 4.1: Stages of chronic kidney disease

CKD is categorised into 5 stages, according to the level of kidney function (measured as the estimated glomerular filtration rate, or eGFR), or evidence of kidney damage (measured as the albumin-to-creatinine ratio, or ACR).

#### Early stages (1–2)

Tests show an eGFR  $\geq 60$  mL/min/1.73m<sup>2</sup> and/or ACR  $\geq 2.5$  mg/mmol for males or ACR  $\geq 3.5$  mg/mmol for females. There are usually no symptoms.

#### Middle stages (3–4)

Tests show an eGFR of 15–59 mL/min/1.73m<sup>2</sup>. Level of waste (urea and creatinine) in the blood rises and kidney function slows down. The person may start to feel unwell.

#### End stage (5)

Tests show an eGFR  $< 15$  mL/min/1.73m<sup>2</sup>. The person requires dialysis or a kidney transplant to stay alive.

For more information see 'Chronic kidney disease' <https://www.aihw.gov.au/reports/australias-health/chronic-kidney-disease>.

Diabetic nephropathy is the most common primary disease among Indigenous Australians receiving ESKD treatment (ANZDATA Registry 2018), and it is often assumed that diabetes is the major cause of CKD among Indigenous Australians. However, a review of kidney biopsy results showed that, although diabetes was more common among Indigenous compared with non-Indigenous Australians with kidney disease, diabetic changes were present in fewer than half of the Indigenous cases, and the results varied considerably with remoteness (Hoy et al. 2012). CKD has also been linked to infections, in particular post-streptococcal glomerulonephritis (PSGN), with adolescents and younger adults with a history of PSGN being 3–4 times as likely as those without to have signs of CKD (Hoy et al. 2012, 2015). PSGN is caused by infection with certain strains of group A streptococcus (GAS) and is common in developing countries and resource-poor settings in developed countries (Worthing et al. 2019). Acute PSGN is notifiable in Western Australia and the Northern Territory, with notification rates highest among Indigenous children aged under 15. Over the years 2009–2016 in the Northern Territory, the notification rate among Indigenous children aged under 15 was almost 19 times that for non-Indigenous children of the same age

(Chaturvedi et al. 2018). McMullen and others (2016) suggested that 75% of PSGN in the Kimberley region of Western Australia was attributable to factors such as the availability of clean water, laundry and bathroom facilities; and housing conditions including overcrowding.

## Acute rheumatic fever and rheumatic heart disease

ARF is an autoimmune response to infection of the throat by GAS bacteria. There is also increasing evidence that GAS infection of the skin may lead to ARF. The first episode of ARF typically occurs between 5 and 15 years of age. The risk of ARF recurrence is high after an initial ARF episode, with repeated episodes increasing the chance of RHD (long-term heart valve damage). Untreated RHD can cause heart failure, arrhythmias, stroke, endocarditis and pregnancy complications, and may be fatal.

ARF and RHD are preventable and treatable diseases. Both ARF and RHD are associated with overcrowding, socioeconomic deprivation, and inadequate access to health hardware and health resources. They are common in low- and middle-income countries, and in high-income countries they usually persist only in socioeconomically disadvantaged populations. Aboriginal and Torres Strait Islander people have among the highest recorded rates of ARF and RHD in the world. Maori and Pacific Islanders and migrants from developing countries are also at high risk.

Clinical registers of people with ARF and RHD in Queensland, Western Australia, South Australia and the Northern Territory are supported under the Australian Government's Rheumatic Fever Strategy. During the 5-year period from 2013 to 2017, among Indigenous Australians across these 4 jurisdictions, there were almost 1,800 ARF diagnoses and more than 1,000 new RHD diagnoses—accounting for 94% and 83% of all reported cases, respectively (AIHW 2019b).

## Eye health

Eye diseases and vision problems are the most common long-term health conditions in Australia, with around 1 in 3 (33%) Indigenous Australians and 1 in 2 (54%) non-Indigenous Australians affected (ABS 2013). While short- and long-sightedness are the most commonly reported vision problems in Australia, preventable conditions such as cataracts, macular degeneration and diabetic retinopathy also cause vision loss. Most of the blindness and vision impairment experienced by Indigenous Australians is caused by conditions that are preventable or can be treated.

Indigenous Australians aged 40 and over have 3 times the rate of vision loss of other Australians, with cataracts and diabetic retinopathy accounting for 1 in 4 cases (AIHW 2018b). Lack of access to and lower uptake of relevant health services are key factors in this disparity (Taylor et al. 2012). In addition, a number of Indigenous communities are affected by trachoma, an eye infection caused by *Chlamydia trachomatis* bacteria. Repeated infection, especially during childhood, may lead to scarring and contraction of the eyelid, causing the eyelashes to rub against the cornea. This is known as trichiasis and, if uncorrected, results in gradual vision loss and blindness. Australia is the only high-income country in the world to still have endemic trachoma (Vision 2020 Australia 2019). In 2017, across 130 remote Indigenous communities considered 'at risk', the prevalence of active trachoma among children aged 5–9 years was 3.8%, with 60 communities having a prevalence of 5% or more in this age group (indicating endemic levels) (Kirby Institute 2017). High rates of trachoma are associated with poor access to clean water and health hardware; household overcrowding; and lack of access to medical services.

## Hearing health

Aboriginal and Torres Strait Islander people experience some of the highest rates of middle ear disease in the world. Further, while non-Indigenous Australians tend to develop hearing loss at older ages, Indigenous Australians with acquired hearing loss tend to have developed it in childhood.

Otitis media (OM) (middle ear infection) is the most common ear disease among Indigenous children. It is largely the result of socioeconomic factors including poverty, crowded housing, lack of adequate health hardware, and limited access to primary health care and treatment. While it affects children across Australia, with an overall prevalence of 2.6% among Indigenous children aged 0–14 (ABS 2019b), the prevalence of OM among young Indigenous children in remote communities is often considerably higher, and has been reported to be as high as 90% in some studies (see, for example, Leach et al. 2016).

Compared with non-Indigenous children, OM in Indigenous children tends to occur earlier in life, to occur more often, to be of greater severity and to last longer. The condition often results in perforation of the eardrum and chronic discharge of mucous from the affected ear. Data from the Northern Territory Outreach Hearing Health Program showed that 47% of Indigenous children and young people who received services in 2018 had hearing loss, and 29% had hearing impairment (AIHW 2019c). Among children under 15, those aged 3–5 were the most likely to have hearing loss.

This affects a child's ability to learn and to interact with others during the critical early developmental years. Children who experience multiple episodes of OM prior to the start of school are likely to have difficulties distinguishing, processing and remembering sounds, and in identifying sounds in words. These skills are critical for developing oral communication, literacy and numeracy. Hearing loss can contribute to poor school performance; absenteeism; dropping out of school and subsequent difficulties gaining employment; and increased interaction with the justice system (AIHW 2018a, Su et al. 2019). For more detail, see 'Indigenous hearing health' <https://www.aihw.gov.au/reports/australias-health/indigenous-hearing-health>.

## Housing and living conditions

Not all Indigenous Australians have benefited from the improvements in living conditions during the 20th century that resulted in the virtual elimination of diseases such as ARF and trachoma in the non-Indigenous population. Colonisation and its ongoing effects have had a significant impact on Indigenous housing conditions and homelessness. Indigenous Australians have less access to affordable or secure housing than other Australians, and are considerably more likely to live in overcrowded conditions, or to experience homelessness (including 'sleeping rough', and living in severely overcrowded dwellings or in other temporary or supported accommodation) (AIHW 2019a). The Australian Medical Association's *2018 report card on Indigenous health* lists 'addressing environmental health and housing' as 1 of 6 fundamental targets required to achieve the Closing the Gap health strategy (AMA 2018). This is also recognised in the *National Aboriginal and Torres Strait Islander Health Plan 2013–2023* (Australian Government 2013).

Both overcrowding and inadequate health hardware (or lack of access to these facilities, as a result of homelessness) increase the risk of repeatedly contracting and spreading infection. These living conditions, combined with lack of access to services, means that infections may not be managed, resulting in higher disease transmission; increased risk of long-term complications; and greater disease burden on individuals and communities.

Skin infections are a common cause of morbidity in disadvantaged populations, especially among children. Two of the most prevalent are scabies and skin sores. Evidence from child health checks undertaken between July 2007 and June 2009 under the Northern Territory Emergency Response showed that 9.9% of the Indigenous children assessed had skin sores and 7.9% had scabies (AIHW & Department of Health and Ageing 2009). Scabies is endemic in remote northern Australia, affecting up to 35% of children and 25% of adults (Romani et al. 2015). It is spread by close physical contact or in some cases through sharing clothes, towels and bedding.

Skin sores (impetigo) are caused by infection with bacteria, with GAS bacteria being the most common cause of skin sores in northern Australia (Parks et al. 2012). It may be spread by direct contact with sores or via contaminated clothing or linens. Remote Aboriginal communities in northern Australia have the world's highest prevalence of skin sores (Romani et al. 2015). In a study of 320 children across 5 remote Aboriginal communities, Kearns and others (2013) found that more than 80% had presented to health services with skin sores by their first birthday. Children infested with scabies are up to 12 times more likely to develop skin sores (Aung et al. 2018).

## Overcrowding

Overcrowding is an important issue that has an impact on the health and wellbeing of individuals and households. Data from the National Aboriginal and Torres Strait Islander Health Survey (NATSIHS) suggested that 18% of Indigenous Australians were living in an overcrowded dwelling in 2018–19 (based on the Canadian National Occupancy Standard; see Box 4.2), with this being considerably more common in remote areas (42% compared with 12% in non-remote areas). In some regions, particularly in northern Australia, relatively large proportions of the Indigenous population were living in overcrowded dwellings (Figure 4.2).

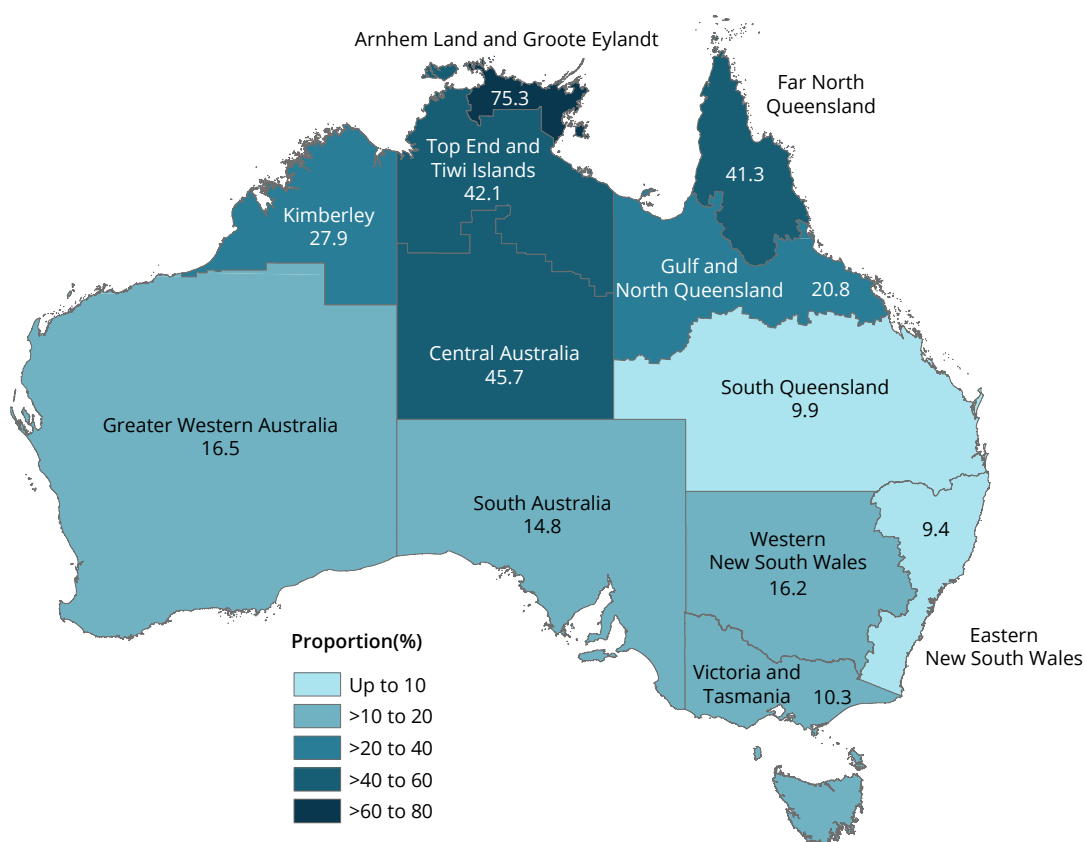
### Box 4.2: The Canadian National Occupancy Standard

Various approaches are used to define and measure the extent of overcrowding. This article uses the definition currently used by the ABS, which is based on the Canadian National Occupancy Standard (CNOS). Using this definition, a dwelling is overcrowded if it requires at least 1 additional bedroom to accommodate the people who usually live there, given their ages, sex and relationships to each other, as follows:

- There should be no more than 2 persons per bedroom
- Children less than 5 years of age of different sexes may reasonably share a bedroom
- Children 5 years of age or older of opposite sex should have separate bedrooms
- Children less than 18 years of age and of the same sex may reasonably share a bedroom
- Single household members 18 years or older should have a separate bedroom, as should parents or couples.

The concept of overcrowding can be a subjective one that is influenced by a number of factors, including cultural and housing design considerations. Memmott and others (2012) note, however, that it is generally the CNOS-type standards that underpin the design of housing even in remote Australia, and that housing stock is usually inadequate to house the large, extended and complex family structures typical of Indigenous communities. Housing represents not only shelter and safety but is a place that supports family, culture and cultural practices. Family visiting during celebrations, sporting or cultural events, for Sorry Business, or at other times may increase the number of residents in Indigenous households for days or weeks. This puts additional pressure on sleeping and living capacity and on kitchen, bathroom and laundry facilities. Dwellings that are inadequate for the number of residents (including long-term visitors) may lead to poor health outcomes, or result in premature failure of health hardware (Healthabitat 2019b).

**Figure 4.2: Proportion of Indigenous Australians living in overcrowded dwellings, by National Indigenous Australians Agency region, 2018–19**



Note: An ‘overcrowded dwelling’ is one that requires at least 1 additional bedroom to accommodate the people who usually live there, as defined by the CNOS.

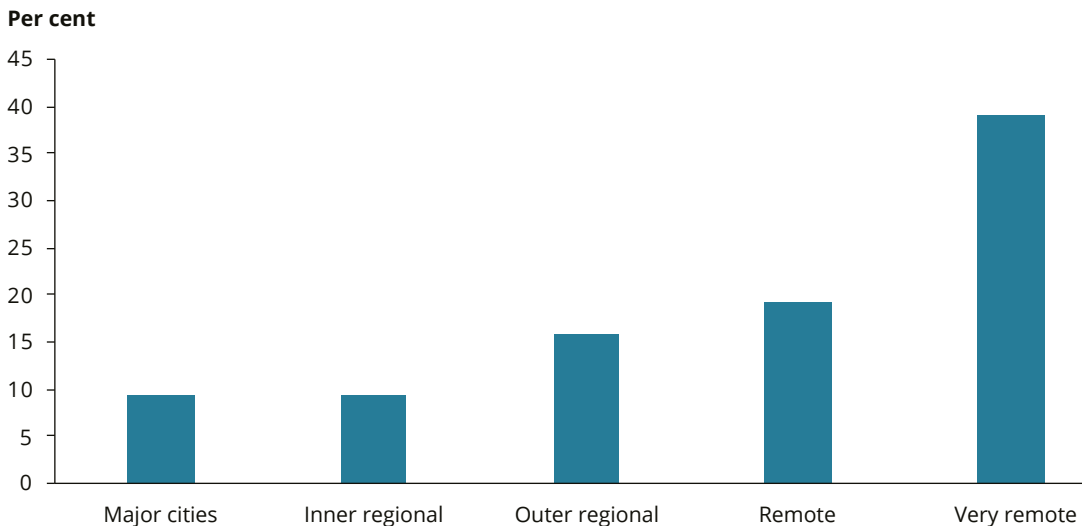
Source: ABS 2019a.

## Health hardware

The Indigenous-specific health and social surveys conducted by the ABS collect self-reported information on defects and issues in the dwellings of respondents, from which data on the proportion of households having working health hardware can be derived. A dwelling with working health hardware is defined in this chapter as one which has working facilities for washing people; for washing clothes and bedding; for safely storing and preparing food; and for safely removing waste.

In 2018–19, around 1 in 7 (13%) Indigenous households were living in dwellings which did not have working health hardware—equating to almost 47,000 households across Australia. Households in *Very remote* areas were up to 4 times as likely as those in other areas to be living in dwellings that did not have working health hardware (Figure 4.3).

**Figure 4.3: Proportion of Indigenous households living in dwellings without working health hardware, by remoteness area, 2018–19**



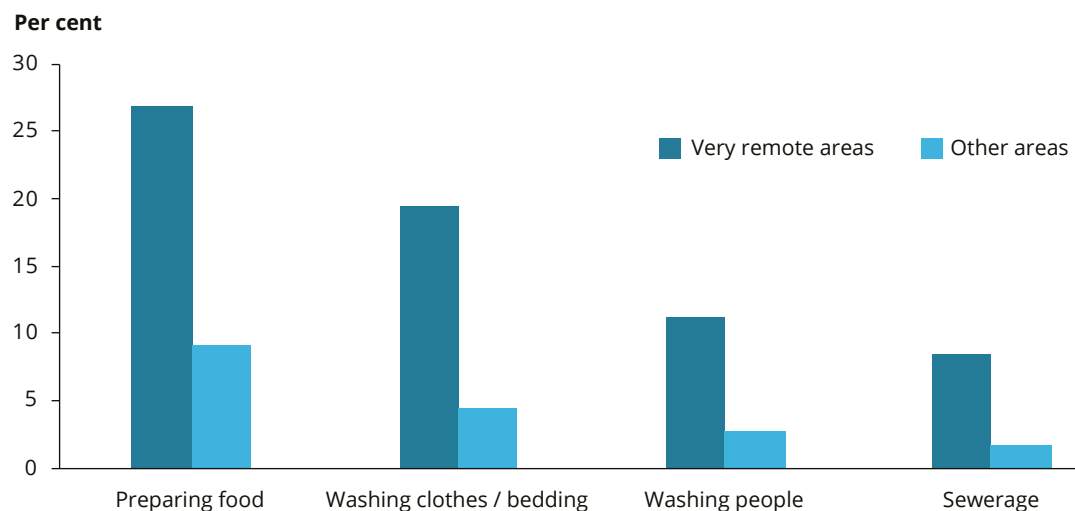
*Note:* A 'dwelling without working health hardware' is one where at least 1 of the following facilities is unavailable or not working: facilities for washing people; facilities for washing clothes and bedding; facilities for safely removing waste; facilities for safely storing and preparing food.

*Source:* ABS 2019a.

The most commonly reported issue related to preparing and storing food, where 27% of *Very remote* households and 7.8% of households in other areas reported not having working facilities (Figure 4.4). Problems with facilities for washing clothes and bedding were also common (20% of *Very remote* households and 3.4% of households in other areas), while facilities for washing people were a problem for 11% of *Very remote* households and 2.1% of households in other areas.



**Figure 4.4: Proportion of Indigenous households living in dwellings without working facilities, Very remote areas compared with other remoteness areas, 2018–19**



Source: ABS 2019a.

These estimates suggest that in 2018–19, more than 39,000 Indigenous Australians were living in dwellings that did not have working facilities for washing clothes, and over 27,000 were living in dwellings that did not have working facilities for washing themselves.

In addition to people living in households without working facilities, or in overcrowded conditions, people who are living in improvised dwellings, tents, or sleeping out ('rough sleepers') may also have considerable difficulty in accessing facilities for washing people and clothes. Rough sleepers and others experiencing homelessness may also have difficulty accessing health services when they are needed, further increasing the risk of poor health outcomes. On Census night in 2016, almost 2,200 Indigenous Australians were sleeping rough, equivalent to a rate of 33 people per 10,000 population—14 times the rate among non-Indigenous Australians (AIHW 2019a).

### Lack of access to health services

In the 2014–15 National Aboriginal and Torres Strait Islander Social Survey, 5.7% of respondents (7.4% in remote areas and 5.1% non-remote areas) reported problems accessing doctors, equating to around 25,000 people aged 15 and over.

The most commonly cited barriers to access included:

- services in the area were not available or inadequate
- transport or distance was an issue
- waiting times were too long or appointments were not available when required (ABS 2016).

Barriers relating to service availability or travel were considerably more likely to be reported by respondents in remote areas, while barriers relating to waiting time or availability of appointments did not vary by remoteness.

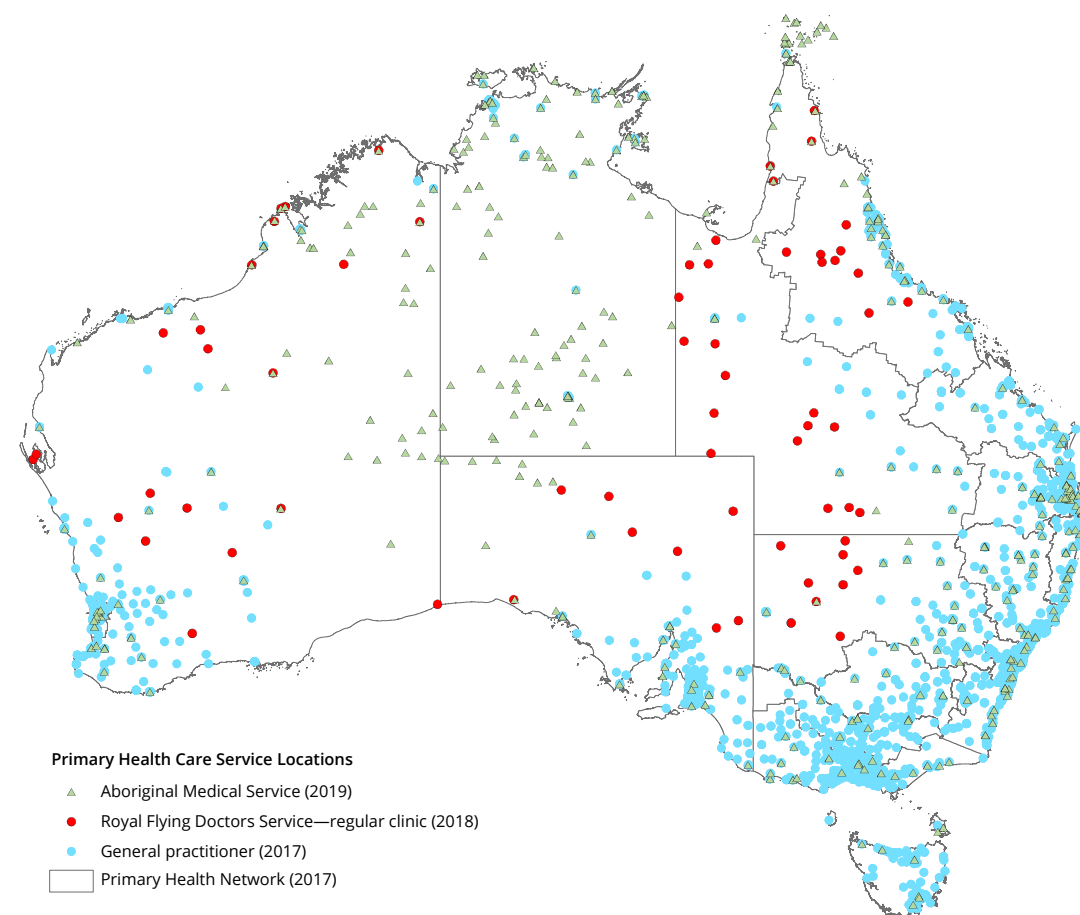
Analyses by the AIHW have examined geographic variations in Indigenous Australians' access to a range of different types of primary health services (both Indigenous-specific and mainstream), hospitals and maternity services. They also examined the distribution of the health workforce relative to the distribution of the Indigenous population. These include general practitioners, nurses, pharmacists, optometrists and dentists (AIHW 2014, 2015, 2016, 2017, 2018a).

Although primary health services are, in general, well-positioned in relation to the Indigenous Australian population, with Indigenous-specific primary health care services supplemented by Royal Flying Doctors Service clinics servicing many remote areas (Figure 4.5), there are still areas where access is difficult. A 'drive-time' analysis revealed there were 40 local areas—including several with populations of more than 600 Indigenous people—where a person seeking care has more than 1 hour's drive to the nearest Indigenous-specific primary health care service (AIHW 2015).

Lack of access to primary health care services, whether these are provided by Indigenous-specific or mainstream health services, means that acute and relatively minor illnesses such as infections may not be managed in a timely way, if at all. Timely management is important not only in reducing the impact of illness on individuals, but also in reducing both the risk of transmission and the risk of progression of an illness (for example, from a throat infection to ARF). For those who have chronic diseases, such as RHD and CKD, lack of access to ongoing and regular management increases the risk of complications and worsening of the disease. This also applies to people who have had ARF, for whom secondary prophylaxis to reduce the risk of RHD (or its progression) needs to be delivered every 21 to 28 days for many years.

Even when there are well-positioned health services available, issues relating to whether individuals perceive a service as being culturally safe may also affect uptake.

**Figure 4.5: Location of primary health care services in Australia, by service type, 2017–2019**



*Note:* Appearance on the map does not necessarily indicate that a site is a regular full-time practice.

*Source:* AIHW 2019b.

## Addressing the problem

The health problems outlined in this article are all related to infection, particularly in childhood. PSGN, ARF, OM, trachoma and skin infections are all most common among children, exposing them to the risk of long-term complications and ongoing health issues throughout their lifetime.

Addressing the basic underlying determinants of adequate housing and access to health services is a key step in meeting these health challenges. Strategies that address basic, (apparently) non-health factors such as living conditions as a means of improving health outcomes are referred to as 'primordial prevention'.

## Reducing risk

Primordial prevention strategies are likely to be multi-sectoral, as responsibility in many cases will lie outside of the health system. The Marmot Review of health inequalities in England (Marmot et al. 2010) noted that action by health departments and health services alone would not reduce health inequalities; action on the social determinants of health needs to involve all central and local government departments as well as the private sector. In addition to multi-sectoral approaches, the interventions required to achieve change can be complex and slow to implement, creating additional challenges (Waters 2001).

The Australian Healthy Skin Consortium (2018) notes that although there is insufficient evidence to determine whether housing improvements directly affect the incidence of skin sores or scabies, there is evidence that housing improvements result in improved skin health in general, and that further research in this area should be a priority. They do state, however, that washing hands with soap is effective in treating and preventing skin sores in resource-limited settings, and therefore access to clean water is critical. According to May and others (2016), improvements in housing quality and access to health care are the top priorities in reducing inequalities in GAS-related outcomes, particularly for Indigenous Australians in remote areas.

In remote areas, access to services and tradespeople is often limited, and fixing problems with plumbing, electricity or appliances can be both slow and expensive. Aboriginal Environmental Health units operate within state and territory health departments, and work with (or within) public health units to improve the conditions in Aboriginal communities by addressing issues relating to utilities, pests, waste management and food safety. For example, in New South Wales, the Housing for Health program has been used to implement change (see Box 4.3).

### **Box 4.3: Housing for Health in New South Wales**

The Housing for Health program has been delivered to Aboriginal communities across New South Wales since 1997, with 118 community Housing for Health projects delivered by the end of 2018. The program has been successful in improving living conditions, with data for projects delivered during 2016–17 and 2017–18 showing a substantial increase in the proportion of dwellings supporting the Healthy Living Practices (Box 4.4) (NSW Health 2019). An evaluation of the program's first 10 years showed a 40% reduction in hospital admissions for infectious diseases among residents of houses within the program, compared with Indigenous residents in other rural areas of New South Wales (NSW Health 2010).

The Housing for Health program aims to improve health in Indigenous communities, particularly among young children, through improving living conditions. The program assesses and then repairs or replaces health hardware so that houses are safe and the occupants have the ability to carry out healthy living practices (see Box 4.4). A key aspect is engaging local community members in all aspects of the process so as to provide employment, build capacity and deliver skills that can be used to help maintain dwellings (Healthabitat 2019a).

#### **Box 4.4: The 9 Healthy Living Practices**

In the mid-1980s, an environmental health review was undertaken in the Anangu Pitjantjatjara (APY) Lands in the north-west of South Australia, through a cooperative initiative by the Nganampa Health Council, the South Australian Health Commission and the Aboriginal Health Organisation of South Australia (1987). The review, *Uwankara Palyanyku Kanyintjaku* (A Strategy for Well-being), identified health problems that could be reduced by changes in the living environment for Indigenous communities in remote Australia. As a result, a prioritised list of 9 'Healthy Living Practices' that could help prevent the spread of infectious diseases was developed. These were adopted by the Australian Government within the National Indigenous Housing Guide (FaCSIA 2012), and underpin the *Housing for Health* program. The practices are largely dependent on environmental services and infrastructure such as drainage, water supply and waste management, along with adequate housing stock with working fixtures:

1. Washing people
2. Washing clothes and bedding
3. Removing waste water safely
4. Improving nutrition and the ability to store, prepare and cook food
5. Reducing the negative impacts of overcrowding
6. Reducing the negative effects of animals, insects and vermin
7. Reducing the health impacts of dust
8. Controlling the temperature of the living environment
9. Reducing hazards that cause trauma.

The first 4 of these are considered critical, as they are essential for people to be able to practice healthy living.

See more on the Healthabitat webpage: <https://www.healthabitat.com/what-we-do/safety-and-the-9-healthy-living-practices/>.

The Fixing Houses for Better Health program, which ran from 1999 to 2011 in all jurisdictions except Tasmania and the Australian Capital Territory, used a similar methodology to improve housing within Indigenous communities. However, while the program resulted in improvements to the way houses supported healthy living practices, no data were collected that could link these improvements to changes in health outcomes in the communities involved (ANAO 2010). In 2008, the 10-year National Partnership Agreement on Remote Indigenous Housing aimed to address overcrowding, homelessness, poor housing conditions and severe housing shortages in remote Indigenous communities across all jurisdictions except the Australian Capital Territory. This was replaced in 2016 by a 2-year National Partnership Agreement on Remote Housing, involving the Australian, Queensland, Western Australian, South Australian and Northern Territory governments. This agreement focused more on new housing, reducing barriers to home ownership and improving tenancy management and rental housing stock. Again, while these programs resulted in improvements to housing, reduced levels of overcrowding and generated local employment, little to no data are available to link these improvements to changes in health outcomes (DPMC 2017). Australian Government funding for Indigenous housing has since been provided to some jurisdictions through individual agreements, as well as more generally via the National Housing and Homelessness Agreement, under which Indigenous Australians are a priority cohort.

## Improving detection by health services

Good quality housing and community facilities (such as childcare centres), with working health hardware, are critical for reducing the transmission of pathogens that cause diseases such as trachoma, OM, ARF, scabies, PSGN, and other infections. Access to timely and responsive primary health care is also important, meaning not only that services need to be available and acceptable to the community, but that health workers need to be able to recognise, diagnose and treat conditions that are not commonly seen in the non-Indigenous population.

There is evidence that conditions such as skin infections may be substantially under-diagnosed even in endemic regions. Yeoh and others (2017) argue that scabies and skin sores are 'normalised' by clinicians working in high prevalence areas, and so cases in patients presenting for other reasons may go undiagnosed and untreated. ARF may also be under-reported as it is complex to diagnose, with identification relying on a combination of pathology, symptoms and exclusions (known as the Jones criteria) rather than a simple diagnostic test (AIHW 2019b). CKD also is known to be under-diagnosed as it may progress to quite significant loss of kidney function without any symptoms that would lead a person to seek medical care.

For ARF and skin infections especially, a factor that may contribute to under-diagnosis is the comparative rarity of these conditions in the non-Indigenous population. Visual aids—such as those developed for the East Arnhem Regional Healthy Skin Project (Andrews et al. 2009) and used in the National Healthy Skin Guideline (Australian Healthy Skin Consortium 2018)—and standard treatment protocols are valuable resources for health workers and clinicians who may be less familiar with the clinical presentation and recommended guidelines for these conditions. Ongoing professional and community education and awareness-raising activities, such as those delivered by RHD Australia and the Northern Territory Outreach Hearing Health program, also provide important support for improving case detection and diagnosis.

## Monitoring progress

Data about the extent of housing adequacy and service access issues; the number of people affected by various health conditions; and evidence for what works to create improvement, are key to reducing the disparities described in this article. Although data on several of these aspects is available, there are gaps where improvements could be made.

Data on the prevalence of CKD; ARF and RHD; and vision and hearing problems among Indigenous Australians are available from a range of national and jurisdictional data collections. For example:

- measured data on kidney problems is available from the ABS National Aboriginal and Torres Strait Islander Health Measurement Survey 2012–13, with self-reported information available from the 2018–19 NATSIHS. The Australian and New Zealand Dialysis and Transplant Registry provides annual data on people beginning or continuing dialysis or living with a kidney transplant. Data on diagnoses of PSGN are available from the Northern Territory and Western Australia, the only jurisdictions in which this is currently a notifiable disease
- the AIHW National Rheumatic Heart Disease Data Collection includes information on people diagnosed with ARF or RHD, sourced from clinical registers in Queensland, Western Australia, South Australia and the Northern Territory. The New South Wales register also provides data to the AIHW, which is included in annual reports (AIHW 2019b)
- the National Eye Health Survey (Foreman et al. 2018) provides data on the prevalence and causes of vision loss among both Indigenous and non-Indigenous Australians, while the trachoma control programs in several jurisdictions provide data on trachoma and trichiasis (National Trachoma Surveillance and Reporting Unit 2018). These and other sources are used by the AIHW to report annually against the Indigenous Eye Health measures (AIHW 2018b)

- detailed data on OM, hearing loss and hearing impairment in Indigenous children and young people is available from the Northern Territory Outreach Hearing Health Program and the Queensland Deadly Ears program, but is not available from other jurisdictions. Some self-reported data are also available from the NATSIHS. A number of research projects and regional studies provide valuable information on the prevalence of conditions such as skin sores, scabies and OM, and on the links between these conditions and social determinants of health.

Detection of vision and hearing problems relies on regular screening and early intervention. The 2018–19 NATSIHS, which included audiometry testing, provides the first national data on hearing loss among Indigenous Australians, and is an important baseline from which to develop policies and identify areas of need (see ‘Indigenous hearing health’ <https://www.aihw.gov.au/reports/australias-health/indigenous-hearing-health>). Repeating this survey in several years would provide follow-up data to allow progress to be assessed.

May and others (2016) suggest that legislating for notification of GAS diseases that disproportionately affect Indigenous Australians (such as ARF, PSGN and impetigo) would facilitate accurate disease monitoring and directed public health responses. They also note that school-based screening programs for sore throat and skin infections exist in New Zealand, where similar issues affect Maori and Pacific Islander peoples.

Although surveys such as the National Aboriginal and Torres Strait Islander Social Survey and the National Social Housing Survey (AIHW 2019d) provide basic information on overcrowding and health hardware, these are based on self-reported information from a sample population. More detailed audits, such as those administered by environmental health units across the states and territories, can provide a more comprehensive picture of the current status of housing and living conditions for Indigenous Australians, and help in identifying areas of need and the types of intervention required. For completeness, both social housing stock and private dwellings (owned or rented) should be included. Health information—both before and after any interventions—is also important: as noted earlier, many of the programs aimed at improving housing in Indigenous communities did not collect data which could enable the assessment of whether the program improved health outcomes. Such information would be highly valuable for both increasing our knowledge of the relationship between housing and health, and for making decisions about the aims and scope of future programs.



Data from the National RHD data collection show cases of ARF occurring in both remote and urban locations, though incidence tends to increase in more remote areas (AIHW 2019b). The National Healthy Skin Guideline also notes that although the burden of skin infections is greatest in remote Indigenous communities, there is also a significant burden for urban Indigenous populations (Australian Healthy Skin Consortium 2018). Although the proportion of people experiencing housing-related problems and the prevalence of related health conditions are considerably greater in remote areas, data from both urban and remote populations is required to ensure the needs of all Indigenous Australians facing these key health challenges are met.

## Conclusion

Housing conditions are associated with several health problems that are prevalent among Indigenous Australians, including CKD, ARF and RHD, eye disorders and hearing problems. Infections, particularly those occurring in childhood, are an important factor in the development of these problems. Good quality, regular and reliable data about these diseases and their underlying determinants (in particular, housing and living conditions)—along with information about access to relevant health services—are critical if these key health challenges are to be met.

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# Potentially preventable hospitalisations— an opportunity for greater exploration of health inequity

5

The health of individuals is the product of complex interactions between biological, social, cultural and economic factors. In ideal circumstances, preventive measures, early intervention, and effective and appropriate primary and community health care may prevent the onset and worsening of conditions that result in hospitalisations. In the late 1980s and early 1990s, this reasoning led to the concept of a potentially preventable hospitalisation (PPH) and its current use as an indicator of primary health care effectiveness (Box 5.1).

Studies have shown a relationship between PPH and various measures of primary health care access, such as physician supply or self-rated access to care (for example, Ansari et al. 2006; Bindman et al. 1995; Laditka et al. 2005). However, many of these studies were from the United States, where the health system is structured differently to Australia. Australian research has shown that PPH are influenced by many factors—some of which are beyond the control of the primary and community health care sector.

Patient characteristics affecting PPH can include age, sex, ethnicity, area of residence, socioeconomic factors, social and family support, mental health, health literacy, health behaviours and disease prevalence (Ansari et al. 2006; Berkman et al. 2011; Falster et al. 2015; Longman et al. 2018; Mohanty et al. 2016; Tran et al. 2014). In some studies, factors like these have been found to account for a greater amount of geographic variation in PPH than general practitioner supply (Falster et al. 2015) or access to primary care services (Mazumdar et al. 2019).

PPH rates are also affected by health system factors such as changes in clinical classification standards, diagnostic practices and hospital admission policies (AIHW 2020a), which can make the interpretation of PPH statistics over time complex.

Despite these reporting and interpretation challenges, PPH remain a valuable tool for exploring health disparities between different populations (ACSQHC & AIHW 2017; Duckett & Griffiths 2016; Health Performance Council 2019; PHIDU 2018; Queensland Health 2018; WAPHA 2017). Knowing who in the Australian community is more at risk of PPH can assist policy makers and health service providers target the delivery of preventive health measures to those most in need. As hospitalisation generally involves higher costs to patients and the health system, preventing and managing health conditions in the community can potentially generate substantial savings in hospital expenditure, as well as resulting in better outcomes for patients (Bellon et al. 2017; Duckett & Griffiths 2016; Hollingworth et al. 2017; Swerissen et al. 2016; Zhao et al. 2014).



This article focuses on three aspects of PPH. First, it presents new data quantifying the economic costs of PPH on the hospital sector and shows how expenditure varies by PPH condition, patient age and sex. Secondly, the question of who is more at risk of PPH is explored through a case study on PPH for *Diabetes complications*. The case study demonstrates the use of recently available data that provide insights into trends in PPH for specific groups within the Australian population, including Aboriginal and Torres Strait Islander people, remote and socioeconomically disadvantaged areas, the very young and older people. Thirdly, the article outlines how current developments in health data linkage present opportunities for a more nuanced understanding of patient care pathways resulting in, and following on from, PPH.

## Box 5.1: Overview of potentially preventable hospitalisations (PPH)

### History of PPH

The concept of PPH (also known as ambulatory care sensitive conditions or potentially avoidable hospitalisations) originated in the United States as a tool for examining socioeconomic and racial disparities in primary care access (Billings et al. 1993). A number of countries—including Australia, the United Kingdom, New Zealand and Canada—adapted the tool as a measure of access to timely, effective and appropriate primary health care (Ansari 2002; Falster & Jorm 2017), although differences between health care systems and indicator definitions limit the use of international comparisons.

### Types of PPH

In Australia, PPH are monitored using a set of conditions that are considered indicators of access to timely, effective and appropriate primary health care. It is important to note that the PPH conditions monitored are not an exhaustive set of all potentially avoidable hospitalisations (Falster & Jorm 2017).

PPH are grouped into 3 main categories (AIHW 2019g):

- *Vaccine-preventable conditions*: hospitalisations due to diseases that can be prevented by vaccination, such as influenza, measles and whooping cough.
- *Acute conditions*: these conditions usually have a quick onset and may not be preventable, but theoretically would not result in hospitalisation if timely and adequate care was received in the community. This category includes conditions such as dental conditions, cellulitis, urinary tract infections and ear, nose and throat infections.

(continued)

### Box 5.1: (continued) Overview of potentially preventable hospitalisations (PPH)

- *Chronic conditions*: these long-lasting conditions may be preventable through lifestyle change but are also manageable in the community health care setting to prevent worsening of symptoms and hospitalisation. This category includes conditions such as diabetes complications, heart failure, chronic obstructive pulmonary disease (COPD) and asthma.

Having a 'potentially preventable hospitalisation' does not mean that the patient did not require hospitalisation at the time, but rather the hospitalisation may have been avoided through improved prevention programs; better care in the primary health care or community setting; and/or better coordination of care between health services.

It is important to note that PPH are based on counts of hospital separations and cannot be used to estimate the number of people with a given condition.

#### Use of PPH in Australia

In Australia, PPH are currently:

- a performance indicator for primary and community health services in the Australian National Healthcare Agreement (COAG 2012)
- an indicator of health system effectiveness under the [Australian Health Performance Framework](#) (AIHW 2019b), and the [Aboriginal and Torres Strait Islander Health Performance Framework](#) (AIHW 2018)
- used by policy makers, health service managers and researchers as a marker of variation to identify and investigate areas or populations of need.

## How common are PPH?

In 2017–18, 1 in every 15 hospitalisations (748,000, or 6.6%) were classified as potentially preventable; these accounted for nearly 3 million hospital bed days (9.8% of all bed days) (AIHW 2020a).

Of the 3 PPH categories, *Chronic conditions* accounted for almost half of all PPH (46%), *Acute conditions* accounted for 44% and *Vaccine-preventable conditions* accounted for 11% (as more than 1 PPH condition may be reported for a hospital admission, the sum of *Vaccine-preventable*, *Acute* and *Chronic* conditions does not equal the number of *Total PPH*).

Between 2012–13 and 2017–18, overall rates of PPH increased by 17%, largely driven by hospitalisations for influenza.

## The cost of PPH

PPH conditions involve a substantial cost to the health system and to patients and their carers (see 'Health expenditure' <https://www.aihw.gov.au/reports/australias-health/health-expenditure> for more information). In the Australian context, it is generally less expensive to prevent disease, or address conditions early and manage these in the primary care setting than it is to treat these conditions, often in a more severe form, in hospitals (Duckett & Griffiths 2016). Analysis of the most recent disease expenditure data for PPH conditions found that they cost the hospital sector \$4.5 billion (or about \$6,600 per PPH) in 2015–16, with *Chronic conditions* costing \$2.3 billion, *Acute conditions* costing \$1.6 billion, and *Vaccine-preventable conditions* costing \$616.7 million (Table 5.1).

Three of the most common chronic PPH conditions—*Congestive cardiac failure*, *COPD* and *Diabetes complications*—had the highest expenditure (Figure 5.1), with more than \$1.5 billion spent on hospitalisations for these three conditions combined in 2015–16. These complex conditions also attract substantial expenditure outside of hospital care, in primary care costs, medication and other management and mitigation (AIHW 2019d).

Some conditions had expenditure that was disproportionate to the number of PPHs (Table 5.1). The highest hospital expenditure per PPH (PPH expenditure divided by number of PPH) was for conditions representing more advanced stages of disease—*Rheumatic heart disease* (\$26,100 per PPH), followed by *Gangrene* (\$24,300 per PPH)—which reflects the need for more complex or longer-term hospital care for these patients.

The PPH conditions with the most same day admissions—*Dental conditions*, *Iron deficiency anaemia* and *Ear, nose and throat infections*—had the lowest costs per PPH, each at about \$2,500 per PPH (Table 5.1).

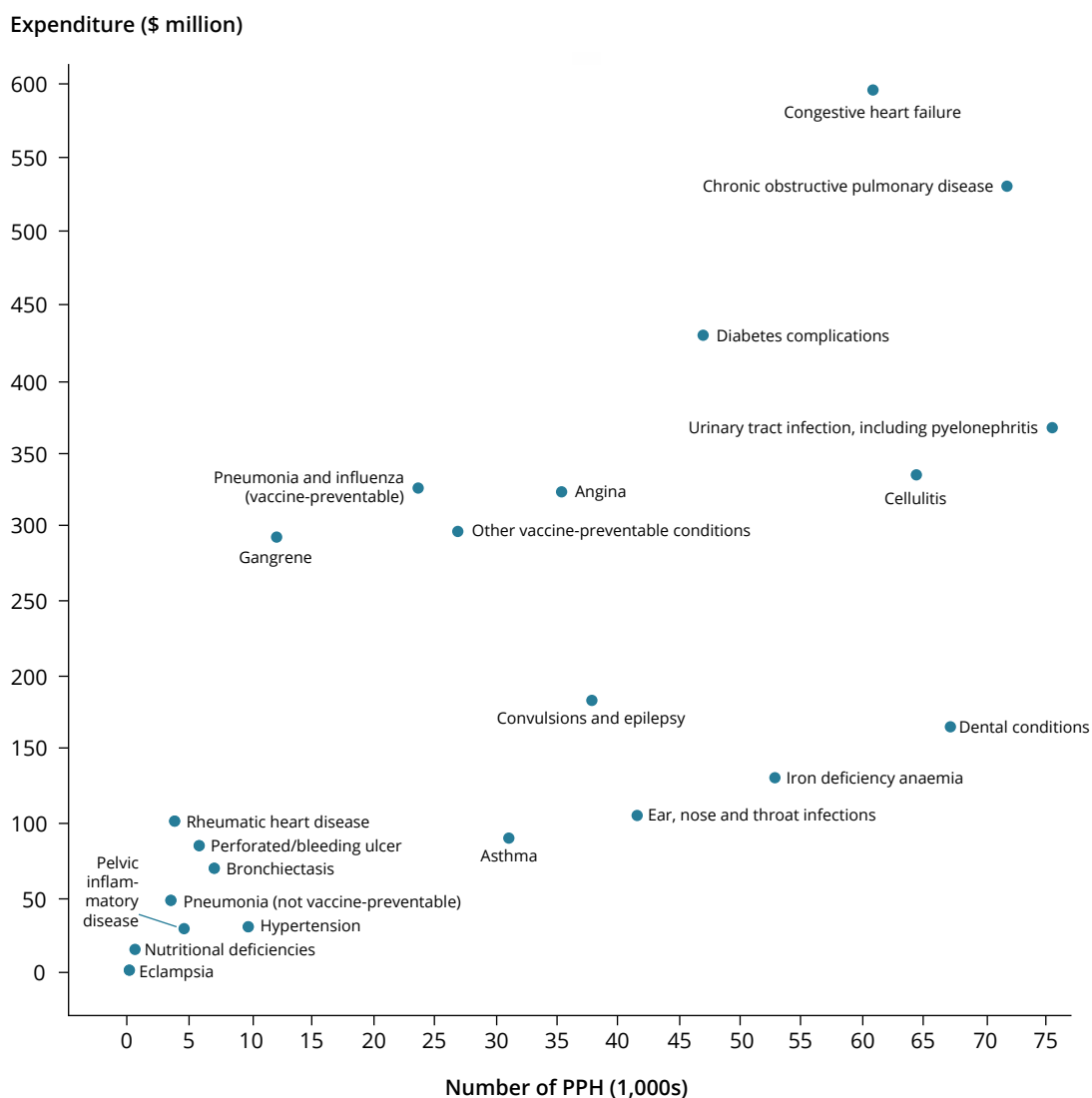
**Table 5.1: Potentially preventable hospitalisations expenditure (average cost per hospitalisation and total cost), 2015–16**

Potentially preventable hospitalisation (PPH) condition	Number of PPH	Average cost per PPH (\$)	Total cost (\$)
<b>Vaccine preventable conditions</b>			
Pneumonia and influenza (vaccine-preventable)	23,774	13,751	326,909,959
Other vaccine-preventable conditions	27,022	11,000	297,230,429
<b>Total vaccine preventable conditions</b>	<b>50,559</b>	<b>12,199</b>	<b>616,748,806</b>
<b>Chronic conditions</b>			
Congestive cardiac failure	60,964	9,798	597,347,284
COPD	71,861	7,391	531,123,111
Diabetes complications	47,112	9,135	430,376,939
<i>Type 1 Diabetes complications</i>	14,615	6,602	96,481,969
<i>Type 2 Diabetes complications</i>	31,726	7,930	251,580,763
Angina	35,401	9,165	324,436,337
Iron deficiency anaemia	53,045	2,477	131,405,658
Rheumatic heart disease	3,874	26,135	101,248,835
Asthma	31,245	2,860	89,365,433
Bronchiectasis	7,119	9,717	69,173,737
Hypertension	9,990	3,021	30,182,634
Nutritional deficiencies	737	19,950	14,702,860
<b>Total chronic conditions</b>	<b>321,340</b>	<b>7,217</b>	<b>2,319,115,130</b>
<b>Acute conditions</b>			
Urinary tract infections	75,617	4,864	367,816,297
Cellulitis	64,572	5,200	335,784,317
Gangrene	12,121	24,275	294,237,263
Convulsions and epilepsy	37,951	4,835	183,495,903
Dental conditions	67,266	2,468	165,990,584
Ear, nose and throat infections	41,624	2,526	105,139,702
Perforated/bleeding ulcer	5,859	14,365	84,162,169
Pneumonia (not vaccine-preventable)	3,497	13,591	47,526,612
Pelvic inflammatory disease	4,619	6,190	28,592,271
Eclampsia	79	7,394	584,148
<b>Total acute conditions</b>	<b>312,803</b>	<b>5,139</b>	<b>1,607,620,257</b>
<b>Total potentially preventable hospitalisations</b>	<b>678,373</b>	<b>6,564</b>	<b>4,452,539,114</b>

Note: As more than 1 PPH condition may be reported for a hospital admission, the sum of *Vaccine-preventable*, *Acute* and *Chronic* conditions does not equal the number of *Total PPH*.

Source: AIHW National Hospital Morbidity Database; AIHW Disease Expenditure Database.

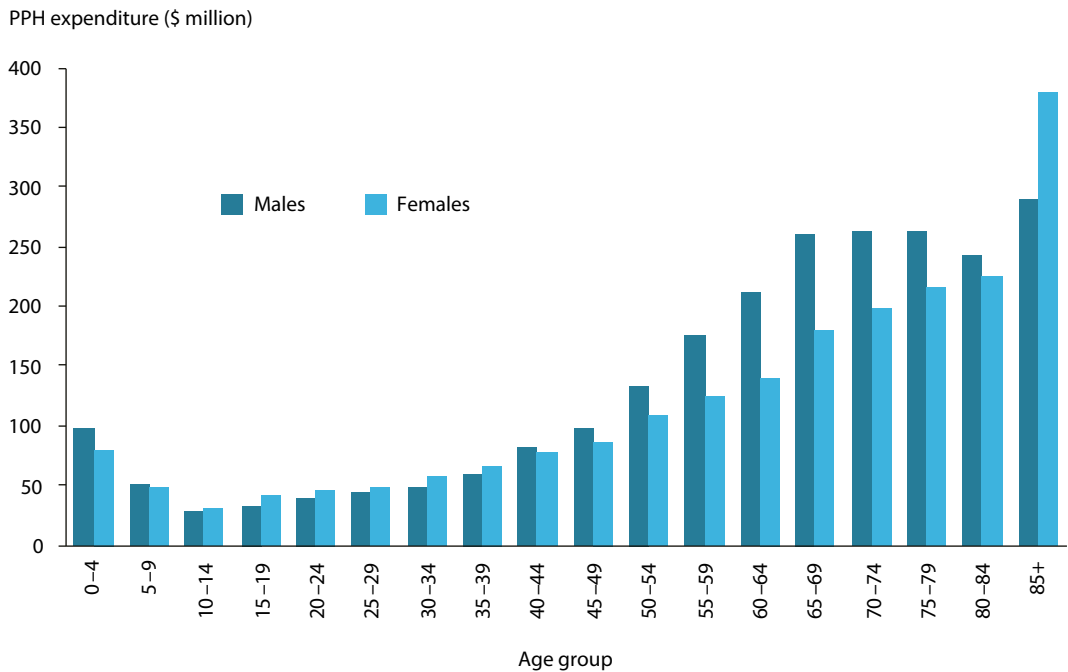
**Figure 5.1: Potentially preventable hospitalisations expenditure relative to number of hospitalisations, by condition, 2015–16**



Source: AIHW National Hospital Morbidity Database, AIHW Disease Expenditure Database.

Hospital expenditure on PPH varied with patient sex and age: after a small peak in the 0–4 age group, expenditure generally rose with age—gradually from the teen years to the 30s, and then more steeply to the 65 and over age group (Figure 5.2). Expenditure was higher for men in middle age onwards until the 80–84 age group. These patterns reflect overall patterns of PPH, with PPH increasingly common in the older age groups and men typically having longer admissions (AIHW 2020b). From the age of 85, expenditure was higher for women, as they make up a greater proportion of this age group and have higher expenditure for *Congestive cardiac failure* and *Urinary tract infections*.

**Figure 5.2: Potentially preventable hospitalisations expenditure, by age, by sex, 2015–16**



Source: AIHW Disease Expenditure Database.

## What can disparities in PPH reveal about health inequities in Australia?

The concept of equity in health is that, ideally, everyone should have a fair opportunity to attain their full health potential and that no one should be hindered in achieving this potential (WHO 2019). Understanding health equity is a core component of the Australian Health Performance Framework (AIHW 2019b) and PPH statistics provide a useful measure for examining this issue. This is because PPH focus on conditions that should theoretically be preventable or manageable in the primary and community care setting, and therefore can draw attention to population characteristics associated with different care outcomes.

Some populations in Australia experience a disproportionately high rate of PPH, and, in recent years, the disparities for some PPH conditions have widened (AIHW 2020a). Demographic and socioeconomic factors can have an important influence on the way in which people access primary and secondary care, and the ways in which they manage their health (Turrell et al. 2006). These factors, and others such as the health service environment, can affect the likelihood of a person developing conditions that may be preventable; the capacity to access early assistance; and the ability to understand and adhere to treatments that may avert hospitalisation (ACSQHC 2014).

It is important that the patient groups most at risk of PPH (and therefore at risk of poor management of their health generally) are identified in communities, and by health policy makers, to ensure they can achieve equitable health outcomes.

In 2020, the AIHW released a large dataset containing information on how rates of PPH have varied over time (AIHW 2020a). The data are interactive and can be explored according to where people live and their circumstances—including their age, whether they are male or female, Aboriginal and/or Torres Strait Islander, live in a lower socioeconomic area, or live in a more remote part of Australia.

The following case study demonstrates how PPH data can be used to illustrate health inequalities, understand demographic and socioeconomic patterns, and play a role in developing targeted and equitable interventions.

## Case study—PPH for diabetes complications

At least 1.2 million Australians (or 4.9% of the total population) self-reported having diabetes in 2017–18 (ABS 2018b). When someone has diabetes, their body can't maintain healthy levels of glucose in the blood (Box 5.2). Early diagnosis, optimal treatment and effective ongoing support and management of all types of diabetes are required to reduce the risk of comorbidities such as heart disease and stroke; eye disease; kidney disease; amputation; and depression or anxiety (Department of Health 2015; Diabetes Australia 2019).

### Box 5.2: Main types of diabetes

- Type 1 diabetes is an autoimmune disease that usually occurs in childhood or early adulthood. It is a life-threatening condition and needs to be closely managed with daily insulin injections and lifestyle modification. Daily monitoring of blood sugar levels is required to prevent short-term and long-term complications.
- Type 2 diabetes is the most common form of diabetes, generally occurring in adulthood. It is largely preventable and is often associated with lifestyle factors such as insufficient physical activity, unhealthy diet, obesity and tobacco smoking. Risk is also associated with genetic and family-related factors. Ongoing maintenance is required to manage disease progression and to prevent short-term and long-term complications.
- Gestational diabetes occurs during pregnancy and is not included in the current PPH specification.
- Other types of diabetes, resulting from a range of different health conditions or circumstances, are not included in the current PPH specification.

See 'Diabetes' <https://www.aihw.gov.au/reports/australias-health/diabetes> for more information.

Diabetes accounts for a substantial burden of disease in Australia. In 2015, type 1 diabetes accounted for 14,700 disability-adjusted life years (DALY—that is, the number of healthy years lost due to ill-health, disability or early death in the Australian population at a point in time) while type 2 diabetes accounted for 103,000 DALY (AIHW 2019a). This burden reduces quality of life and opportunities for those with the condition and is costly to the health system. In 2015–16, there were 14,600 PPH for type 1 *Diabetes complications*, and 31,700 PPH for type 2 *Diabetes complications*, with a cost to hospitals of nearly \$97 million (\$6,600 per PPH) and \$252 million (\$7,900 per PPH), respectively (Table 5.1).

Hospitalisation data provides insights into one of the many aspects of disease burden experienced by people with diabetes. Much can be learned from and about PPH for *Diabetes complications* in terms of how well the health system may be functioning for different sectors of the Australian population.



As part of primary care performance monitoring, PPH for type 1 and type 2 diabetes are often reported under the one condition, *Diabetes complications*. However, the age of onset, biological mechanisms of development, and management of type 1 and type 2 diabetes vary substantially; and therefore, reporting them under one condition limits our ability to observe differences in hospital admission patterns for these conditions.

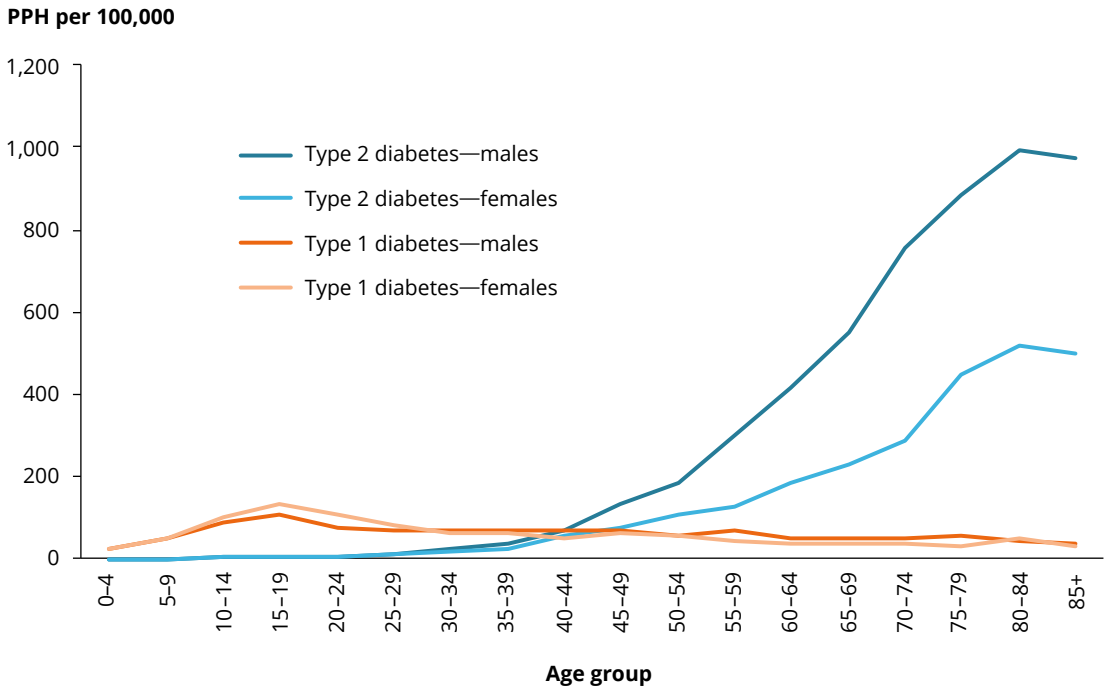
To better understand which groups in the community are affected by PPH for *Diabetes complications*, we have examined type 1 and type 2 *Diabetes complications* separately, and explored patterns of PPH by age, sex, Indigenous status, and for areas of socioeconomic disadvantage and remoteness.

## Age profiles of PPH for diabetes complications

PPH for type 1 and type 2 *Diabetes complications* in 2017–18 showed different patterns by patient age (Figure 5.3). Rates of PPH for type 1 *Diabetes complications* were highest in the teen years, reflecting the usual diagnosis of disease in childhood and adolescence (AIHW 2020c). One in 5 (21%) PPH for type 1 *Diabetes complications* were in young people aged 10–14 and 15–19, and rates decreased with age. There was no difference between males and females in the overall rate of PPH for type 1 *Diabetes complications* (both 64 per 100,000) (AIHW 2020b). However, the pattern by age differed slightly, with females having higher rates of PPH in earlier years and males having higher rates from age 30 onwards.

Rates of PPH for type 2 *Diabetes complications* were highest in older age groups—more than 60% were for people aged 65 and older (Figure 5.3), reflecting the association of type 2 diabetes with lifestyle risk factors, the effects of which accumulate with age—such as obesity, tobacco smoking and physical inactivity (AIHW 2019c). Men aged 65 and over had more than double the PPH rate of women in this age group (762 PPH per 100,000 compared with 360 PPH per 100,000, respectively) (AIHW 2020b).

**Figure 5.3: Rate of potentially preventable hospitalisations for type 1 and type 2 diabetes complications, by age and sex, 2017–18**



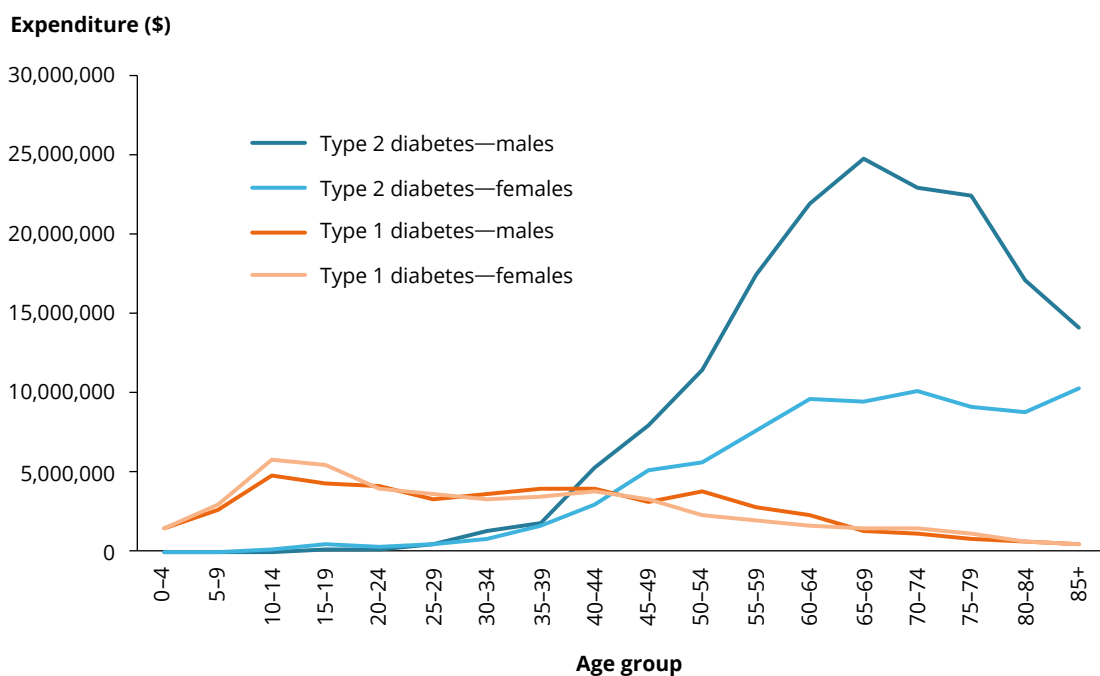
Source: AIHW National Hospital Morbidity Database.

## Hospital expenditure for PPH for diabetes complications

The hospital expenditure for PPH for *Diabetes complications* (both type 1 and type 2) differed across age groups and by sex (Figure 5.4). In 2015–16, expenditure for type 1 *Diabetes complications* was highest for females aged 10–14 and 15–19. By contrast, PPH expenditure for type 2 *Diabetes complications* was substantially higher for men than for women, increasing from ages 35–39 onwards and peaking in the 65–69 age group.

The hospital expenditure per PPH for type 1 *Diabetes complications* was similar for males and females (about \$6,600). However, expenditure per PPH for type 2 *Diabetes complications* was higher for males than females (\$8,200 compared with \$7,400), which is likely to reflect the longer average length of stay in hospital for males (6.5 days compared with 5.8 days for females). This may be due to males having a higher likelihood of comorbidities such as cardiovascular disease or chronic kidney disease (AIHW 2014a), which require more complex care.

**Figure 5.4. Potentially preventable hospitalisations expenditure for type 1 and type 2 diabetes complications, by age and sex, 2015–16**



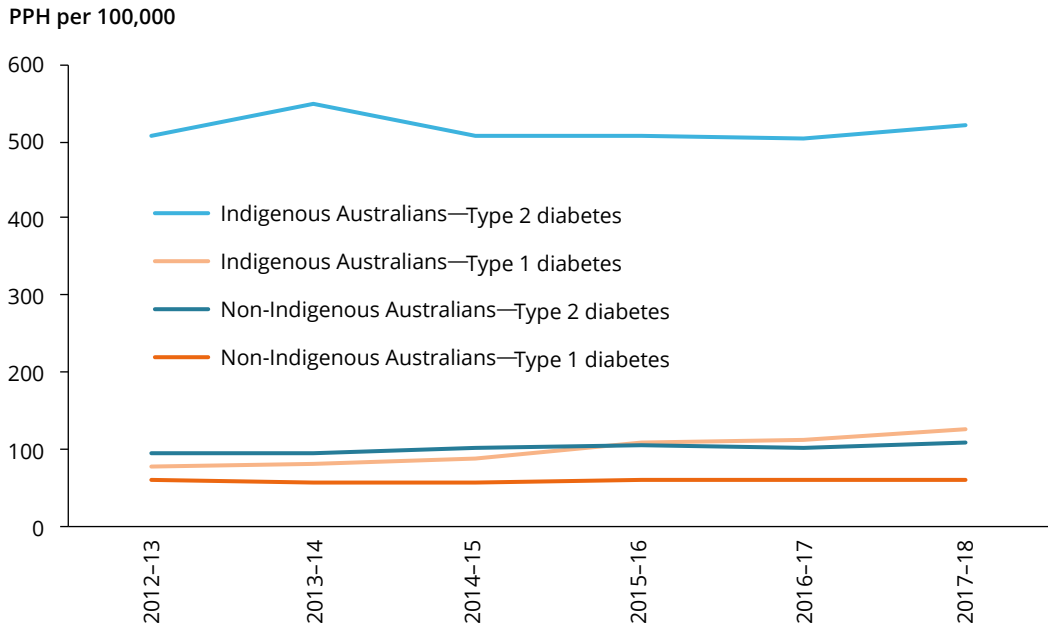
Source: AIHW Disease Expenditure Database.

## Indigenous Australians have higher rates of PPH for diabetes complications

Diabetes (predominantly type 2) is one of the leading causes of disease burden for Indigenous Australians (AIHW 2016; Department of Health 2015). In 2018–19, the diabetes prevalence rate was 2.9 times as high among Indigenous Australians as non-Indigenous Australians, based on age-standardised self-reported data (ABS 2019).

Historically, incidence rates of type 1 diabetes have been lower for Indigenous Australians compared with non-Indigenous Australians, although rates were similar in 2017 (AIHW 2019c). Between 2012–13 and 2017–18, age-standardised rates of PPH for type 1 *Diabetes complications* increased by 64% for Indigenous Australians, compared with almost no change for non-Indigenous Australians (Figure 5.5). In 2017–18, the age-standardised rate of PPH for type 1 *Diabetes complications* among Indigenous Australians was double that of non-Indigenous Australians (128 per 100,000 compared with 61 per 100,000, respectively). Changes in clinical practice and/or coding of diabetes type among Indigenous Australians may have contributed to these data, including the challenges of coding intermediate phenotypes of diabetes reported in young Indigenous people (with elements of each of type 1 and type 2 diabetes) (Stone et al. 2013).

**Figure 5.5. Age-standardised rate of potentially preventable hospitalisations for type 1 and type 2 diabetes complications, by Indigenous status, 2012–13 to 2017–18**

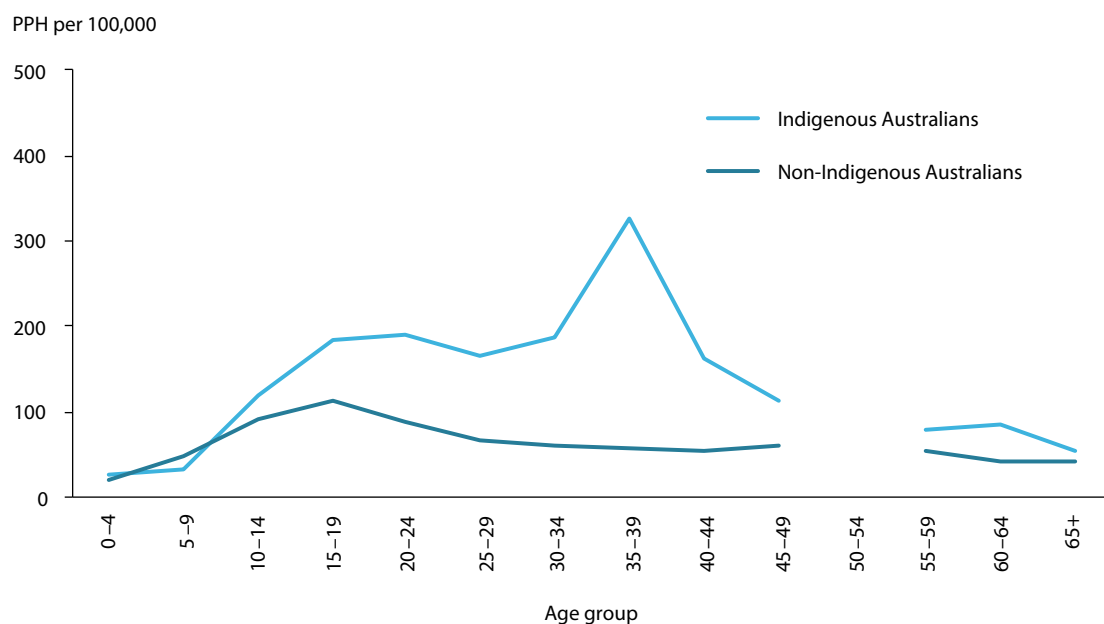


Note: Hospitalisations where Indigenous status was *Not stated* were not included in the analysis.

Source: AIHW National Hospital Morbidity Database.

The age profile of PPH rates for type 1 *Diabetes complications* in 2017–18 shows considerable differences between Indigenous and non-Indigenous Australians (Figure 5.6). While Indigenous and non-Indigenous Australians had similar rates in the first 10 years of life, rates of PPH among Indigenous Australians were substantially higher from the 10–14 age group onwards. A peak in the 35–39 age group was seen in 2016–17 and 2017–18, but not in previous years (AIHW 2020b). Further analysis found that this peak was unlikely to be solely due to data fluctuations, and correlated with an increased proportion of admissions for sub-optimal glucose levels, particularly in women. This age group warrants further scrutiny in coming years' data in case they represent an emerging issue. PPH rates for type 1 *Diabetes complications* for non-Indigenous Australians peaked in the 15–19 age group and then decreased.

**Figure 5.6. Rate of potentially preventable hospitalisations for type 1 diabetes complications, by age and Indigenous status, 2017–18**



*Notes*

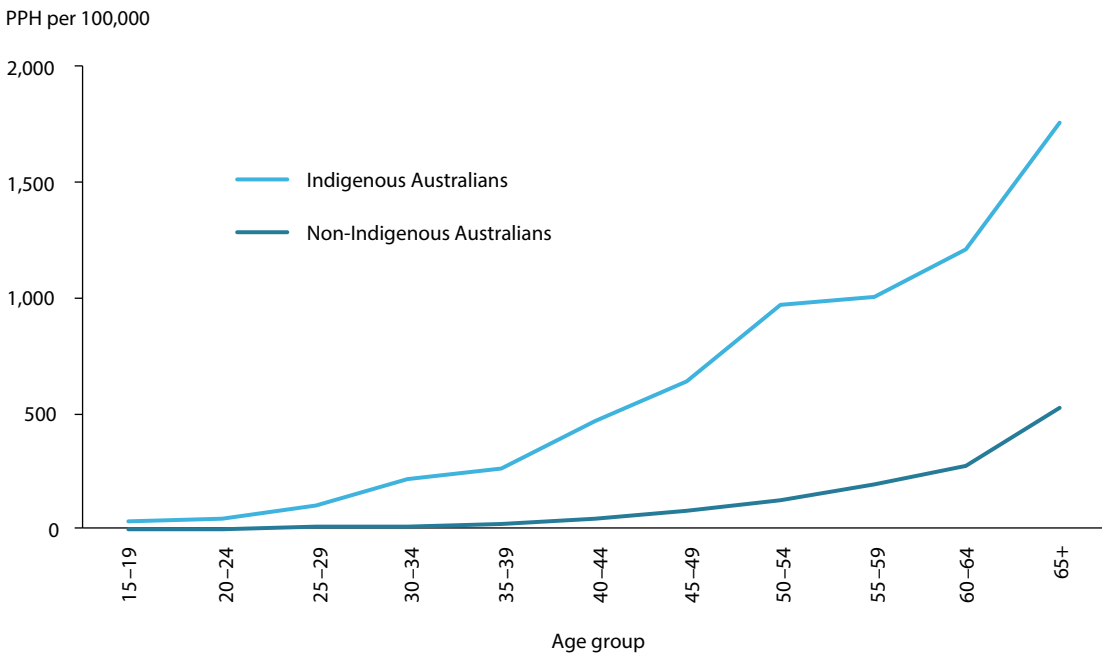
1. Hospitalisations where Indigenous status was *Not stated* were not included in the analysis.
2. Data suppressed due to low numbers (ages 50–54) are excluded from the figure.

Source: AIHW National Hospital Morbidity Database.

Rates of PPH for type 2 *Diabetes complications* among Indigenous Australians have been consistently high, and in 2017–18 were 4.7 times the rate for non-Indigenous Australians (522 per 100,000 compared with 110 per 100,000, respectively) (Figure 5.5). The age profile of PPH for type 2 *Diabetes complications* differs between Indigenous and non-Indigenous Australians (Figure 5.7). In 2017–18, the age at which rates of PPH for type 2 *Diabetes complications* began to rise was far earlier for Indigenous Australians (at 25–29 years) than for non-Indigenous Australians (at 45–49 years). Rates of PPH for type 2 *Diabetes complications* in Indigenous males were 1.2 times higher than Indigenous females, while rates in non-Indigenous males were double those of non-Indigenous females (AIHW 2020b).

These data suggest a complex interplay of factors influencing diagnosis, disease management (including use of diabetes technologies) and hospitalisation for diabetes among Indigenous Australians. It should also be noted that incomplete and inconsistent reporting of Indigenous status might occur, which may result in an underestimate of the differences in PPH between Indigenous and non-Indigenous Australians.

**Figure 5.7. Rate of potentially preventable hospitalisations for type 2 diabetes complications, by age and Indigenous status, 2017–18**



*Notes*

1. Hospitalisations where Indigenous status was *Not stated* were not included in the analysis.
2. Data suppressed due to low numbers (ages 0–14) are excluded from the figure.

Source: AIHW National Hospital Morbidity Database.

## Socioeconomic disadvantage—the health gap for diabetes complications has widened

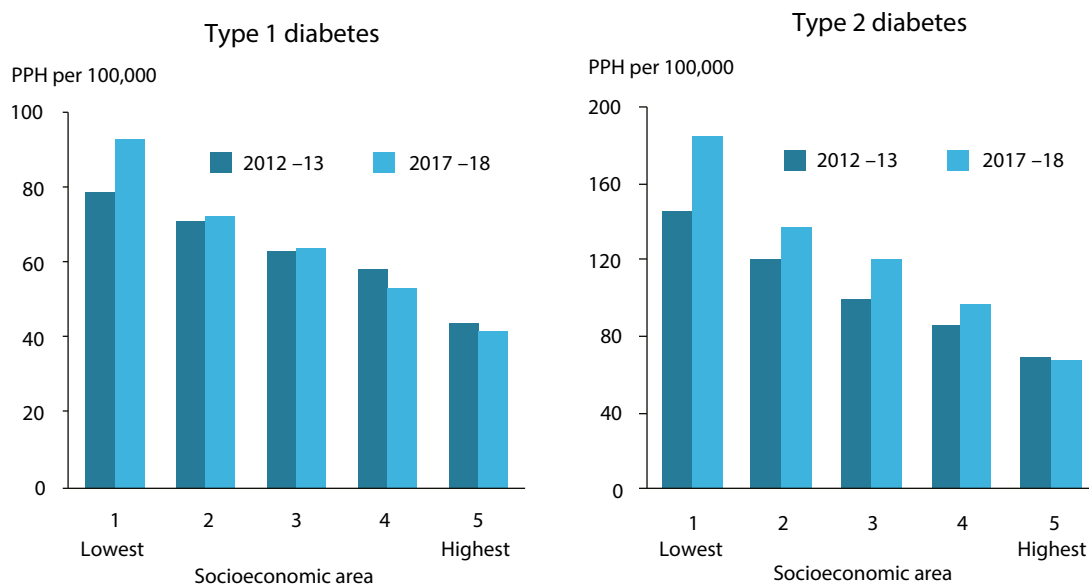
The prevalence of diabetes, particularly type 2 diabetes, increases with increasing socioeconomic disadvantage (AIHW 2019c), and there are large socioeconomic inequalities in diabetes prevalence, hospitalisation and deaths (AIHW 2019e). (See 'Diabetes' <https://www.aihw.gov.au/reports/australias-health/diabetes> for more information).

In 2017–18, the rate of PPH for type 1 *Diabetes complications* for people living in the lowest socioeconomic areas was more than double the rate in the highest socioeconomic areas (93 per 100,000 compared with 42 per 100,000, respectively) (Figure 5.8). The difference was even greater for type 2 *Diabetes complications*: people living in the lowest socioeconomic areas had almost 3 times the rate of people living in the highest socioeconomic areas (184 per 100,000 compared with 67 per 100,000, respectively) (Figure 5.8).

This gap in PPH rates between the highest and lowest socioeconomic areas has increased in recent years (Figure 5.8). People living in the lowest socioeconomic areas had the largest increases in PPH rates for *Diabetes complications* between 2012–13 and 2017–18:

- an 18% increase in PPH rates for type 1 *Diabetes complications* (from 79 per 100,000 in 2012–13 to 93 per 100,000 in 2017–18), compared with no change, or a slight decrease, for people living in other areas
- a 27% increase in PPH rates for type 2 *Diabetes complications* (from 145 per 100,000 to 184 per 100,000), compared with almost no change for people living in the highest socioeconomic areas.

**Figure 5.8. Age-standardised rate of potentially preventable hospitalisations for type 1 and type 2 diabetes complications, by socioeconomic area, 2012–13 and 2017–18**



*Note:* Socioeconomic areas are based on the ABS Index of Relative Socio-economic Disadvantage (IRSD). The 5 groups represent area-based socioeconomic disadvantage, from the least disadvantaged 20% of areas to the most disadvantaged 20%. Data from 2012–13 were calculated using 2011 IRSD scores; data from 2017–18 were calculated using 2016 IRSD scores.

*Source:* AIHW National Hospital Morbidity Database.

## PPH rates for type 2 diabetes complications increase with increasing remoteness

The relationship between remoteness and type 1 diabetes prevalence appears to be complex, and is likely to be influenced by the lower capture of Indigenous Australians and people living in *Remote and very remote* areas in the primary data sources of the National (insulin-treated) Diabetes Register (AIHW 2020c). In 2017, the prevalence of type 1 diabetes in children aged 0–14 was higher in *Inner regional* and *Outer regional* areas (169 per 100,000 and 149 per 100,000, respectively) and lower in *Remote and very remote* areas (86 per 100,000) and *Major cities* (134 per 100,000) (AIHW 2019c).

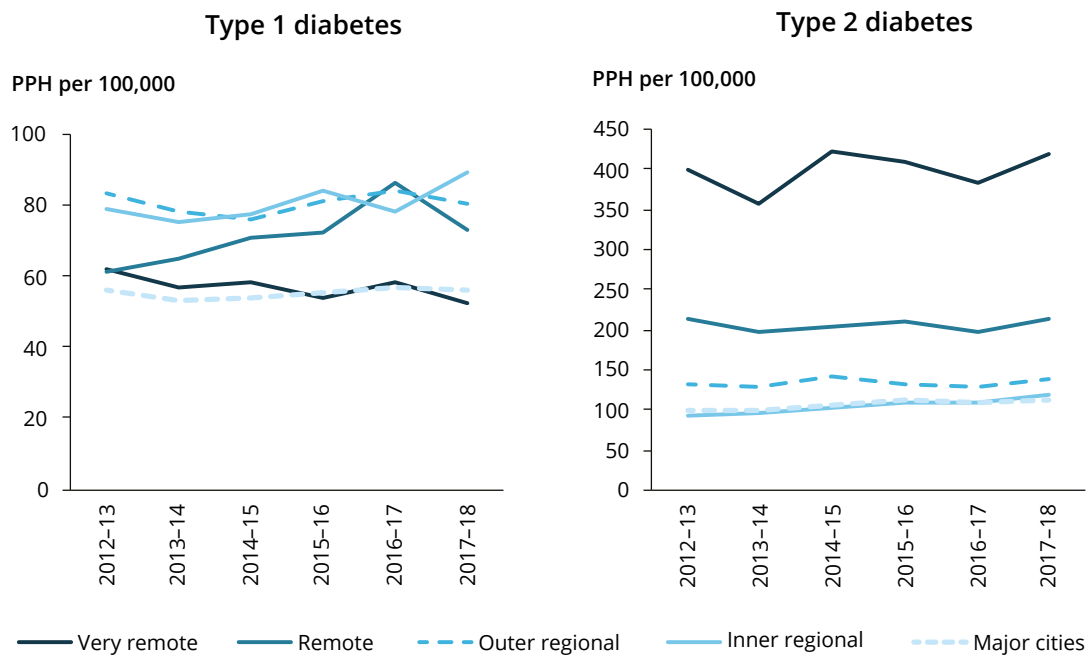
Similarly, in 2017–18, people living in *Inner* and *Outer regional* areas had the highest rates of PPH for type 1 *Diabetes complications* (89 per 100,000 and 80 per 100,000, respectively), and people living in *Very remote* areas and *Major cities* had the lowest rates (52 per 100,000 and 56 per 100,000, respectively) (Figure 5.9). Unlike most areas, where rates remained relatively stable, rates of PPH for type 1 *Diabetes complications* for people living in *Remote* areas increased from 61 per 100,000 in 2012–13 to 73 per 100,000 in 2017–18.

In 2017–18, the prevalence of type 2 diabetes among adults (based on self-reported data) was higher for people living in *Outer regional and remote* areas (6.0%) than for people living in *Inner regional* areas (4.2%) and in *Major cities* (4.8%) (AIHW 2019c).

Correspondingly, rates of PPH for type 2 *Diabetes complications* increased with increasing remoteness (Figure 5.9), and in 2017–18, people living in *Very remote* areas had 3.7 times the rate of PPH for type 2 *Diabetes complications* of people living in *Major cities* (418 per 100,000 and 113 per 100,000, respectively). Males and females living in *Very remote* areas had similar rates of PPH for type 2 *Diabetes complications*, but in all other areas, males had higher rates than females (AIHW 2020b).



**Figure 5.9. Age-standardised rate of potentially preventable hospitalisations for type 1 and type 2 diabetes complications, by remoteness area, 2012–13 to 2017–18**



Source: AIHW National Hospital Morbidity Database.

It is important to note that PPH statistics are determined based on where patients live, not where they go to hospital. It can be difficult to assess the implications of remoteness for health due to interactions between remoteness, low socioeconomic position and the higher proportion of Indigenous Australians in many of these areas compared with *Major cities*—for example, nearly half of all people living in *Very remote* areas are Indigenous (ABS 2018a; AIHW 2019i). The impact of remoteness and socioeconomic disadvantage on the likelihood of a PPH does appear to be stronger for Indigenous Australians than for non-Indigenous Australians (AIHW 2014b; Banham et al. 2017; Falster et al. 2016a; Harrold et al. 2014; Productivity Commission 2019).

In addition, a number of other factors may affect PPH rates for patients from regional and remote areas. For example, smaller regional hospitals acting as a substitute for primary health care services may represent an appropriate use of local resources (Falster et al. 2019). Higher rates of short-stay PPH at these hospitals (Falster et al. 2019) may be due to the admission of low-acuity patients for observation to avoid long travel times, or subsequent transfer of patients with more complex conditions to larger hospitals (which are counted as separate admissions) (ACSQHC & AIHW 2017; Falster et al. 2019).

# How can PPH be used to improve health care provision and health outcomes?

Many disparities in health outcomes in Australia, from disease prevalence to mortality rates (for example, AIHW 2019e), raise questions about population health, risk factors (including those outside the health sector such as housing and employment) and how the health system works for different groups of people. Disparities in PPH are a particularly useful measure to examine because, through their focus on conditions that could be prevented, or looked after through improved care models, they highlight those differences that influence how well peoples' health is managed.

This article demonstrates how the recently available PPH data can guide investigations concerning PPH. Knowing 'who' has high rates of PPH and how rates are changing can assist policy makers and health service providers to target the delivery of preventive health programs and effective health care to those most in need.

The PPH indicator provides scope to explore a wide range of conditions, however, it should be noted that it is a representative, not comprehensive set of potentially avoidable hospitalisations, and does not include all conditions for which there are disparities in disease burden, such as chronic kidney disease or suicide (AIHW 2016).

The *Second Australian Atlas of Healthcare Variation* (ACSQHC & AIHW 2017) discusses strategies for reducing PPH, particularly those for chronic diseases, with an emphasis on disease prevention and coordinated, integrated multi-disciplinary care to manage disease where it already exists. A number of community-based programs have led to reductions in potentially avoidable hospitalisations for chronic conditions (Erny-Albrecht et al. 2016). Strategies focusing on vulnerable populations include increasing patient health literacy, making the health system easier to navigate and health information easier to understand, and designing culturally safe models of care in partnership with Indigenous communities (ACSQHC & AIHW 2017; Wakerman & Shannon 2016).

Although access to preventive care and early intervention in the community is essential, it is important not to assume that higher rates of PPH always indicate a less effective primary care system. There are many reasons why an area or group of people may have higher rates of PPH—including higher rates of disease, lifestyle factors and other risks. Some PPH may not be avoidable, such as those for patients with complex illnesses. Older people hospitalised for a PPH have reported that they did not consider their admission to be preventable, due to a number of factors such as lack of social support; mental health difficulties; poor health literacy and understanding of their condition;

and capacity to adhere to treatment (Longman et al. 2018). Indeed, reductions in PPH rates are not necessarily associated with improved clinical outcomes (Katterl et al. 2012) and rates of PPH might rise following improvements in disease screening or health checks (AIHW 2019f, 2019h), or changes in hospital admission practices (AIHW 2020a).

## Exploring patient care pathways

There are likely to be a number of explanations for variation in PPH rates, and without exploring and understanding patient care pathways that result in PPH, it is very difficult to paint a complete picture. For example, with the current data, we cannot distinguish the hospitalisation of a patient with a first diagnosis of type 1 diabetes—for whom some time in hospital may be unavoidable—from that of a patient whose type 1 diabetes is not well controlled.

Studies using linked health data have found that people with PPH admissions tended to have high levels of engagement with primary care services before their hospitalisation (Falster et al. 2016b). This suggests that, in at least some cases, PPH may reflect an appropriate use of hospital services in response to need. A number of other studies using linked patient data are underway across Australia, for example, to determine the true preventability of PPH (Passey et al. 2015), and to explore broader social factors influencing PPH in Indigenous children (McNamara et al. 2018). Future analysis of PPH using linked patient data has the potential to provide insights into the relationships between different groups of people with PPH and disease prevalence; the use of primary and community care; the use of medicines; and health outcomes. For example, the AIHW's National Integrated Health Services Information Analysis Asset (NIHSI AA) will enable analysis of patient journeys associated with PPH. This would allow better targeting of resources across the health and social services sectors to help achieve health equity for all Australians.

For further information about PPH in Australia, please see the recently released report *Disparities in potentially preventable hospitalisations across Australia, 2012–13 to 2017–18* (AIHW 2020a) and the accompanying data tables and interactive graphs (AIHW 2020b).

## Further reading

The following AIHW publication relating to potentially preventable hospitalisations may be of interest:

- AIHW 2018. A potentially preventable hospitalisation indicator for general practice: consultation paper. Cat. no. HSE 214. Canberra: AIHW.

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# Funding health care in Australia

6

The Australian health system is complex, with a division of roles and responsibilities in terms of both service delivery and funding (AIHW 2018a, 2020). In 2017–18, an estimated \$185.4 billion was spent on health goods and services in Australia (AIHW 2019a). This expenditure was financed through a range of different funding sources and through different administrative arrangements. The funders of the Australian health system can be broadly categorised as either government or non-government. Government funders include the Australian Government and state and territory governments which jointly fund some areas of expenditure, such as public hospitals. Non-government funders include individuals (who provide funding through out-of-pocket payments), private health insurers (funded in turn by individuals' premium outlays, net of the government subsidy) and other non-government funders (for example, workers' compensation schemes). An overview of the funders of the Australian health system, and their relative contributions across different areas of health care, is presented in Figure 6.1.

Over two-thirds (68.3% or \$126.7 billion) of total health expenditure during 2017–18 was funded by governments (AIHW 2019a). The Australian Government contribution to total health expenditure was 41.6% (or \$77.1 billion) and the state and territory contribution was 26.7% (\$49.5 billion). About one-third (31.7% or \$58.8 billion) of total Australian health expenditure during 2017–18 was funded by non-government sources (AIHW 2019a). The contribution of individuals' out-of-pocket spending to total health expenditure was 16.5% (or \$30.6 billion); private health insurers 9.0% (or \$16.6 billion); and other non-government sources 6.2% (or \$11.5 billion).

See 'Health expenditure' <https://www.aihw.gov.au/reports/australias-health/health-expenditure> for more information.

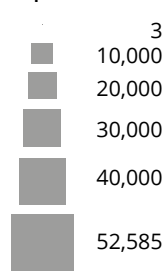
Over the decade to 2017–18, health expenditure grew at an annual average rate of 3.9% in real terms (AIHW 2019a). There have been a range of changes to the funding of the health system, including changes to the relative contribution of different funders across different areas of health expenditure during this period.

The main purpose of this chapter is to provide an overview of the arrangements in place to fund the different components of the Australian health system, and how this is changing over time. The discussion centres around the data that is within the scope of the Australian National Health Accounts (AIHW 2019a), and so excludes health-related sectors classified as 'welfare' (including aged care and disability support services) (AIHW 2019b).

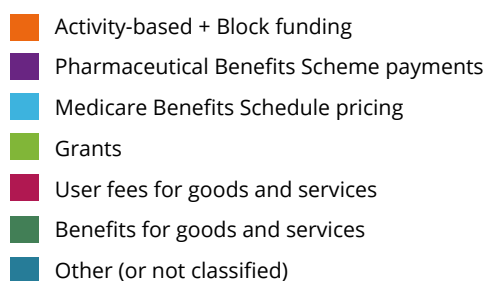
**Figure 6.1: Funding by area of expenditure, source, and key transfer mechanisms, 2017–18**

Recurrent or capital	Broad area of expenditure	Detailed area of expenditure	Funding source			
			Government	Health insurance providers	Individuals	Other
Recurrent expenditure	Hospitals	Public hospital services	■	■	■	■
		Private hospitals	■	■	■	■
	Primary health care	Community health and other	■			
		Public health	■			
		Benefit-paid pharmaceuticals	■		■	
		All other medications	■		■	
		Dental services	■	■	■	
		Other health practitioners	■	■	■	
		Unreferred medical services	■		■	■
	Referred medical services	Referred medical services	■	■	■	
	Other services	Aids and appliances	■	■	■	
		Patient transport services	■	■		
		Administration	■	■		
Research	Research	■				
Capital expenditure	Capital expenditure	■			■	

**Expenditure 2017–18 (\$m)**



**Key mechanisms**



**Notes**

- Figure 6.1 excludes the medical expenses tax rebate (equivalent to 0.01% of total health expenditure in 2017–18).
- 'Other' funding sources include workers' compensation schemes, compulsory third-party motor vehicle insurers, miscellaneous non-patient revenue that health care providers receive, private non-profit organisations, and other private funding.

Source: AIHW health expenditure database.

## Box 6.1: Health system financing

### Models of health system financing

The financing of health systems varies between countries and can be broadly categorised as either a state financed model, a privately financed model or a hybrid model (that is, a mix of both state financed and private models) (Dixit & Sambasivan 2018; Donaldson et al. 2005; Duckett & Willcox 2011).

There are differences between member countries in the Organisation for Economic Co-operation and Development (OECD) in terms of the funding arrangements that exist in their respective health systems. In some countries, the main source of funds is through general taxation (for example, United Kingdom) and for others it is via compulsory insurance contributions (for example, France). A number of countries fund their health systems through a combination of general taxation and compulsory insurance contributions. Voluntary private health insurance is also key to funding some health systems, either as the main source of funds (for example, the United States of America, prior to the introduction of the Affordable Care Act, which mandated enrolment) or in combination with other funding approaches (for example, the Netherlands).

The Australian health system is a hybrid system where health care can be funded through either taxation or privately, with a regulated voluntary health insurance system being a key aspect. It should be noted that this system relates to the source of the money used to pay for health goods and services, rather than who necessarily provides those services. Tax revenue, for example, is used by governments to purchase health goods and services from both public providers (for example, public hospitals) and from private providers (for example, general practitioners (GPs)). Similarly, individuals can choose to use private funds to access services in public or private settings (for example, public or private hospitals).

### Government funding and compulsory contributory health insurance across countries

Across the OECD, government and compulsory contributory health insurance schemes generally account for the majority of countries' health financing (Figure 6.2). In 2017, their contribution ranged from a minimum of 51.5% in Mexico to a maximum of 86.8% in Germany.

*(continued)*

### **Box 6.1 (continued): Health system financing**

In Australia, according to the System of Health Accounts (SHA) methodology used by the OECD, government funding was estimated to contribute 68.6% of total health expenditure (AIHW 2019a). This is similar to the level seen in Canada, though the mechanics of funding mechanisms differ across the 2 countries (Allin & Rudoler 2019). In Australia, government funding includes the private health insurance premium rebate funded by the Australian Government.

Compulsory contributory health insurance differs from government financing schemes in that coverage is generally instated by hypothecated taxation payments or some other proactive action on an individual's behalf; it differs from voluntary private health insurance in that is compulsory (OECD 2019b).

In the United States (as reflected in Figure 6.2), most private health insurance was classified as compulsory health insurance in 2017 by the OECD. This is because the country's introduction of the Affordable Care Act compelled individuals to either purchase health insurance, or be charged a penalty (OECD 2019a). This did not mean that everyone had private health insurance and, as of January 2019, this penalty no longer applies at the Federal level (United States Centers for Medicare & Medicaid Services 2020). In France, the government manages a statutory health insurance (SHI) scheme which provides universal and compulsory coverage to residents. It is financed through a combination of taxation (including payroll tax, income tax, taxes levied on voluntary health insurance companies) and state subsidies (Durand-Zaleski et al. 2019), and the central government shapes the mechanisms through which funds are transferred to providers. In the Netherlands, SHI coverage is purchased from private insurers, and funded through a contribution of income-related payments, government endowments (for young people), and individual premiums (unrelated to health status) (Wammes et al. 2019). In the Netherlands case, insurers negotiate payment mechanisms with health care providers.

#### **Voluntary health care payments across countries**

The contribution of voluntary health care payments (including private health insurance) to total health care expenditure varies considerably across the OECD, from a minimum of 0.4% in Norway to 17% in Ireland (Figure 6.2). In Australia, according to the OECD methodology, voluntary health insurance schemes financed 9.8% of health care spending in 2017.

*(continued)*

### **Box 6.1 (continued): Health system financing**

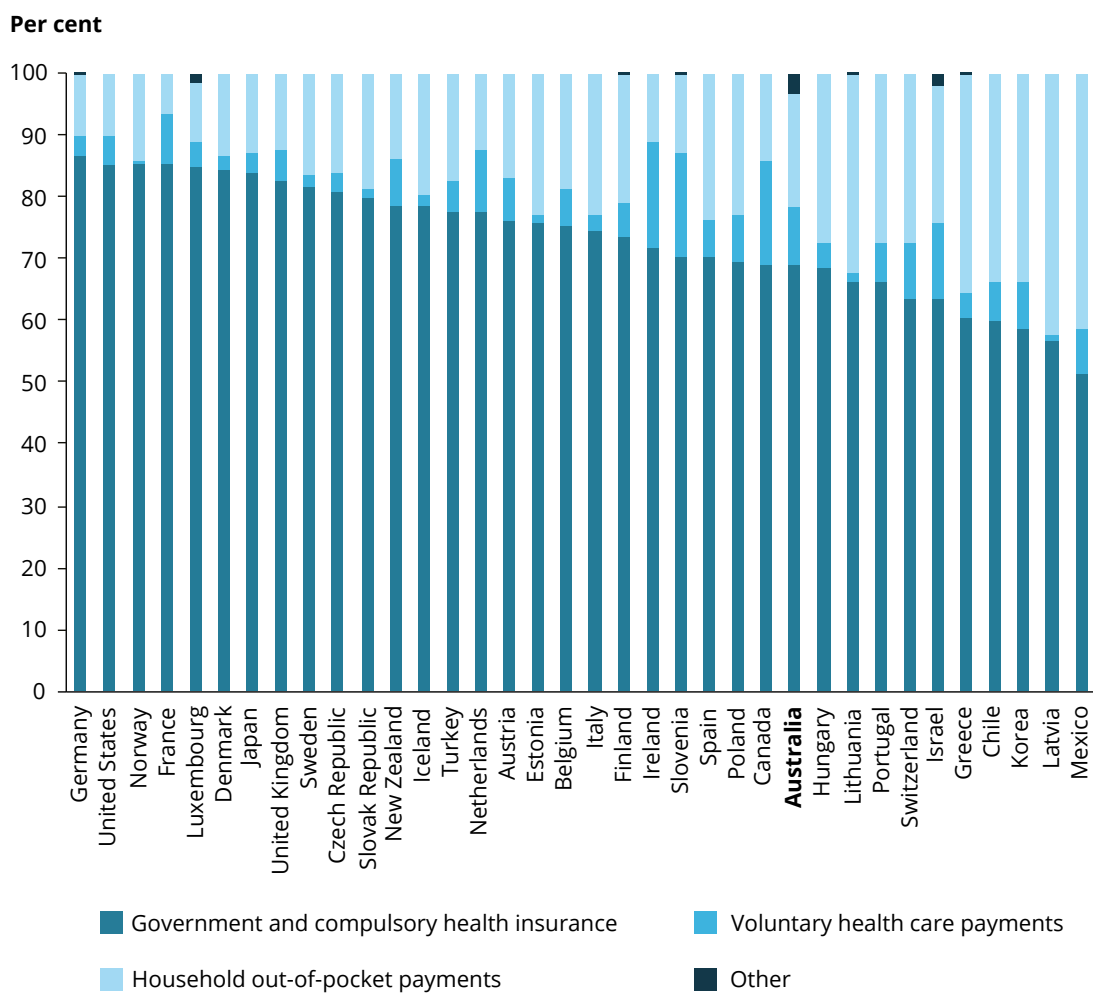
The role of private health insurance differs across countries. Private health insurance can be either complementary or supplementary to government-provided coverage in Australia, in that it provides coverage for both additional health services (such as dental care), as well as differentiated care (for example, faster access to treatment). In some European countries, such as France, voluntary health insurance is primarily complementary, as its benefits are directed toward meeting the payments associated with other financing schemes (though some additional services are also covered).

#### **Out-of-pocket spending across countries**

In 2017, the share of individuals' out-of-pocket spending in total health care expenditure ranged from 6.7% in France to 42.6% in Latvia (Figure 6.2). In Australia, this share was 17.9%—higher than some other comparative countries, such as Canada. However, it is noted that out-of-pocket spending data might not be captured well in some OECD countries.

Many countries in the OECD have policies which cap or reduce individuals' out-of-pocket payments for health care, though these work in different ways across different countries. Australia implements several safety-net schemes, including Medicare and pharmaceutical safety nets. These schemes provide higher subsidies when individuals or families spend over particular thresholds on certain health goods and services, with differential conditions for some segments of the population (low-income households). In Germany, the government has implemented a cap limiting an individual's out-of-pocket spending at 2% of their income; in Norway out-of-pocket spending is capped at a fixed dollar amount; while in Denmark, a cap on out-of-pocket expenditure on medical goods is targeted to the chronically ill (Commonwealth Fund 2011).

**Figure 6.2: Financing arrangements as a proportion of total health expenditure, OECD countries, current prices and local currency, 2017**



Notes

1. 'Other' refers to other financial contributions, some of which are from foreign countries.
2. Spending by long-term care facilities is excluded from health expenditure figures for all countries, to ensure comparability with Australia (where residential long-term care is classified as 'welfare' for expenditure purposes).
3. The 2011 SHA framework is used by the OECD to ensure consistency in analysing the consumption, provision and financing of health care across countries (OECD et al. 2017).
4. The proportions for Australia are estimates calculated by AIHW. Due to country-specific differences, caution should be taken when comparing between countries.

Sources: AIHW health expenditure database; OECD 2019b.

# Main health service funding mechanisms

There are various approaches to the funding of health services in the Australian health system. These can be broadly categorised as either volume-based funding or block funding.

This section will consider the funding arrangements for selected areas of funding.

## Public hospitals

Throughout recent history (beginning when Medicare was established in the 1980s), the Australian Government has entered into a series of national agreements with states and territories to provide funding for public hospitals to support the provision of fee-free treatment for public patients (Department of the Senate 2016). Up until 2011, under these agreements, Australian Government funding for public hospitals was primarily through 'block funding' transfers which were agreed largely through negotiation but also included adjustments to reflect population growth and demographic changes and health sector inflation.

In 2011, the National Health Reform Agreement (NHRA) saw a number of changes to public hospital funding arrangements implemented from 2012–13. These included a mixture of activity-based funding (ABF) and block funding for the Australian Government contributions, with a preference for ABF where appropriate. The 2011 NHRA also involved the establishment of a 'national funding pool'. This funding pool includes dedicated accounts for each state and territory through which it was agreed that all Australian Government and state and territory ABF payments to public hospitals would be administered. States and territories determine how both their own and the Australian Government contribution is spent through Service Agreements with Local Hospital Networks.

ABF is designed to reflect the volume and case-mix of services provided by a hospital. This is service (hospital separation) based rather than based on individual patients (as a single patient may have multiple separations within a given hospital stay). The level of funding provided for a given hospital separation reflects an estimate of the 'efficient cost' (the National Efficient Price) of providing similar public hospital services nationally (IHPA 2019). Currently, the types of hospital services that are funded using an ABF approach include emergency department services, admitted patient care (including mental health services), sub-acute and non-acute care (for example, palliative care), and non-admitted care (for example, outpatient care) (NHFB 2019).



Block funding (an aggregated funding payment) is provided for those public hospital services that are not suitable to fund through ABF, either because of a lack of adequate data or the nature of the service. These include, for example, some specialist hospital services; teaching; training; research and services in areas with small volumes and large fixed costs, for example, in regional and rural communities (NHFB 2019). Block funding levels reflect the average cost of providing relevant services in similar settings (IHPA 2018).

Not all public hospital funding is managed through the ABF and block funding arrangements. This includes, for example, specific funding for highly specialised drugs; funding for blood and organ donation programs; and funding provided by the Department of Veterans' Affairs (AIHW 2019a). These other public hospital funding arrangements are a mixture of both volume and block funding arrangements.

An insured person with hospital coverage can opt to be treated as a public patient in a public hospital or can elect to be treated as a private patient in a public hospital (Department of Health 2019b). In this case, funding is also sourced from health insurers and potentially through individual out-of-pocket payments. These patients are able to access certain benefits in hospital; for example, while public patients are treated by doctors nominated by the hospital, in many circumstances private patients are able to choose their doctor (Department of Health 2019e; Private Health 2019).

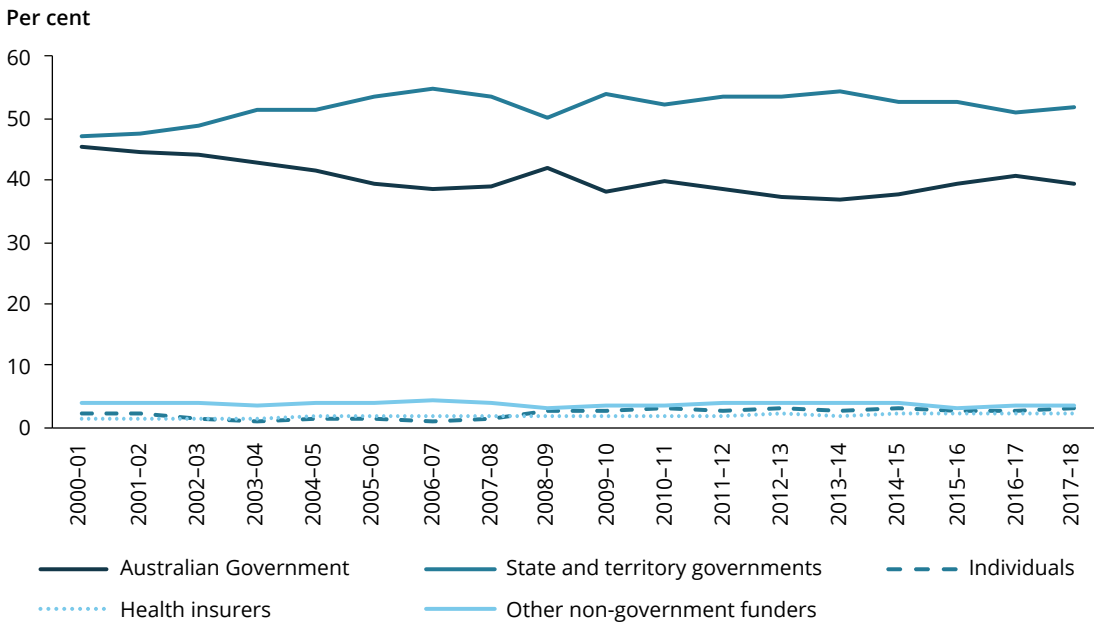
The estimates of expenditure reported in the Australian National Health Accounts include both NHRA-based payments as well as the other public hospital funding schemes (see AIHW 2019a:Table A11).

In 2017–18, public hospital expenditure in the National Health Accounts was \$57.7 billion (AIHW 2019a). Funders included:

- state and territory governments (51.7% or \$29.9 billion)
- the Australian Government (39.3% or \$22.7 billion)
- individuals (2.9% or \$1.7 billion)
- health insurers (2.2% or \$1.2 billion)
- other non-government funders (3.8% or \$2.2 billion).

Prior to the NHRA, there were several years where state and territory governments contributed an increasing share of public hospital funding, relative to the Australian Government. Since the NHRA was introduced, the Australian Government share has generally increased relative to states and territories (Figure 6.3). Overall, expenditure on public hospitals grew at an annual average rate of 3.9% in real terms over the decade to 2017–18 (AIHW 2019a). The growth rates in 2017–18 were affected by the previous year having included one-off capital expenditure on projects such as the new Royal Adelaide Hospital as well as a previous spike in Australian Government spending on new drugs to treat hepatitis C.

**Figure 6.3: Proportion of public hospital expenditure, by source of funds, current prices, 2000–01 to 2017–18**



Source: AIHW health expenditure database.

## Private hospitals

In 2017–18 private hospital expenditure was \$16.3 billion (AIHW 2019a). There was a range of funders including:

- health insurers (50.0% or \$8.2 billion)
- the Australian Government (23.0% or \$3.8 billion)
- individuals (13.4% or \$2.2 billion)
- state and territory governments (6.0% or \$1.0 billion)
- other non-government funders (7.6% or \$1.2 billion).

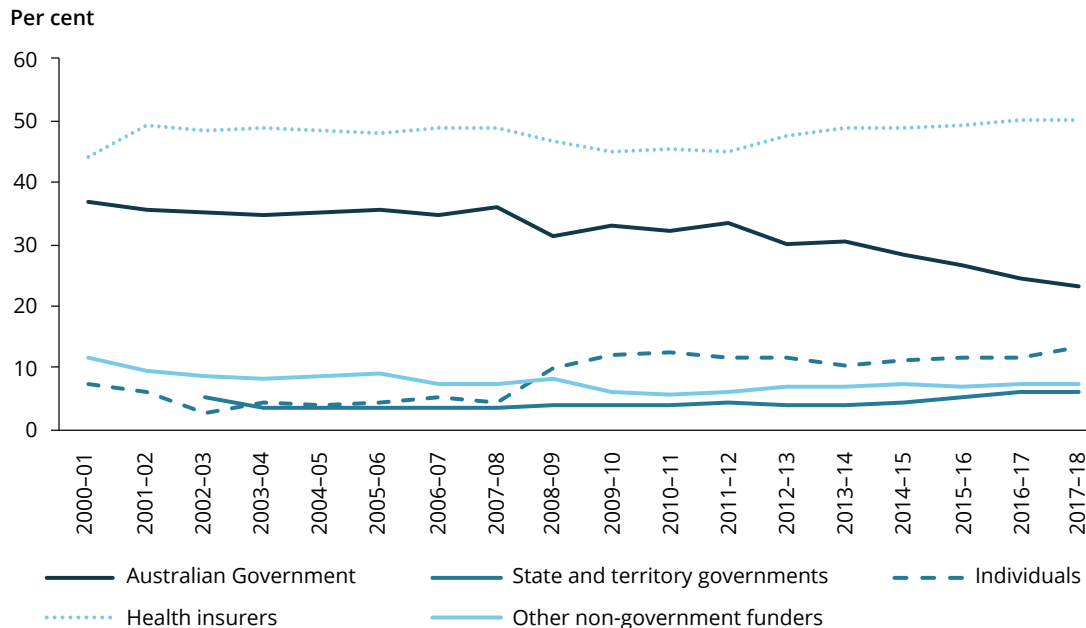
To avoid double counting, these figures reflect spending on goods and services by the different funders and do not include the insurance premiums paid by individuals (insurance not being categorised as a health good or service). The health insurers' amount, for example, reflects the amount spent by insurers on health care. Similarly, spending by individuals includes the payments paid directly to services, not the insurance premiums. An exception to this is the contribution from the Australian Government, provided in the form of a premium rebate. To ensure this amount is appropriately captured, it is treated as spending on private hospital services by the Australian Government, rather than spending on insurers. Total expenditure on private hospitals grew by an annual average of 5.1% in real terms over the decade to 2017–18 (AIHW 2019a).

The scope of hospital insurance coverage for private patients varies across different insurance products. Insurance products have been categorised into gold, silver, bronze or basic tiers, with some products providing more than the standardised coverage package in each category (Department of Health 2018).

Private hospital funding is also provided through the Medicare Benefits Schedule (MBS–Medicare), and is captured as expenditure on referred medical services. Private health insurance covers a minimum of 25% of the MBS schedule fee associated with services provided in hospital, with Medicare covering 75%, but if a doctor charges more than the MBS schedule fee (or more than that covered by the insurer plus Medicare), patients may be required to pay an out-of-pocket gap payment (Department of Health 2019e).

The relative contribution of different funders has changed over the decade to 2017–18. The proportion of spending on private hospitals by private health insurers has increased slightly, while the Australian Government proportion has decreased, particularly following the introduction of income testing for eligibility to the premium rebate (Figure 6.4) (AIHW 2019a).

**Figure 6.4: Proportion of private hospital expenditure, by source of funds, current prices, 2000–01 to 2017–18**



Note: Private hospital expenditure from State and territory governments has been collected since 2002–03.

Source: AIHW health expenditure database.

## Primary health care

There is currently no single definition of what constitutes primary health care. For the purposes of the health spending analysis and the Australian National Health Accounts, primary health care includes unreferral medical services (for example, general practice care); dental services, other health practitioners, community health, public health and medications.

See 'Primary health care' <https://www.aihw.gov.au/reports/australias-health/primary-health-care> for more information.

In 2017–18, primary health care expenditure was \$63.4 billion (AIHW 2019a). There was a range of funders including:

- the Australian Government (44.3% or \$28.1 billion)
- individuals (31.7% or \$20.1 billion)
- state and territory governments (15.8% or \$10.0 billion)
- health insurers (4.7% or \$2.9 billion)
- other non-government funders (3.5% or \$2.2 billion).

Expenditure on primary health care grew by an annual average of 3.3% in real terms over the decade to 2017–18 (AIHW 2019a). The real annual average growth per capita was 1.6%. In considering this rate of growth, it should be noted that, between 2013 and mid-2019, the Australian Government maintained a 'freeze' on indexation of MBS fees as part of a budget savings plan.

Funding arrangements differ for the different service types classified as primary health care.

Some primary health goods and services are primarily funded by government through program-specific block grants. These include community health programs (largely funded by state and territory governments) and public health programs (funded jointly by Australian and state and territory governments) (AIHW 2019a).

Much of primary health care is funded through a fee-for-service approach. The MBS lists medical services subsidised by the Australian Government and their associated schedule fees, which provide a benchmark level for the public subsidy. The government reimburses 100% of the schedule fee for GP services and there are no out-of-pocket costs to an individual when a doctor bills Medicare directly—a practice known as 'bulk billing' (Private Health 2019). However, when a doctor charges more than the schedule fee, the individual will be required to fund the gap payment. In 2016–17, 86% of GP consultations were bulk billed (AIHW 2018c). If, over the course of a year, an individual or family's annual out-of-pocket medical expenses exceeds a certain threshold, higher subsidies become available through the operation of Medicare safety nets (Department of Human Services 2019a).

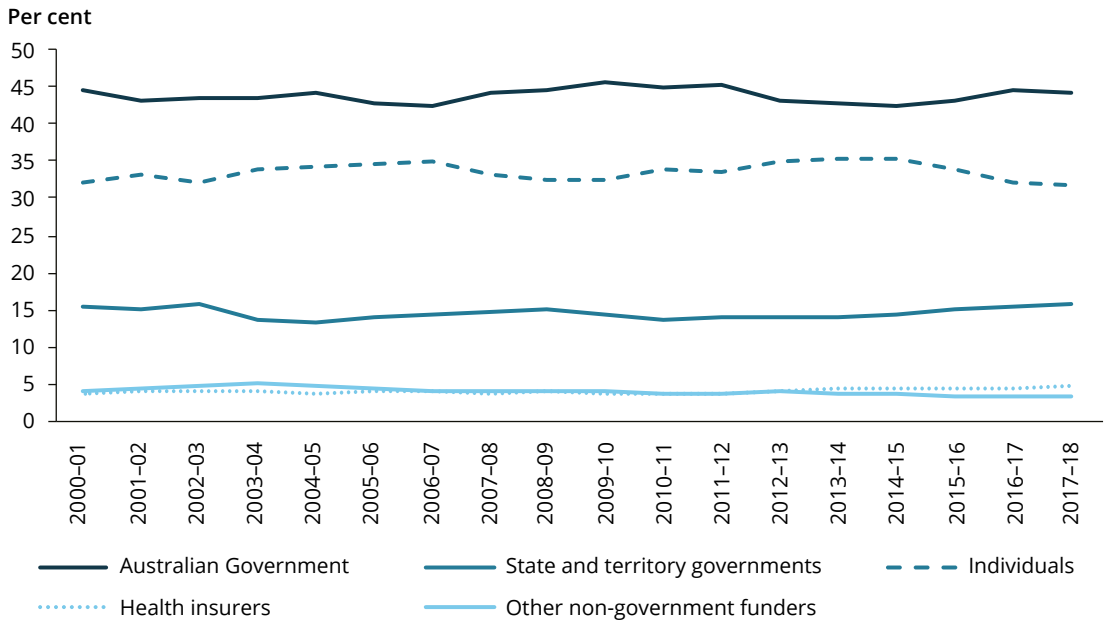
By law, private health insurance funds do not cover out-of-hospital services provided by medical practitioners, including consultations with GPs (Department of Health 2019e). Private health insurance coverage is available for ancillary goods and services not covered by Medicare (that is, extras cover), such as dental services, physiotherapy, chiropractic treatment, home nursing, and glasses and contact lenses (Department of Health 2019e). The range of extras services covered differs across policies, and the extent of coverage for a particular type of service is usually capped (for example, at some dollar amount over the course of a year, or at a specified proportion of the total spend). Consumers pay the provider price for health goods and services not covered by Medicare—or a gap-fee in circumstances where an individual has private insurance coverage—but the benefit under their policy does not completely cover the service cost. Some insurers are directly engaged in the provision of some types of services (such as dental care), and incentivise attendance at in-house providers by limiting out-of-pocket costs for such attendances.

See 'Private health insurance' <https://www.aihw.gov.au/reports/australias-health/primary-health-care> for more information.

Although governments do not provide universal coverage for dental services in Australia, a number of Australian Government and state and territory government schemes exist to subsidise access to dental services for vulnerable populations, including young children (for example, the Australian Government's Child Dental Benefits Schedule; Department of Health 2019d) and people living in low-income households. For the wider population, out-of-pocket spending on dental services is 20% of total out-of-pocket health expenditure (AIHW 2019a).

The Pharmaceutical Benefits Scheme (PBS) lists medicines subsidised by the Australian Government. The listings are based on recommendations by the independent Pharmaceutical Benefits Advisory Committee, based on a medicines' health impact (relative to its main alternative therapy) and cost-effectiveness. On listing a medicine on the PBS, the Australian Government negotiates a price with the supplier. Individuals (generally) contribute a co-payment on purchasing medicines listed on the PBS (Department of Health 2019a), rather than paying the provider price for unlisted medicines. The PBS provides higher subsidies for concession-card holders, and, through the PBS Safety Net, provides higher subsidies when total annual contributions made by individuals or their families exceed specified thresholds (Department of Human Services 2019b). Individuals fund the vast majority (92.1%) of expenditure on medication which is not subsidised (for example, private prescriptions and over-the-counter medicines) through out-of-pocket payments.

**Figure 6.5: Proportion of primary health care expenditure, by source of funds, current prices, 2000–01 to 2017–18**



Source: AIHW health expenditure database.

## Referred medical services

For the purposes of the health spending analysis and the Australian National Health Accounts, referred medical services are those where a person had been referred by a GP or specialist for further medical care. This includes referrals for consultations with medical specialists (such as obstetricians or oncologists) and with allied health professionals (such as psychologists or podiatrists), and referrals to diagnostic services such as (pathology and medical imaging providers).

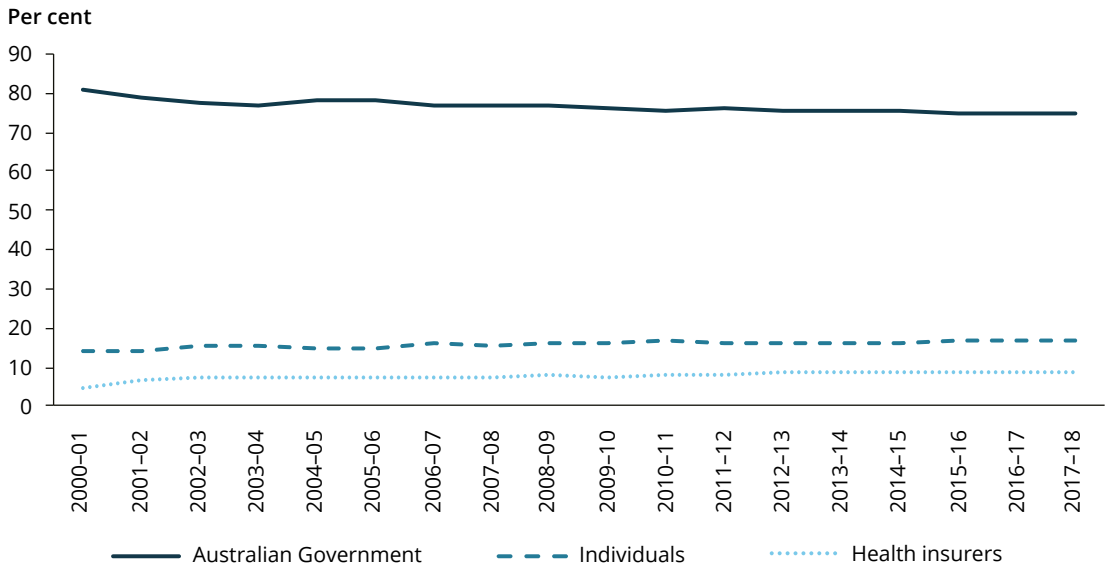
In 2017–18, expenditure on referred medical services was \$19.4 billion (AIHW 2019a). There were a range of funders including:

- the Australian Government (74.5% or \$14.4 billion)
- individuals (16.6% or \$3.2 billion)
- health insurers (8.9% or \$1.7 billion).

Expenditure on referred medical services grew by an annual average rate of 4.4% in real terms over the decade to 2017–18 (AIHW 2019a). As seen for primary health care, the ‘freeze’ on indexation of MBS fees should be considered for this growth.

As with other areas of the health system, the Australian Government provides subsidies for referred medical services that are listed on the MBS. Individuals also contribute a proportion of funding through additional out-of-pocket payments.

**Figure 6.6: Proportion of referred medical services expenditure, by source of funds, current prices, 2000-01 to 2017-18**



Source: AIHW health expenditure database.

## Health financing in future

### Managing growing costs

Recent trends suggest health care costs are likely to continue to rise into the future, although this will be dependent on broader economic and social factors such as wealth growth and policy decisions. Health care costs have increased substantially in Australia over the past 2 decades, reflecting advances in the provision of health care, as well as increased wealth within the community, population growth and population ageing. During this period, health expenditure has grown faster than inflation and population growth combined. Total health expenditure in Australia increased from \$77.5 billion to \$185.4 billion in real terms (2017-18 dollars) over the twenty-year period to 2017-18. Over the same period, spending per person increased from \$4,189 to \$7,485 (2017-18 dollars), implying average annual growth of 2.9%. As a proportion of Australia’s gross domestic product (GDP), health expenditure increased from 7.6% in 1997-98 to 10.0% in 2017-18 (current prices; AIHW 2019a).

This trend of growing health care costs is evident across all OECD countries, with average health expenditure per person growing by an average annual rate of 2.4% in real terms from 2000 to 2017, measured in 2010 prices (OECD 2019b). Over the same period, the average OECD ratio of health expenditure to GDP increased from 6.9% to 8.1% (OECD 2019b). The OECD projects that health expenditure as a share of GDP will continue to rise across its member countries in the coming decade to 2030 (OECD 2019a).

In the context of rising health care costs, and a growing prevalence of complex, long-term chronic conditions, many countries are exploring ways to improve the sustainability of health care provision and financing. As outlined in this chapter, the majority of health services in Australia are activity-funded (as is common in other countries). Other funding mechanisms, such as value-based health care models, capitation-based funding and bundled pricing are being explored for their potential to provide alternative incentive structures around the provision health care, particularly in cases where health care needs are complex and long-term.

## Value-based health care

Value-based health care, including pay-for-performance financing, is an approach to service provision which emphasises ‘value over volume’ in financing health services. It aims to incentivise the provision of the health care which most improves the outcomes that patients value (EIU 2016). There are some widely acknowledged challenges associated with implementing pay-for-performance funding models (including around defining and measuring performance), and associated risks to health care provision (including the risk of reducing incentives to care for patients with health issues that are particularly challenging to overcome) (Kyeremanteng et al. 2019).

In Australia, the Australian Commission on Safety and Quality in Health Care has supported a patient-centred approach to care through the development of the Australian Hospital Patient Experience Question Set. This questionnaire is administered at hospitals and health care services to collect information about patients’ experiences of treatment and care, with results relayed back to practitioners (ACSQHC 2019). Patient-reported outcome measures have also been collected and used elsewhere in the Australian context, including as a benchmarking tool in the provision of palliative care (through the Palliative Care Outcomes Collaboration) and of care for patients with prostate cancer (through the Prostate Cancer Outcomes Registry) (AIHW 2018b).

Data relating to patient outcomes and experiences of health services, as well as considered assessments of cost-effectiveness, are key to the effective provision of any health funding scheme, including value-based health care. In some countries,



health technology assessment organisations have been established to support the development of this knowledge base. For example, the German government's Institute for Quality and Efficiency in Healthcare has prepared evidence-based reports on various health services to support a transition to value-based health care (IQWiG 2019). Some agencies, such as the National Health Service in the United Kingdom, publish reviews of health services to support transparency and better decision making (EIU 2016). In the Netherlands, some hospitals are using metrics created by the International Consortium for Health Outcomes Measurement to measure patient outcomes (EIU 2016).

## Capitation payments

Capitation-based funding involves remunerating providers based on the number (and potentially the case-mix) of patients they have enrolled or registered, rather than the volume (or type) of health care services provided (Biggs 2014). This funding approach has the potential to encourage early interventions which reduce the demand for health care over the longer-term, and to remove any incentive to provide interventions with minimal benefit to patients.

In New Zealand, a capitation-based payment mechanism has been implemented to fund GP services. Since different demographic groups require varying levels of care, the payments reflect the demographic structure of patient cohorts (NZ MoH 2019). The funding scheme also includes a mechanism to limit co-payments associated with accessing services, enabling greater access to care for Indigenous Māori and encouraging preventive visits (Thomson 2019).

A recent initiative centred around a capitation approach in Australia is the Voluntary Patient Enrolment Program for GPs, which is expected to commence 1 July 2020. Under this scheme, quarterly payments will be made to GPs, based on the number of patients they have voluntarily enrolled with their practice. Though enrolment is not mandatory and enrolled patients are allowed to see other GPs, this approach is expected to formalise patient-doctor relationships, and support the provision of more flexible, digitally enabled care (Department of Health 2019c).

The Indigenous Australians' Health Programme Primary Health Care Funding Model developed by the Australian Government is a combination of both capitation and activity-based approaches. The capitation aspect of the funding model acknowledges that services provided by Aboriginal Community Controlled Health Services are not all clinical activities and cannot always be claimed by Medicare (Department of Health 2019b).

The efficacy and challenges associated with these approaches is largely unknown at this point.

## Bundled payments

Bundled payment mechanisms and capitation mechanisms are closely related. ‘Bundled pricing’ refers to a financing arrangement where a single payment is made to cover health services and care within a particular episode—to treat a patient’s particular medical condition over a particular period of time and (potentially) across a variety of settings (Porter & Kaplan 2016).

A recent investigation into the potential use of bundled payments for funding maternity care in Australia highlighted several possible benefits of the approach—including its potential to support innovation in the provision of care (IHPA 2017). However, in this case, practical barriers were uncovered which prevent implementation at the present time.

## Blended payments

In general, any particular funding model might work well in some circumstances and for some classes of patients, and less well in other circumstances and for other patients. Blended funding models—combining aspects of fee-for-service remuneration, capitation payments, pay-for-performance, and/or other funding models—may be adopted to balance different incentives when providing health services. In practice, much of the exploration of alternative approaches to health care funding (beyond established ABF mechanisms) could be considered as falling into this category.

## Health funding and data

Data relating to health expenditure and financing are shaped by both health systems activity and health funding mechanisms. The reverse relationships also hold: health system activity and funding mechanisms are affected by the availability, and feasibility, of good quality data collection. As a result, changes in health funding mechanisms in future are likely to prompt related changes in data collection and reporting, and vice-versa.

In addition to influencing broad data categorisations (for example, the classification of medicines by whether or not they are subsidised under the PBS), funding mechanisms have the potential to affect the types of data collected, and the resources available to support relevant data collection. In Australia, the maturation of the ABF mechanism—which relies upon highly detailed hospital records for its implementation—is recognised to have strengthened efforts to improve the quality of activity-related data collections, which is beneficial for both the clinical and administrative applications of these data (see, for example, Heslop 2019). Challenges around defining appropriate metrics, and holistically monitoring improvements in

health, come to the fore when data plays a central role in funding mechanisms. The consistency of data classifications and methods across settings, and collaboration among funders, providers and other stakeholders, is clearly important.

Although growing health care costs present a challenge to the sector, in Australia and across the world, there have been efforts to further evolve funding mechanisms to more efficiently and effectively support people's long-term wellbeing. This experience has shown the collection and use of accurate, timely and high quality data to be increasingly central.

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# Changes in people's health service use around the time of entering permanent residential aged care

7

Entering permanent residential aged care is a significant life transition. From an individual perspective, life at home provides a degree of privacy and autonomy that may be difficult to maintain in a residential aged care facility where resources are shared, and nursing and personal care staff provide supervision and assistance potentially round-the-clock: these facilities are often also called 'nursing homes'. On the other hand, moving into residential aged care can open up more forms of support for a frail older person, such as increased opportunities for social interaction and access to in-house services.

The need for a higher level of care can be triggered by different factors (for example, chronic and complex health issues or everyday self-care activities can become increasingly difficult to manage due to a decline in a person's cognitive or physical abilities). People may experience falls or other acute health events; there are concerns for their safety; or their carer becomes unavailable, prompting a change in living conditions.

Exploring how people use health services in the months before and after entry into permanent residential aged care provides some insight into the nature of health service use during this transition. Health services cover a broad range of medical care provided by doctors, dentists, nurses, pharmacists and other allied health professionals in various settings. Analysis in this chapter focuses on general practitioner (GP) and specialist attendances and prescriptions dispensed for selected medicines of interest using linked administrative data (Box 7.1).

### **Box 7.1: What are the data sources in this chapter?**

Data on Medicare Benefits Schedule (MBS) claims and prescriptions dispensed under the Pharmaceutical Benefits Scheme (PBS)/Repatriation Pharmaceutical Benefits Scheme (RPBS) were linked with aged care program data, and with deaths from the National Deaths Index, to create an integrated data set covering 5 years from 2012–13 to 2016–17. As MBS and PBS data are administrative, only those health care services and prescriptions that were processed by the respective schedule/scheme are captured (Box 7.2). While data from other aged care programs were included in the linkage, only residential aged care is reported here.



## Potential interactions between health service and medicine use in residential aged care

People living in permanent residential aged care are often frail older people with complex care needs who require not only basic assistance with mobility or eating, but also nursing care through health care procedures and medicine management. Many everyday living supports, nursing care and allied health services are expected to be provided routinely in residential aged care. In addition, people often require other health services, such as those provided by GPs and specialists. Use of multiple medicines is also common (AIHW 2019; Elliott & Woodward 2011; Morin et al. 2016; Poudel et al. 2015; Roughead et al. 2008) and use of certain medicines has been shown to increase after people move into residential aged care (Harrison et al. 2020a, 2020b).

Access to care and services is influenced by the workforce available within residential aged care; the interaction aged care has with health services; and the availability of health care professionals in the local area, as well as health care provision, prescribing practices and medicine regimes within facilities (Harrison et al. 2019; Hillen et al. 2016; Somers et al. 2010; Westbury et al. 2018b). The change in living setting itself may be associated with changes in how people access health services.

Residential aged care facilities have difficulty attracting and retaining health care professionals (Eagar et al. 2019; RCACQS 2019a). The staffing profile in residential aged care has changed in the last 12 years: the number of personal care attendants increased by 169% between 2003 and 2016, while the number of registered nurses increased by only 23%. Over the same time period, the number of people living in permanent residential aged care increased by 25% (GEN 2020b; Mavromaras et al. 2017). Personal care attendants can provide some basic nursing care but are not qualified nurses. While some facilities may employ other types of workers, such as allied health staff, access to allied health and dental care in residential aged care is often limited (Hearn & Slack-Smith 2014; Mavromaras et al. 2017).

Regular consultations with a GP can help people transition into residential aged care. GPs assess people's medical and functional needs comprehensively and plan for their current and future needs, as well as providing a point of liaison between specialists, allied health services and residential aged-care staff (RACGP 2020). But, in practice, GPs may have limited time available to visit a facility or may only be able to do so at less optimal times, such as after-hours (Gadzhanova & Reed 2007; Hillen et al. 2016; Pearson et al. 2018). People can also leave a facility to attend a GP at a practice, but frailty and medical complexity may make this difficult.

Regular and timely access to GPs can improve not only the interactions health care professionals have with each person and their representatives, and their ability to fully assess people's care needs, but also the interactions between various health care professionals (Hillen et al. 2016; RACGP 2020). Whether this is coordinated or happens by chance, collaboration is important to planning for people's care needs (Harrison et al. 2019; RACGP 2020)—particularly as direct access to certain health care professionals, such as specialists, is relatively rare for people living in permanent residential aged care (AIHW 2019).

GPs also play a central role in prescribing medicines for older people in residential aged care and access to medicines can be relatively straightforward in these settings. For example, where facilities use National Residential Medication Chart (NRMC)-compliant systems to record the ordering and administration of medicines, pharmacies are able to dispense the medicines directly from information on a person's medicine chart without the need for a traditional paper prescription. This also allows the pharmacy to make streamlined PBS claims (ACSQHC 2014).

There has been considerable interest in how medicines are used within residential aged care. Most recently, in delivering its October 2019 interim report, the Royal Commission into Aged Care Quality and Safety (RCACQS) highlighted issues around the aged-care workforce and potentially problematic use of certain medicines. It recommended immediate action to reduce the use of antipsychotic medicines as a chemical restraint (that is, the use of medicines to influence people's behaviour, other than medicines prescribed for relevant health conditions) (RCACQS 2019a, 2019b).

Specific legal requirements were already in place for providers regarding physical and chemical restraint, as part of the quality standards for residential aged care (ACQSC 2019; Quality of Care Principles 2014). From 1 July 2019, the Quality of Care Amendment (Reviewing Restraints Principles) 2019 further amended the Quality of Care Principles 2014 to state that chemical restraint should only be used as a last resort.

In general, medicines that act on the central nervous system have been of particular interest due to their effects on older people, and many are prescribed at high rates in residential aged care (AIHW 2019; Harrison et al. 2019; Morin et al. 2016; Westbury et al. 2018b). Medicines that act on the central nervous system are a broad group within the Anatomical Therapeutic Chemical (ATC) Classification System, and this group covers many different types of medicines that have an effect on the brain or spinal cord. These medicines can be taken for different reasons, such as to reduce fever, suppress nausea or relieve pain, or to manage particular health conditions and their symptoms (this group includes many common treatments for mental health and neurological conditions).

Certain medicines within this group are problematic for older people as the risks of harm increase with increasing age, frailty and medical complexity (AGS 2019; Elliott & Woodward 2011; O'Mahony et al. 2015; Box 7.3). In particular, anti-dementia, antidepressant, antipsychotic, benzodiazepine and opioid medicines are all associated with dizziness or drowsiness and this brings an increased risk of falls (AGS 2019; Cox et al. 2016; Epstein et al. 2014; Fraser et al. 2015; O'Mahony et al. 2015). Partly as a consequence of this, many of these medicines are also associated with other adverse health outcomes, such as fractures and hospitalisations, as well as being associated with an increased risk of death—they also commonly interact with other medicines and health conditions (AGS 2019; O'Mahony et al. 2015; Shash et al. 2016).

At any time, around half of people living in permanent residential aged care have diagnosed dementia (GEN 2020c), and many others live with other similar degenerative illnesses or may have undiagnosed dementia. (See 'Dementia' <https://www.aihw.gov.au/reports/australias-health/dementia> for more information.) The behavioural and psychological symptoms of dementia (BPSD) are varied, but can include sleep disturbances, depression, disruptive behaviours and agitation or aggression (see glossary). Some degree of BPSD is experienced by most people with dementia (RANZCP 2016). BPSD may reflect stress, unmet need or pain (and the inability to communicate these clearly) or it may relate to the biological neurodegenerative processes of the dementia itself (Arvanitakis et al. 2019; RACGP 2020).

Instead of pharmacological treatments such as antipsychotics, the recommended primary approaches for addressing BPSD are one-on-one care; individualised behavioural management; and occupational therapy strategies (ACSQHC 2018; Arvanitakis et al. 2019; GAC 2016; Marx et al. 2017; RACGP 2020; RANZCP 2016; Westaway et al. 2018). Targeted interventions that address the prescribing culture within facilities, particularly through education and interdisciplinary involvement, have been shown to reduce reliance on medicines and to improve care (Harrison et al. 2019; McDerby et al. 2018; Poudel et al. 2015; Westbury et al. 2018a).

Considered against the background of frailty and medical complexity, the health care provided to people living in permanent residential aged care and the prescribing practices within it become increasingly crucial. This chapter examines access to GPs and specialists through the Medicare scheme, and PBS-reimbursed prescriptions dispensed for selected medicines in the 6 months before and after people first enter permanent residential aged care. In addition to looking at these broad patterns, the chapter also looks at people who were 'new users' of these medicines, to examine when anti-dementia, antidepressant, antipsychotic, benzodiazepine and opioid medicines were initiated.

## Characteristics of people entering care

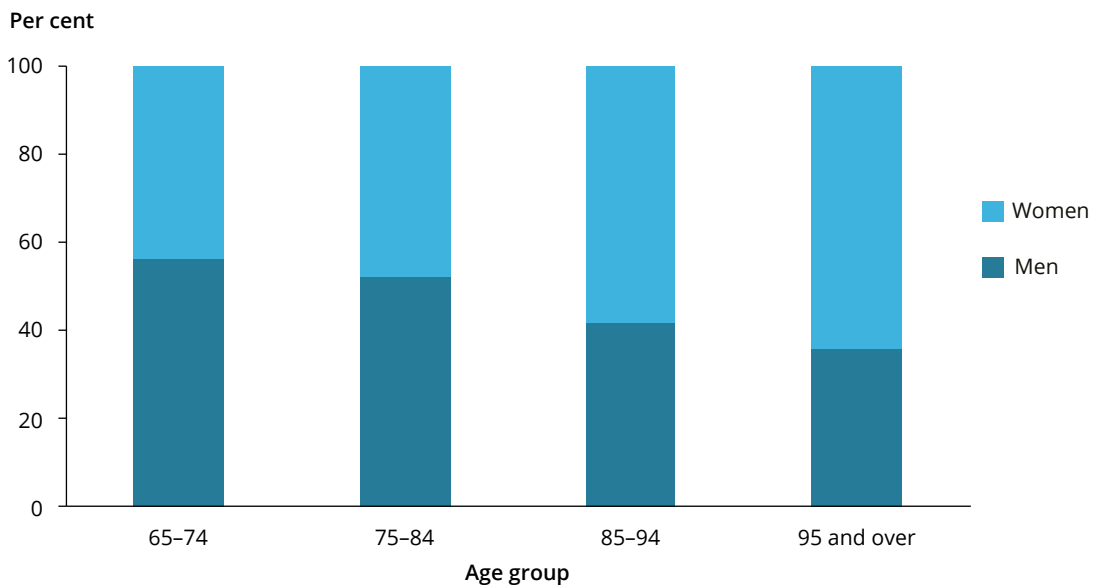
The people included in this study first entered permanent residential aged care in the 3 months from 1 July to 30 September in 2014, 2015 and 2016; were aged 50 and over at the start of the financial year; and had an Aged Care Funding Instrument (ACFI) assessment while in care. In all, in these 3-month periods in these 3 years, there were around 45,000 people who moved into permanent residential aged care and had never used it before. These people are described as 'new entrant' groups.

The number of people entering permanent residential aged care fluctuates throughout the year, influenced not only by people's need for care, but also by whether a place is available, whether people can afford the care and whether they can access other support in the community. People also commonly use respite residential aged care before entering permanent residential aged care. Respite care can be short, regular and planned episodes over a long period of time, but it can also cater for unplanned admissions; for people waiting for a place in permanent residential aged care to become available; or for those trying out residential aged care ahead of a permanent move. Respite use can be an indication of people experiencing an acute deterioration in their health and needing care immediately. In 2014, 31% of the new entrant cohort had used respite care in the 7 days before their first admission to permanent residential aged care, it was 39% in 2015 and 41% in 2016.

### Most new entrants are women

Permanent residential aged care is the 'highest' level of aged care, in that it provides people with up to 24-hour nursing care and assistance. People who use permanent residential aged care tend to be older, and they are also more likely to be women. In each of the 3 groups, there was little difference in the median age on admission, which was 85 years (86 for women and 84 for men). Overall, 3 in 5 (60%) people entering permanent residential aged care for the first time were women, and this proportion increased with age (Figure 7.1). This is similar to the distribution in the older population more generally, reflecting women's longer life expectancy.

**Figure 7.1: Sex distribution of the ‘new entrant’ groups, by age, 2014 to 2016 (all years)**



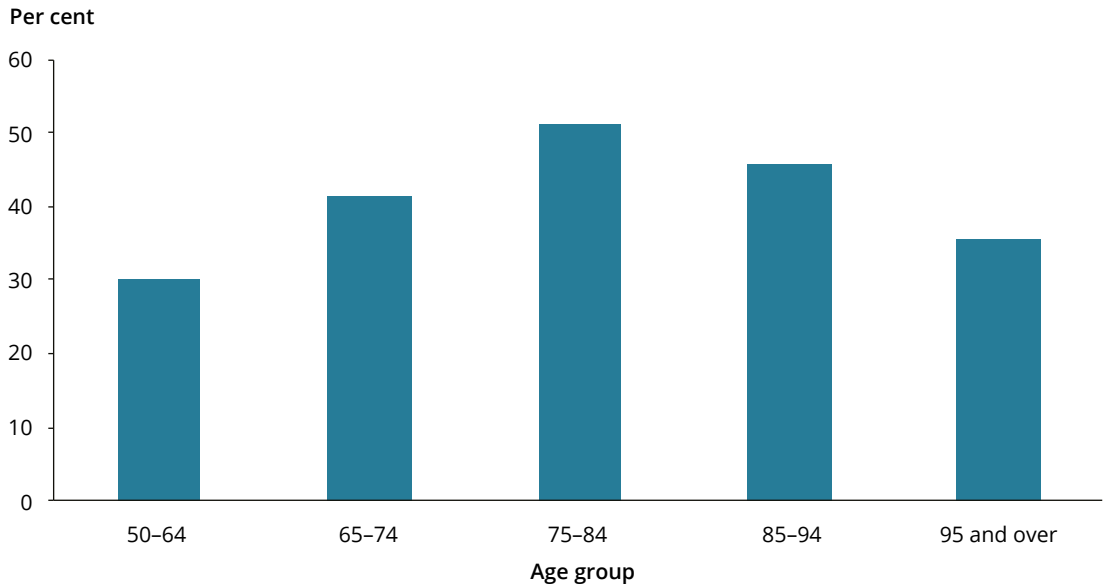
Source: Linked aged care, MBS and PBS data.

## Around half have diagnosed dementia

One of the most common health conditions among people in permanent residential aged care is dementia. While this is an umbrella term for a number of different conditions, they all affect people’s ability to reason, remember and move—and to live independently. (See Chapter 8 ‘Dementia in Australia—understanding the gaps and opportunities’). Around half (46%) of people in each of the 3 new entrant groups had a diagnosis of dementia captured on their first ACFI assessment after admission (noting that the ACFI is a funding instrument and its primary focus is on assessing the cost of care). Diagnosis of dementia varied by age, with the youngest and oldest age groups least likely to have dementia recorded (Figure 7.2).

In addition to information on diagnosed health conditions, ACFI assessments provide some indication of people’s functional status across 3 domains (activities of daily living; behaviour and cognition; and complex health care). Regardless of their exact health conditions, people entering permanent residential aged care have broadly similar needs around core activities (such as movement, self-care and communication), and difficulties with 1 or more of these everyday activities contribute to their move into residential aged care.

**Figure 7.2: Proportion of people in the 'new entrant' groups who had diagnosed dementia at first ACFI assessment after admission, by age, 2014 to 2016 (all years)**



*Note:* Data for this figure are available in Supplementary Table S7.1.

*Source:* Linked aged care, MBS and PBS data.

The proportions of people assessed on their first ACFI assessment after admission as having 'high' need for care in each of the 3 domains were 17% in 2014; 21% in 2015; and 20% in 2016. Put simply, this means that their ability to perform common activities of daily living was impaired; they had behavioural or cognitive needs that affected others; and they required regular complex health care.

### Almost one-third die in the year they enter care

Many people enter permanent residential aged care towards the end of their lives. Almost one-third (29%) of people in each of the 3 groups died in the same financial year in which they entered permanent residential aged care (meaning that they died within 12 months of their admission). People who entered permanent residential aged care at an older age were more likely to die by the end of the financial year (particularly older men) (Table 7.1).

**Table 7.1: Proportion of people in the ‘new entrant’ groups who died in the financial year of admission, by sex and age group, 2014 to 2016**

Sex/age group	2014	2015	2016
		%	
<b>Women</b>			
50–64	19.9	21.8	20.0
65–74	22.0	20.2	24.4
75–84	23.5	22.5	20.0
85–94	23.4	24.1	25.2
95+	33.1	34.2	36.0
<b>Total women</b>	<b>23.9</b>	<b>24.0</b>	<b>24.2</b>
<b>Men</b>			
50–64	29.8	25.6	29.2
65–74	30.1	27.6	25.9
75–84	34.7	33.3	32.1
85–94	40.3	38.4	39.1
95+	43.2	53.0	48.0
<b>Total men</b>	<b>36.6</b>	<b>35.3</b>	<b>35.0</b>

Note: ‘Financial year’ refers to the period from 1 July to 30 June.

Source: Linked aged care, MBS and PBS data.

As the focus of this chapter is on the immediate period around admission, it does not take into account all deaths for the 3 groups (that is, those occurring beyond the end of the financial year). The patterns of health-service use shown in the next section also capture only a part of some people’s time in permanent residential aged care. People can continue to live a considerable number of years in aged care—for example, 25% of those who entered in the 3-month sample period in 2014 were still living in the same residential aged care facility at 30 June 2017. The average length for an episode of permanent residential aged care is around 2.5 years (noting that some people go on to have more than 1 episode of care, for example due to moving between facilities) (GEN 2020a).

## Use of GP and specialist services

Health service use by people living in residential aged care may be influenced by a number of factors. For example, some facilities have in-house health services, but the services available to people can vary considerably between facilities (and these are not captured in the available data). Issues that affect the aged care industry generally—such as workforce availability and interactions with health services and prescribing practices—can also affect individual facilities differently. Outside of the facility, it can be difficult for people to attend appointments or to find appropriate services—and where they do, this can be affected by the same constraints as health service use in the broader population, with rural and remote areas generally having lower rates of use (AIHW 2018b).

### People are more likely to see a GP after admission and less likely to see a specialist

Most people see a GP both before and after entry to a residential aged care facility, but the proportion of those seeing a GP and the rate of GP attendances were both higher in the 6 months after entering permanent residential aged care, compared with the 6 months before entry. For example, where people had seen a GP at least once prior to entry, they saw one around 3 times as often after entry (Table 7.2). The proportions of people seeing a GP before and after entry to permanent residential care also increased over the 3 years, as did the rate of GP attendances after entry to care.

On the other hand, the proportion of people who saw a specialist decreased after entry, and, for those who had them, the number of specialist attendances was lower (decreasing by around half after entry to permanent residential aged care) (Table 7.2). This may not fully reflect the services people are able to access—some specialist care can, for example, be provided through outreach services not captured in MBS data—but nonetheless, this suggests that for many people, the patterns of health service use do change in the 6-month period before and after entry into permanent residential aged care.



**Table 7.2: Proportion of people in the ‘new entrant’ groups with GP/specialist attendances in the 6 months before/after entry into permanent residential aged care, 2014 to 2016**

Attendance type	Admission year							
	2014		2015		2016		Total	
	Before	After	Before	After	Before	After	Before	After
<b>GP attendances</b>								
% with at least 1	80.4	90.0	81.7	91.2	82.7	92.3	81.7	91.3
Average number (per person)	5.5	13.9	5.5	14.5	5.5	15.1	5.5	14.6
<b>Specialist attendances</b>								
% with at least 1	38.8	31.6	39.4	34.0	40.2	35.1	39.5	33.7
Average number (per person)	8.5	3.8	7.9	3.8	8.3	4.2	8.2	4.0

Note: Data for this table are available online in Supplementary tables S7.2 and S7.3.

Source: Linked aged care, MBS and PBS data.

The proportion of people with a GP or specialist attendance decreased with age. Compared with younger age groups, a smaller proportion of people aged 85 and over had seen a GP or specialist in the 6 months either before or after their entry into permanent residential aged care. The proportions were lowest for men aged 95 and over: in the 6 months after entering care, 74% of men in this age group had a GP attendance and just 20% had a specialist attendance. Similarly, the average number of attendances decreased with age (tables 7.2 and 7.3). The reasons for this are not clear but may be related to the fact that data are restricted to MBS claims (Box 7.2).

**Box 7.2: MBS data scope**

The MBS data analysed in this chapter relate only to those GP and specialist services that were subsidised by the scheme and does not present a full picture of health service use. For example, the data do not include admitted patient care or out-patient care in the public system, or services provided through programs such as the Dementia Behaviour Management Advisory Service or the Severe Behaviour Response Teams that operate in residential aged care. People may receive equivalent services outside of MBS—either because no MBS claim was made, or because the service was delivered through another funding arrangement or paid for privately.

Many people in permanent residential aged care are eligible for Department of Veterans' Affairs (DVA) funding and may access GP and specialist services this way. At 30 June 2017, there were over 26,000 DVA clients in residential aged care, accounting for 14% of people in residential aged care (AIHW 2018a).

While there are limitations to what MBS data cover, the data are consistent across the time periods analysed here: any services that would be excluded because they were outside of MBS data scope are thus excluded for both the 6 months before and 6 months after entry into permanent residential aged care.

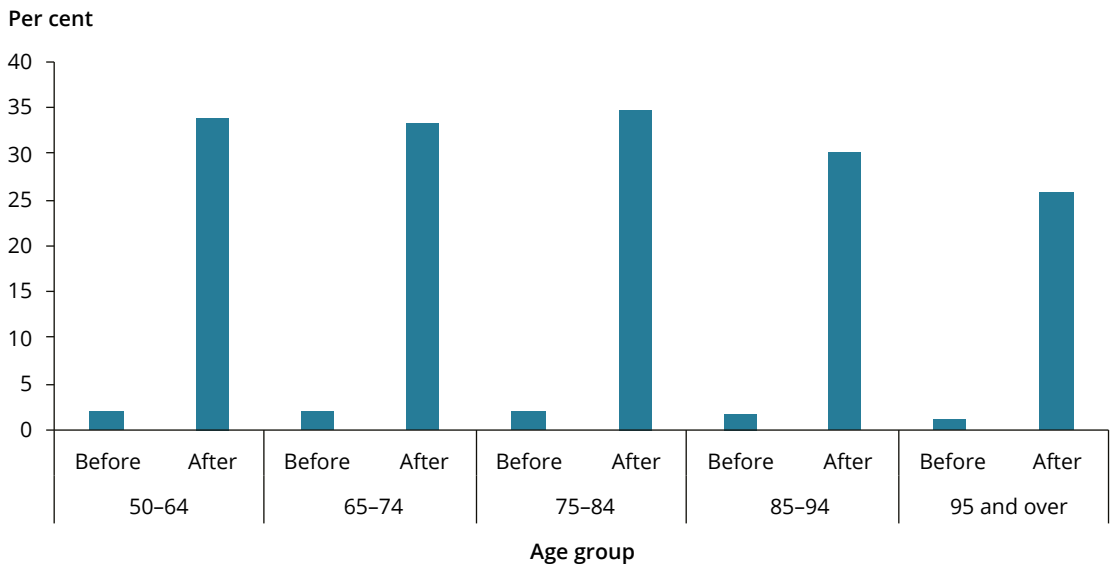
The most common types of specialists seen in the 6 months before entry were consultant physicians in general medicine, geriatric medicine and rehabilitation medicine (accounting for 18%, 18% and 12% of specialist attendances, respectively). In the 6 months after entry, the most common types of specialists were consultant physicians in geriatric medicine and general medicine (15% and 13%, respectively), followed by ophthalmologists (9.0%)—while attendances with consultant physicians in rehabilitation medicine accounted for only 3.8% of all specialists attendances in the 6 months after entry.

These attendance patterns before and after entry may be influenced by different factors, such as what other health services people access, or the aged care services they use, and how well these meet their needs for health care. The patterns may also relate to the changes in people's health and functional status that precipitated their entry into residential aged care. Further, this time-limited view of GP and specialist attendances does not fully reflect the overall patterns of use for those living in the community or in residential aged care. For example, in the lead-up to entering permanent residential aged care, specialists can be consulted more frequently to finalise paperwork for diagnoses and comprehensive assessments, as well as for initiating certain new medicines, whereas additional GP attendances may be required soon after entry to assess care needs and to review existing or prescribe new medicines.

## Around one-third have a medicine review after admission

Medicine reviews that involve both GPs and pharmacists are captured in MBS data. These collaborative reviews are intended to ensure that people's medicine regimes are appropriate and to minimise possible risks of harm. Few people had an MBS claim for a medicine review in the 6 months before their entry, but the proportion increased considerably after entry to permanent residential aged care (from 1.8% to 32%). This also varied by age group: around 1 in 3 (34%) people in the younger age groups had their medicines reviewed after admission, while only 1 in 4 (26%) in the oldest age group did (Figure 7.3).

**Figure 7.3: Proportion of people in the 'new entrant' groups with a medicine review in the 6 months before and after admission, 2014 to 2016 (all years)**



Source: Linked aged care, MBS and PBS data.

People may also have their medicines reviewed as part of an in-patient stay in hospital—either by the GP as part of a general consultation, or through a community pharmacy alone—and this would not be visible in the MBS data.

## Use of selected prescription medicines

Older people often have multiple health conditions and use a number of different prescription medicines. For community-dwelling older people, the most common type of prescription medicines used are cardiovascular medicines, while for people living in permanent residential aged care, medicines that act on the central nervous system are the most common (AIHW 2019). The medicines analysed here all belong to this broad group. The 5 medicine types of interest are anti-dementia, antidepressant, antipsychotic, benzodiazepine and opioid medicines (Box 7.3).

### Box 7.3: Selected prescription medicines

The analysis in this chapter is focused only on prescriptions dispensed for selected medicine types of interest, and does not include all prescriptions dispensed through PBS/RPBS, or all medicines used, as some people may obtain medicines outside of the PBS/RPBS, either privately, in hospital or bought over the counter (meaning they do not attract a government subsidy).

The selected medicines of interest here were identified by ATC codes. They are prescribed to older people relatively commonly, particularly to those living in residential aged care (AIHW 2019), and they are used for various reasons:

- Anti-dementia medicines may relieve symptoms of dementia and are mostly prescribed for people with mild-to-moderate Alzheimer's disease (noting that it can be difficult to identify the type of dementia accurately).
- Antidepressant medicines are commonly used to treat symptoms of depression and anxiety, but some can also be prescribed for other mental health conditions such as bipolar disorder or bulimia, as well as for diabetic neuropathy and neuropathic pain.
- Antipsychotic medicines can be used to manage the symptoms of certain mental health conditions, such as schizophrenia (where delusions, hallucinations and paranoia are common symptoms), and some are used to manage the behavioural symptoms of dementia.
- Benzodiazepine medicines can be used to manage the symptoms of certain mental health conditions, such as anxiety disorders, and to treat insomnia, seizures or muscle spasms.
- Opioid medicines can help to relieve pain and relax muscles; some may be used in palliative care.

While these medicines can be beneficial, they also present a risk of harm through potential side effects such as sedation, confusion and dizziness (AGS 2019; Lapane et al. 2015; O'Mahony et al. 2015). One of the most noteworthy issues with antidepressant, antipsychotic, benzodiazepine and opioid medicines is their association with an increased risk of falls and fractures in older people (AGS 2019; Cox et al. 2016; Epstein et al. 2014; Fraser et al. 2015; O'Mahony et al. 2015). The likelihood of harm increases as a person ages, and many of these medicines should only be used for particular indications and for restricted periods of time, and prescribed in lower doses for older people.

They can also exacerbate issues that older people already commonly experience. The potential side effects of these medicines can arise from the medicine itself, or from how it interacts either with other medicines the person is prescribed, or with other health conditions the person has, such as frailty, dementia or heart disease (AGS 2019; O'Mahony et al. 2015). In addition, the way medicines contribute to these conditions can be under-recognised or inappropriately attributed to a health condition, geriatric syndromes or the ageing process. For example:

- antipsychotic medicines prescribed for a person with pre-existing swallowing difficulties (for example due to dementia) may increase these swallowing difficulties, and thus the likelihood of the person developing pneumonia and/or malnutrition. Some antipsychotic medicines are also associated with adverse cardiovascular effects such as arrhythmias and hypotension (AGS 2019; O'Mahony et al. 2015) and a higher risk of mortality (Harrison et al. 2020a)
- benzodiazepine medicines are associated with memory problems and cognitive impairment, and may worsen gait or other physical abilities, as well as exacerbate existing dementia symptoms (AGS 2019; O'Mahony et al. 2015; Shash et al. 2016)
- opioid medicines can affect balance and have a number of other potential effects, such as reduced respiration rates and increased constipation and cognitive impairment (AGS 2019; Chokhavatia et al. 2016; O'Mahony et al. 2015).

## A higher proportion of people have prescriptions dispensed after entry

Generally, for most of these selected medicines, people were more likely to have prescriptions dispensed in the period following entry into permanent residential aged care than before entry. The proportion of people who had a prescription dispensed for anti-dementia medicines was similar in the 6 months before and after entry, but for antidepressant, antipsychotic and opioid medicines, the proportion of people in the

'new entrant' groups who were dispensed at least 1 prescription increased in the 6 months after entry (Table 7.3). For example, the proportion of people who had a prescription dispensed for an antipsychotic medicine increased, from around 1 in 6 (15%–16%) people in the 6 months before entry, to 1 in 4 (24%–25%) people in the 6 months after entry.

**Table 7.3: Proportion of people in the 'new entrant' groups with prescription for selected medicine types in the 6 months before and after entry into permanent residential aged care, 2014 to 2016<sup>(a)</sup>**

Medicine type	Admission year							
	2014		2015		2016		Total	
	Before	After	Before	After	Before	After	Before	After
	%							
Anti-dementia	10.7	9.4	10.9	9.8	11.1	10.1	10.9	9.8
Antidepressant	36.0	42.0	36.1	42.2	37.5	43.1	36.6	42.5
Antipsychotic	15.3	24.8	15.9	24.6	16.4	24.0	15.9	24.5
Benzodiazepine	24.1	32.4	23.2	29.6	23.5	30.3	23.6	30.6
Opioid	32.9	45.8	33.2	46.1	34.1	46.4	33.4	46.1

(a) Proportion of people with at least 1 prescription dispensed in the 6 months before/after their admission date into permanent residential aged care.

Note: Data for this table are available in online Supplementary Table S7.4.

Source: Linked aged care, MBS and PBS data.

Some of these medicines are used for particular indications, and this may affect their patterns of use. For example, opioid medicines are commonly given as pain relief and to ease breathing towards the end of life (Lapane et al. 2015; Morin et al. 2016). The increasing pattern of use around entry into permanent residential aged care was less marked for this medicine type when subsequent deaths were taken into account— noting that the use of opioid medicines (regardless of why they are used) may also increase mortality (AGS 2019; O'Mahony et al. 2015). Among people who died in the same financial year as their admission into aged care, 2 in 5 (41%) were dispensed an opioid medicine in the 6 months before entry, and 2 in 3 (65%) were dispensed one in the 6 months after entry. For people who did not die in that time period, the respective proportions were 30% and 38%.

On the other hand, people who had a dementia diagnosis recorded on their first ACFI assessment were less likely to be dispensed opioid medicines, but the proportions nonetheless also increased following entry into permanent residential aged care: in the 6 months before entry, 25% were dispensed at least 1 opioid medicine, and 40%

in the 6 months after entry (compared with 41% and 52%, respectively, among those who did not have a dementia diagnosis). People with dementia were also more likely to be dispensed antipsychotic medicines after entry: 24% of people with dementia were dispensed at least 1 prescription for this medicine type in the months before, and 36% in the months after entry (compared with 8.8% and 14%, respectively, among those who did not have a dementia diagnosis).

## Prescriptions are commonly written by GPs

For each medicine of interest, the majority of prescriptions dispensed were written by GPs, and these proportions increased after entry, reflecting the reduced access to specialists following admission into permanent residential aged care. For prescriptions for anti-dementia medicines dispensed in the 6 months before entry, 75% were written by GPs (increasing to 89% after entry). Specialists accounted for the remainder of the prescriptions. For the other 4 medicines, the pattern was less pronounced—92% of prescriptions for antidepressant medicines, 87% of antipsychotic medicines, 93% of benzodiazepine medicines and 92% of opioid medicines were written by GPs (increasing to 96%, 96%, 98% and 97%, respectively, in the 6 months after entry).

## Antipsychotic medicines may be dispensed at a higher volume after entry

Each prescription of medicine can be for a different quantity and amount of medicine (meaning that the number of pills and the volume of active ingredient can vary considerably within the same medicine type). Prescriptions can also be written as PRN (pro re nata—that is, to be taken as required). In residential aged care, these may be ordered and dispensed ahead of when they are required in order to have the medicine available in case it is later required, rather than because it is currently being used. Regularly prescribed medicines may also have additional directions to take more as required, or to allow flexibility for existing use to be tapered up or down (Stasinopoulos et al. 2018; Westbury 2018a, 2018b).

The directions for how the medicine is to be taken are not recorded in PBS data, nor do the data capture compliance—how well those directions were followed. With these limitations in mind, another way of estimating consumption is the defined daily dose (DDD) (WHO 2003, 2019). PBS data record the amount and quantity of medicine dispensed and, using this in combination with prescribing guidelines, it is possible to estimate consumption. These calculations give an estimate of the number of days for which the person may have used a medicine if it was used as indicated in prescribing guidelines (Box 7.4).

### Box 7.4: Defined daily dose

The DDD is a World Health Organization (WHO) measure for estimating the consumption of a medicine. The WHO determines the assumed average maintenance dose per day for its main indication in adults, and this can be used to estimate the volume of medicine use and the number of days on which a person may have taken the medicine.

This assumed dose is often different to the dose prescribed or recommended to the person: the DDD is an international measure based on a whole-of-population approach and does not take into account local differences in prescribing practices or best-practice prescribing for different sub-populations. For these analyses, the Australian prescribing guidelines for the usual dose were used to determine the assumed dose. To facilitate international comparisons, data for the WHO DDD are also shown in Supplementary Table S7.5.

Risperidone has been identified as the most commonly dispensed distinct antipsychotic medicine after entry into residential aged care (Harrison et al. 2020a, 2020b; Inacio et al. 2019), and this was the case for the 'new entrant' groups in this study as well; risperidone accounted for 43% of the antipsychotic prescriptions dispensed to new entrants in the 6 months before entry, and 47% of those dispensed in the 6 months after entry. Its common indication is for management of schizophrenia (and this is the indication for the WHO DDD calculation), but for older people with dementia, it may also be prescribed for managing BPSD.

Using Australian prescribing guidelines from the Australian Medicines Handbook (AMH)—which recommend a usual dose of 1mg per day for this purpose, although doses up to 2mg can be used—the estimated median number of days of use differed in the months before and after entry. For people with dementia who were dispensed oral risperidone in the 6 months before entry into permanent residential aged care, the estimated median days the medicine was used for was 2 months (60 days), and half of these people may have used the medicine for between 1 and 4 months in the 6-month period (the interquartile range was 30–120 days). The estimated median days of use increased by more than a month in the 6 months after entry: for people with dementia who were dispensed oral risperidone, the medicine was potentially used for over 3 months (100 days), and half of these people may have used the medicine for between 2 and 6 months (the interquartile range was 60–180 days).



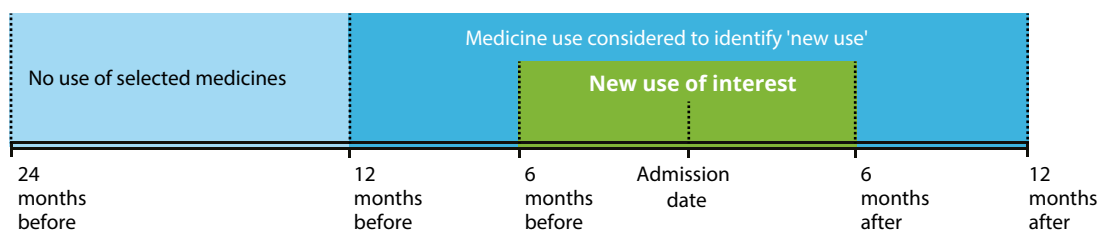
The AMH guidelines for prescribing risperidone for BPSD state that the maximum period of use at a time should be 3 months (AMH 2019). However, where the facility uses NRMC-compliant medicine charts, these charts are valid for up to 4 months at a time and guidelines allow nurses to order medicines over the duration of the chart (ACSQHC 2014), meaning that the volumes estimated here may be influenced by medicine management practices within facilities.

## New users and their use of selected medicines

Looking at when people are first dispensed particular medicines provides additional insight into how their patterns of use change around entry into residential aged care. This section on ‘new users’ only includes people who were newly dispensed a prescription for anti-dementia, antidepressant, antipsychotic, benzodiazepine or opioid medicines, and again focuses on prescriptions dispensed in the 6 months before or after a person’s entry into permanent residential aged care (Box 7.5).

### Box 7.5: Who are ‘new users’ of the selected medicines?

‘New use’ was defined here in stages. First, broader prescribing patterns for the selected medicines were examined to identify whether people had prescriptions dispensed in the 12 months before and after their entry into permanent residential aged care. This longer timeframe was used to capture a broader period of use and to allow for seasonal patterns in dispensing (in particular, there is commonly a peak towards the end of a calendar year as people have reached the PBS safety net and stockpile medicines at lower cost for the coming calendar year). In addition, to be counted as ‘new users’, people must not have had any prescriptions dispensed for the selected medicine in the 12–24 months before entry.



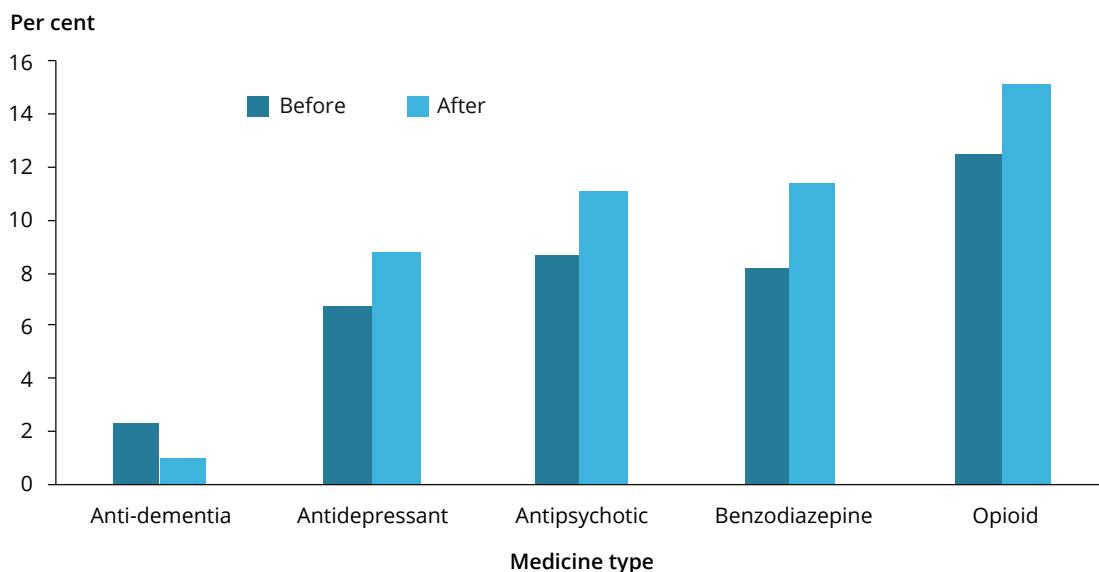
The analysis then focused only on those people who had had no prescriptions of interest dispensed in this longer retrospective period, but who went on to have these prescriptions dispensed to them in the 6 months before or after their entry.

By this definition, the majority (38,400, or 86%) of the 45,000 people in the 3 ‘new entrant’ groups were new users of at least 1 of these medicines (anti-dementia, antidepressant, antipsychotic, benzodiazepine or opioid medicines). Relatively few people were newly prescribed anti-dementia medicines in the 6 months before or after their entry into permanent residential aged care (1,500 people, or 3.3% of the 3 ‘new entrant’ groups). On the other hand, 6,900 people (15%) were new users of antidepressants, and just under 9,000 (20%) were new users of antipsychotic or benzodiazepine medicines. Opioid medicines were newly prescribed to over 12,000 people (28%).

## For most medicines, new use is more likely to be initiated after entry

For anti-dementia medicines only, new users were more likely to have the first prescription dispensed in the 6 months before entry. For antidepressant, antipsychotic, benzodiazepine and opioid medicines, new users were more likely to have their first dispensing at or after entry (Figure 7.4).

**Figure 7.4: Proportion of people in the 3 ‘new entrant’ groups who were new users of selected medicine types, 2014 to 2016 (all years)<sup>(a)</sup>**



(a) Proportion of people with at least 1 prescription dispensed in the 6 months before/after their admission into permanent residential aged care for whom that medicine type had not previously been dispensed.

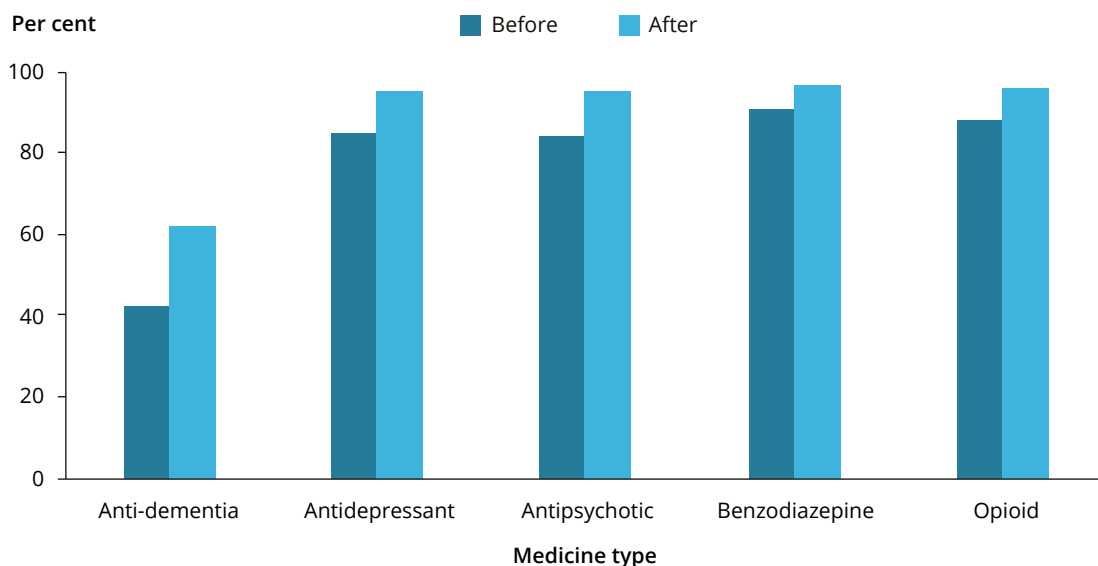
Source: Linked aged care, MBS and PBS data.

Identifying the halfway point in the distribution of days between the first prescription being dispensed for a new user and their entry date into permanent residential aged care showed a similar pattern. Anti-dementia medicines were commonly initiated before entry, with the new users' first prescription dispensed a median of 43 days before the entry date. For the other medicine types, the timing of first dispensing frequently coincided with entry into permanent residential aged care. For new users, antidepressant medicines were dispensed a median of 3 days after the entry date, while antipsychotic and benzodiazepine medicines were dispensed a median of 1 day after the entry date and opioid medicines a median of 0 days. In particular, the short median time between the entry date and when a prescription for an antipsychotic medicine was dispensed may indicate that there was little time to trial a non-pharmacological approach.

## Most new users have their first prescription written by a GP

A higher proportion of new prescriptions dispensed for all 5 medicines in the 6 months after entry were written by a GP, compared with the 6 months before (Figure 7.5).

**Figure 7.5: New users of selected medicines who had their first prescription written by GP, by whether first prescription was dispensed before or after admission, 2014 to 2016 (all years)<sup>(a)</sup>**



(a) Proportion of people with at least 1 prescription dispensed in the 6 months before/after their admission into permanent residential aged care for whom that medicine type had not previously been dispensed.

Source: Linked aged care, MBS and PBS data.

## Multiple medicines may indicate potentially inappropriate use

Nine in 10 (90%) people who were newly dispensed antipsychotic medicines in the 6 months before or after entry also had at least 1 other prescription dispensed for an antidepressant, benzodiazepine or opioid medicines in the same year. Combined use of antidepressant, antipsychotic, benzodiazepine or opioid medicines could be appropriate for some people, but can also indicate potentially inappropriate use of medicines, as these medicines affect people in similar ways and they can further compound existing health issues (AGS 2019; Box 7.3).

The data do not include exact timing of use or whether people adhered to directions in using the medicines, but this group of people were potentially vulnerable to additional harm from medicines. They were more likely to have dementia (69%) or to have been rated 'high' across the 3 ACFI domains (27%) than people in the 'new entrant' groups overall—and, combined, 1 in 5 (19%) had dementia and were rated 'high' on all 3 domains.

## Conclusion

Selected aspects of people's health service and medicine use changed in the 6 months after entry into permanent residential aged care from the 6 months that preceded their entry. While people can experience specific acute events that trigger entry to residential aged care, admission into permanent residential aged care can often be accompanied by a long-term decline in people's health and functional ability. Sometimes this declining health can lead to admission into care, and sometimes people's overall care needs change incrementally. However, moving into permanent residential aged care marks a change in people's health service and medicine use that may also be directly related to this change in their living conditions.

Almost everyone in the 'new entrant' groups had a GP attendance after entry to permanent residential aged care, and the rate of GP use was considerably higher than before entry. On the other hand, fewer people had a specialist attendance after entry; the rates of specialist attendances declined; and the nature of specialist attendances also changed, with fewer attendances by specialists in rehabilitation medicine after entry than before. Dispensing patterns for selected medicines showed a similar change, in that where people were dispensed these medicines in the 6 months after entry into permanent residential aged care, a higher proportion of the prescriptions were written by a GP than by a specialist, compared with the 6 months before entry.

In addition, the use of anti-dementia, antidepressant, antipsychotic, benzodiazepine and opioid medicines changed between the 2 time periods, with a higher proportion of people dispensed at least 1 prescription for most of these medicines after entering care (with the exception of anti-dementia medicines, which remained relatively steady).

The proportions varied depending on the medicine type and particular characteristics of the person: for example, people with dementia were more likely to be dispensed antipsychotic medicines (both before and after entry), and to be newly dispensed these medicines, than were people without dementia.

The most common specific type of antipsychotic medicine (risperidone) is approved for short-term management of BPSD, but the results here indicate that the volumes dispensed can cover a longer period of risperidone use than recommended by Australian prescribing guidelines. In addition, other antipsychotic medicines—as well as antidepressant, benzodiazepine and opioid medicines—may all be used in residential aged care to manage sleep disturbances, agitation and other behaviours of concern, regardless of whether these constitute the most appropriate approach.

The primary evidence-based approaches for addressing BPSD are all psychosocial and non-pharmacological, and often multidisciplinary, meaning that it can take time to identify and implement the most appropriate care. Despite this, access to specialists decreased following entry into permanent residential aged care, at the same time as people were more likely to be prescribed medicines, including antipsychotic medicines. The median time between admission and dispensing date would suggest that, for some people, there was little time to trial a non-pharmacological approach before an antipsychotic medicine was dispensed. As has been discussed, this does not mean the medicine was used, but it may indicate that it is not always used as a last resort.

The analyses presented here did not consider changes in people's use of health service and medicine use beyond the 6 months before and after their entry into permanent residential aged care. Furthermore, the analysis was somewhat limited by using MBS-reimbursement data to describe GP and specialist use. It was also not possible to consider the appropriateness of the use of these medicines, or the benefits and harms that may be experienced. As people settle into their new living arrangements, or their health and functional ability undergoes further changes, these patterns may continue to evolve. Some people live in residential aged care facilities for years and, as a vulnerable population, have been particularly impacted by COVID-19 (see Chapter 2: 'Four months in: what we know about the new coronavirus disease in Australia' for more information).

The AIHW is undertaking ongoing work using linked data to examine different aspects of the interfaces between aged care and health systems in Australia. (More information is available through the AIHW website <https://www.aihw.gov.au/reports/aged-care/interfaces-between-the-aged-care-and-health-system/contents/summary>).

While administrative data sources cannot fully account for the person's experience, this work shows the value of using existing data collections and these findings should be considered in any redesign of the aged care system.

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# Dementia data in Australia— understanding gaps and opportunities

8

Dementia is one of Australia’s biggest health issues, causing substantial illness, high levels of dependency and death. Dementia was the fourth leading cause of burden of disease and injury in Australia in 2015 and the second leading cause in people aged 65 and over (AIHW 2019a). Furthermore, in 2018 it was the second leading cause of all deaths in Australia and the leading cause of death for females (ABS 2019).

### **Box 8.1: What is dementia?**

Dementia is a term used to describe a collection of symptoms that are progressive in nature and caused by numerous conditions affecting brain function (WHO 2019). Dementia mainly occurs among people aged 65 and over but is not a normal part of ageing. When it occurs in people under 65, it is known as ‘younger-onset dementia’ (Dementia Australia 2019). Dementia is commonly associated with memory loss but can also affect speech, cognition, emotional control, behaviour and mobility (WHO 2019).

There are many different types of dementia, with Alzheimer’s disease being the most well-known. An increased risk of developing dementia is also linked to the presence of other neurological conditions (such as Parkinson disease and Huntington disease); prolonged alcohol abuse; HIV/AIDS; Down syndrome and traumatic brain injury. It is possible to have multiple types of dementia at once— known as ‘mixed dementia’—with the most common combination being Alzheimer’s disease and vascular dementia.

The progression of dementia is complex and each person with dementia will experience it differently. Disease progression varies but, on average, a person with Alzheimer’s disease is expected to live 8–10 years following diagnosis (Musicco et al. 2009). Factors impacting dementia progression include age of onset; genetics; overall physical health; existing health conditions (such as diabetes and cardiovascular disease); and type of dementia (Livingston et al. 2017).

While no cure for dementia exists, there are a number of management strategies that can support a better quality of life as dementia progresses. Most people with dementia live in the community and require considerable support from family and friends, and through formal care arrangements such as community-based aged-care services and respite facilities. People with advanced dementia experience substantial cognitive and physical decline and require extensive assistance with most or all activities of daily living. This care is typically provided in permanent residential aged care, where it is estimated just over half of residents have dementia (AIHW 2020c).

It is estimated that between 400,000 and 459,000 Australians are living with dementia in 2020 (AIHW 2018; Dementia Australia 2020a). Dementia cost Australia \$428 million in direct health expenditure in 2015–16 and, based on modelling undertaken by the National Centre for Social and Economic Modelling (NATSEM), an estimated \$14.7 billion was spent on dementia-related health- and aged-care expenditure, productivity loss and other indirect costs in 2017 (AIHW 2019b; NATSEM 2017). Assuming no significant breakthrough in treatment, the number of people with dementia is projected to more than double between 2020 and 2050, placing an even greater demand on Australia's health and aged-care systems (AIHW 2018; NATSEM 2017).

The Royal Commission into Aged Care Quality and Safety has exposed systemic issues in the current aged-care sector, and has called for fundamental reforms to an aged-care system that is failing to care appropriately for people who require care, including the growing number of people with dementia (RCACQS 2019b). With over half of people in residential aged-care facilities having dementia, and with a large proportion of people with dementia living at home, improving the quality of care and services available for older Australians, and of those with dementia, is essential.

Despite dementia being a major health challenge, there are significant gaps in robust Australian dementia data. For example, the exact number of Australians with dementia is not known, with current estimates based on small, outdated Australian studies and international data. Monitoring dementia—and its impact on individuals, their carers and Australia's health and aged-care systems—is essential for the development of evidence-based health, aged care and social policy and associated service planning.

This article discusses:

- current issues and gaps in Australia's dementia data and its impact on our knowledge of dementia in Australia
- recent investments made by the Australian Government to improve Australia's dementia data
- other potential data development opportunities to ensure Australia has sufficient data to inform dementia policy and service planning.

In addition, it discusses novel findings from the 2020 AIHW report: *Patterns of health service use by people with dementia in their last year of life*.

See 'Dementia' <https://www.aihw.gov.au/reports/australias-health/dementia> for the latest available statistics on dementia in Australia.

See 'International comparisons of health data' <https://www.aihw.gov.au/reports/australias-health/international-comparisons-of-health-data> for information on how the prevalence of dementia in Australia compares with other countries. Note: the Australian dementia prevalence rate shown in the international comparisons snapshot are produced by the Organisation for Economic Co-operation and Development (OECD).

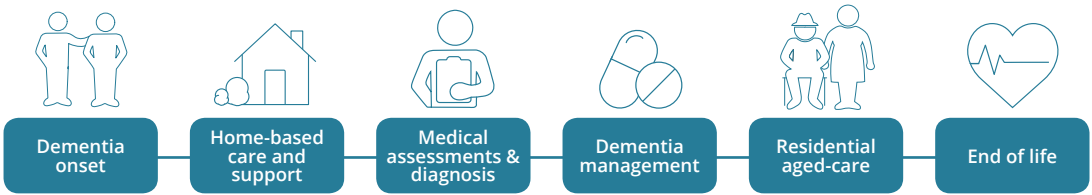
Due to methodological differences, these rates differ from the Australian dementia prevalence estimates described in this article; the OECD dementia prevalence rates are used for international comparisons only.

## Dementia data gaps & implications

Unlike other leading chronic conditions in Australia, there is no national approach for monitoring and reporting dementia. Australia’s dementia statistics are derived from a variety of data sources of varying quality, including administrative data from government services (such as hospitals and aged-care services), survey data and epidemiological studies (both Australian and international). Emerging evidence suggests the incidence and prevalence rate of dementia is declining in several high-income countries due to improvements in the prevention and management of vascular risk factors for dementia (hypertension and cardiovascular disease) (Roehr et al. 2018). However, it is not currently known whether rates in Australia are also declining.

To understand why major dementia data gaps exist, it is important to understand how dementia is diagnosed and managed; at which stages national data useful for monitoring dementia are collected; and the limitations of the data. Figure 8.1 illustrates a potential care pathway for a person with dementia, along with the stages at which national data are collected for use in monitoring dementia. While there are opportunities to monitor dementia along most of the care pathway, each data source has certain limitations, including capturing only a subset of people with dementia. A summary of key data sources that can be used to monitor dementia, and their benefits and limitations, is shown in Table 8.1.

**Figure 8.1: Dementia pathway and associated national data collections, their coverage and limitations for reporting dementia**



**National data collections and dementia data limitations**

**GP and specialist care data:**  
No national dementia-specific data

**Prescription data:**  
PBS subsidy data available only for people diagnosed with Alzheimer's disease and dispensed at least 1 of the 4 PBS-subsidised anti-dementia medications

**Income support data:**  
Recorded only for care recipients and carers receiving a Carer Payment and not for other income support payments

**Hospitals data:**  
Available, however dementia inconsistently coded in hospital data

**Community aged-care data (including assessments):**  
Currently only available in assessment data up to 2015 or if a person is receiving a dementia & cognition supplement

**Residential aged-care data (including assessments):**  
Available in current funding data, but assessment data currently available only up to 2015

**Deaths data:**  
Available, however cause of death coding standards change over time

**National survey data:**  
Available, but questionable national representation; relies on self-reporting of dementia status or use of non-standardised diagnosis tools; and has limited information for population groups of interest

PBS = Pharmaceutical Benefits Scheme

**Table 8.1: Summary of main national data sources for monitoring dementia, and their benefits and limitations for dementia monitoring<sup>(a)</sup>**

Source	Description	Benefits	Limitations
Pharmaceutical Benefits Scheme (PBS)	Information on PBS listed prescription medications, including those for people with Alzheimer's disease who were prescribed dementia-specific medication.	<ul style="list-style-type: none"> <li>- National coverage</li> <li>- Routinely collected</li> </ul>	<ul style="list-style-type: none"> <li>- Not all people with dementia are prescribed dementia-specific medication</li> <li>- The PBS currently subsidises dementia-specific medications only for people diagnosed with Alzheimer's disease</li> </ul>
Hospital admissions	Information about admitted patient activity in Australian hospitals and reason for admission.	<ul style="list-style-type: none"> <li>- National coverage</li> <li>- Routinely collected</li> </ul>	<ul style="list-style-type: none"> <li>- Inconsistent coding of dementia</li> <li>- Under-diagnosis and under-disclosure of dementia</li> </ul>
Emergency department presentations	Information about patient activity in Australian hospital emergency departments and their reason for admission.	<ul style="list-style-type: none"> <li>- National coverage of public hospitals with emergency departments</li> <li>- Routinely collected</li> </ul>	<ul style="list-style-type: none"> <li>- Missing data from private hospitals</li> <li>- Inconsistent coding</li> <li>- Under-diagnosis and under-disclosure of dementia</li> </ul>
Aged-care assessments	Information on people assessed by Aged Care Assessment Teams (including some medical information) in order to receive a range of aged-care services.	<ul style="list-style-type: none"> <li>- Detailed dementia diagnosis</li> <li>- More likely to identify mild and moderate dementia</li> </ul>	<ul style="list-style-type: none"> <li>- Changes over time in how data are held and reported</li> <li>- Data currently unavailable post 2015</li> <li>- Includes only people who accessed formal aged-care services</li> </ul>
Residential aged care	Information relating to the administration of residential aged-care subsidies, includes some medical information.	<ul style="list-style-type: none"> <li>- National coverage of people in permanent residential aged care</li> </ul>	<ul style="list-style-type: none"> <li>- May under-estimate people with dementia</li> <li>- Incomplete coverage in very remote areas</li> </ul>



Source	Description	Benefits	Limitations
Income support and allowances	Claims and payments data for recipients of certain government income support and allowances with a medical diagnosis of Dementia (and their carers).	<ul style="list-style-type: none"> <li>- National coverage</li> <li>- Routinely collected</li> </ul>	<ul style="list-style-type: none"> <li>- Dementia may not be recorded if claim for payment is based on another medical condition</li> </ul>
Deaths	Information on deaths in Australia and their underlying cause of death or associated cause of death.	<ul style="list-style-type: none"> <li>- National coverage</li> <li>- Routinely collected</li> </ul>	<ul style="list-style-type: none"> <li>- Dementia under-reported</li> <li>- Unlikely that mild-to-moderate dementia will be recorded</li> </ul>
Survey of Disability, Ageing and Carers	Large survey designed to measure the entire spectrum of disability, the underlying conditions and causes of disability, and disability-related need for assistance. It records dementia along with other health conditions.	<ul style="list-style-type: none"> <li>- Nationally representative</li> <li>- Comparable methods over time, allowing for time-series analysis</li> </ul>	<ul style="list-style-type: none"> <li>- Likely under-estimates number of people with dementia</li> <li>- Unable to assess subgroups of interest (e.g. those with younger-onset dementia)</li> <li>- No coverage in very remote areas</li> </ul>
General practitioners and specialists <sup>(b)</sup>	No national dementia-specific data currently available. Dementia diagnoses captured in various practice management systems.		<ul style="list-style-type: none"> <li>- Suitability of dementia data from practice management systems still being ascertained</li> </ul>

- (a) There are other datasets, not listed above, that can be used to monitor dementia when linked with the listed datasets. However, care must be taken as the limitations listed against each data source are likely to apply to the linked datasets as well.
- (b) The Medicare Benefits Schedule (MBS), which captures information on general practitioners (GPs) and specialist services, does not capture dementia diagnosis information. The Bettering the Evaluation and Care of Health (BEACH) program, which captured information on conditions managed by GPs in Australia, ceased in 2016.

## Lack of national GP and specialist data collections

Dementia is a complex condition, with a diagnosis made after comprehensive cognitive and medical evaluations. As there is no single conclusive diagnostic assessment available, obtaining a diagnosis is often long and difficult. The pathway to a diagnosis also varies from person to person and the stigma associated with dementia can impede help-seeking and treatment, even when symptoms are present (Herrmann et al. 2018). General practitioners (GPs) are often the first point of contact for a diagnosis, with a referral made to other medical specialists or specialist memory services if dementia is suspected.

GPs and other medical specialists, such as geriatricians, are essential in dementia diagnosis and management. However, there are no national GP or specialist data collections with dementia-specific diagnostic information. The Medicare Benefits Schedule (MBS), which captures a wide range of medical services including consultations, procedures and tests subsidised by the Australian Government, does not contain specific items to identify dementia diagnosis. While various practice management systems capture information on dementia diagnoses and can include a large number of providers, the suitability of these datasets to monitor dementia is still to be determined.

From 1998–2016, some information on conditions managed by GPs in Australia was collected through the Bettering the Evaluation and Care of Health (BEACH) program. This was a repeated cross-sectional study of GP clinical activity and comprised of almost 1.7 million GP encounters from 10,300 individual GPs in 2015 (Britt et al. 2016). Since the cessation of the BEACH program in 2016, there is no national data collection with GP diagnostic data. There is also no national data collection with diagnostic information from other specialists involved in diagnosing and managing dementia. However, the AIHW is working to improve primary health care data through the development of the National Primary Health Care Data Asset (AIHW 2020e), which may lead to improvements for dementia reporting within the next decade.

## Limitations in current administrative and survey data

Despite the lack of suitable GP and other specialist data, information on people with dementia can be informed by other administrative data, including:

- death certificates
- admitted patient episodes of care
- emergency department presentations
- specialised mental health episodes of care

- assessments for people seeking to access, or who are currently accessing, aged-care services
- dispensing of government subsidised anti-dementia medications
- income support from a variety of Australian Government pensions and benefits for people with dementia and/or their carers receiving financial assistance.

These data sets serve an important secondary purpose in monitoring dementia, but they each have their limitations.

Dementia is known to be under-reported and/or inconsistently recorded in a number of health administrative data collections (AIHW 2013, 2020a; Waller et al. 2017). Reporting consistency has been affected by changes in clinical guidelines for recording and managing dementia and increased awareness of dementia among health professionals and the community. Dementia can be difficult to diagnose, and decisions made by health professionals and clinical coders also impact the recording of dementia in a single episode of care (Cummings et al. 2011). Further, changes in the International Classification of Diseases (ICD-10) instructions for coding deaths data have resulted in the assignment of some deaths to vascular dementia (F01) where previously they may have been coded to cerebrovascular diseases (I60-I69) (ABS 2012).

The aged-care sector also provides information on people with dementia in Australia. However, changes to government aged-care programs over time has resulted in differences in the information captured on people with dementia accessing these services. The Aged Care Funding Instrument (ACFI) captures information on the main health conditions of people living in permanent residential aged care at the time of appraisal. In contrast, information on the health conditions of people accessing community-based aged-care services is inconsistently collected. For example, data are not collected on the health conditions of people receiving Home Care Packages—a program providing access to services to assist with daily living for people who want to stay at home (AIHW 2020a). Data from the Aged Care Assessment Program provided useful diagnosis information until June 2015, but data have been unavailable for statistical purposes since that time.

In addition to administrative data, representative national surveys are pivotal for dementia monitoring. They may capture people who do not access government funded health, aged-care or income support services and can be used to validate dementia measures based on administrative data. They can also provide information that is usually missing from administrative data, such as personal experiences among individuals with dementia and their carers. However, existing national surveys also have limitations: a study by Anstey and others (2010) found prevalence estimates of

probable dementia from national surveys differed from those of international meta-analyses and pooled dementia studies with a focus on dementia and cognitive decline. As a result, the authors concluded that existing national surveys were unsuitable for reporting or estimating the prevalence of dementia or cognitive impairment in Australia.

## Limited data on groups of interest and broader initiatives

Australia is lacking comprehensive national data on dementia among population groups of interest, including but not limited to Aboriginal and Torres Strait Islander people; culturally and linguistically diverse (CALD) populations; veterans; people with younger-onset dementia; and people with intellectual disabilities (Low et al. 2019). Most studies of dementia in Indigenous Australians and CALD populations come from site-specific epidemiological studies or national surveys (such as the Australian Bureau of Statistics (ABS) Survey of Disability, Ageing and Carers (SDAC)). Small sample sizes in national surveys limit analysis specifically for dementia in groups of interest (such as people with younger-onset dementia). Additionally, site-specific epidemiological studies are irregular, precluding recurrent analysis over time.

National information on unpaid carers—who provide essential care and support for many people with dementia—and their health and wellbeing is available through the SDAC, with most information limited to the ‘primary carer’. Information on all carers of people with dementia is important considering the well-documented detrimental health, emotional, social and financial outcomes often experienced by unpaid carers of people with dementia (Brodaty & Donkin 2009; Connell et al. 2001). Income support data are another source of information for informal carers. However, this information is limited to only those eligible carers who applied for and received a government carer payment or allowance. The AIHW has recently been tasked with constructing an enduring longitudinal National Disability Data Asset to improve understanding of how people with disability and their carers are supported through services, payments and programs (PM&C 2019). The proposed dataset will link key administrative datasets, making it a promising development for improving data on people with dementia and their carers.

There is evidence that insufficient training among health and aged-care workers contributes to the substandard care of people living with dementia (RCACQS 2019b; SCRGSP 2020). Better data on dementia-relevant training among health- and aged-care providers alongside currently available national data on the formal health workforce (including their broad skills and qualifications) could be used to monitor care provision and identify where further training is needed.

Although there is no cure for dementia, there are a number of ways to maintain quality of life for people with dementia that go beyond clinical and pharmacological interventions. These include implementing person-centred care models; providing cognitive training, rehabilitation and re-enablement; engaging in physical and social activities tailored to people with dementia; and designing homes and communities that support people with dementia. While many of these initiatives already exist across Australia, there are no comprehensive data that can be used to monitor and report on their availability, provision and efficacy (RCACQS 2019a). Capturing these data is important for supporting and evaluating initiatives aimed at improving the quality of life of people with dementia.

## Implications of gaps in dementia data

Issues with inconsistent administrative data and the lack of diagnostic data from GPs and other specialists have contributed to uncertain Australian dementia estimates for key population measures, including estimates of prevalence, incidence and burden of disease. In 2020, the AIHW estimated there were 400,000 people living with dementia, while NATSEM estimated 459,000 (AIHW 2018; Dementia Australia 2020a). Both studies relied on modelling estimates from small-scale Australian and international studies with known methodological limitations, but vary due to differences in data sources and the methodologies employed to generate Australia-specific dementia rates. In fact, of the 10 leading causes of disease burden in Australia, dementia has the lowest data quality rating, due to the lack of up-to-date Australian-specific dementia prevalence and severity data (AIHW 2019b).

The lack of national GP and other specialist data creates knowledge gaps with respect to dementia diagnosis, including age of onset, existing health conditions (comorbidities), risk factors, post-diagnosis support for people recently diagnosed, and the prevalence of mild dementia or mild cognitive impairment. Improvements in GP and other specialist diagnostic data would also improve understanding of how these factors are changing over time, and help predict how they may change in the future.

People with dementia often have co-morbid conditions and complex care needs, and need to transition between different care settings and health care providers (RCACQS, 2019a). However, existing datasets are currently unable to capture the complexity of care and support often required by individuals with dementia. Furthermore, the risk for developing dementia is linked to several modifiable risk factors, and the incidence of key risk factors—such as cardiovascular disease, obesity and diabetes—is changing quickly (Livingston et al. 2017). These data are essential to prepare for the emerging challenges that dementia poses, including delivering high-quality services to the

growing number of people with dementia and their carers; providing relevant training for health and aged-care workers; and funding research into areas such as effective prevention and treatment strategies.

Current dementia data gaps have a substantial impact on the development of evidence-based dementia policy, service planning and provision; provision of support and assistance to individuals with dementia and their carers; and evaluation of existing guidelines, services and initiatives. This in turn limits the extent to which quality care is provided and monitored, especially at local levels.

## Improving Australia's dementia data

Recent international and national strategies to respond to the challenges dementia poses, coupled with substantial Australian Government investments to improve dementia research and data assets, are important advancements towards closing key dementia data gaps.

The *National Framework for Action on Dementia 2015–2019* (the Framework) was developed under the Australian Health Ministers Advisory Council to guide improvements in the quality of life for those living with dementia and their carers in Australia. Priorities and actions identified in the Framework include:

- increasing dementia awareness
- reducing dementia risk
- reducing time to diagnosis
- ensuring access to care and ongoing support in all areas (particularly post-diagnosis support, and support during and after hospital care, and palliative care support)
- promoting and supporting dementia research (Department of Health 2019).

The Framework also noted improving clinical coding of dementia in hospital data as an action to provide better evidence for research. An evaluation of the effectiveness of the Framework is currently under way and this will provide an opportunity to inform and scope options for national strategies to address dementia in the future.

To coincide with outcomes of the Framework's evaluation, a national dementia data development plan (providing a comprehensive and co-ordinated approach to dementia data improvements) would assist in improving Australia's dementia data. Developed in consultation with key national data stakeholders to ensure alignment with policy and research priorities, the plan would outline responsibilities, steps, timeframes and costs involved in improving dementia data. This would include steps to enhance the quality of current data sources used for dementia monitoring; priorities for data

integration and analysis; and suggestions for new data sources with the potential to improve dementia information in remaining areas. Developing and implementing such a plan would better enable policy makers and researchers to consistently examine key dementia knowledge gaps, such as the impact of new policies and trends over time.

In 2015, the Australian Government committed an additional \$200 million specifically for dementia research in Australia over 5 years, with the National Health and Medical Research Council National Institute for Dementia Research (NNIDR) established to coordinate the strategic expansion of dementia research in Australia. The NNIDR offered a series of Boosting Dementia Research Grants for dementia researchers, with one round offering \$3 million for projects aimed at strengthening Australia's national dementia data assets and capabilities. Two years of funding was awarded in 2019 to 2 projects—one aiming to use national linked administrative data to develop methods for improving Australia's dementia statistics through a collaboration between academics, the ABS and the AIHW, and the other aiming to link electronic primary health care records to administrative data to develop methods for monitoring dementia, risk factors and management (NHMRC 2019). The NNIDR was disestablished on 30 June 2020.

As GP and other specialist diagnostic data are the biggest data gaps for estimating dementia incidence and prevalence in Australia, better primary health care data have the potential to greatly improve dementia monitoring. In 2018, the AIHW was funded to develop a National Primary Health Care Data Asset. It is envisaged that the Data Asset will contain reliable, detailed, high-quality data about primary health care, which could help inform the diagnosis of dementia and its management in primary care (AIHW 2020e).

## Maximising use of data linkage for dementia monitoring

Data linkage brings together data from multiple sources that relate to the same individual or institution. Data linkage provides opportunities to substantially improve the quality of dementia monitoring in Australia and has been used for dementia monitoring internationally (Box 8.2). For example, an individual may not have a dementia diagnosis recorded in hospitals data, but may be taking dementia-specific medications subsidised by the PBS. In this case, by bringing together, or linking, administrative hospital and medication data, dementia identification is improved. In addition, linked data are useful to answer current dementia knowledge gaps, which include assessing:

- health outcomes and trajectories
- quality of care
- pathways through, and interfaces between, the health and aged-care systems and interactions

- service use and associated costs
- patterns of care and how variations in care impact health outcomes
- the experience and training of the formal health workforce
- informal carers of people with dementia
- population groups of interest
- social and economic outcomes for people with dementia and their carers
- the impact of policy changes on the delivery of health and aged-care services.

The dementia data improvement projects funded by the NNIDR Boosting Dementia Research Grant are important initiatives for advancing dementia research at a population level by leveraging data linkage.

### **Box 8.2: Examples of international dementia surveillance**

In countries where national strategies and integrated systems for dementia surveillance have been implemented, there have been substantial gains in consistent monitoring. In the UK, data from different sources are brought together to monitor quality outcomes for people with dementia and their carers, such as the proportion of dementia patients whose dementia care plan has been reviewed in the last 12 months, and the proportion of dementia carers (such as family and friends) experiencing social isolation (PHE 2019).

In Sweden, national guidelines for quality dementia care and 7 clinical indicators, are tracked in SveDem, the national dementia quality registry. SveDem provides important population health indicators that encourage consistent approaches to diagnosing dementia (such as conducting cognitive testing) and ensuring high-quality care is provided to patients (such as limiting the use of antipsychotics) (Religa et al. 2015).

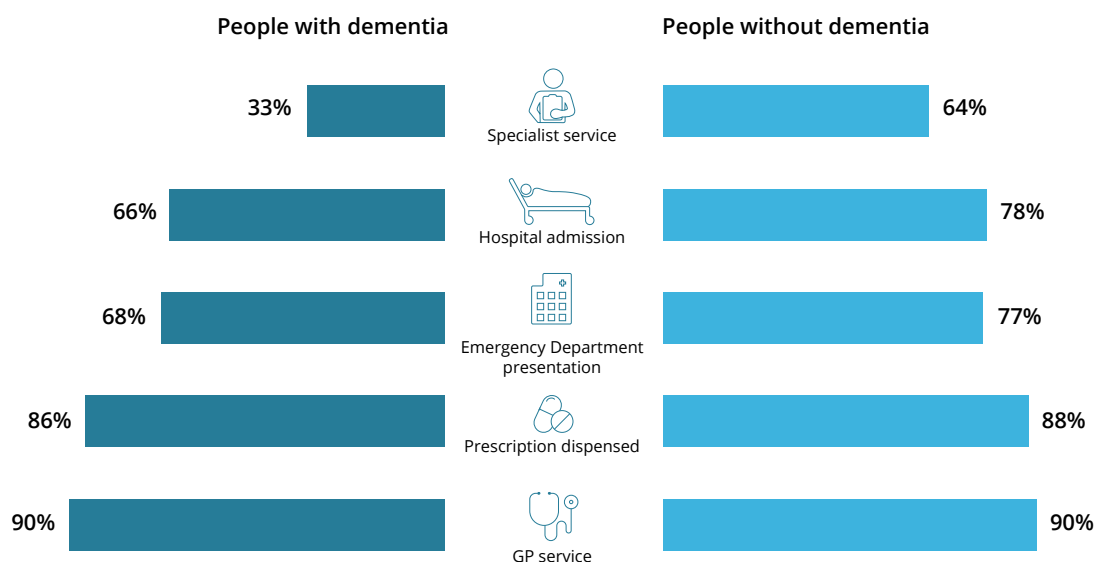
The value of linking datasets is shown in a 2020 AIHW study, *Patterns of health service use by people with dementia in their last year of life* (AIHW 2020d). Health-service usage in the last year of life was examined for over 70,000 people who died in 2013 to assess how dementia affects service use (GP and specialist services, admitted hospital care, emergency department care and dispensing of prescriptions). The linked data set



contained de-identified hospitals data from New South Wales and Victoria linked to the MBS, PBS and deaths data. Aged-care service data was not included in the linked data available for use in the study. The following results are for people who died aged 65 and over.

The study found that, with the exception of GP services, a smaller percentage of people with dementia used each health service at least once in their last year of life, compared with people without dementia (Figure 8.2). The greatest difference was seen in the use of specialist services, followed by admitted patient care and emergency care.

**Figure 8.2: Percentage of people who used a health service at least once in their last year of life, by dementia status and type of health service, 2013**



*Notes*

1. GP services excludes services provided to Department of Veteran Affairs (DVA) card holders where care is reimbursed through DVA, as well as services provided by salaried GPs in residential aged care or outpatients departments.
2. Analysis includes people who died in 2013 aged 65 or over and resided in New South Wales or Victoria.

Source: AIHW 2020d.

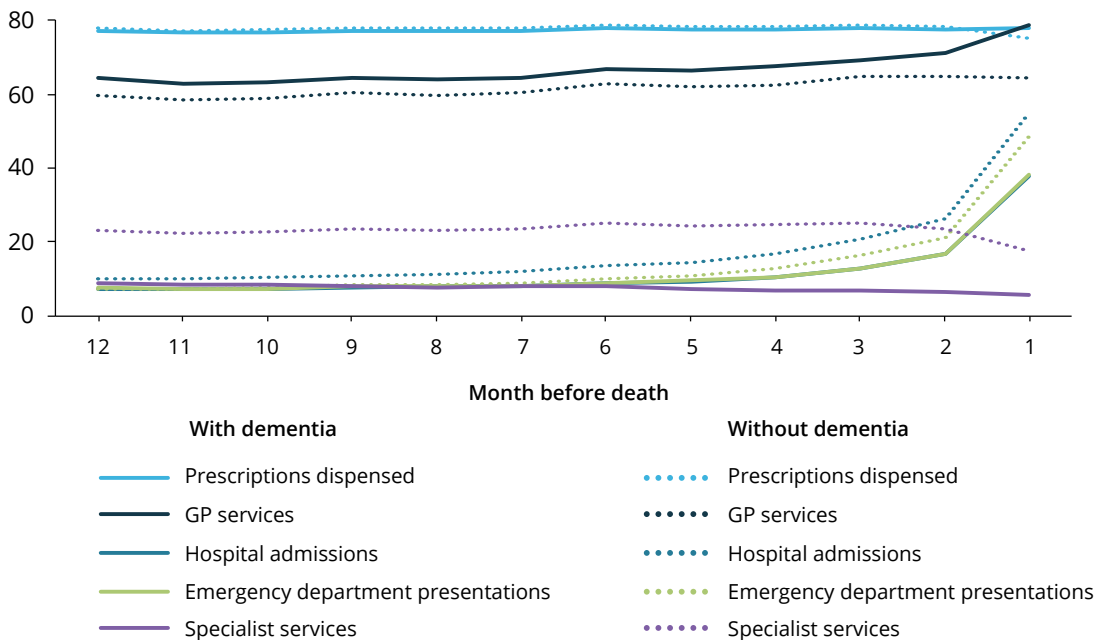
The frequency of health service use also varied based on if a person had dementia or not. Compared with a person without dementia in their last year of life, a person with dementia on average had:

- 3 more GP services
- 3 fewer specialist services
- 6 fewer prescriptions dispensed
- 2 fewer hospital admissions
- a similar number of emergency department presentations.

The type and usage of health services varied over the last 12 months of life, reflecting the need for particular services at different end-of-life stages (Figure 8.3). For example, for people with dementia, the percentage who used a GP service at least once increased in the final month of life, while this pattern was not observed in people without dementia.

**Figure 8.3: Health service use in the last 12 months of life, by dementia status and month before death, 2013**

Percentage of people using a health service at least once



**Notes**

1. The line for 'Hospitalisations (dementia)' is shown behind the 'ED presentations (dementia)' line, as the percentage of people with dementia who had a hospital admission was similar to the percentage who presented to the emergency department in the last 12 months of life.
2. 'GP services' excludes services provided to Department of Veteran Affairs (DVA) card holders where care is reimbursed through DVA, as well as services provided by salaried GPs in residential aged care or outpatients departments.
3. Analysis includes people who died in 2013 aged 65 or over and resided in New South Wales or Victoria.

Source: AIHW 2020d.

Factors influencing health service use by people with dementia towards the end of life were not able to be examined in this study. This is a recognised knowledge gap not only in this study but also in international dementia research. It has been suggested that service use at end of life by people with dementia may be influenced by place of care; care needs and quality of care; advanced care planning; health care access; and the number and type of comorbidities (Browne et al. 2016; Dyer et al. 2018; Forma et al. 2011). Furthermore, the frequency of health service use by people with dementia may not necessarily reflect the burden dementia places on the health and aged-care systems. For example, the average cost of hospital care has been shown to be greater for people with dementia than for those without dementia, and people with dementia have higher ratings in 2 of the 3 domains of care assessed for people in aged-care facilities than those without dementia (AIHW 2013, 2020b).

It was also not possible to identify people living in residential aged-care facilities in this study. Different patterns of use among people in residential aged care could explain differences in health care usage between people with and without dementia and is an important area of future research. Another study also undertaken by the AIHW, using linked data to explore the interface between the health and aged-care systems, found that people aged 65 and over in residential aged care were less likely to see a specialist than those receiving aged-care services in the community or those not receiving any aged-care services. See Chapter 7: ‘Changes in people’s health service use around the time of entering permanent residential aged care’ for more information.

Both the aforementioned AIHW studies used one-off linked datasets, which limits their use for ongoing dementia monitoring. There are ongoing efforts to develop enduring and regularly updated linked health data assets (referred to as Multi-source Enduring Linked Data Assets (MELDAs)), which will provide new opportunities for dementia monitoring and novel research, such as the inter-dependencies between health and aged-care services, and how this changes by dementia progression, type and number of comorbidities and care settings. See Chapter 1: ‘Health data in Australia’ for more information on MELDAs and developments in person-centred data.

## Leveraging electronic health records and developing a national dementia registry

The emerging availability of comprehensive electronic health records could help provide better dementia data in the future—subject to the Australian community supporting use of this data for research purposes and generating adequate uptake by individuals and health care professionals. For dementia, this also relies on uptake by GPs and other specialists involved in dementia diagnosis and management.

Comprehensive clinical data from health care services held in electronic health records have the potential to greatly improve dementia monitoring. For example, as there can be shared care arrangements between GPs and other specialists when prescribing dementia-specific medications, comprehensive health records would help better understand patient journeys and health care use (Dementia Australia 2020b).

Statistical analysis of data stored in My Health Record—an electronic summary of individuals' clinical information—presents a potentially valuable future resource to overcome the fragmented documentation of dementia across Australia's health and aged-care systems. It also presents a future opportunity to contribute essential clinical data for a national dementia registry. Efforts to develop a clinical quality registry that directly collects data generated by clinical processes for the diagnosis and management of dementia, are already underway through the Australia Dementia Network (ADNet) (NHMRC 2019).

By combining existing data collections with electronic clinical records and data from clinical trials, a nationally-coordinated, clinically-based dementia registry is a future possibility to assess not only incidence and prevalence but also dementia risk factors, time of diagnosis, progression, comorbidities, treatment and management, quality of care, service needs and health expenditure.

## Conclusion

Timely, comprehensive dementia data are needed to truly understand the existing and emerging challenges dementia poses, as well as to develop and evaluate policies and programs to most effectively combat these challenges. High-quality data are also indispensable in supporting the Australian Government's stated priority of monitoring and improving the quality of care provided to older Australians—many of whom suffer from dementia and are particularly vulnerable.

There are major gaps in the currently available dementia data, including a lack of dementia diagnosis in GP and other specialist data; inconsistent reporting of dementia diagnoses across different datasets and over time; irregular funding for studies providing data on special groups of interest; and poor data integration across different health care types. These gaps impede the development of robust estimates on key population health indicators for dementia.

Nonetheless, there are also encouraging examples of innovative approaches to overcome existing data gaps, with data linkage efforts already providing benefits, including more accurately detecting dementia cases and tracking patterns of health care use. Improved government funding has been essential in instigating these efforts,

but continued investment will be needed to build on these initial achievements. Strategic efforts through the development of a data improvement plan will help prioritise data improvements and provide reliable monitoring and reporting of key dementia statistics.

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# Improving suicide and intentional self-harm monitoring in Australia

9

Suicide and intentional self-harm are serious public health issues of concern to governments and communities across Australia and around the world. In 2018, 3,046 deaths by suicide were registered in Australia (ABS 2019a). Each death by suicide can have a lasting impact on families, friends and communities. The incidence of intentional self-harm (which includes suicide attempts and non-suicidal self-injury) is even greater, with the number of cases of hospitalised injury due to intentional self-harm more than 10 times that of deaths by suicide—in 2016–17, there were more than 33,000 cases of hospitalised injury due to intentional self-harm (AIHW: Pointer 2019). The number of people who self-harmed but are not hospitalised is largely unknown. Yet intentional self-harm and suicide may be prevented with timely, evidence-based interventions. It is feared that suicide and intentional self-harm may increase due to reductions in employment resulting from restrictions on business activities designed to limit the transmission of COVID-19.

The prevalence, characteristics and methods of suicide and intentional self-harm vary between different communities, demographic groups and over time. Collection of data on suicide and intentional self-harm (including means and modifiable risk factors) is an essential component of suicide prevention; it enables us to define the extent of the problem, to identify trends and emerging areas of concern, and to highlight vulnerable populations. Data underpins the appropriate targeting of prevention strategies and research, and suicide and self-harm statistics are widely used as progress indicators in Australia (AIHW 2009). For these reasons, it is important that monitoring of both suicide and self-harm is as comprehensive and informative as possible.

This chapter provides an overview of the policy context for the monitoring of suicide and intentional self-harm in Australia and examines the existing national sources of data (administrative databases and surveys) currently used—including their strengths, limitations and any data gaps. It also discusses potential new sources of data that may enhance the evidence base, with particular reference to Aboriginal and Torres Strait Islander people and to current serving, reserve and contemporary ex-serving Australian Defence Force (ADF) personnel. The article does not discuss current approaches to suicide prevention or emerging advice for service planning.

See ‘Suicide and intentional self-harm’, ‘Indigenous health and wellbeing’, ‘Indigenous life expectancy and deaths’ and ‘Health of veterans’ at [www.aihw.gov.au/australias-health/snapshots](http://www.aihw.gov.au/australias-health/snapshots) for more information.

The AIHW recognises that each number reported here represents an individual and wishes to acknowledge the devastating effects suicide and self-harm can have on people, their families, friends and communities.

If this report raises any issues for you, these services can help:

- [Lifeline](#) 13 11 14
- [Suicide Call Back Service](#) 1300 659 467
- [Kids Helpline](#) 1800 55 1800
- [MensLine Australia](#) 1300 78 99 78
- [Beyond Blue](#) 1300 22 4636.

Crisis support services can be reached 24 hours a day.

## Suicide prevention: a public health priority

In 2013, the 66th World Health Assembly adopted the first Mental Health Action Plan (2013–2020) of the World Health Organization (WHO) (WHO 2013). In its subsequent report, *Preventing suicide: a global imperative* (WHO 2014), the WHO provided actionable steps for the implementation of effective national suicide prevention strategies.

Key components were the strengthening of suicide surveillance by improving the quality and timeliness of national data on deaths by suicide and suicide attempts, and establishing an integrated data collection system to help identify specific groups, vulnerable individuals and high-risk situations.

### The policy context for suicide monitoring in Australia

Suicide has long been a significant health issue in Australia. More recently, there has been an increased emphasis on suicide prevention by Australian governments. In 2017, actions to address suicide as a priority area were included in the Fifth National Mental Health and Suicide Prevention Plan (COAG Health Council 2017). This plan committed all Australian governments to a collaborative national approach to mental health planning and service delivery, including improving the quality and timeliness of data collection on suicide; suicide attempts; and intentional self-harm in Australia. These data would provide much needed information to those responsible for the planning, funding, delivery and evaluation of suicide prevention strategies.

Suicide prevention in Australia is a complex area of policy with interconnected responsibilities. Governments, policy makers and service providers all have a role in reducing deaths by suicide as well as cases of intentional self-harm. The reasons for suicide are often complex and different for each individual. Research has shown that a range of factors are commonly present in the histories of those who died by suicide, including mental and behavioural disorders; physical illness; and psychosocial factors (including alcohol and/or other drug problems; relationship or legal issues; bereavement; impacts of chronic health conditions; disability; unemployment; homelessness; and bullying) (ABS 2019b; Clapperton et al. 2019). Therefore, effective suicide prevention requires action from a correspondingly broad range of government agencies, including those responsible for health, education, employment, urban planning, welfare and law enforcement agencies.

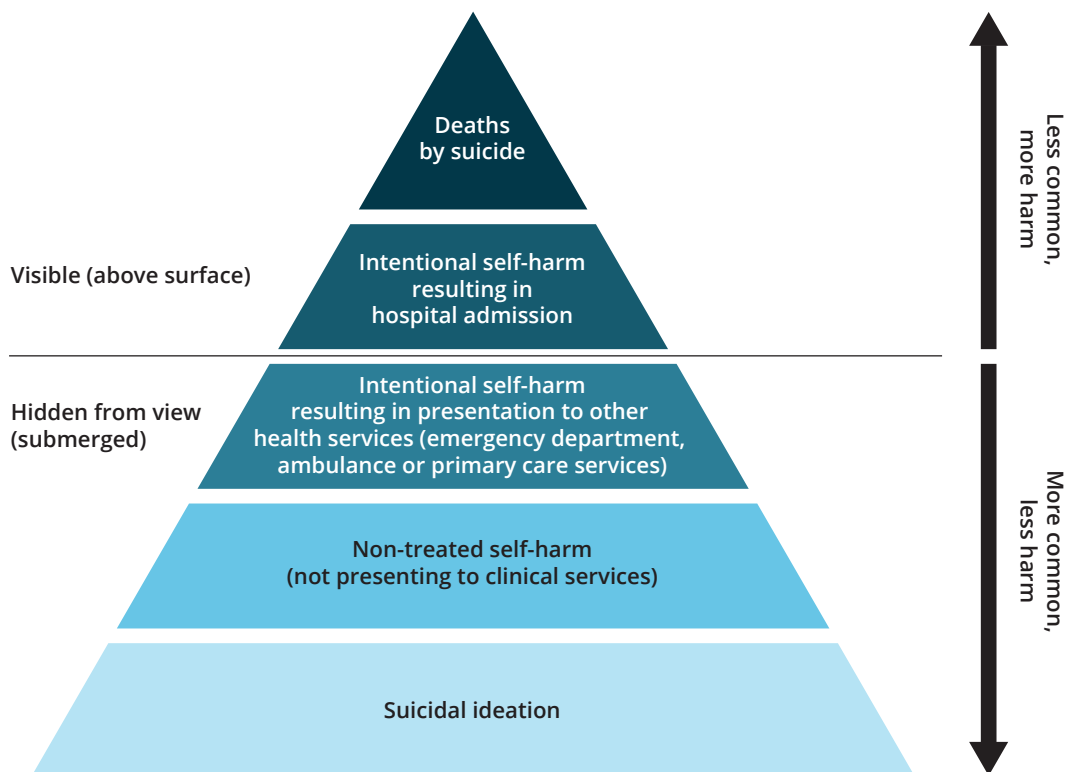
In acknowledgement of the devastating effects of suicide and the pivotal role governments have to play in addressing it, the Australian Government has made suicide prevention a national whole-of-government priority, and indicated a commitment to the aspirational goal of working 'Towards Zero' deaths by suicide (Department of Health 2019c). To this end, the first National Suicide Prevention Adviser reporting directly to the Prime Minister has been appointed and a National Suicide Prevention Taskforce has been established to coordinate collaboration between government agencies and across different levels of government.

The AIHW is currently actively involved in data improvement activities to expand the collection or availability of data on deaths by suicide and on the occurrence of intentional self-harm in 2 specific populations: Indigenous Australians and current serving, reserve and contemporary ex-serving ADF personnel. Rates of suicide among Indigenous Australians are higher than those of the non-Indigenous population. For the 5 years from 2014 to 2018, the age-standardised suicide rate for Indigenous Australians was almost twice that of the non-Indigenous population (23.7 vs 12.3 per 100,000 population) (ABS 2019a). In the 2019–20 Budget, the Australian Government committed a further \$15 million to suicide prevention for Indigenous Australians (Department of Health 2019b). Also, on 5 February 2020, the Australian Government announced the appointment of a National Commissioner for Defence and Veteran Suicide Prevention. The AIHW and the Australian Commission on Safety and Quality in Health Care, along with coronial and legal experts, will provide technical expertise to support the Commissioner's work.

## Improving the evidence base

In Australia, the extent of intentional self-harm and suicidal behaviours in the broader community is largely unknown, as those presenting to emergency departments (EDs) or primary health care—or not seeking treatment—are not captured by clinical data. The ‘iceberg’ model has been used to represent the relative incidence of suicide and intentional self-harm and the difficulty of monitoring the incidence of suicide, intentional self-harm and suicidal behaviours (Arensman et al. 2017; Geulayov et al. 2018; McMahon et al. 2014; Pollock et al. 2018). In this model (Figure 9.1), the extent to which suicide, intentional self-harm and suicidal ideation are currently captured by administrative data sets can be represented as an ‘iceberg’ for which only the tip—representing suicide or intentional self-harm that results in hospital admission—is visible. Intentional self-harm that results in presentation to other health services (such as EDs, primary health care or ambulance services) or does not result in medical treatment are more common but largely hidden from view because they cannot be identified with clinical data—thus forming the ‘submerged’ part of the iceberg.

**Figure 9.1: Iceberg model illustrating the extent to which suicide, intentional self-harm and suicidal behaviours are currently captured by clinical data in Australia**



Adapted from: Pollock et al. 2018.

Finally, suicidal behaviours, such as making a suicide plan or having suicidal thoughts, are even more common; however, information about these behaviours may not be captured by clinical data. Instead, an indication of the prevalence of these behaviours in the community may be derived from surveys of representative samples of the population.

In recognition of the fact that data are critical to the development of effective suicide and intentional self-harm prevention policies and services, the National Suicide and Self-harm Monitoring System was announced as a component of the Australian Government's Prioritising Mental Health Package (Department of Health 2019a). The aim of the monitoring system is to collate and coordinate data and information on suicide, intentional self-harm and suicidal behaviours in Australia to improve their coherence, accessibility, quality and timeliness. The AIHW has been funded \$5 million per year for 3 years (2019–20 to 2021–22) to deliver the monitoring system. Data improvement activities to enhance the comprehensiveness of data, and the creation of a monitoring system to support the accessibility and useability of data for stakeholders, will make it a key resource to assist governments, services and communities to improve suicide and intentional self-harm prevention strategies. The National Suicide and Self-harm Monitoring System will draw on the expertise of the National Injury Surveillance Unit (NISU) at Flinders University, a collaborating unit of the AIHW, and on other subject matter experts as required.

Currently available national sources of data on suicide, intentional self-harm and suicidal behaviours include mortality data; data on the provision of hospital services; and population-based mental health surveys. These sources, and potential new sources of data to fill gaps in our understanding of suicide, intentional self-harm and suicidal behaviours in Australia, are summarised in Table 9.1 at the end of the chapter. How the data are obtained, and the limitations of each data set, are also discussed below. Examples of initiatives under the National Suicide and Self-harm Monitoring system project are also described, including those that aim to make greater use of existing data sources to identify populations at risk and to allow more timely, localised responses.

## Deaths by suicide

The collation of national data on deaths by suicide in Australia requires the collaboration of multiple state and national government bodies (Box 9.1). Despite the fact that Australia has strong systems in place for the collection of death statistics, accurate reporting of deaths by suicide is particularly challenging for a number of reasons.

Generally, deaths due to external causes, including suspected suicides, are referred to a coroner for investigation of the cause and, if applicable, the intention of the deceased. Some deaths by suicide may be misclassified as ‘accidental’ or ‘undetermined’ due to the difficulty in determining the true intent of the deceased and, as a result, may lead to under-reporting (Senate Community Affairs References Committee 2010). Additionally, the international medical coding system used to classify causes of death (the WHO International Statistical Classification of Diseases and Related Health Problems, 10th revision: ICD-10), does not distinguish between suicidal and non-suicidal intent (WHO 2016). While a decision has not yet been made on whether or when ICD-11 will be adopted for coding deaths in Australia, the new classification developed by the WHO has made provisions for a new dimension to capture the ‘intended result’ (suicidal intent) of intentional self-harm (intent pending; suicidal/non-suicidal intentional self-harm) (WHO 2019).

The quality of cause of death coding can be affected by the length of time required for coronial processes to be finalised (ABS 2019a). To improve the quality of ICD coding, all coroner-certified deaths are now subject to a revisions process (Box 9.1) (ABS 2019a).

National data can mask regional variation due to significant demographic, economic or cultural differences between different regions of Australia. Therefore, more granular, regional-level mortality data can be useful in developing and monitoring local suicide prevention strategies. However, a major challenge with suicide mortality data is that suicide deaths are statistically rare events, meaning that it is difficult to achieve the statistical power that is necessary to identify patterns and causation, or to draw conclusions about reductions in the suicide rate (AHA 2014; AIHW 2011; Morris et al. 2018). These methodological challenges exist at the national level, where around 3,000 deaths per year are suicides, but for the reporting of suicide deaths at lower regional levels (for example, state/territory, local government area) or by demographic variables (for example, age and sex) these issues are compounded, as data are broken down into even smaller population groups. To date, issues relating to data volatility and robustness for measurements of rates and trends have had limited statistical analysis.

### Box 9.1: Suicide mortality data

The registration of deaths in Australia is required by law and is the responsibility of state and territory Registries of Births, Deaths and Marriages. As part of the registration process, information about the cause of death is supplied by the medical practitioner certifying the death, or by a coroner. The information is provided to the Australian Bureau of Statistics (ABS) for coding of causes of death (according to the WHO International Statistical Classification of Diseases and Related Health Problems, 10th revision; ICD-10) and compilation into aggregate statistics on an annual basis (ABS 2019a). In addition, the ABS supplements these data with information from the National Coronial Information System (NCIS), a national database of coronial findings, post-mortem, toxicology and police reports (ABS 2019a). These data are sent to the Australian Coordinating Registry (ACR) who acts on behalf of all the Registries to coordinate release of the data. The AIHW receives the data from the ACR and maintains these data in the National Mortality Database (NMD), a historical (1964–2018), coherent and accurate database for analysis, linkage and reporting purposes (AIHW 2019a).

Deaths that are referred to a coroner can take time to be finalised and the coroner's case closed. To account for this, the ABS undertakes a revisions process for those deaths where coronial investigations remained open at the time an initial cause of death was assigned. Usually, data are deemed preliminary when first published, revised when published the following year and final when published after a second year (ABS 2019a).

Problems with the reporting of small numbers in population groups—such as regional areas (AIHW 2019d), certain demographic characteristics (AIHW 2019c), or in specific populations including Indigenous Australians (AIHW: Kreisfeld & Harrison 2020) or current serving, reserve and contemporary ex-serving ADF personnel (AIHW 2019f)—have been avoided by aggregating multiple years of data to ensure confidentialisation and privacy.

### State-based suicide registers

While the quality of Australian mortality data is high by world standards and historical data are available, the annually available mortality data sets have limited usefulness in informing time-sensitive responses. Delays between a death by suicide and its reporting to policy makers and service providers can be an impediment to the early detection of systematic trends and appropriate intervention responses aimed at preventing further suicides.



Coronial suicide registers have been established by some jurisdictions in Australia (including Victoria, Queensland, Western Australia and Tasmania). Information from these registers can be used to assist coroners formulate evidence-based recommendations to prevent suicide and may also be shared with local governments and service providers to better target and inform suicide prevention activities (Leske et al. 2019; Sutherland et al. 2018; Tasmanian Department of Health and Human Services 2016).

These registers have the potential to provide timely data on deaths suspected to have been by suicide and may be useful for identifying trends in locations or in the methods used for suicide. For example, the Victorian suicide register enables basic information on a suspected death by suicide (including cause of death, location of death, usual place of residence, age, sex and occupational information) to be coded within 24–48 hours of the coroner being notified of a death suspected to be by suicide (Sutherland et al. 2018). More comprehensive contextual information about modifiable risk factors (for example, the deceased’s physical and mental health history, interpersonal stressors, psychosocial factors, and other circumstances surrounding their death) are also collected from a variety of sources, such as toxicology autopsy and police reports; however, this information can take longer to be made available. The establishment of such registers does not replace the collection of nationally consistent deaths data but may enhance the development of timely interventions and appropriate localised suicide prevention strategies.

### **Embedding psychosocial risk factors in national mortality data**

Making greater use of existing data sets removes duplication of effort, reduces costs and minimises reporting burden. In 2019, the ABS published results of a pilot study to enhance the national Causes of Death data set, by coding psychosocial risk factors for all coroner-referred deaths (including deaths by suicide) registered in 2017, via a comprehensive manual review of reports included in the NCIS (ABS 2019b). Psychosocial factors (for example, a past history of self-harm; relationship problems; legal issues; bereavement; unemployment; homelessness; and disability) were identified in 63% of all deaths by suicide. The findings of this pilot study were limited by the amount of information that was voluntarily captured in post-mortem, toxicology or police reports and coronial findings included in the NCIS. However, there is potential to enhance what the NCIS captures by requiring the recording of risk-factor information in suspected cases of suicide. The ABS is currently working to embed risk factors into the national mortality data set to provide comprehensive information on the combination of factors contributing to deaths by suicide. This data initiative is being funded as part of the Suicide and Self-harm Monitoring System project to enable monitoring of emerging trends and improve evaluation of the effectiveness of suicide prevention strategies.

## Data linkage with mortality data

Data integration can enrich the value and maximise the use, and re-use, of nationally collected information, while preserving individual privacy and the security of sensitive data. It also has the potential to expand the evidence base to better support research and policy development. By combining information from existing surveys, administrative data collections and censuses, a more complete picture of the circumstances of individuals and households can emerge. Integrated data sets can also be combined with additional point-in-time and/or longitudinal information to help assess the effectiveness of policies and programs. A pilot project has shown that data integration has the potential to provide valuable insights into contextual factors (for example, employment and marital status) associated with deaths, including those by suicide (ABS 2016c). This project combined national mortality data with data from the 2011 Census through a process of probabilistic record linkage.

The integration of multiple, cross-agency data sets for use as a resource has evolved more recently. The Multi-Agency Data Integration Project (MADIP) is a cross-agency partnership between the Departments of Social Services, Health, Human Services, Australian Taxation Office and the ABS. Its purpose is to create enduring, linked, research data sets. Improvements in linkage and the ability to combine and repurpose data will provide improved measurement of outcomes for population groups of interest as well as richer statistics (ABS 2016b). As part of the Suicide and Self-harm Monitoring System project interrogation of MADIP data will be used to better understand the social determinants of death by suicide, such as educational attainment and housing tenure, and to identify population groups at increased risk.

The AIHW has also been working with the Department of Health along with state and territory health authorities to develop the National Integrated Health Services Information Analysis Asset (NIHSI AA) which includes mortality data together with hospital admissions, Medicare Benefits Schedule (MBS), Pharmaceutical Benefits Scheme (PBS) and residential aged care data. This analysis asset will enable examination of service-use patterns and the demographic profiles of those using (and, by inference, those not using) services. The AIHW will analyse the NIHSI AA to report on the service use of people in their last 12 months of life, including those who died by suicide. The potential insights from this project and analysis of other integrated data assets will greatly enhance our understanding of people-centred service use and modifiable risk factors for suicide.

## Suicide attempts and intentional self-harm

The most common predictor of death by suicide or premature mortality of any kind, including accidental drug overdose, is a personal history of a previous suicide attempt or act of self-harm (ABS 2019b; Carr et al. 2017). As a consequence, monitoring of the incidence, demographic patterns and methods used in suicide attempts or instances of self-harm have the potential to improve the development of suicide prevention strategies.

### Hospitalisations for intentional self-harm

Currently in Australia, the national source of intentional self-harm data is the AIHW National Hospital Morbidity Database (NHMD), a compilation of administrative data supplied by state and territory health authorities for patients admitted to public and private hospitals (AIHW 2019e). The NHMD includes demographic, length of stay and diagnosis data including external causes of injury and poisoning, as well as the procedures patients underwent in hospital, the place where the injury occurred and the type of activity being undertaken by the person when injured (AIHW 2019b). Diagnosis, intervention and external cause data are reported to the NHMD by all states and territories using the International statistical classification of diseases and related health problems, 10th revision, Australian modification (ICD-10-AM) and the Australian Classification of Health Interventions (ACHI). Information from this database can be useful to monitor trends in intentional self-harm over time and to provide, albeit limited, insights into those at risk of further self-harm. Indigenous status is included in the NHMD (AIHW 2019b) and the AIHW is investigating the feasibility of several options on reporting intentional self-harm in ADF personnel.

The ICD-10 AM coding system does not distinguish between suicidal and non-suicidal intentional self-harm (AIHW: Harrison & Henley 2014). However, suicidal ideation in the absence of a mental health condition is captured and assigned using ICD-10-AM (ACCD 2018). Although a decision has not yet been made on whether or when ICD-11 will be adopted for coding hospital admitted cases in Australia, the new classification developed by the WHO has made provisions for a new dimension to capture the suicidal/non-suicidal intention of intentional self-harm injuries (WHO 2019).

Hospitals data on intentional self-harm can only provide a partial picture of those self-harming (Figure 9.1). Other sources of data on intentional self-harm and suicidal behaviours, such as ED data, ambulance and police attendances, crisis line calls and treatment provided by mental health or primary health care services, have the potential to provide a more complete picture of these behaviours in Australia and identify opportunities for improved intervention or postvention.

## Hospital emergency department data

The hospital ED is often the first point of contact with the health system for people who have harmed themselves or who have suicidal thoughts (Perera et al. 2018). State and territory health authorities provide ED data to the AIHW for collation into the National Non-admitted Patient Emergency Department Care Database (NNAPEDCD) (AIHW 2019g). The NNAPEDCD captures information on the patient's principal diagnosis (the diagnosis mainly responsible for the attendance) and coexisting additional diagnoses. Unlike the NHMD, information on the external cause of injury, the place of occurrence or the type of activity are not captured in the NNAPEDCD (AIHW 2019g). This means presentations to the ED relating to suicide attempts or intentional self-harm cannot be identified in the current national ED data collection. Also, this data set may not capture the complexity of mental health presentations to the ED (AIHW 2019g). Therefore, information on suicidal behaviours is not coded or may only be captured in clinical notes. A technical report on the use of ED data to improve the routine surveillance of all types of injuries concluded the utility of the data source would be enhanced by including external cause data in the NNAPEDCD (AIHW: Henley & Harrison 2018).

In recognition of the key need for better data around suicide attempts and self-harm in ED data, the Australian Health Ministers' Advisory Council has funded the Mental Health Information Strategy Standing Committee to undertake 2 projects in 2019–20 to support improvements in identification of suicide and self-harm-related presentations to EDs. These include the development of a methodology to identify presentations relating to suicide attempts within jurisdictional data and a scoping paper outlining opportunities and barriers to developing a nationally consistent data collection on suicide-related ED presentations, including recommendations for data improvements. The AIHW has been funded to develop the scoping paper, which will require engagement with a range of stakeholders, including the Mental Health Information Strategy Standing Committee and Emergency Department data custodians.

## Police and ambulance attendance data

State- and territory-held police and ambulance attendance data may provide insights into self-harming and suicidal behaviours in Australia at a stage when intervention to prevent further harm or subsequent suicide may be possible. Currently, the clinical coding of ambulance presentations data is limited, with data collected for some states over a short period of time each year (Turning Point 2019) while police reports are not standardised across Australia making national analysis difficult.

A study by Turning Point and Monash University coded and analysed clinical patient records from ambulance call-outs to men presenting with acute mental health issues, intentional self-harm, suicidal behaviours, or alcohol or drug intoxication in the Australian Capital Territory, the Northern Territory, Queensland, Tasmania, Victoria and New South Wales between July 2015 and June 2016 (Turning Point 2019). The study found that coded ambulance data are an important source of information to establish the number and characteristics of presentations for mental illness, intentional self-harm or suicidal behaviours—and may address evidence gaps by capturing information that is not currently identified by other health morbidity data sets such as ED or hospital admissions, including:

- details of the nature and background to the attendance, including information about what was observed 'on scene' (such as bystander accounts, evidence of drug use and suicide intent)
- types of people most at risk (for example, those who call an ambulance multiple times or those with increasingly harmful behaviour)
- the location of the event (which may allow for geographic and temporal mapping)
- the clinical outcome.

Following this initial study, the National Suicide and Self-harm Monitoring System will include the collection, improvement and dissemination of national coded ambulance data for intentional self-harm and suicidal behaviours, as well as:

- alcohol and other drug-related ambulance attendances, including intentional alcohol and other drug poisoning and type of drug involved
- mental health-related ambulance attendances, including the presence of symptoms, history of mental illness and risk indicators both at the time of presentation and through the life course.

This data set will address a significant gap in service-level data for populations at risk of suicide or intentional self-harm. Such a data set may also provide opportunities for data linkage to allow insights, for example, into service use patterns or cohort analysis.

### **Community health care data**

Community health care data on intentional self-harm and suicidal behaviours are limited. Self-harming and suicidal behaviours occurring in the community may be treated by general practitioners or community and residential mental health services; however, data collections from these sources do not routinely capture this information.

Also, although MBS, PBS or Repatriation Schedule of Pharmaceutical Benefits (RPBS) data can provide information about medical services provided or prescriptions processed, by themselves these sources cannot provide information about those at risk of suicide, intentional self-harm or suicidal behaviours. Nevertheless, these sources of data may be useful in terms of adding to data linkage projects.

## Suicidal ideation

Measuring the incidence of suicidal ideation with routinely collected clinical data is also limited because the majority of people with suicidal thoughts do not tend to seek medical treatment (Geulayov et al. 2018). Self-reports of suicide attempts, plans or thoughts in health surveys of representative samples of the population provide information about suicidal behaviours in the community. On the basis of survey data, suicidal behaviours are far more common than deaths by suicide or intentional self-harm (Slade et al. 2009). People who experience suicidal ideation and make suicide plans are at increased risk of suicide attempts, and people who experience all forms of suicidal thoughts and behaviours are at greater risk of death by suicide (Slade et al. 2009).

## Survey data

The National Survey of Mental Health and Wellbeing (2007) indicated that, at some point in their lives, 13% of Australians aged 16–85 years had had serious thoughts about taking their own life (an estimated 2.1 million Australians), 4% (over 600,000) made a suicide plan and 3% (over 500,000) had attempted suicide (Slade et al. 2009). In 2007, the number of registered deaths by suicide in Australia was 2,229 (ABS 2016a).

The second Australian Child and Adolescent Survey of Mental Health and Wellbeing, conducted between 2013 and 2014, captured information from Australian young people aged 12–17 years about self-harming activity and suicidal behaviours (Lawrence et al. 2015). Around 1 in 10 surveyed 12–17-year-olds (10.9%, equivalent to an estimated 186,000 young people) reported having ever self-harmed and about three quarters of these had harmed themselves in the previous 12 months (8%, equivalent to an estimated 137,000 young people). Around 1 in 13 (7.5%, equivalent to an estimated 128,000 young people) 12–17-year-olds had seriously considered attempting suicide in the previous 12 months and of these, one third (or 2.4% of all 12–17-year-olds) reported having attempted suicide in the previous 12 months. Both of these national surveys relied on self-reported responses, and therefore should be interpreted with caution, as respondents may not feel comfortable reporting on intentional self-harm or suicidal behaviours.

In 2019, the Government announced funding for an Intergenerational Health and Mental Health Study (Hunt 2019). This study will include components on general and mental health, including lived experiences of suicide and related services, and will provide updated results to compare with the 1997 (ABS 1998) and 2007 National Survey of Mental Health and Wellbeing (Slade et al. 2009).

### **Crisis line calls and help-seeking websites**

Several organisations in Australia provide tele-counselling for people in crisis, for example, Lifeline, MensLine Australia, Kids Helpline, Beyond Blue and the Suicide Call Back Service. Each helpline has its own data capture system; however, data are not standardised and governance agreements are not currently in place to allow de-identified data to be shared and analysed. Better use of these data may provide useful information on help-seeking behaviours and identify populations at risk of suicide, intentional self-harm and suicidal behaviours.

## **Suicide and intentional self-harm in specific populations**

Rates of suicide and intentional self-harm in Indigenous Australians and current serving, and contemporary ex-serving ADF personnel have been a cause of concern in Australia. However, there are significant challenges in monitoring suicide and intentional self-harm in these populations, which can make detecting changes in outcomes and assessing the impact of suicide prevention activities difficult. The AIHW is currently actively involved in data improvement activities to expand the collection and availability of data on deaths by suicide and the occurrence of intentional self-harm in these populations.

### **Aboriginal and Torres Strait Islander people**

In 2018, 169 Indigenous Australians died by suicide, accounting for 5.3% of all Indigenous deaths (ABS 2019a). Age-standardised rates of Indigenous deaths by suicide have increased over time, from 20.2 per 100,000 persons in 2009–2013 to 23.7 per 100,000 persons in 2014–2018 (ABS 2019a).

Age-standardised suicide rates for Indigenous males have increased from 30.4 per 100,000 in 2009–2013 to 36.4 in 2014–18. The change in the rate for Indigenous females has been less marked (10.7 per 100,000 in 2009–2013 compared with 11.6 in 2014–2018) (ABS 2019a).

Suicide is a pronounced issue for Indigenous youth—in the 5 years from 2014 to 2018, suicide rates were highest for those aged 25–34 years (47.1 per 100,000) and 15–24 (40.5 per 100,000) but then declined with age to less than 10 per 100,000 for those aged 65 and over (ABS 2019a).

Indigenous males are more likely than females to die by suicide—there were around 3 times as many deaths by suicide in Indigenous males (129) as females (40) in 2018 (ABS 2019a)—while Indigenous females were more likely than males to be hospitalised for intentional self-harm (1,736 cases or 445 per 100,000 population, compared with 1,113 cases or 325 per 100,000 population) in 2016–17 (AIHW: Pointer 2019).

In the ABS Causes of Death data set, the Indigenous status of a deceased person is captured through the death registration process; however, it is recognised that this does not always occur, leading to under-identification (ABS 2019a). Due to these known data quality issues, the ABS Causes of Death data set only reports rates of Indigenous deaths (including those by suicide) in those states and territories that have official records with reliable identification data for Indigenous people (New South Wales, Queensland, Western Australia, South Australia and the Northern Territory) (ABS 2019a).

In order to improve suicide prevention activities targeted at Indigenous Australians, and to accurately assess their progress, it will be critical to improve the evidence base around this population group. Through the National Civil Registration and Statistics Improvement Committee, the ABS is working closely with the state and territory Registries of Births, Deaths and Marriages to progress towards improved identification in a nationally consistent way.

There is a growing body of research literature around what works in the prevention of Indigenous suicide, including a range of success factors that can be used to guide interventions targeting at-risk groups and individuals (Dudgeon et al. 2016). The AIHW will add to this evidence base by developing an online Indigenous mental health and suicide-prevention clearinghouse. The clearinghouse will be an authoritative source on the latest information and will include articles by subject matter experts; accessible data and evidence on specific topic areas; and a register of relevant research and evaluations.

## **Current serving, reserve and contemporary ex-serving Australian Defence Force personnel**

In 2016, in response to concerns within the ADF and the wider Australian community, the Department of Veterans' Affairs commissioned the AIHW to monitor the number and rate of deaths by suicide in serving, reserve and ex-serving ADF personnel (AIHW 2019g). To date, analysis includes current serving, reserve and contemporary ex-serving ADF personnel who have at least 1 day of service from 2001.



From 2001 to 2017 there were 419 certified deaths by suicide among men and women with at least 1 day of ADF service since 1 January 2001 (AIHW 2019g). Of these, 229 (55%) occurred among contemporary ex-serving personnel. The crude rate of suicide among contemporary ex-serving men between 2002 and 2017 was 27 per 100,000 population, which was 18% higher than in Australian men after adjusting for age. The suicide rate in current serving and reserve men was 12 per 100,000 population which was half the rate in Australian men after adjusting for age (AIHW 2019f). Detailed analysis published in 2017 found that younger age, a short length of service (less than 1 year), discharge with a rank other than a commissioned officer, or involuntary discharge (particularly medical discharge) were risk factors for suicide in ex-serving men (AIHW 2017). Between 2002 and 2017, the crude suicide rate in contemporary ex-serving women was 15 per 100,000, which was higher than in Australian women after adjusting for age; reporting of suicide rates for current serving and reserve women is not possible at this time due to confidentiality constraints and the small numbers in these cohorts.

Deaths by suicide in current serving and contemporary ex-serving ADF personnel are identified using personnel management system data from the Department of Defence, which includes those with service from 1 January 2001 (AIHW 2019f). The AIHW is currently investigating the feasibility of using additional data sources to extend the coverage of the available data. Further information on the use of health services by ADF personnel following a suicide attempt or an incident of intentional self-harm would also help to provide a more comprehensive understanding of these behaviours in this population.

## The important role of data

Suicide and intentional self-harm are complex problems. Evidence-based interventions to help prevent suicide and self-harming behaviour require an understanding of the 'who, when, where, and how' of suicide and intentional self-harm in order to provide insights about 'why'. While better data on its own cannot prevent suicide, bringing together multiple relevant data sources in a coherent manner is required to develop timely, targeted and effective prevention strategies.

The AIHW will work collaboratively and in consultation with all jurisdictions to design and implement the National Suicide and Self-harm Monitoring System so that it successfully brings together regional- and demographically-specific data on the incidence of suicide and intentional self-harm, and so better informs the planning and targeting of prevention and intervention strategies by governments, service providers and communities.

**Table 9.1: Overview of current and potential sources of data for suicide, intentional self-harm and suicidal behaviours in Australia**

	Outcome as a number or % (Most recent year available)	Strengths	Limitations	Opportunities
Deaths by suicide	3,046 (2018) <sup>(a)</sup>	National coverage (epidemiological data set) Mandatory collection Includes all deaths Method of suicide reported High quality Standardised, coded data set Timely for an epidemiological data set International comparison Data are revised as more information becomes available	Not suitable for timely suicide surveillance because the data are updated annually Issues with quality of geo-coded data for place of occurrence Data quality issues with Indigenous status	Identification of psychosocial risk factors Improved identification of Indigenous status Improved geo-coding of incident and fatality location Data linkage
	n.a.	National coverage Standardised, coded data set Demographic, contextual and circumstantial information on reportable deaths	Available by application, only to approved users	Improved geo-coding of incident and fatality location Inclusion of risk factor information

	Outcome as a number or % (Most recent year available)	Data source	Strengths	Limitations	Opportunities
Deaths by suicide, continued	n.a.	Suicide registers	State-based Timely Can be used as a surveillance data set Demographic, contextual and circumstantial information on all reportable deaths	No nationally consistent approach to data collection and reporting Subject to change at time of use	Improved geo-coding of incident and fatality location More timely data on suspected suicides
Hospitalisations for intentional self-harm	33,131 cases (2016–17) <sup>(b)</sup>	NHMD	Administrative data from each state and territory Standardised, coded data set Indigenous status Method of suicide reported	A record is included for each separation, not for each patient.	Improved identification of populations at risk Data linkage
ED presentations for intentional self-harm	n.a.	NNAPEDCD	Administrative data from each state and territory Standardised, coded data set Indigenous status	Does not capture the cause of the injury, intent and/or self-harm	Develop a methodology to identify intentional self-harm Data linkage

	Outcome as a number or % (Most recent year available)		Data Source	
Measure	Data source	Strengths	Limitations	Opportunities
Prevalence of suicide attempts in the community	National Survey of Mental Health and Wellbeing (2007)	National sample of 8,841 Australian households, excluding very remote areas Participants aged 16–85 years Prevalence estimate	Self-reported survey data Non-private dwellings excluded (e.g. hospitals, correctional facilities) One-off, point-in-time data collection Indigenous status	Update survey Data linkage
	Second Australian Child and Adolescent Survey of Mental Health and Wellbeing (2013–14)	2.4% of 12–17 year olds in the previous 12 months National sample of 6,310 families with children aged 4–17 years (questions on self-harm and suicidal behaviours were only asked of those aged ≥12 years), excluding very remote areas Prevalence estimate	Self-reported survey data Non-private dwellings excluded (e.g. hospitals, correctional facilities) Small sample size limiting modelling of risk factors <sup>(d)</sup>	Data linkage
	Ambulance call-outs	n.a. State-based electronic patient care records Feasibility established for coding of ambulance clinical records for mental health, self-harm, alcohol or drugs attendances <sup>(e)(f)</sup>	No system for the collation of nationally consistent paramedic data, including intentional self-harm and suicidal behaviours	Coding, collation and reporting of national ambulance presentations data Data linkage

	Outcome as a number or % (Most recent year available)			Data Source	
Measure	Data source	Strengths	Limitations	Opportunities	
Prevalence of suicide attempts in the community, continued	Police data	n.a.	State-based police incident forms	No system for the collation and reporting of nationally consistent police data	Reporting of national, standardised police data
Prevalence of suicidal ideation	National Survey of Mental Health and Wellbeing (2007)	13.3% lifetime prevalence <sup>(c)</sup>	As above	As above	As above
	Second Australian Child and Adolescent Survey of Mental Health and Wellbeing (2013–14)	7.5% of 12–17 year olds in the previous 12 months	As above	As above	As above
	Crisis help line use	n.a.	Existing telephone and web-based support services for suicide prevention (e.g. Lifeline, Kids Helpline, MensLine, Suicide Call Back Service, Headspace)	No national system for the collation and reporting of nationally consistent crisis support data	Coding, collation and reporting of national crisis support data.

	Outcome as a number or % (Most recent year available)		Data Source	
Measure	Data source	Strengths	Limitations	Opportunities
Prevalence of suicidal ideation, continued	Primary health care (GP)	Existing clinical information systems	Suicide and intentional self-harm data not included	Coding, collation and reporting of national health care data
	Treatment provided by mental health professionals	Existing community and residential mental health National Minimum Data Sets (NMDS)	Suicide and intentional self-harm data not included	Data linkage

(a) ABS 2019a. 2018 preliminary data; 2017 and 2016 revised data; 2015 and earlier finalised data

(b) AIHW: Pointer 2019

(c) at any point in the respondent's lifetime

(d) Kyron et al. 2019

(e) Scott et al. 2018

(f) Turning Point 2019

Note: ABS = Australian Bureau of Statistics; ADF = Australian Defence Force; AIHW = Australian Institute of Health and Welfare; ED = emergency department; n.a. = Not available; NCI = National Coronial Information System; NHMD = National Hospital Morbidity Database; NNAPEDCD = National Non-Admitted Patient Emergency Department Care Database; NMD = National Mortality Database.

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# Longer lives, healthier lives?

10

Over many decades, life expectancy in Australia has increased substantially. People born in the early 1900s were expected to live, on average, to around age 55, compared with people born after 2010 who are expected to live, on average, to age 80 or more. But are longer lives also healthier lives? It is important to differentiate years lived in full health from years lived in ill health: are people who live longer also staying sick for longer—and thus increasing the amount of ill health in the country? If more of the years gained are expected to be affected by disease and injury, this has an impact on quality of life of individuals. It will also have implications for health planning and future health system costs and demand for aged-care and community services, particularly for older Australians.

Older Australians experience a significant proportion of the burden of ill health. In 2015, Australians aged 65 and over represented 15% of the population but experienced one-third (33%) of the burden of ill health. Chronic conditions—musculoskeletal disorders, neurological conditions, cardiovascular diseases and respiratory diseases—accounted for 60% of this burden (AIHW 2019a). See ‘Burden of disease’ <https://www.aihw.gov.au/reports/australias-health/burden-of-disease> for more information.

Whether or not the amount of ill health experienced by older Australians has increased has been the subject of ongoing debate. There are 3 main theories of healthy ageing that offer a useful framework for assessing improvements in health and increases in life expectancy. These theories are referred to as:

- **expansion of morbidity**—where increasing life expectancy is accompanied by more illness and injury before death. As chronically ill people survive for longer, we can expect an increase in the proportion of their lives spent with illness (Greunberg 1975)
- **compression of morbidity**—where increasing life expectancy is accompanied by better health. As the population ages, there is a delay in the age of onset of disease, and we can expect a reduction in the proportion of life spent in ill health (Fries 1980)
- **dynamic equilibrium**—where the proportion of the lifetime spent living with illness remains relatively constant over time. As life expectancy increases, so does the onset and progression of disease—but as diseases grow more prevalent they may also be less severe (Howse 2006).

This chapter provides some unique insights to help us assess whether there has been an expansion or compression of morbidity—or an equilibrium between morbidity and mortality—as older Australians are living longer. Using burden of disease analysis—specifically health-adjusted life expectancy (HALE) (Box 10.1), which combines health-related quality of life (years lived with disability (YLD)) and life expectancy into a single measure—can help determine which of these theories best describes the picture of health in Australia.

## **Box 10.1: Terms used in this chapter**

### **Health-adjusted life expectancy (HALE)**

HALE extends the concept of life expectancy by considering the time spent living with the health consequences of disease and injury. It provides a more comprehensive picture of health than other summary measures (for example, life expectancy, infant mortality and disease prevalence). The measure reflects the average number of years of life expected in full health. Over a period of 1 year, a person at any age can potentially live a year in full health or spend some of the year living with illness. Illnesses vary by duration and severity, so the amount of time lost to ill health is measured by combining the duration and severity of the illness; the remaining time in that 1 year is considered as time in full health. HALE uses YLD rates and life expectancy estimates in its calculation.

### **Years lived with disability (YLD)**

YLD quantifies the average experience of health loss, based on the prevalence of all health conditions adjusted for the severity and comorbidity of diseases. YLD rates expressed per person can be interpreted as the proportion of the year that each person, on average, lost due to ill health, thereby providing a measure of average ill health in the population during that year.

This chapter focusses on HALE at age 65—a measure that represents the number of years of life expectancy at this age that could be expected to be lived in full health. Focussing on this age group highlights trends in the health of Australia's ageing population and helps to describe whether or not the years of life (expectancy) gained are healthy years. As statistics at the national level can mask disparities between different population groups, this chapter also explores differences in HALE for Australians from different socioeconomic areas.

At a national level, what is evident from these analyses is that, for people aged 65, with continuing increases in life expectancy, the proportion of their lifetime spent in ill health has remained constant (that is, supporting the 'dynamic equilibrium' theory). However, this picture is not the same for all population groups. Available data suggest there has been an expansion of morbidity for people living in the lowest socioeconomic areas, and a compression of morbidity in the highest socioeconomic areas.

These findings, and the analyses underpinning them, are discussed in more detail below.

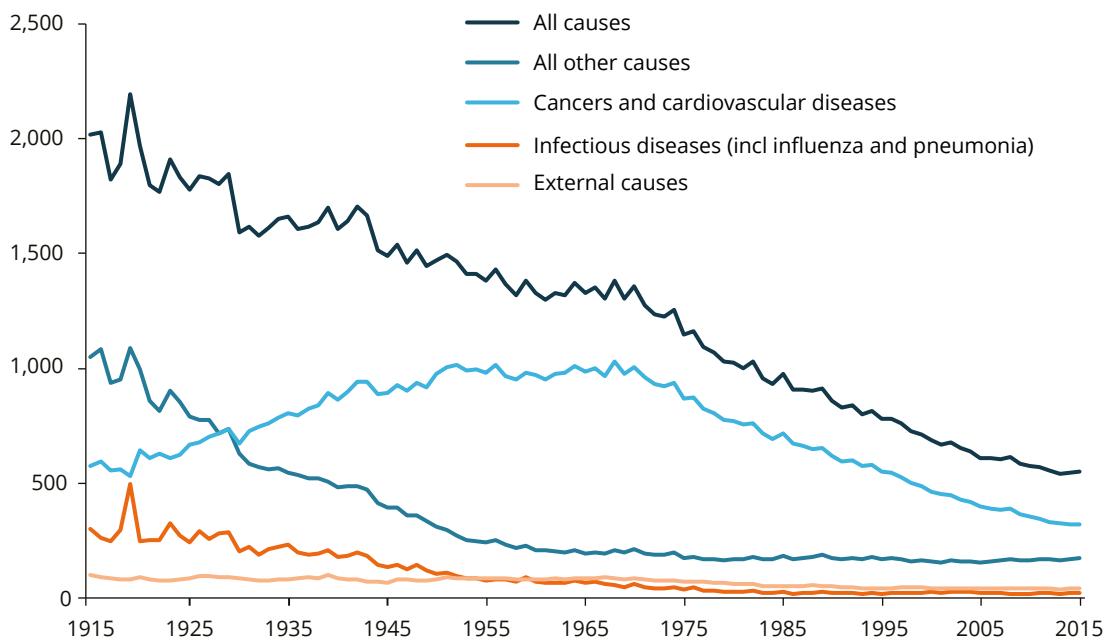
## Living longer

Advances in disease prevention and treatment over the 20th and 21st centuries have resulted in large reductions in mortality rates in Australia. While reductions were more dramatic in the first half of last century, age-standardised mortality rates have still declined by 59% since 1967, from around 1,300 deaths per 100,000 persons to 552 in 2015 (Figure 10.1). Also, in the first half of last century, deaths due to chronic disease (such as cancer and cardiovascular diseases) were on the rise, while deaths due to infectious diseases were declining. Chronic diseases are now more prevalent and are responsible for the majority of deaths: in 2015, 58% of deaths were due to cancer and cardiovascular diseases compared with 23% in 1915 (AIHW 2019b).

For the latest mortality and life expectancy statistics please refer to 'Causes of Death' <https://www.aihw.gov.au/reports/australias-health/causes-of-death> and 'How healthy are Australians' <https://www.aihw.gov.au/reports/australias-health/how-healthy-are-australians>.

**Figure 10.1: Age-standardised mortality rates, by causes of death, 1915–2015**

Deaths per 100,000 population



Source: AIHW 2019b.

Increasing longevity is occurring at all ages. For example, if you were aged 65 in 1905, you would have been expected to live on average for 11.3 more years, compared with an average of 19.6 more years if you were aged 65 in 2015. Similarly, if you were aged 85 in 1905, you would have been expected to live on average for 3.7 more years, compared with an average of 6.2 more years if you were aged 85 in 2015.

During the 40 years to 2015, the average male life expectancy—at birth and at ages 65 and 85—increased by 16%, 50% and 40% respectively. There were similar but less pronounced increases among females (increasing by 10%, 30% and 33% respectively). That is, life expectancy has been increasing for those of older ages as well as for newborns (Table 10.1). For Australians aged 65, life expectancy increased by 6.5 years over this period for males (from 13.1 years in 1976 to 19.6 in 2015) and by 5.2 years for females (from 17.1 to 22.3 years) (ABS 2019).

**Table 10.1: Life expectancy at selected ages and time periods, by sex, 1901–2016**

Age (years)	1901–1910	1932–1934	1953–1954	1975–1977	1994–1996	2014–2016
<b>Males</b>						
0	55.2	63.5	67.1	69.6	75.2	80.5
25	40.6	44.4	45.5	46.9	51.5	56.2
45	24.8	26.9	27.2	28.3	32.8	37.1
65	11.3	12.4	12.3	13.1	15.8	19.6
85	3.7	3.9	4.0	4.5	5.2	6.2
<b>Females</b>						
0	58.8	67.1	72.8	76.6	81.1	84.6
25	43.4	47.2	50.2	53.1	56.9	60.1
45	27.6	29.7	31.4	34.0	37.5	40.6
65	12.9	14.2	15.0	17.1	19.6	22.3
85	4.2	4.3	4.5	5.5	6.4	7.3

*Note:* Life expectancy is based on limited historical data. Reference years were selected to approximate 20-year intervals.

*Source:* ABS 2019.

## Measuring whether longer lives are healthier lives

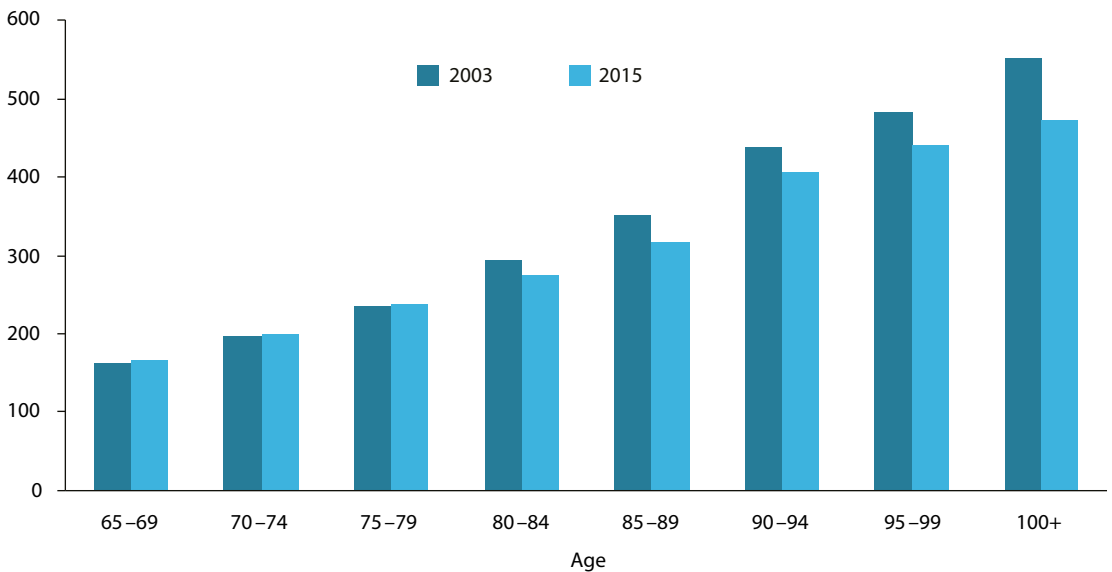
To understand whether the amount of ill health experienced in the population is increasing or decreasing requires a comprehensive measure of the health of a population that is comparable over time and between population groups. A comprehensive measure needs to combine the prevalence of all diseases and the degree of impact of these diseases on health.

Burden of disease analysis provides such a metric: it measures the impact of diseases on health by quantifying the health loss due to all health conditions. YLD rates provide a measure of the average number of years spent living with disease or injury per person in the population.

Figure 10.2 shows YLD rates by age for people aged 65 and over. In both 2003 and 2015, YLD rates increased progressively with age. For example, the YLD rate for those aged 65–69 in 2015 was 167 YLD per 1,000 persons, compared with 318 for those aged 85–89. That is, on average, as people age they lose more healthy years due to ill health. This figure also suggests there has been a decline in YLD rates in the older age groups between 2003 and 2015.

**Figure 10.2: Years lived with disability (YLD) rates among people aged 65 and over, by age group, 2003 and 2015**

YLD rates (years lived with disability per 1,000 population)



Source: AIHW 2019a.

HALE uses YLD rates in its calculation and reflects the average number of years an individual can expect to live in full health, taking into account mortality and disease/injury. HALE data presented below use life expectancy estimates based on Australian mortality rates and YLD rates from the Australian Burden of Disease Study (ABDS) 2015 (AIHW 2019a).

## Compression, expansion or equilibrium?

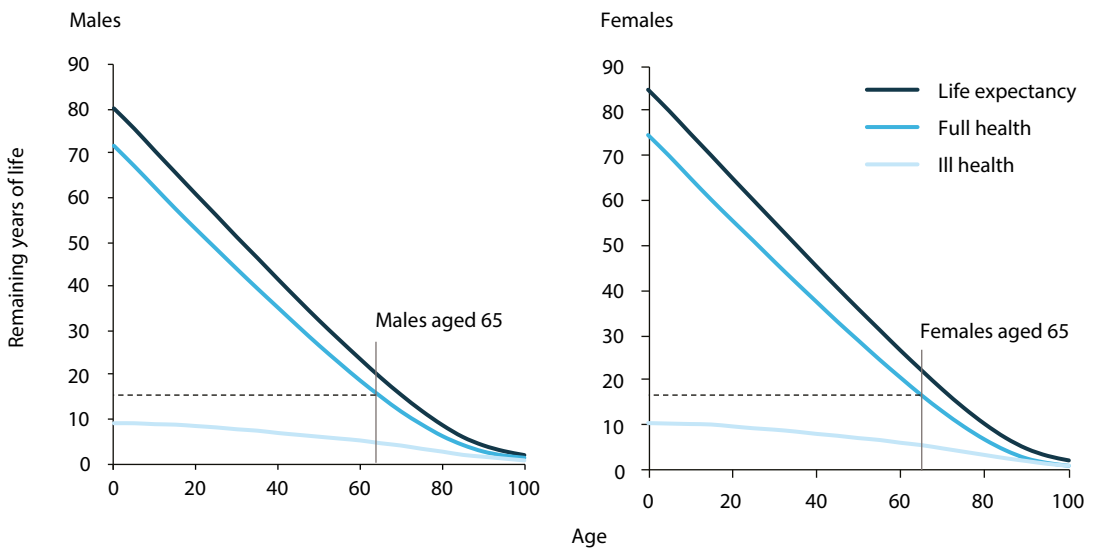
Assessment of how the relationship between life expectancy and HALE has changed over time (by analysing the ratio and difference between the 2 measures) provides an opportunity to examine which of the scenarios of healthy ageing—compression or expansion of morbidity, or equilibrium—provides the best insight into whether longer lives are healthier lives.



## The national picture—equilibrium

Figure 10.3 presents the remaining years of life at each age for males and females (life expectancy) apportioned into the time spent in 2 health states: full health and ill health. Life expectancy at birth (age 0) shows that boys born in 2015 would be expected to live to 80.4 years with 71.5 of these years in full health and 8.9 in ill health, while girls would be expected to live 84.6 years with 74.4 of these in full health and 10.2 years in ill health.

**Figure 10.3: Life expectancy, by years spent in full health and ill health, by sex and age, 2015**



Source: AIHW 2019a.

Males aged 65 years in 2015 have a life expectancy of 19.6 years, during which a total amount of 15.0 years would be expected in full health (indicated by the dotted line in Figure 10.3) with 4.6 healthy years lost due to ill health. For females, of their remaining 22.3 years, 16.8 years would be expected to be in full health (Figure 10.3) and 5.5 healthy years lost due to ill health.

### Changes over time

Extending the analysis to compare changes over time in life expectancy, HALE and years lost due to ill health can aid understanding of the extent to which gains in life expectancy are accompanied by a decrease or increase in living with ill health: that is, the compression or expansion of morbidity.

Over the period 2003 to 2015, males gained 1.8 years of life expectancy—with 1.5 of these years in full health and 0.3 years in ill health. Females gained 1.2 years of life expectancy—with 0.8 of these years in full health and 0.4 years in ill health. So, for both men and women, the number of years expected in full health and in ill health increased over the period 2003 to 2015 (Table 10.2).

While life expectancy and HALE increased over this period, the proportion of time spent in full health at age 65 was similar at each time point (around 75% and 76% for both males and females).

This analysis indicates that, while increasing life expectancy is associated with some extra time in ill health, the proportion of people’s lives spent in ill health remains about the same. At the national level, for people aged 65, changes in morbidity are in keeping with changes in mortality: that is, there is no indication that morbidity is compressing or expanding among this age group. Rather, the picture reflects a dynamic equilibrium between morbidity and mortality.

**Table 10.2: Life expectancy at age 65 by years in full health and ill health, by sex, 2003 and 2015**

	Number of years		Proportion of life expectancy	
	2003	2015	2003	2015
<b>Men</b>				
<b>Expected years of life at age 65</b>				
In full health (HALE)	13.5	15.0	75.8	76.5
In ill health	4.3	4.6	24.2	23.5
<b>Total (life expectancy)</b>	<b>17.8</b>	<b>19.6</b>	<b>100.0</b>	<b>100.0</b>
<b>Women</b>				
<b>Expected years of life at age 65</b>				
In full health (HALE)	16.0	16.8	75.8	75.3
In ill health	5.1	5.5	24.2	24.7
<b>Total (life expectancy)</b>	<b>21.1</b>	<b>22.3</b>	<b>100.0</b>	<b>100.0</b>

Sources: ABS 2019; AIHW 2019a.

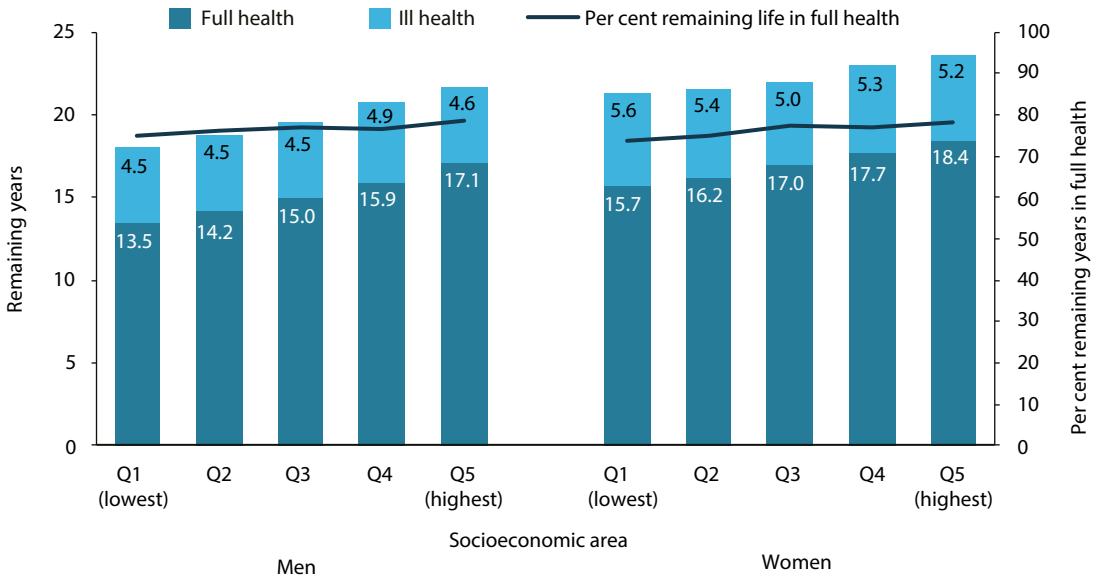
## Expansion in the lowest socioeconomic areas and compression in the highest socioeconomic areas

Like many aspects of population health, the national picture for HALE (of equilibrium in morbidity and mortality as we age) is not shared by all Australians. There is a clear trend of increased life expectancy and years lived in full health in higher (more advantaged) socioeconomic areas (Figure 10.4).

Men and women aged 65–69 living in the lowest (least advantaged) socioeconomic areas had shorter life expectancy and a smaller percentage of life in full health, compared with those living in the highest socioeconomic areas:

- In 2015, men aged 65–69 in the lowest socioeconomic areas had a life expectancy of 18.1 years compared with 21.7 years in the highest socioeconomic areas. For women, these figures were 21.2 and 23.6 years respectively.
- Similar differentials are apparent for years in full health: men and women in the lowest socioeconomic areas experienced 3.6 and 2.7 fewer years, respectively in full health, than those in the highest socioeconomic areas.
- The proportion of life expectancy spent in full health in the lowest socioeconomic areas was lower than in the highest areas. For men it was 74.6% in the lowest socioeconomic areas compared with 78.8% in the highest areas and for women, these figures were 74.1% and 78.0%, respectively.

**Figure 10.4: Life expectancy at age 65–69, by years in full health and ill health, by sex and socioeconomic area, 2015**



Note: Socioeconomic areas are based on the socioeconomic characteristics of the population and are presented as quintiles (fifths). Quintile 1 (Q1) represents the 20% of the population with the lowest socioeconomic characteristics. The level of socioeconomic position increases through to the 20% of the population with the highest socioeconomic characteristics (Q5).

Source: AIHW 2019a.

## Changes over time

The ABDS 2015 is the first study to provide consistent estimates of non-fatal burden for socioeconomic areas for 2 points in time, 2011 and 2015. While the ABDS 2015 also produced burden of disease estimates for the reference year 2003, these are not available by subnational populations (including by socioeconomic area).

Available data over this 4-year period suggest there are some differences over time in HALE and life expectancy by socioeconomic area. For people aged 65–69 living in the lowest (least advantaged) socioeconomic areas:

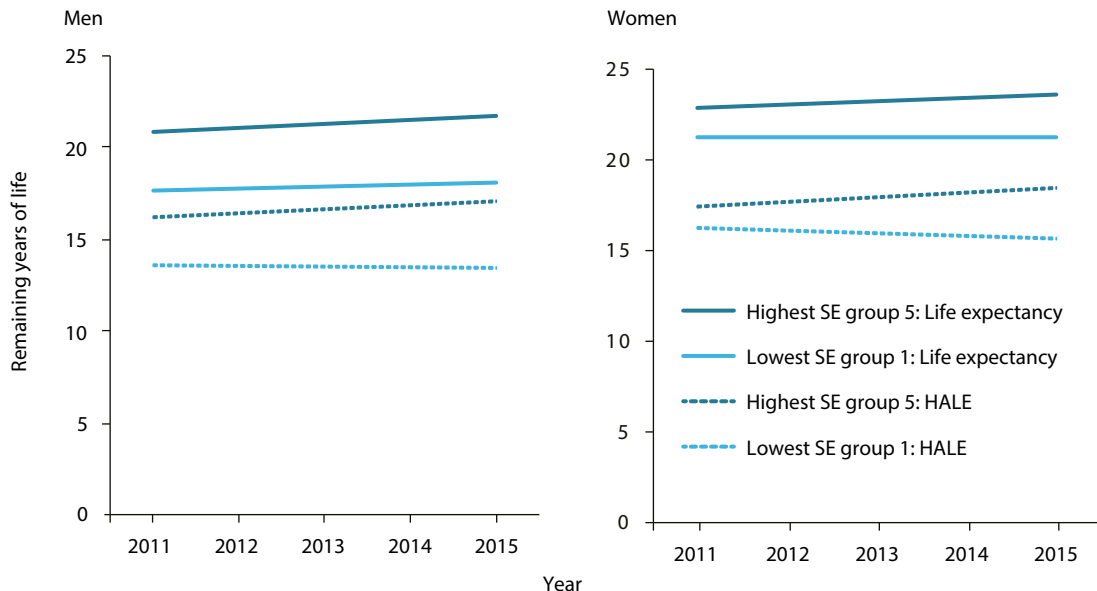
- life expectancy increased over time for men and stayed the same for women. For men, it rose from 17.7 years in 2011 to 18.1 years in 2015. For women, life expectancy was 21.2 years at both time points
- HALE decreased over time for women and stayed the same for men. Men expected 13.5 years in full health in 2015 (and 13.6 years in 2011). Women expected 15.7 years in full health in 2015 down from 16.2 years in 2011

- years in ill health increased over time, from 4.1 to 4.5 years for men and from 4.9 to 5.6 years for women (Figure 10.5)
- proportion of life expectancy in full health decreased over time, from 77.1% to 74.8% for men and from 76.8% to 73.8% for women.

In contrast, for people aged 65–69 living in the highest (most advantaged) socioeconomic areas:

- life expectancy increased over time—rising from 20.9 years in 2011 to 21.7 years in 2015 for men and for women, rising from 22.9 to 23.6 years
- HALE increased over time. Men could expect to live 17.1 years in full health in 2015, up from 16.2 years in 2011. Similarly, women could be expected to live 18.4 years in full health in 2015, up from 17.5 years in 2011
- years in ill health decreased over time—from 4.7 to 4.6 years for males and from 5.5 to 5.2 years for females (Figure 10.5)
- proportion of life expectancy in full health increased over time—from 77.6% to 78.7% for males and from 76.1% to 78.0% for females.

**Figure 10.5: Life expectancy and health-adjusted life expectancy (HALE), at ages 65–69, by sex and socioeconomic area, 2011–2015**



**Notes**

1. Lowest SE group refers to the approximate 20% of the population living in areas with the lowest socioeconomic characteristics.
2. Highest SE group refers to the approximate 20% of the population living in areas with the highest socioeconomic characteristics.

Source: AIHW 2019a.

In summary, for men and women aged 65–69 living in the lowest (least advantaged) socioeconomic areas, the number and proportion of expected healthy years declined over a relatively short period of time (2011 to 2015). In contrast, it increased over time for men and women living in the highest (most advantaged) socioeconomic areas.

This indicates an expansion of morbidity in the lowest socioeconomic areas, and a compression of morbidity in the highest socioeconomic areas.

See ‘Health across socioeconomic groups’ <https://www.aihw.gov.au/reports/australias-health/health-across-socioeconomic-groups> for more information on socioeconomic disparities.

## Future work

While this work focusses on HALE at a specific age (age 65), the same analysis can be undertaken for different age groups (for example at ages 45 or 85) to assess whether the patterns and conclusions drawn here in regards to the 3 theories of healthy ageing (compression or expansion of morbidity, or equilibrium) differ by age.

A more detailed report on this topic is planned to be published by the AIHW in late 2020 which will include analysis for different age groups.

It is important to note that the analyses shown here are based on burden of disease data currently available. For the national analysis, a longer period of data was available, enabling a comparison over time between 2003 and 2015. For assessment by socioeconomic area, there were only 2 time points (2011 and 2015) available at the time of this analysis. More time points are needed for continued monitoring of this important measure of the health of Australians. In addition, this analysis uses socioeconomic areas which have some limitations compared with individual-based measures. It reflects the overall or average socioeconomic characteristics of the population of an area; it does not show how individuals living in the same area might differ from each other (AIHW 2016), or how the characteristics of people who live in an area may change over time.

The AIHW is currently undertaking work to update Australia’s burden of disease estimates to the 2018 reference year, which will include estimates of HALE. This will extend the time series to examine whether the patterns of healthy ageing presented here are changing over time.

## Further reading

The following reports provide further information on HALE and theories of healthy ageing:

- AIHW 2012. Changes in life expectancy and disability in Australia 1998 to 2009. Bulletin no. 111. Cat. no. AUS 166. Canberra: AIHW.
- AIHW 2017. Health-adjusted life expectancy in Australia: expected years lived in full health 2011. Australian Burden of Disease Study series no.16. Cat. no. BOD 17. Canberra: AIHW.
- AIHW 2019. Australian Burden of Disease Study: impact and causes of illness and death in Australia 2015. Australian Burden of Disease series no. 19. Cat. no. BOD 22. Canberra: AIHW.

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AIHW (Australian Institute of Health and Welfare) 2016. Australia's health 2016. Australia's health series no. 15. Cat.no. AUS 199. Canberra: AIHW.

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# Abbreviations

ABDS	Australian Burden of Disease Study
ABF	Activity-Based Funding
ABS	Australian Bureau of Statistics
ACFI	Aged Care Funding Instrument
ACHI	Australian Classification of Health Interventions
ACR	Australian Coordinating Registry
ACSQHC	Australian Commission on Safety and Quality in Health Care
ADF	Australian Defence Force
ADNet	Australia Dementia Network
AHPF	Australian Health Performance Framework
AIHW	Australian Institute of Health and Welfare
AMH	Australian Medicines Handbook
ANZDATA	Australian and New Zealand Dialysis and Transplant Registry
ARF	acute rheumatic fever
ATC	Anatomical Therapeutic Chemical (Classification System)
BEACH	Bettering the Evaluation and Care of Health
BPSD	behavioural and psychological symptoms of dementia
CKD	chronic kidney disease
CNOS	Canadian National Occupancy Standard
CDNA	Communicable Diseases Network Australia
COAG	Council of Australian Governments
COPD	Chronic obstructive pulmonary disease
DALY	Disability-adjusted life year
DATA	Data Availability and Transparency Act
DDD	defined daily dose
DVA	Department of Veterans' Affairs
ED	Emergency Department
EIU	Economist Intelligence Unit
ESKD	end-stage kidney disease
GAS	group A streptococcus
GDP	Gross Domestic Product
GP	General Practitioner
HALE	Health-adjusted life expectancy
HPV	human papillomavirus

ICD	International Classification of Disease
ICD-10 AM	International Statistical Classification of Diseases and Related Health Problems, 10 <sup>th</sup> Revision, Australian Modification
ICD-10	International Classification of Disease, 10 <sup>th</sup> edition
ICD-11	International Classification of Disease, 11 <sup>th</sup> edition
IHPA	Independent Hospital Pricing Authority
IQWiG	Institute for Quality and Efficiency in Health Care (Germany)
IRSD	Index of Relative Socio-economic Disadvantage
MADIP	Multi-Agency Data Integration Project
MBS	Medicare Benefits Schedule
MELDA	Multi-source Enduring Linked Data Asset
METeOR	Metadata Online Registry
NATSEM	National Centre for Social and Economic Modelling
NATSIHS	National Aboriginal and Torres Strait Islander Health Survey
NCIS	National Coronial Information System
NDLDP	National Data Linkage Demonstration Project
NHFB	National Health Funding Body
NHMD	National Hospital Morbidity Database
NHPA	National Health Performance Authority
NHRA	National Health Reform Agreement
NIHSI AA	National Integrated Health Services Information Analysis Asset
NISU	National Injury Surveillance Unit
NMD	National Mortality Database
NMDS	National Minimum Data Set
NNAPEDCD	National Non-Admitted Patient Emergency Department Care Database
NNDSS	National Notifiable Diseases Surveillance System
NNIDR	National Health and Medical Research Council National Institute for Dementia Research
NRMC	National Residential Medication Chart
NZ MoH	New Zealand Government Ministry of Health
OECD	Organisation for Economic Co-operation and Development
OM	otitis media
ONDC	Office of the National Data Commissioner
PBS	Pharmaceutical Benefits Scheme
PPH	Potentially preventable hospitalisation
PRN	pro re nata (as needed)
PSGN	post-streptococcal glomerulonephritis

RACGP	Royal Australian College of General Practitioners
RCACQS	Royal Commission into Aged Care Quality and Safety
RHD	rheumatic heart disease
RPBS	Repatriation Pharmaceutical Benefits Scheme
SDAC	Survey of Disability, Ageing and Carers
SE	socioeconomic
SHA	System of Health Accounts
SHI	Statutory Health Insurance
WHO	World Health Organization
YLD	Years lived with disability

## Symbols

%	per cent
\$	Australian dollars, unless otherwise specified
<	less than
>	more than
≤	less than or equal to
≥	more than or equal to
..	no data/insufficient data
'000	thousands
mg/mmol	microgram per millimole
mL	millilitre
m2	met
n.a.	not available

# Glossary

**Aboriginal or Torres Strait Islander:** A person of Aboriginal and/or Torres Strait Islander descent who identifies as an Aboriginal and/or Torres Strait Islander. See also **Indigenous**.

**acute care:** Care provided to patients admitted to hospital that is intended to cure illness, alleviate symptoms of illness or manage childbirth.

**acute rheumatic fever:** An autoimmune response to infection of the throat (and possibly of the skin) by group A streptococcus bacteria. See also **rheumatic heart disease**.

**additional diagnosis:** The diagnosis of a condition or recording of a complaint—either coexisting with the principal diagnosis or arising during the episode of admitted patient care (hospitalisation), episode of residential care or attendance at a health care establishment—that requires the provision of care. Multiple diagnoses may be recorded.

**ADF personnel:** Serving, reserve and ex-serving members of the Australian Defence Force, civilian personnel employed by the Department of Defence are excluded.

**administrative data:** This refers to information that is collected, processed, and stored in automated information systems. Administrative data include enrolment or eligibility information, claims information, and managed care encounters.

**administrative data collection:** Data set that results from the information collected for the purposes of delivering a service or paying the provider of the service. This type of collection is usually complete (that is, all in-scope events are collected), but it may not be fully suitable for population-level analysis because the data are collected primarily for an administrative purpose.

**admission:** An admission to hospital. The term **hospitalisation** is used to describe an episode of hospital care that starts with the formal admission process and ends with the formal **separation** process. The number of separations has been taken as the number of admissions; hence, 'admission rate' is the same as 'separation rate'.

**admitted patient:** A patient who undergoes a hospital's formal admission process to receive treatment and/or care and ends with a formal separation process.

**aged-care services:** Daily living and nursing-care services provided through residential, home or flexible care arrangements run by governments, not-for-profit organisations or private businesses.

**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.

**Alzheimer's disease:** A degenerative brain disease caused by nerve cell death resulting in shrinkage of the brain. A common form of **dementia**.

**antibodies:** Blood proteins produced in response to and counteracting a specific **antigen**. Antibodies combine chemically with substances which the body recognizes as alien, such as bacteria, viruses, and foreign substances in the blood.

**anti-dementia medicines:** A group of medicines that can be used to manage the symptoms of dementia in people with mild-to-moderate Alzheimer's disease.

**antidepressant medicines:** A group of medicines that can be used to manage the symptoms of certain mental health conditions, particularly depression and anxiety.

**antigen:** A toxin or other foreign substance which induces an immune response in the body, especially the production of **antibodies**.

**antipsychotic medicines:** A group of medicines that can be used to manage the symptoms of certain mental health conditions, particularly schizophrenia.

**antiviral:** A drug or treatment effective against **viruses**.

**anxiety disorders:** A group of mental disorders marked by excessive feelings of apprehension, worry, nervousness and stress. Includes generalised anxiety disorder, obsessive-compulsive disorder, panic disorder, post-traumatic stress disorder and various phobias.

**associated cause(s) of death:** Any condition(s), diseases and injuries—other than the **underlying cause of death**—considered to contribute to a death. See also **cause of death**.

**asymptomatic transmission:** Refers to **transmission** of an infectious agent from a person who does not develop symptoms.

**average length of stay (ALOS):** The average of the length of stay for admitted patient episodes (hospitalisations). ALOS is calculated by dividing total patients days in a given period by the total number of hospital **separations** in that period.

**back pain and problems:** A range of conditions related to the bones, joints, connective tissue, muscles and nerves of the back. Back problems are a substantial cause of disability and lost productivity.

**Basic Reproduction Number ( $R_0$ ):** The reproduction number when there is no immunity from past exposures or vaccination, nor any deliberate intervention in disease transmission.

**behavioural and psychological symptoms of dementia (BPSD):** Behaviours and feelings that are commonly experienced by people with dementia, including agitation, wandering, delusions and anxiety. These symptoms may relate to the dementia itself or indicate another underlying cause, such as illness, pain or fear.

**benzodiazepine medicines:** A group of medicines that can be used to manage the symptoms of certain mental health conditions, particularly anxiety disorders.

**built environment:** The built environment refers to the human-made surroundings where people live, work and recreate. It includes buildings and parks as well as supporting infrastructure such as transport, water and energy networks (Coleman 2017).

**burden of disease and injury:** The quantified impact of a disease or injury on an individual or population, using the **disability-adjusted life year** (DALY) measure.

**cancer (malignant neoplasm):** A large range of diseases where some of the body's cells become defective, begin to multiply out of control, invade and damage the area around them, and can then spread to other parts of the body to cause further damage.

**carer:** A person who cares for another person (often a relative or friend) and has the responsibility for making decisions about that person's daily care. In the Australian Bureau of Statistics Survey of Disability, Ageing and Carers, a carer is defined as a person who provides any informal assistance (help or supervision) to people with disability or older people, with assistance being ongoing, or likely to be ongoing, for at least 6 months.

**cataract:** A mostly degenerative condition in which the lens of the eye clouds over, obstructing the passage of light to the retina and causing vision impairment and, potentially, blindness.

**cause of death:** 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—that are entered on the Medical Certificate of Cause of Death.

**child:** A person aged 0–14 unless otherwise stated.

**chronic:** Persistent and long lasting.

**chronic kidney disease (CKD):** All conditions of the kidney, lasting at least 3 months, where a person has had evidence of kidney damage and/or reduced kidney function, regardless of the specific cause.

**chronic obstructive pulmonary disease (COPD):** Serious, progressive and disabling long-term lung disease where damage to the lungs (usually because of both **emphysema** and chronic **bronchitis**) obstructs oxygen intake and causes increasing shortness of breath. By far the greatest cause of COPD is cigarette smoking.

**clinical guidelines:** Systematically developed statements to inform practitioner and patient decisions on appropriate health care for specific clinical circumstances.

**cohort:** A group of people who share a similar characteristic (for example, age).

**comorbidity:** A situation where a person has 2 or more health problems at the same time.

**complication:** A secondary problem that arises from a disease, injury or treatment (such as surgery) that makes the patient's condition worse and treatment more complicated.

**Compression of Morbidity:** A theory of healthy ageing suggesting that the lifetime burden of illness could be reduced if the onset of chronic illness could be postponed.

**condition (health condition):** A broad term that can be applied to any health problem, including symptoms, diseases and certain risk factors, such as high blood cholesterol and obesity. Often used synonymously with 'disorder' or 'problem'.

**confidence interval:** A range determined by variability in data, within which there is a specified (usually 95%) chance that the true value of a calculated parameter lies.

**constant prices:** Account for inflation by removing the effect of changes in prices over time. This allows for comparisons of spending over different time periods to be made. Constant price estimates indicate what expenditure would have been had the same prices applied across all years. See also **real expenditure**.

**contemporary ex-serving (Australian Defence Force):** Australian Defence Force members who have had at least 1 day of full-time or reserve service on or after 1 January 2001 and who have since been discharged from the Australian Defence Force.

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

**current prices:** 'Expenditure at current prices' refers to expenditure that is not adjusted for movements in price (inflation) from one year to another and therefore represents the dollar amount spent in that year.

**current serving (Australian Defence Force):** Australian Defence Force members who have had at least 1 day of full-time service on or after 1 January 2001 and are still serving in the Australian Defence Force.

**DALY:** See **disability-adjusted life year**.

**data linkage:** Bringing together (linking) of information from 2 or more different data sources that are believed to relate to the same entity (for example, to the same individual or the same institution). This linkage can yield more information about the entity and, in certain cases, provide a time sequence—the term is used synonymously with ‘record linkage’ and ‘data integration’.

**deidentified:** A process which involves the removal or alteration of personal identifiers, followed by the application of additional techniques or controls to remove, obscure, aggregate, alter and/or protect data so that it is no longer about an identifiable (or reasonably identifiable) individual.

**dementia:** A group of conditions that affect the brain: dementia is generally progressive and characterised by symptoms such as impaired thinking, behaviour and ability to perform the activities of daily living. Common types of dementia are **Alzheimer’s disease**, vascular dementia and mixed types of dementia.

**demographics:** Statistical data relating to population groups, such as age, sex, economic status, education level and employment status, among others.

**depression:** A mood disorder with prolonged feelings of being sad, hopeless, low and inadequate, with a loss of interest or pleasure in activities and often with suicidal thoughts or self-blame.

**depressive disorders:** A group of mood disorders with prolonged feelings of being sad, hopeless, low and inadequate, with a loss of interest or pleasure in activities and often with suicidal thoughts or self-blame.

**determinant:** Any factor that can increase the chances of ill health (risk factors) or good health (protective factors) in a population or individual.

**diabetes (diabetes mellitus):** A chronic condition where the body cannot effectively use its main energy source, the sugar glucose. This is due to a relative or absolute deficiency in insulin, a hormone produced by the pancreas that helps glucose to enter the body’s cells from the bloodstream and to 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. The 3 main types of diabetes are **type 1 diabetes**, **type 2 diabetes** and **gestational diabetes**.

**diabetic nephropathy:** Damage to the blood-filtering capillaries in the kidneys, caused by high blood sugar levels.

**diabetic retinopathy:** A complication of diabetes. Refers to damage to the blood vessels in the retina which can result in blindness.

**dialysis:** An artificial method of treating kidney failure by removing waste substances from the blood and regulating levels of circulating chemicals—functions usually performed by the kidneys.

**digital health:** The electronic management of health information. This includes using technology to collect and share a person’s health information. It can be as simple as a person wearing a device to record how much exercise they do each day, to health care providers sharing clinical notes about an individual.

**disability-adjusted life year (DALY):** A year of healthy life lost, either through premature death or equivalently through living with ill health due to illness or injury. It is the basic unit used in **burden of disease and injury** estimates.



**disease:** A physical or mental disturbance involving symptoms (such as pain or feeling unwell), dysfunction or tissue damage, especially if these symptoms and signs form a recognisable clinical pattern.

**disorder (health disorder):** A term used synonymously with **condition**.

**Dynamic Equilibrium:** A theory of healthy ageing which suggests that the proportion of the lifetime spent living with illness remains relatively constant over time, because there is a trade-off between increasing prevalence and decreasing severity of diseases.

**Effective Reproduction Number (Re):** The reproduction number when there is some immunity or some intervention measures in place.

**end-stage kidney disease (ESKD):** The most severe form of **chronic kidney disease (CKD)**, also known as Stage 5 CKD or kidney failure. It occurs when kidney function has deteriorated so much that it is no longer sufficient to sustain life, and kidney replacement therapy (KRT) in the form of dialysis or kidney transplantation is required for the patient to survive.

**epidemic:** Widespread occurrence of an infectious disease in a community at a particular time.

**Expansion of Morbidity:** A theory of healthy ageing which suggests that increasing life expectancy will be accompanied by higher prevalence of disease, resulting in more disability from illness and injury before death.

**exponential growth:** Growth that increases at a consistent rate. While it starts slowly, it can rapidly result in enormous quantities.

**fomites:** Objects or materials, such as clothes, utensils, and furniture, which are likely to carry infectious agents.

**general practitioner (GP):** A medical practitioner who provides primary, comprehensive and continuing care to patients and their families in the community.

**genomics:** The study of genes and their functions, and related techniques. Genomics addresses all genes and their interrelationships to identify their combined influence on the growth and development of the organism.

**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. See also **diabetes (diabetes mellitus)**, **type 1 diabetes** and **type 2 diabetes**.

**gross domestic product (GDP):** A statistic commonly used to indicate national wealth. It is the total market value of goods and services produced within a given period after deducting the cost of goods and services used up in the process of production but before deducting allowances for the consumption of fixed capital.

**group A streptococcus infection (GAS):** Is caused by bacteria known as Group A (beta-haemolytic) Streptococcus, GAS is a common infection that can cause sore throats (pharyngitis), scarlet fever or impetigo (skin sores).

**health:** The World Health Organization (WHO) defines health as a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.

**health and aged-care system:** The interaction of funding, institutions, workforce and resources that support the delivery of health and aged-care services.

**health hardware:** The physical equipment needed to support good health in a domestic setting, including safe electrical systems, access to water, facilities for washing people and clothing, facilities for storing and preparing food, and waste removal systems.

**health literacy:** The ability of people to access, understand and apply information about health and the health care system so as to make decisions that relate to their health.

**health outcome:** A change in the health of an individual or population due wholly or partly to a preventive or clinical intervention.

**health promotion:** A broad term to describe activities that help communities and individuals increase control over their health behaviours. Health promotion focuses on addressing and preventing the root causes of ill health, rather than on treatment and cure.

**health status:** The overall level of health of an individual or population, taking into account aspects such as **life expectancy**, level of **disability**, levels of disease **risk factors** and so on.

**health-adjusted life expectancy (HALE):** The average number of years that a person at a specific age can expect to live in full health, taking into account years lived in less than full health due to the health consequences of disease and/or injury.

**hearing loss:** Any hearing threshold response in either ear, to any sound stimuli, that is outside the normal range, measured using audiometry (the testing of a person's ability to hear various sound frequencies). Hearing loss in a population describes the number of people who have abnormal hearing. Hearing loss may affect one ear (unilateral) or both ears (bilateral).

**hospital services:** Services provided to a patient who is receiving admitted patient services or non-admitted patient services in a hospital.

**hospitalisation:** An episode of hospital care that starts with the formal admission process and ends with the formal separation process (synonymous with **admission** and **separation**). An episode of care can be completed by the patient's being discharged, being transferred to another hospital or care facility, or dying, or by a portion of a hospital stay starting or ending in a change of type of care (for example, from acute to rehabilitation).

**household:** A group of two or more related or unrelated people who usually live in the same dwelling, and who make common provision for food or other essentials for living; or a single person living in a dwelling who makes provision for his or her own food and other essentials for living, without combining with any other person.

**housing adequacy:** A measure to assess whether a dwelling is overcrowded. The number of bedrooms a dwelling should have in order to avoid crowding, as determined by the Canadian National Occupancy Standard. This standard assesses bedroom requirements based on the following criteria:

- there should be no more than 2 people per bedroom
- children aged under 5 of different sexes may reasonably share a bedroom
- children aged 5 and over of opposite sexes should have separate bedrooms
- children aged under 18 and of the same sex may reasonably share a bedroom
- single household members aged 18 and over should have a separate bedroom, as should parents or couples.

**illness:** A state of feeling unwell, although the term is also often used synonymously with disease.

**immunisation:** The process of both receiving a **vaccine** and becoming immune to the disease as a result.

**immunity:** The ability of an organism to resist a particular infection or toxin by the action of specific antibodies or sensitized white blood cells.

**incidence:** The number of new cases (of an illness, injury or event, and so on) occurring during a given period. Compare with **prevalence**.

**incubation period:** The time from the moment of exposure to an infectious agent until signs and symptoms of the disease appear.

**indicator:** A key statistical measure selected to help describe (indicate) a situation concisely so as to track change, progress and performance; and to act as a guide for decision making.

**Indigenous status:** Whether or not a person identifies as being of Aboriginal and/or Torres Strait Islander origin.

**Indigenous:** A person of Aboriginal and/or Torres Strait Islander descent who identifies as an Aboriginal and/or Torres Strait Islander. See also **Aboriginal or Torres Strait Islander**.

**infectious disease:** Disease or illness caused by infectious organisms or their toxic products. The disease may be passed directly or indirectly to humans through contact with other humans, animals or environments where the organism is found. Also referred to as a communicable disease.

**interoperability:** The ability of different information systems, devices and applications ('systems') to access, exchange, integrate and cooperatively use data in a coordinated manner.

**intentional self-harm:** Attempted suicide, as well as cases where people have intentionally hurt themselves, but not necessarily with the intention of suicide (for example, acts of self-mutilation).

**International Statistical Classification of Diseases and Related Health Problems (ICD):** The World Health Organization's internationally accepted classification of death and disease. The Tenth Revision (ICD-10) is currently in use. The ICD-10-AM is the Australian Modification of the ICD-10; it is used for diagnoses and procedures recorded for patients admitted to hospitals.

**life course:** A series of life stages that people are normally expected to pass through as they progress from birth to death. For example, stages often included are: birth and infancy, childhood, youth, working age, and older age.

**life expectancy:** An indication of how long a person can expect to live, depending on the age they have already reached. Technically, it is the number of years of life left to a person at a particular age if death rates do not change. The most commonly used measure is life expectancy at birth.

**long-term condition:** A term used to describe a health condition that has lasted, or is expected to last, at least 6 months. See also **chronic diseases**.

**macular degeneration:** A progressive deterioration of the macula of the retina (the central inner-lining of the eye). It is often positively related to old age (usually referred to as 'age-related macular degeneration'), and results in a loss of central vision.

**Medicare:** A national, government-funded scheme that subsidises the cost of personal medical services for all Australians and aims to help them afford medical care. The Medicare Benefits Schedule (MBS) is the listing of Medicare services subsidised by the Australian Government. The schedule is part of the wider Medicare Benefits Scheme (Medicare).

**medicines that act on the central nervous system:** A group of medicines that have an effect on the central nervous system (brain and spinal cord). These are used for many different conditions.

**mental illness (or mental disorders):** Disturbances of mood or thought that can affect behaviour and distress the person or those around them, so that the person has trouble functioning normally. They include **anxiety disorders, depression** and schizophrenia.

**mesothelioma:** An aggressive form of cancer occurring in the mesothelium—the protective lining of the body cavities and internal organs, such as the lungs, heart and bowel.

**modifiable risk factor:** A risk factor where the level of associated risk can be increased or decreased through changes in behaviours or exposures.

**monitoring (of health):** A process of keeping a regular and close watch over important aspects of public health and health services, using various measurements, and then regularly reporting on the situation, enabling health systems and society more generally to plan and respond accordingly. The term is often used interchangeably with surveillance, although surveillance may imply more urgent watching and reporting—such as the surveillance of infectious diseases and epidemics. Monitoring can also be applied to individuals, such as hospital care where a person's condition must be closely assessed over time.

**morbidity:** The ill health of an individual and levels of ill health in a population or group.

**mortality:** Number or rate of deaths in a population during a given time period.

**My Health Record:** An online platform for storing the health information of individuals, including their Medicare claims history, hospital discharge information, diagnostic imaging reports and details of allergies and medications.

**non-admitted patient:** A patient who receives care from a recognised non-admitted patient service/clinic of a hospital, including emergency departments and outpatient clinics.

**non-fatal burden:** The quantified impact on a population of ill health due to disease or injury, measured as years lived with disability (YLD).

**non-Indigenous:** People who have declared that they are not of Aboriginal or Torres Strait Islander descent. Compare with **Other Australians**.

**obesity:** Marked degree of overweight, defined for population studies as a **body mass index** of 30 or over. See also **overweight**.

**occupational exposures and hazards:** Chemical, biological, psychosocial, physical and other factors in the workplace that can potentially cause harm.

**odds ratio:** A measure of the association between an exposure and an outcome. The odds ratio represents the odds that an outcome will occur, given a particular exposure, compared with the odds of the outcome's occurring in the absence of that exposure. The value of the odds ratio is interpreted as:

- An odds ratio close or equal to 1 means that the exposure has little or no effect on the odds of the outcome's occurring
- An odds ratio greater than 1 means that the exposure increases the odds of the outcome's occurring
- An odds ratio less than 1 means that the exposure decreases the odds of the outcome's occurring.

**opioid medicines:** A group of medicines that can be used to relieve pain and relax muscles, some of which may be used in palliative care.

**Other Australians:** People who have declared that they are not of Aboriginal or Torres Strait Islander descent, and people whose Indigenous status is unknown. Compare with **non-Indigenous**.

**otitis media:** All forms of inflammation and infection of the middle ear. Active inflammation or infection is nearly always associated with a middle ear effusion (fluid in the middle ear space).

**outcome (health outcome):** A health-related change due to a preventive or clinical intervention or service. (The intervention may be single or multiple, and the outcome may relate to a person, group or population, or be partly or wholly due to the intervention.)

**out-of-pocket costs:** The total costs incurred by individuals for health care services, over and above any refunds from the MBS, the PBS or private health insurance funds.

**overcrowding:** Situation in a dwelling where one or more additional bedrooms would be required to adequately house its inhabitants, according to the Canadian National Occupancy Standard. See also **housing adequacy**.

**overweight:** Defined for the purpose of population studies as a **body mass index** of 25 or over. See also **obesity**.

**pandemic:** A new infectious disease that is rapidly spreading across a large region, or worldwide, and affecting large numbers of people.

**permanent residential aged care:** Care for older people provided in residential aged-care facilities (also often called 'nursing homes'). People live in the facility, either in private or shared rooms, and commonly receive assistance with activities of daily living (such as eating and personal care), as well as nursing care. Many facilities also provide respite residential aged care for short-term stays.

**person-centred data:** An approach to analysis which focusses on the experiences and outcomes of individuals, rather than organising information by specific topics, services or systems.

**personalised medicine:** a type of medical care in which treatment is customized for an individual patient.

**Pharmaceutical Benefits Scheme (PBS):** A national, government-funded scheme that subsidises the cost of a wide variety of pharmaceutical drugs, covering all Australians, to help them afford standard medications. The PBS lists all the medicinal products available under the PBS and explains the uses for which subsidies can apply (see **Repatriation Pharmaceutical Benefits Scheme**).

**population health:** Typically, the organised response by society to protect and promote health and to prevent illness, injury and disability. Population health activities generally focus on:

- prevention, promotion and protection rather than on treatment
- populations rather than individuals
- the factors and behaviours that cause illness.

It can also refer to the health of particular subpopulations, and comparisons of the health of different populations.

**post-streptococcal glomerulonephritis:** Inflammation of the kidneys by certain strains of streptococcus bacteria, associated with a previous infection of the skin or throat.

**post-traumatic stress disorder (PTSD):** PTSD is a form of anxiety disorder in which a person has a delayed and prolonged reaction after being in an extremely threatening or catastrophic situation such as a war, natural disaster, terrorist attack, serious accident or witnessing violent deaths.

**potentially preventable hospitalisation (PPH):** Hospital separations for specified conditions which could potentially have been prevented through the provision of appropriate health interventions and early disease management for individuals. The proposed preventive measures could usually have been delivered in primary care and community-based care settings (including by general practitioners, medical specialists, dentists, nurses and allied health professionals). PPH conditions are classified as vaccine-preventable, chronic and acute. Descriptions of each PPH condition can be found at 'Disparities in potentially preventable hospitalisations across Australia: Exploring the data'.

**premature deaths (or premature mortality):** Deaths that occur at a younger age than a selected cut-off. The age below which deaths are considered premature can vary depending on the purpose of the analysis and the population under investigation. In this report, deaths among people aged under 75 are considered premature.

**presenteeism:** The practice of going to work despite being sick or unwell.

**presymptomatic transmission:** **Transmission** of an infectious disease before the infected person displays symptoms.

**prevalence:** The number or proportion (of cases, instances, and so forth) in a population at a given time. Compare with **incidence**.

**primary health care:** Services delivered in general practices, community health centres, Aboriginal health services and allied health practices (for example, physiotherapy, dietetic and chiropractic practices) and which come under numerous funding arrangements.

**principal diagnosis:** The diagnosis established, after study, to be chiefly responsible for an episode of patient care (hospitalisation), residential care or attendance at a health care establishment. Diagnoses are recorded using the relevant edition of the International statistical classification of diseases and related health problems, 10th revision, Australian modification (ICD-10-AM).

**private patient:** A person admitted to a private hospital, or person admitted to a public hospital who decides to choose the doctor(s) who will treat them or to have private ward accommodation. This means they will be charged for medical services, food and accommodation.

**pro re nate (PRN) medicines:** Medicines prescribed to be taken as required (as opposed to medicines that are prescribed to be taken regularly, for example 3 times a day).

**psychological distress:** Unpleasant feelings or emotions that affect a person's level of functioning and interfere with the activities of daily living. This distress can result in having negative views of the environment, others and oneself, and manifest as symptoms of mental illness, including anxiety and depression.

**psychosocial:** Involving both psychological and social factors

**public health:** Activities aimed at benefiting a population, with an emphasis on prevention, protection and health promotion (as distinct from treatment tailored to individuals with symptoms). Examples include provision of a clean water supply and good sewerage, conduct of anti-smoking education campaigns, and screening for diseases such as cancer of the breast and cervix.

**public patient:** A person admitted to hospital who has agreed to be treated by doctors of the hospital's choice and to accept shared ward accommodation. Such patients are admitted and treated at no charge and are mostly funded through public sector health or hospital service budgets.

**rate:** One number (the numerator) divided by another number (the denominator). The numerator is commonly the number of events in a specified time. The denominator is usually the population 'at risk' of the event. Rates—crude, age-specific and age-standardised—are generally multiplied by a number such as 100,000 to create whole numbers.

**real expenditure:** Expenditure that has been adjusted to remove the effects of inflation (for example, expenditure for all years compiled using 2017–18 prices). Removing the effects of inflation allows comparisons to be made between expenditures in different years on an equal dollar-for-dollar basis. Changes in real expenditure measure the change in the volume of goods and services produced (see **constant prices**).

**remoteness classification:** Each state and territory is divided into several regions based on road distance that must be travelled to access goods and services (such as general practitioners, hospitals and specialist care). These regions are categorised using the Accessibility/Remoteness Index of Australia and (from 2011 onwards) defined as Remoteness Areas by the Australian Statistical Geographical Standard in each Census year. The 5 Remoteness Areas are *Major cities*, *Inner regional*, *Outer regional*, *Remote* and *Very remote*.

**Repatriation Pharmaceutical Benefits Scheme (RPBS):** An Australian Government scheme that provides a range of pharmaceuticals and wound dressings at a concessional rate for the treatment of eligible veterans, war widows/widowers and their dependants.

**reserve (Australian Defence Force):** Australian Defence Force members who have had at least 1 day of reserve service on or after 1 January 2001.

**respiratory condition:** A condition affecting the airways and characterised by symptoms such as wheezing, shortness of breath, chest tightness and cough. Conditions include **asthma** and **chronic obstructive pulmonary disease (COPD)**—which includes **emphysema** and chronic bronchitis.

**rheumatic heart disease:** Damage to the heart valves as a result of one or more episodes of **acute rheumatic fever**.

**risk:** The probability of an event occurring during a specific period of time.

**risk factor:** A factor that represents a greater risk of a health disorder or other unwanted condition or event. Some risk factors are regarded as causes of disease; others are not necessarily so. Along with their opposites, protective factors, risk factors are known as **determinants**.

**secondary use of data:** any application of data beyond the reason for which they were first collected (known as the primary use or purpose).

**separation:** The formal process where a hospital records the completion of an episode of treatment and/or care for an admitted patient.

**sexual violence:** The occurrence, attempt or threat of sexual assault experienced by a person since the age of 15. Sexual violence can be perpetrated by partners in a domestic relationship, former partners, other people known to the victims, or strangers.

**sexually transmissible infection:** An infectious disease that can be passed from one person to another by sexual contact. Examples include **chlamydia** and **gonorrhoea** infections.

**smoker:** Someone who reports smoking daily, weekly or less than weekly.

**social determinants of health:** The circumstances in which people are born, grow up, live, work and age, and the systems put in place to deal with illness. These circumstances are in turn shaped by a wider set of forces including economics, social policies and politics.

**social exclusion:** A situation where people do not have the resources, opportunities and capabilities they need to learn, work, engage with or have a voice in their communities. Composite measures of social exclusion weight indicators such as income level, access to education, unemployment, poor English, health services and transport, and non-material aspects such as stigma and denial of rights. These measures are typically divided into three levels: marginal exclusion, deep exclusion and very deep exclusion.

**Socio-Economic Indexes for Areas (SEIFA):** A set of indexes, created from Census data, that aim to represent the **socioeconomic position** of Australian communities and identify areas of advantage and disadvantage. The index value reflects the overall or average level of disadvantage of the population of an area; it does not show how individuals living in the same area differ from each other in their socioeconomic group. This report uses the **Index of Relative Socio-Economic Disadvantage**.

**socioeconomic position:** An indication of how 'well off' a person or group is. In this report, socioeconomic areas are mostly reported using the **Socio-Economic Indexes for Areas**, typically for five groups (**quintiles**)—from the most disadvantaged (worst off or lowest socioeconomic area) to the least disadvantaged (best off or highest socioeconomic area).

**specialist services:** Services that support people with specific or complex health conditions and issues, who are generally referred by primary health care providers. These services are often described as 'secondary' health care services. In many cases, a formal referral is required for an individual to be able to access the recommended specialist service

**substance use disorder:** A disorder of harmful use and/or dependence on illicit or licit drugs, including alcohol, tobacco and prescription drugs

**suicidal behaviours:** The collective term for **suicidal ideation**, suicide plans and suicide attempts.

**suicidal ideation:** Serious thoughts about ending one's own life.



**suicide:** An action to deliberately end one's own life.

**surveillance:** Systematic ongoing collection, collation, and analysis of data and the timely dissemination of information to those who need to know so that action can be taken.

**telemedicine:** The remote delivery of health care services, such as health assessments or consultations, over the telecommunications infrastructure

**trachoma:** An eye disease caused by infection with *Chlamydia trachomatis* bacteria.

**transmission:** The act of transferring something, such as an infectious disease, from one person to another.

**type 1 diabetes:** A form of **diabetes** mostly arising among children or younger adults and marked by a complete lack of insulin. Insulin replacement is needed 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 primary or main cause of death: the condition, disease or injury that initiated the sequence 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**.

**vaccination:** Treatment with a **vaccine** to produce **immunity** against a disease.

**vaccine:** A substance used to stimulate the production of **antibodies** and provide **immunity** against one or several diseases, prepared from the causative agent of a disease, its products, or a synthetic substitute, treated to act as an **antigen** without inducing the disease.

**virus:** An infective agent that typically consists of a nucleic acid molecule in a protein coat, is too small to be seen by light microscopy, and is able to multiply only within the living cells of a host

**wellbeing:** A state of health, happiness and contentment. It can also be described as judging life positively and feeling good. For public health purposes, physical wellbeing (for example, feeling very healthy and full of energy) is also viewed as critical to overall wellbeing. Because wellbeing is subjective, it is typically measured with self-reports, but objective indicators (such as household income, unemployment levels and neighbourhood crime) can also be used.

**workforce:** People who are employed or unemployed (not employed but actively looking for work). Also known as the labour force.

**years lived with disability (YLD):** A measure calculated as the prevalence of a condition, multiplied by a severity weight for that condition (that is, its disabling effect). YLD represent the non-fatal burden of disease or disability.



*Australia's health 2020: data insights* presents an overview of health data in Australia and explores selected health topics in 10 original articles.

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