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Australia's health 2024

data insights

The AIHW is a Corporate Commonwealth entity producing authoritative and accessible information and statistics to inform and support better policy and service delivery decisions, leading to better health and wellbeing for all Australians.

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Australian Government
Australian Institute of
Health and Welfare

The Hon Mark Butler MP
Minister for Health and Aged Care
Parliament House
Canberra ACT 2600

Dear Minister

On behalf of the Board of the Australian Institute of Health and Welfare (AIHW), I am pleased to present to you *Australia's health 2024,* as required under subsection 31(1) of the *Australian Institute of Health and Welfare Act 1987.*

The *Australia's health 2024* suite of products continues the AIHW tradition of delivering high quality evidence and analysis on health. This edition provides comprehensive coverage of health topics via online webpages and explores a selection of important health issues and data improvements. It also brings together a holistic summary of the state of health in Australia in the PDF report, *Australia's health 2024: in brief*.

I commend *Australia's health 2024* to you as a significant contribution to national information on health-related issues, and to the development of policies and programs in Australia.

Yours sincerely

The Hon Nicola Roxon

Chair
AIHW Board
10 June 2024

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About Australia's health 2024

Australia's health 2024 is the AIHW's 19th biennial health report.
It consists of 3 products:


Australian Government
Australian Institute of Health and Welfare
AIHW
Australia's health 2024
in brief

Australia's health 2024: in brief

This report provides a summary of the state of health in Australia today.

Australia's health: topic summaries

This is a collection of over 60 web pages that present key information and statistics on the health of Australians, the health system, and factors that can influence our health (some are updated when new data are available).

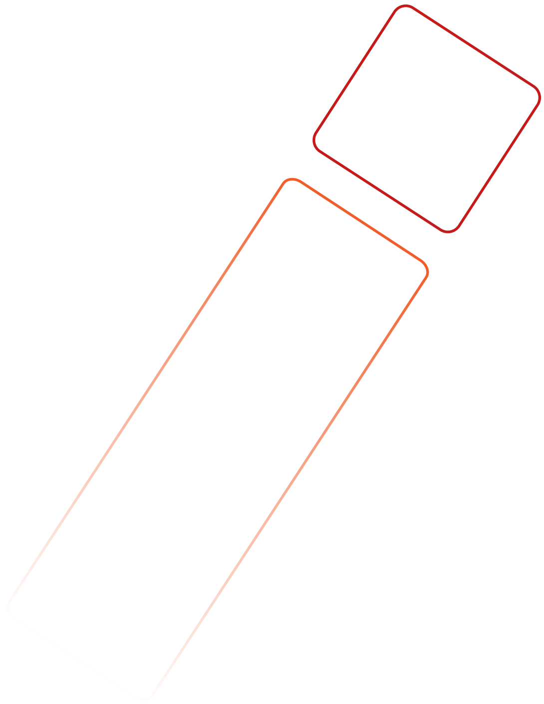

Australian Government
Australian Institute of Health and Welfare
AIHW
Australia's health 2024
data insights

Australia's health 2024: data insights

This report is a collection of 11 in-depth web articles on selected health topics, with a focus on the importance of a strong evidence base for supporting the health of Australians.

All products can be viewed or downloaded at:
www.aihw.gov.au/reports-data/australias-health

Contents



Preface

Every 2 years, the Australian Institute of Health and Welfare (AIHW) produces its flagship report on Australia's health – this year marks the 19th edition in the series.

Australia's health 2024 comes at a time when we consider how Australia and the health system are faring after a once in a century event.

While COVID-19 poses continuing risks for some people in Australia, the overall risks for the Australian population have reduced with the widespread uptake of vaccines and treatment. *Australia's health 2024* considers where Australia's health and health system stand now, and what other ongoing and future health challenges remain.

Australia generally ranks well internationally on important health measures; for example, life expectancy is high and infant mortality is low.

Over the last 100 years, life expectancy in Australia has increased considerably, and deaths from infectious diseases have declined. However, in 2022, COVID-19 became the third leading cause of death in Australia – marking the first time in over 50 years that an infectious disease had been in the top 5 causes of death. For the first time since the mid-1990's, Australia also saw a very slight drop in life expectancy in 2020–22, but it was considerably smaller than in countries such as the United States and United Kingdom.

Today, chronic conditions – also known as long-term health conditions – are an ongoing cause of substantial ill health, disability and premature death in Australia. Three in 5 people are living with at least one chronic condition and 2 in 5 are living with 2 or more.

Chronic conditions present a key challenge for individuals, health providers and society as a whole. Individuals with chronic conditions often have complex needs that require services from all levels of the health system. Australia's ageing population presents an extra challenge through the increased demand for services to care for and support people living with chronic conditions.

Australia's population is diverse, and health and health outcomes differ across groups and by geographical location. Health inequalities persist for many population groups – including for Aboriginal and Torres Strait Islander (First Nations) people and people living in rural and remote communities.

In recent years, the health system has been tested. The emergence of COVID-19 triggered an upsurge in demand for health services, and the redirection and repurposing of health resources. *Australia's health 2024* shows that, early in the pandemic, cancer screenings and procedures were missed or delayed. Elective surgeries were also disrupted and numbers have not yet returned to pre-pandemic levels.

But the pandemic also led to innovations in telehealth, digital health, and pandemic response strategies; for example, the report shows that changes to delivery of services via telehealth in Australia show no signs of reverting to pre-pandemic levels.

A notable by-product of the pandemic is that – for a time – health data were at the forefront of Australians' minds.

At the pandemic's peak, daily case numbers improved risk awareness and influenced individuals' behaviours. Simultaneously, surveillance and monitoring data were used to inform health guidance and recommendations on measures such as mask-wearing, physical distancing and vaccines.

But the usefulness of health data extends far beyond such emergencies.

High-quality data and information are essential for monitoring all types of population health challenges, enabling long-term planning, the development of health-care policies, promotion of health equity, support for research and innovation and improved delivery and quality of healthcare services.

As did past editions of *Australia's health*, this year's flagship demonstrates the value of our national health data collections. It does so by answering fundamental questions about the health of Australians and Australia's health services.

The report presents some good news stories – for example, since the National Cervical Screening Program was introduced in 1991, the mortality rate for cervical cancer has halved in women aged 25–74.

It also explores current activities to improve the evidence base available to support decision making – such as national data linkage projects, which bring together information from multiple data sources to provide more detailed health information about Australia's population. For example, the National Health Data Hub has yielded important findings about Australians living with dementia in the community and their movement into aged care following a stay in hospital.

Australia's health 2024 comprises 3 products:

- *Australia's health 2024: data insights* (this report) – a collection of in-depth articles on selected health topics.
- Australia's health: topic summaries – a collection of 60+ web pages that present key information and statistics on the health of Australians, the health system and factors that can influence health (some are periodically updated)
- *Australia's health 2024: in brief* – a summary report presenting key findings and concepts for a holistic picture of health in Australia.

Since its first release in 1988, *Australia's health* has been an authoritative source of health information for policy advisors, service providers, researchers and the public. I am confident *Australia's health 2024* will continue this trend and play an important role in supporting better decisions today on health policy and service delivery.

I would like to thank everyone involved in producing this report and acknowledge the valuable advice provided by many experts throughout the drafting and review stages.

We are committed to improving the usefulness and relevance of our flagship reports and welcome your feedback via flagships@aihw.gov.au

Dr Zoran Bolevich

CEO

Introduction

Health is ‘a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity’ (World Health Organization 1946). It encompasses many important aspects of a person’s life, including their physical condition, emotional state, social relationships and overall quality of life.

There is a close relationship between people’s health and their living circumstances, and many factors interact to influence a person’s health outcomes. These include socioeconomic and environmental conditions, cultural factors, health behaviours, biological factors, genetics, and social and community networks.

The health information landscape in Australia comprises data collected about health-care practice, health status, the health system – and about the people who provide health services. High-quality information supports a sound understanding of health behaviours, health care and outcomes, and can identify possible areas for improvement.

Overall, health is a complex feature of life that matters to all people.

This report – Australia’s health 2024: data insights – examines issues related to the health of Australians, the health system and the data supporting our understanding of these things. It contains 11 original articles on important health topics and their information environments.

Each article highlights the crucial role of high-quality data in understanding and improving the health of Australians.

Articles

Australia's health data landscape	This article examines Australia's data environment in terms of understanding the population's health and the health system.
Australia's dental data landscape	This article describes the state of dental data in Australia. It examines how data on the oral health of Australians and their use of dental services are currently collected and translated into actionable information. It explores barriers to collecting and using dental data and opportunities to strengthen the evidence base.
Concussions in Australia over the last decade	Most concussion hospitalisations in Australia are linked to falls, transport crashes or assault. This article analyses the causes, nature and severity of reported concussions in Australia.
Electronic cigarette use (vaping) in Australia in 2022–2023	This article reports on the prevalence of e-cigarette use in Australia and examines the reasons for vaping in the general population.
Enhancing communicable disease monitoring in Australia through data linkage	This article describes the data sharing arrangements and technical processes required to effectively monitor communicable diseases. It reports on the development of the AIHW's COVID-19 Register – a linked data asset designed to improve understanding about the health outcomes and health service use of people diagnosed with COVID-19.
Extreme weather related injuries in Australia over the last decade	In Australia, extreme heat causes more hospitalisations than other extreme weather events (that is, bushfires, storms and extreme cold). This article reports on the frequency and type of injuries linked to these weather events.
Improving Australia's dementia data for national action	The impact of dementia on the lives of Australians is increasing, but Australia still has some major data gaps on dementia. This article explores these gaps, and the activities underway to rectify them.
The ongoing challenge of chronic conditions in Australia	Over 90% of Australia's non-fatal burden of disease is related to chronic conditions (also known as long-term health conditions). This article examines the nature and type of chronic conditions in Australia and the current and future challenges they present.

Size and sources of the health gap for Australia's First Nations people 2017–2019	A large part of the 'health gap' between First Nations and non-Indigenous people can be attributed to differences in the social determinants of these 2 groups (such as employment status, income and level of education) and health risk factors (such as smoking). To close the 'health gap', these differences must be resolved.
Use of Medicare services and pharmaceuticals by mental health patients in Australia over the last decade	This article provides an overview of mental health patients who accessed mental health and non-mental health services provided through the Medicare Benefits Schedule and the Pharmaceutical Benefits Schedule. It examines how patient profiles and use patterns changed between 2012 and 2021.
Using nowcasting and projections for statistical understandings in health	The most recent data contained in some national collections can be several years old. This article discusses how providing projections to the current period (nowcasting) and projections for future periods can provide statistical health understandings about today and beyond.

Reference

WHO (World Health Organization) (1946) Preamble to the Constitution of the World Health Organization as adopted by the International Health Conference, New York, 19–22 June, 1946, WHO website, accessed 20 March 2024.

List of Australia’s health: topic summaries

Australia’s health: topic summaries are web pages that present key information and statistics on the health system, health of Australians and factors that can influence our health.
The full list of topic summaries is provided here and can accessed at http://www.aihw.gov.au/australias-health/summaries.

Alcohol

Alcohol and other drug treatment services

Biomedical risk factors

Built environment and health

Burden of disease

Cancer

Cancer screening

Chronic conditions

Chronic kidney disease

Chronic musculoskeletal conditions

Chronic respiratory conditions

COVID-19

Dementia

Determinants of health for First Nations people

Diabetes

Diet

Digital health

Family, domestic and sexual violence

First Nations people and the health system

General practice, allied health and other primary care services

Health and wellbeing of First Nations people

Health care safety and quality

Health expenditure

Health of children

Health of mothers and babies

Health of older people

Health of people experiencing homelessness

Health of people in prison

Health of people with disability

Health of veterans

Health of young people

Health promotion and health protection

Health system overview

Health workforce

Heart, stroke and vascular disease

Hospitals

Illicit drug use

Immunisation and vaccination

Infectious and communicable diseases

Injury

Life expectancy and causes of death

Measures of health and health care for Australia and similar countries

Medicines in the health system

Mental health

Mental health services

Multimorbidity

Natural environment and health

Oral health and dental care

Overweight and obesity

Palliative care services

Pathology, imaging and other diagnostic services

Physical activity

Physical health of people with mental illness

Profile of Australia’s population

Profile of First Nations people

Referred medical specialist attendances

Rural and remote health

Social determinants of health

Stress and trauma

Suicide and intentional self-harm

Tobacco and e-cigarettes

Understanding health and health data

What are determinants of health?

Australia’s health data landscape

Key messages

The health data landscape continues to evolve and respond to changes in health and to broader changes in the data landscape. Key current and future developments include:

- streamlining and capitalising on the use of linked data to better understand priority populations and patient pathways
- making optimal use of artificial intelligence, machine learning and natural language processing (to automate coding and other data processes) and of facilitative modelling, forecasts and projections (for health planning and service delivery)
- responding to current and future health developments – such as virtual care and vaping – by developing standards and monitoring processes.

Introduction

Data and information are critical for developing evidence-based decision-making – for example, informing timely government responses during crises – and for increasing productivity. Broadly, health data are used to:

- provide clinical care
- generate population health statistics
- help governments and other entities manage the resources and performance of the health system
- develop policy.

Health data have been used for many years to inform decisions about health, both at an individual and a population level. Key examples of the use of population health data in Australia include:

- Knowing the rates of preventive activities (such as cancer screening or immunisation) among different population groups has enabled health promotion campaigns to be targeted at these groups.
- Calculation of population-level cancer survival rates has provided valuable information for both individuals and clinicians. For example, survival statistics may be useful for someone with cancer to understand their prognosis.
- Rates of biomarkers by population groups has informed general practitioner (GP) guidelines for recommended ages for testing blood pressure, cholesterol and other biomarkers – particularly for Aboriginal and Torres Strait Islander (First Nations) people.

- Monitoring tobacco smoking, risky drinking and food intake has both informed and helped to guage the impact of policies such as plain packaging for tobacco products and health star ratings on food packaging.
- Monitoring infectious diseases facilitates response and recovery – for example, as happened for the COVID-19 pandemic.
- Monitoring health service use (including the use of hospitals and mental health services) during the COVID-19 pandemic enabled service needs and gaps to be understood and planned for.
- Estimates from the Australian Burden of Disease Study for a range of health conditions and risk factors were used to inform and measure progress against the National Preventive Health Strategy 2021–2030.
- Assessment of the impact of the bowel cancer screening program identifying cancers at earlier stages shows that the program reduces the risk of premature death.

During the last decade, many changes have occurred in both the health and broader data landscape. These have been driven by a range of factors, including increased need as well as availability, accountability and technology. Key factors include:

- the move from paper to electronic recording
- the advent of 'big data' – that is, the extremely large and complex data sets that cannot be effectively processed or analysed using traditional techniques
- the ability and technology to support data linkage
- the recognition of the importance of the need to govern, manage and use data well.

At the same time, the greater availability of data and rapid advancements in technology have led to different challenges, such as ensuring privacy and managing cyber security risks.

Data on the health status of people

A range of data sources are used to understand the health status of Australians – including information about health conditions, medications and treatments, functioning ability and general wellbeing. These data are essential not only to inform policies, programs and service planning but also to assess trends over time and to indicate disparities in health status.

Data sources used to monitor the health status of people include surveys, administrative data sets, disease-specific registries and disease-surveillance systems (Box HD.1).

Box HD.1: Data sources to monitor the health status of people

Health administrative data sets

Every year, millions of Australians connect with the health system. When they do, their information is collected to ensure that health care is delivered to the highest possible standard. When a GP records information about a patient or a pharmacist fills a script for medicine, the details of these and many more interactions are collected. These collected data guide the health system. Examples of these data sources are the Medical Benefits Schedule (MBS), the Pharmaceutical Benefits Scheme (PBS) and hospital admission records.

Surveys

Surveys are used to gain further insights into not only people’s health – such as health conditions and risks factors – but also the factors that influence health. Both cross-sectional and longitudinal surveys are used. Examples of cross-sectional surveys are:

- the Australian Bureau of Statistics (ABS) National Health Survey, which collects a wide range of information about a person’s demographic and socioeconomic characteristics and self-reported health conditions and health risk factors
- the AIHW National Drug Strategy Household Survey (NDSHS), which collects information on people’s consumption of tobacco, alcohol and other drugs, and their attitudes towards and perceptions of these drugs.

Longitudinal surveys include the Household, Income and Labour Dynamics in Australia Survey, the Australian Longitudinal Study on Women’s Health and Ten to Men: the Australian Longitudinal Study on Male Health. These surveys collect information to enable a better understanding of changes in health status and risk factors over time.

Clinical registries

Clinical information obtained during health-care encounters or through clinical trials is primarily used in individual patient treatment and management. It may also be collated and stored in condition-specific clinical registries that support research on treatments. For example, the Australia and New Zealand Dialysis and Transplant Registry collects information on the treatment outcomes of patients with end-stage kidney failure.

Surveillance systems

Australia has well-established surveillance systems, such as the National Notifiable Diseases Surveillance System, that collect data in close to real time, providing information to guide action to combat current threats.

Other data sources

Cross-sectoral data (for example, on education, employment and aged care services), new consumer transactional sources (such as banking and supermarket data), and larger and more complex data sets (such as genomic data, electronic health records and multi-source linked data sets) can also contribute to an understanding of the health and wellbeing of the people of Australia.

Data on the health status of population groups

Some population groups and communities in Australia face more challenges in accessing health services and information – and experience poorer health – than the broader Australian population.

The National Preventive Health Strategy 2021–2030 refers to these groups of people as 'priority populations'; they include, but are not limited to:

- First Nations people
- culturally and linguistically diverse (CALD) people
- lesbian, gay, bisexual, trans/transgender, intersex, queer and/or other sexuality (LGBTIQ+) and gender diverse people
- people with mental health conditions
- people in low socioeconomic groups
- people with disability
- people living in rural, regional and remote areas.

Improving data on the health status of population groups

A large amount of data is already available about many of these priority population groups. (See for example, First Nations people, Rural and remote health). However, some areas still have limited data.

A range of data development work is underway to improve the collection of demographic information in national data sets to identify priority population groups – for example, to include the ABS Standard for Sex, Gender, Variations of Sex Characteristics and Sexual Orientation Variables in data sets (Box HD.2).

Box HD.2: Data on the health of the LGBTIQ+ population

The acronym 'LGBTIQ+' refers to a diverse population of people who identify as lesbian, gay, bisexual, trans/transgender, intersex, queer, asexual, other sexuality, gender, and bodily diverse.

Data sets in Australia that include information on diverse sex, gender, variations in sex characteristics and sexual orientation are limited (AIHW 2024a).

However, the NDSHS recently used questions from the ABS *Standard for Sex, Gender, Variations of Sex Characteristics and Sexual Orientation Variables*. In additon to sexual orientation, the survey collected information on sex at birth and gender which allowed for reporting on the use of tobacco, alcohol and other drugs by gay, lesbian, bisexual, trans and gender diverse people (AIHW 2024b).

Other development work includes data linkage to better identify and report on the health of CALD populations (Box HD.3).

Box HD.3: Data on the health of CALD populations

A CALD classification can cover a range of aspects, including a person's country of birth, their ancestry, where their parents were born, what language/s they speak, and their religious affiliation.

The AIHW web report *Chronic health conditions among culturally and linguistically diverse Australians, 2021* explored the differences in health status by various CALD variables to describe the diverse experiences of this population.

Using integrated data can help to meet the challenge of identifying CALD populations, such as refugees, in administrative health data sets. The AIHW web report *Health of refugees and humanitarian entrants in Australia* used the ABS Person Level Integrated Data Asset (PLIDA) to combine information that identifies refugees from the settlement database with other health data sets such as the PBS and MBS. This work provided valuable data to inform the Refugee and Humanitarian Entrant Settlement and Integration Outcomes Framework.

Data from health systems

Sources of Australia's health information can be summarised into 3 distinctive categories:

- *Primary health:* This covers a person's first contact with the health system, including GPs, pharmacy, dentistry and allied health care for which PBS and Medicare data are key resources. The AIHW's Medicare Benefits Scheme funded services: monthly data dashboard:
    - reports regularly on the proportion of fees charged by service providers that attracted a subsidy through the MBS, as opposed to being funded by patient contributions (including out-of-pocket payments, private health insurance and other sources)
    - shows the volume of MBS services claimed per person in the population for each broad type of service.

  This dashboard is updated every month with a 1-month lag (for example, February data are published at the end of March).
- *Hospitals:* The well-established national hospitals databases track interactions at every public hospital and most private hospitals in Australia. They record granular information, such as time of admission, admission type, demographic information and locality. These databases can show trends reaching back decades.
    - One example of where these data are made available is the AIHW's MyHospitals reporting. MyHospitals explores various topics, such as emergency department care, admitted patient care, elective surgery and the health workforce. It provides vital data on hospital access, activity, safety and quality, and spending.
- *My Health Record:* This centralised electronic health record system improves the accessibility and coordination of health information to empower the individual.

> Individuals have the option to create a record to consolidate their key health information, such as allergies, medications, pathology results and immunisation history. Patients and authorised health-care providers can access this information to support informed decision-making and continuity of care.

Primarily, information collected from health systems informs health-care service delivery; for example, to bill for transactions and to monitor workforce and facility capacity. While useful, these data sources do not necessarily provide all the information needed to monitor the health of the population. They do not always include detailed information about why the health service was used, what occurred at the health service, and what was done – nor do they include all desired demographic information. However, for particular situations, these data sources can be very informative and have very detailed information not available elsewhere – often at the population level and not just a sample. For example, almost all people who experience a non-fatal heart attack will be treated in hospital and their hospital record will contain rich data about that admission.

Data gaps and development

Considerable progress has been made over recent years in developing new sources of, and insights into, information to fill data gaps.

Maternity care

One notable example is in maternity care with the development of the maternity models of care data collection. This collection provides information on:

- the different types of maternity care available
- how many people are using them
- how the outcomes differ by the different care types.

Developing a maternity models of care data collection

Maternity models of care describe how maternity care is provided to women during pregnancy, birth and the postnatal period. The model of care may vary by maternity service and location, as well as between public and private providers.

The AIHW collects models of care information from each maternity service in Australia using the Maternity Care Classification System (MaCCS). This system was developed jointly by the National Perinatal Epidemiology and Statistics Unit at the University of New South Wales and the AIHW, as part of the National Maternity Data Development Project.

The MaCCS allows the AIHW to report on how many models of care there are, and the characteristics of these models, including, for example, the women for whom they are designed, the carers involved in providing the models of care, and the continuity of care within them. Each model of care can be classified into one of 11 categories based on its characteristics.

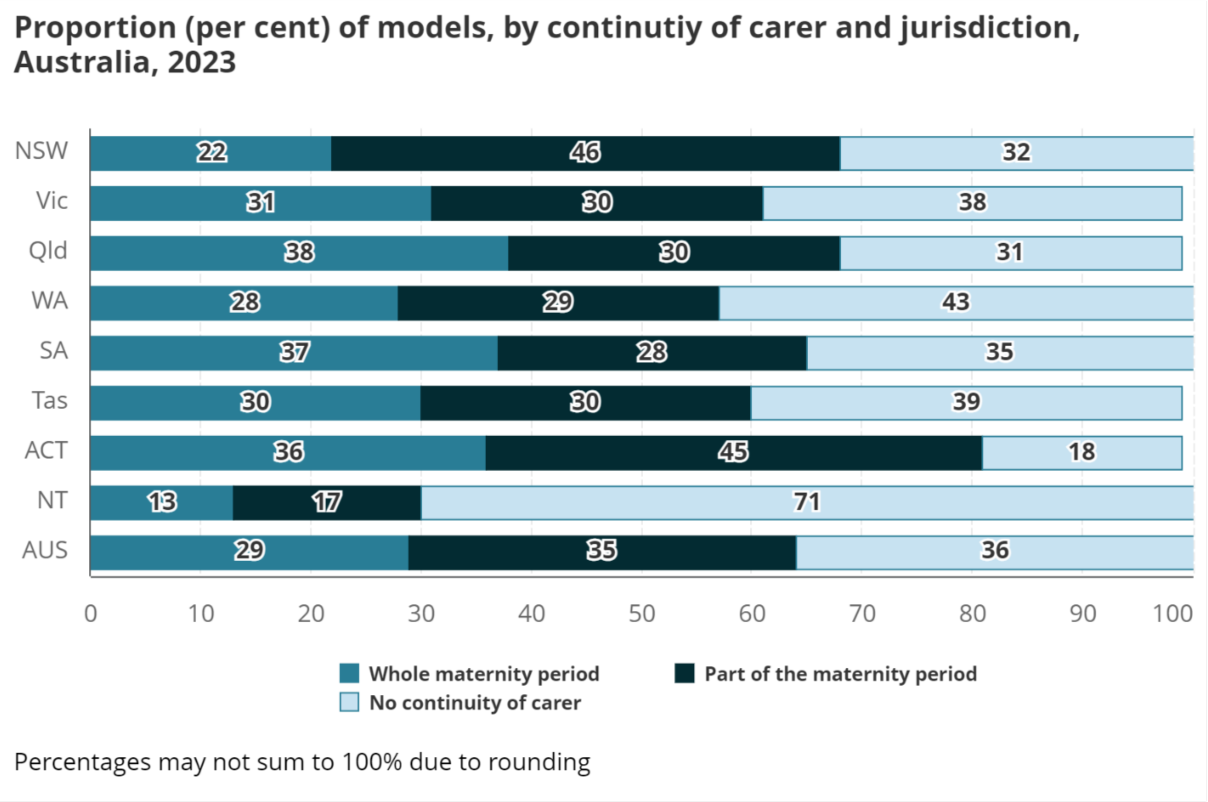
In 2023, maternity services reported around 1,000 models of care across Australia. Most of these (81%) fall into 4 categories:

1. public hospital maternity care (41% of all models)
2. shared care (15% of models)
3. midwifery group practice caseload care (14% of models)
4. private obstetrician specialist care (11% of models).

Around 29% of the models have continuity of carer (the same caregiver) across the whole maternity period, 35% have some continuity of carer (for example, in the antenatal period only) and 36% have no continuity of carer (Figure HD.1).

For more information see Maternity models of care in Australia and METEOR.

Figure HD.1: The continuity of carer within models of care varies across Australia



Proportion (per cent) of models, by continutiy of carer and jurisdiction, Australia, 2023

Percentages may not sum to 100% due to rounding

Source: AIHW analysis of the Model of Care National Best Practice Data Set.

Collecting and reporting data on maternity models of care will:

- tell us about the maternity care available to women across Australia, and how this changes over time
- support the inclusion of model of care data elements in the National Perinatal Data Collection. Linking models of care information with perinatal data allows us to explore which models of care women giving birth use, whether they experience continuity of care, and if this varies by maternal characteristics such as age and geographic location (see *Maternity models of care infocus*)
- allow outcomes for mothers and babies by their model of care to be explored, including for different populations – such as First Nations women, women from rural and remote areas, and women from CALD backgrounds. This will support the monitoring and evaluation of *Women-centred care: strategic directions for Australian maternity services*.

Primary care

Another key data gap is in the area of primary care – there is no ongoing national data collection on the reasons for visits to primary care, or for treatments provided.

The AIHW is committed to a work program that advances the provision of primary health care data by developing processes for their governance, standardisation, collection, analysis and reporting in Australia. This work will ultimately form a National Primary Health Care Data Collection, initially focused on GP activity data, to provide a better understanding of health conditions managed, and outcomes for individuals.

The AIHW is working with:

- Primary Health Networks to understand the quality and uses of GP data, using dementia as a use case
- the Commonwealth Scientific and Industrial Research Organisation (CSIRO) on the creation and use of national Fast Healthcare Interoperability Resources standards in health-care information exchange
- a multijurisdictional project team to support the *National Primary and Acute Care Data Linkage Project (Design Phase)*.

The *National Primary and Acute Care Data Linkage Project (Design Phase)* is co-led by NSW Health, Commonwealth Department of Health and Aged Care and AIHW, in partnership with all state and territory health departments. The project is engaging key stakeholders, such as those from the Primary Health Network, general practice and Aboriginal community controlled health sectors, during the consultation process to inform a blueprint for a hub-and-spoke data linkage system. It is envisaged that de-identified data from general practices would be linked with other health data by leveraging existing infrastructure and successes across jurisdictions, such as the Lumos project in NSW, to provide better insights into patient journeys across the health system.

Data linkage

Data linkage is the other area where considerable progress has been made in filling data gaps.

Australia has been at the forefront of the development of data linkage systems and the use of linked data. Western Australia led the way in Australia through the establishment in 1995 of the WA Data Linkage System (WADLS) – a system of linkages within and between health and non-health data collections in that state.

The AIHW has been linking mortality data to the incidence of cancer to estimate cancer mortality rates since 1990. It also produces a large volume of linked data sets to support important medical research and to monitor the health of the population each year.

The Population Health Research Network (PHRN), established in 2009, is a national collaboration that brings together existing data across Australia and makes the resultant linked data available for research. The network comprises project participants and data linkage units.

The AIHW serves as the PHRN's National Linkage Unit; the state and territory data linkage units are:

- the Centre for Health Record Linkage in New South Wales
- the Centre for Victorian Data Linkage
- Data Linkage Queensland
- the Western Australian Data Linkage Branch
- the SA–NT Datalink
- the Tasmanian Data Linkage Unit.

Data linkage can allow data and their context to be viewed more comprehensively than is possible by looking at individual data sets in isolation. While the complexity and scale of data linkages has expanded substantially in recent years, the increased capacity to facilitate data sharing within existing legislations has enabled enduring linked data sets to be developed that make data linkage more efficient and accelerate the analysis of the linked data.

The following sections describe some examples of enduring linked assets.

National Health Data Hub

The National Health Data Hub (NHDH), formerly known as the National Integrated Health Services Information Analysis Asset (NIHSI), was created to provide better insights into a person's journey through the health system (AIHW 2024b). It includes data on a person's:

- hospital visits in most jurisdictions (admissions, and outpatient and emergency department services)
- processed claims related to services that qualify for a benefit via the MBS

- processed claims related to prescription medicines that qualify for a benefit via the PBS
- use of aged care services
- immunisation history and death information (via the Immunisation Register and National Death Index, respectively).

A key benefit of the NHDH is the ability to look at person-level information – such as how many times a person is admitted to hospital as opposed to just counting the total number of hospitalisations – as well as understanding a person’s pathway through the health system.

The following sections on treatment pathways for people hospitalised with acute coronary syndrome and transitions from hospital to residential aged care for people living with dementia give examples of analysis using the NHDH.

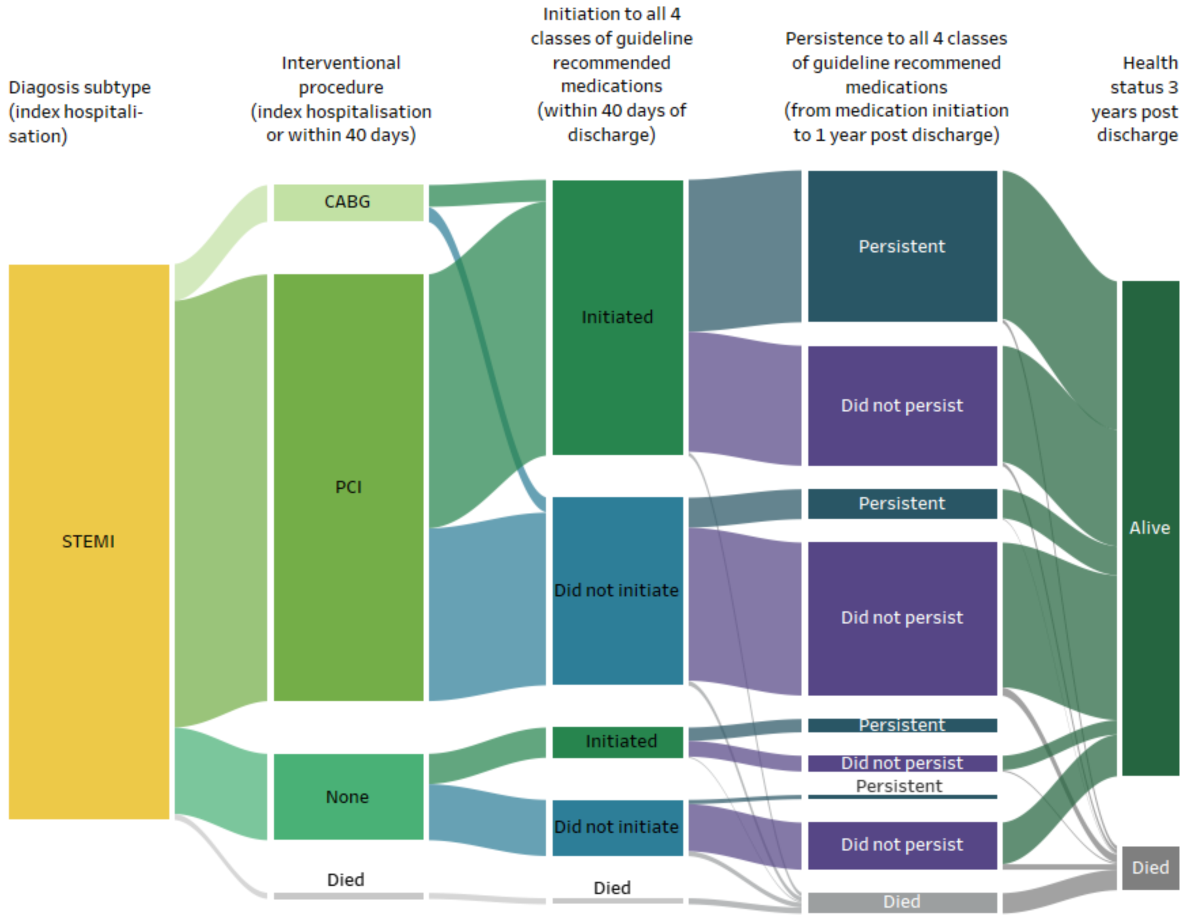
Treatment pathways for people hospitalised for acute coronary syndrome

A project conducted using the NHDH provided a snapshot of almost 35,800 people (aged 25 to 84) who survived an acute coronary syndrome (ACS) hospitalisation (AIHW 2024c). The project used data about a person’s interventional procedures and medication use to describe their ‘treatment pathway’ after an ACS hospitalisation.

A key finding was that only 31% of people filled a prescription for all 4 classes of recommended medications within 40 days of surviving an ACS hospitalisation. People who did not initiate the guideline recommended medication (all 4 classes of recommended medications within 40 days) were more likely to be women, be aged 75–84 or have identified prior coronary heart disease.

Figure HD.2 shows treatment pathways and outcomes for people with a diagnosis of ST-segment elevation myocardial infarction (STEMI), a type of heart attack almost always caused by a complete blockage to a major coronary artery.

Figure HD.2: Treatment pathways and outcomes, among people with STEMI



Note: CABG = coronary artery bypass surgery/graft ; PCI = percutaneous coronary intervention (formerly known as angioplasty with stent).
Source: AIHW NIHSI 2016-17 to 2019-20, analysis of NIHSI
https://www.aihw.gov.au

The findings from this project have implications for policy development and clinical practice. They also provide direction for additional research which is needed to identify why these groups are less likely to follow guideline recommendations.

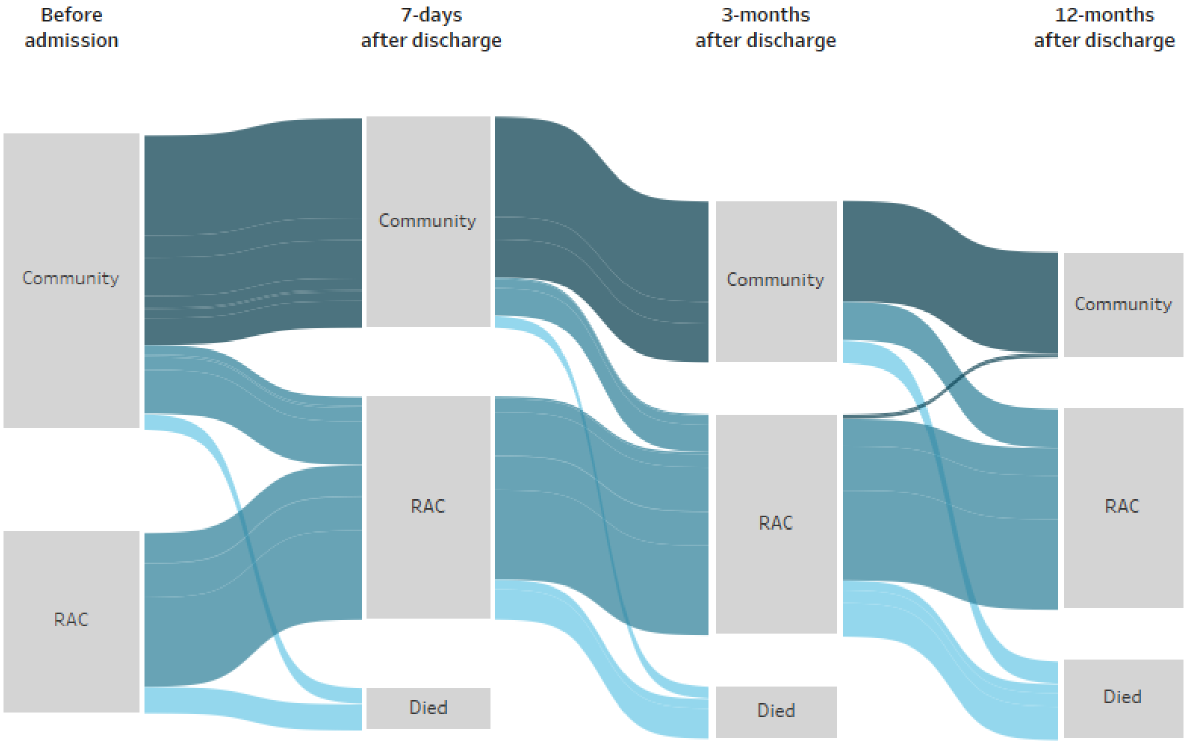
For more information, see Treatment pathways for people hospitalised for acute coronary syndrome and Medication use for secondary prevention after coronary heart disease hospitalisations: Patient pathways using linked data.

Transitions from hospital to residential aged care for people living with dementia

The NHDH was used to examine movements between residential aged care and hospital for Australians living with dementia who were aged 65 or older and hospitalised in 2017 (Figure HD.3).

Results included that 1 in 4 people with dementia who were living in the community moved into aged care after a hospital stay. By comparison, 1 in 50 people without dementia who were living in the community moved into residential aged care in the 7 days after being discharged from hospital (Figure HD.4).

Figure HD.3: Transitions to residential aged care or mortality up to 12 months after first hospitalisation for people living with dementia



RAC = residential aged care.

Notes:

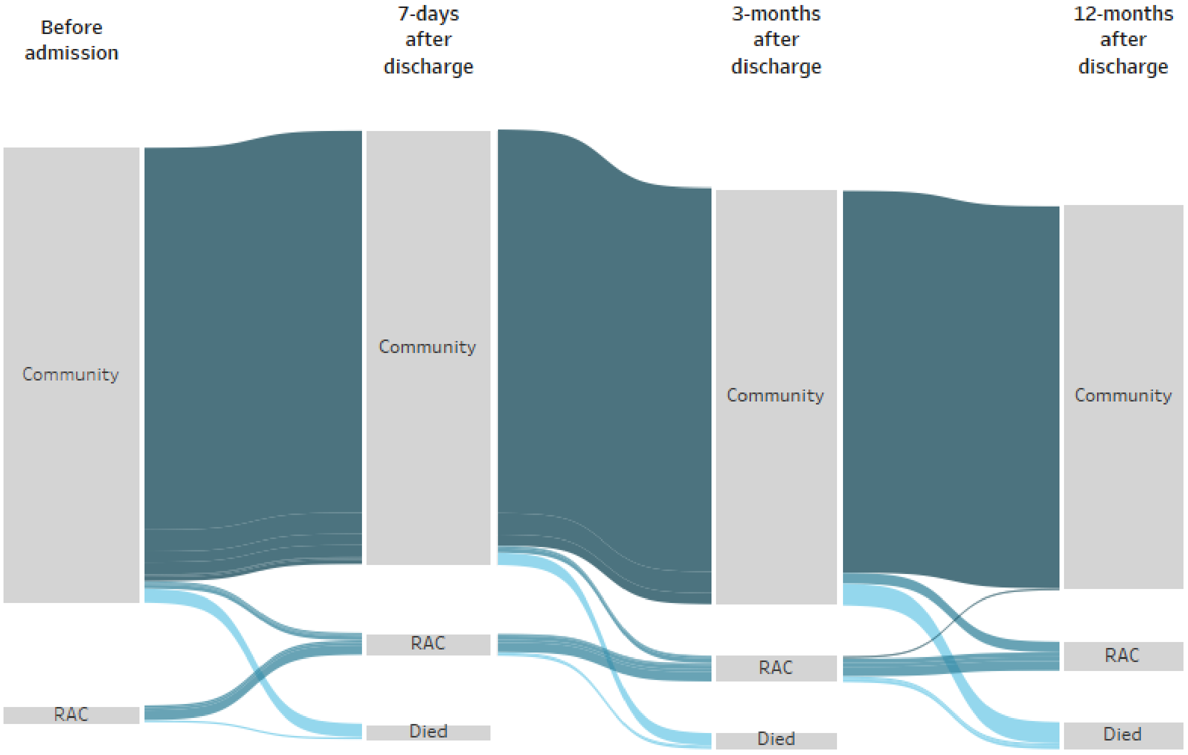
Deaths within 7 days of discharge include deaths during first hospitalisation in 2017.

Sankey based on the work of Olivier Catherin and Jeffry Shaffer. Sankey calculations and data template from Kevin and Ken Flerlage.

Source: AIHW NIHSI 2018-19.

https://www.aihw.gov.au

Figure HD.4: Transitions to residential aged care or mortality up to 12-months after first hospitalisation for people without dementia



RAC = residential aged care.

Notes:

Deaths within 7 days of discharge include deaths during first hospitalisation in 2017.

Sankey based on the work of Olivier Catherin and Jeffry Shaffer. Sankey calculations and data template from Kevin and Ken Flerlage.

Source: AIHW NIHSI 2018-19.

https://www.aihw.gov.au

For more information, see Transitions to residential aged care after hospital for people living with dementia.

Person Level Integrated Data Asset

The ABS's PLIDA combines information on health, education, government payments, income and taxation, employment, and population demographics (including from the ABS Census of Population and Housing) over time. It provides whole-of-life insights on various population groups in Australia, such as:

- the interactions between their characteristics
- their use of services like health care and education
- their outcomes like improved health and employment.

A key benefit of the PLIDA is the ability to gain insights into the social determinants of health, and population demographics such as education, income and CALD populations.

Box HD.4 describes a key project using PLIDA.

Box HD.4: Health of refugees and humanitarian entrants in Australia

Australia has a long history of resettling refugees and people in humanitarian need. A range of government and non-government organisations provide services to facilitate successful settlement in Australia. While data are routinely collected on the health and welfare outcomes of the broader Australian population, there are limited data available to measure and assess the health of refugees and humanitarian entrants – which is one of the key factors critical for successful settlement.

Analysis of the health outcomes, health service use and causes of death for all humanitarian entrants who arrived in Australia from 2000 to 2020 using PLIDA showed that almost 9 in 10 entrants attended a general practice at least once in 2021 – and around 99% of these attendances were bulk billed.

For more information, see Health of refugees and humanitarian entrants in Australia.

National Disability Data Asset

The National Disability Data Asset (NDDA) – designed to be an enduring national asset – comprises a collection of linked, de-identified data from across multiple national, state and territory government service systems to inform insights on people with disability and their pathways through services. When operational, the NDDA will be used to:

- provide a more complete picture of the programs and services used by people with disability
- help governments improve these programs and services
- share information about how opportunities and outcomes could be improved
- improve reporting on outcomes for people with disability for *Australia's Disability Strategy 2021–2031*.

Australian National Data Integration Infrastructure

The Australian National Data Integration Infrastructure (ANDII) is being collaboratively developed by Australian, state and territory governments to deliver shared national infrastructure for data sharing and integration. It is proposed as a national source of high-quality and timely linked data for Australian policy makers, analysts and researchers to provide insights for national and local benefit. The ANDII is the underlying infrastructure established to deliver the NDDA. Subject to future agreements and funding, the ANDII could be used to facilitate the creation of other specific data assets on other important policy issues.

The ANDII also includes:

- data governance and streamlined data sharing arrangements will enable the creation of the data asset, as well as workflow management (including data access, and use and release processes), an ANDII ICT Solution to support secure hosting and transfer of data as permitted across the national/state/territory ANDII Network, as well as data linkage, analytical asset build and analytical activity.

The NDDA is being established using the *Data Availability and Transparency Act 2022* (Cwlth), together with a range of other existing legislation. The new national infrastructure will build on and complement existing data integration practices at the national and state/territory level.

Future of data

The health data landscape is changing rapidly. Data are being used more and more in policy making, and how routinely collected data can be better used in this space is increasingly being considered.

Responding to change

Changes are occurring in many areas. We need to ensure that data are collected not only to measure this change but also to understand the impact of this change on other aspects of health.

- One example of this changing landscape is the importance of measuring the uptake of vaping and the relationship between that and rates of smoking. While smoking rates are declining, rates of vaping are increasing, particularly among young people and people from least disadvantaged areas.
- Another example is the increased use of virtual care – for example, delivering health care via telephone or video conferencing. Currently, there are no standards for measuring virtual care. Different jurisdictions have started collecting information in different ways; this is affecting the ability to establish how many admitted patients there are as opposed to how many are receiving their care virtually. Future work is planned to develop standards to ensure consistent collection and reporting of data on virtual care service delivery.

Collecting data currently not harnessed

Additional data are being collected in many settings that are currently not harnessed. Examples include:

- information about children collected through the Maternal and Child Health Program
- information about smoking and vaping status collected as part of the public dental program
- extensive data collected through electronic medical Records (EMRs).

Technological advances

Technological advances are creating opportunities to automate and accelerate many aspects of work. The development of generative artificial intelligence and the advancements in machine learning and natural language processing (NLP) will provide new opportunities to automate the way data are captured, coded, transmitted and reported.

For example, the use of machine learning and NLP will also likely change the way health data are coded in Australia, with a number of studies already undertaken to demonstrate this possibility (Liu et al. 2022). Within the AIHW, machine learning and associated AI tools are being used; they will continue to be used to support the automation of combining data sets and analysis of linked data sets such as predictive modelling, forecasts and projections for health planning and service delivery.

Australia has been active in developing and advancing new standards, terminologies and classifications that will help to deal with the challenges posed by these technical advances – such as SNOMED-CT AU, ICD-11, and health data exchange standards such as fast health interoperability resources (FHIR).

The use of SNOMED-CT AU is rapidly becoming the basis of structured data capture in EMRs in General Practice and hospitals, including its use within the FHIR standards.

In addition to this, the AIHW is leading the work to consider how Australia can leverage ICD-11 in a range of health care settings. The 11th revision of the ICD is fully digital for the first time which means it has the potential to integrate with other terminologies and tools to automate classification of health conditions across the healthcare continuum, including primary care (WHO 2022). This would significantly improve our understanding of the health of the population in a consistent way, particularly as models of care change.

Improving timely access to data

Timely data continue to be imperative, particularly for the reporting and management of communicable diseases. A key development in this area is the establishment of the interim Australian Centre for Disease Control (the Australian CDC). Part of its statement of intent is to improve timely access and sharing nationally of consistent data, information and advice. Such action is essential to the work of the Australian CDC to enable rapid risk assessment and response, and to support informed public health decision-making.

Looking to the future

An important focus for the future will be on ensuring that data are collected, stored and analysed in a safe and secure way and that these data are both accessible and ultimately used to inform, manage and monitor health outcomes. Emphasis will be on filling data gaps, particularly across all population groups and geographic areas – both through data linkage and other mechanisms – and on presenting information in a way that is useful and easy to interpret.

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Australia's dental data landscape

Key messages

- In Australia, dental services can be accessed, and are funded, in several ways. Hence, dental data sources are varied; no national comprehensive dental data set currently exists.
- National population surveys and administrative data sets provide some information for Australia's dental data landscape.
- Work is underway to develop a national public dental data set for use at the national and jurisdictional level to accurately measure and describe public dental service activity and recipients of services.

Data on the oral health of Australians and their use of dental services are of fundamental importance as they can serve as the foundation for evidence-based decision-making in dental health care policy and practice. Accurate, comparable and comprehensive data enable authorities to:

- identify oral health trends
- assess the effectiveness of existing dental programs
- allocate resources efficiently
- develop targeted strategies for improving oral health outcomes.

Moreover, such data can facilitate early intervention, preventive measures and better-informed patient care, ultimately contributing to the overall wellbeing and quality of life of the population.

This article describes the dental data landscape in Australia. It examines ways that data on the oral health of Australians and their use of dental services are currently collected and translated into information that can be actioned. It comments on inconsistencies in, and barriers to, collecting and using that information, and on opportunities to innovate and enhance the landscape, strengthening the evidence base.

Brushing up on oral health

Oral health refers to the condition of a person's teeth and gums, and the health of the muscles and bones in their mouth. Poor oral health – mainly tooth decay, gum disease and tooth loss – affects many Australian children and adults.

Good oral health is fundamental to overall health and wellbeing. Without it, a person's general quality of life and the ability to eat, speak and socialise is compromised, resulting in pain, discomfort and embarrassment (COAG 2015).

A dental visit gives a person a chance to receive preventive dental care and treatments that can maintain and enhance their oral health and may even reverse oral diseases and damage to their teeth and gums.

Untreated tooth decay reflects the level of dental decay in the population and access to dental treatment.

Dental caries

Dental caries is a bacterial disease of the teeth. It becomes apparent when a tooth has decayed to the point of permanent damage to its enamel in the form of little holes that expose the inner structure and nerves of the tooth. The level of dental caries in the population is a key indicator of oral health and is measured by counts per person of the number of teeth that are decayed, missing or have had caries filled by a dentist. This measure can be counted either as:

- a dmft, which is a decayed, missing or filled tooth in the 'primary dentition' (the first set of teeth a person has, sometimes referred to as baby teeth)
- a DMFT, which is a decayed, missing or filled tooth in the 'permanent dentition' (a person's second set of teeth, sometimes referred to as adult teeth).

The average numbers of dmft/DMFT in different populations are shown in Table DD.1. The data presented are the most up to date currently available. (The timeliness of the surveys from which they are derived is discussed in further detail below.)

Table DD.1: Oral health status of children and adults

	Average number of decayed, missing or filled teeth	Proportion with untreated decay
Children aged 5–10(a) – primary dentition	1.5 dmft	27%
Children aged 6–14(b) – permanent dentition	0.5 DMFT	11%
Adults aged 15 and over(c)	11.2 DMFT	32%

(a) Data are for 2012–14 and report caries experience in the primary dentition.

(b) Data are for 2012–14 and report caries experience in the permanent dentition.

(c) Data are for 2017–18 and report caries experience in the permanent dentition.

Sources: Do and Luzzi 2019; Ha et. al. 2016.

Australia’s National Oral Health Plan

In recent years, national-level data needs relating to oral health care have been largely framed by Australia’s National Oral Health Plan 2015–2024 (NOHP). Given that the current NOHP is due to expire at the end of 2024, the Department of Health and Aged Care is developing a new NOHP.

The goal of the NOHP is ‘to improve health and wellbeing across the Australian population by improving oral health status and reducing the burden of poor oral health’ (COAG 2015).

Foundation areas and priority principles

The NOHP outlines guiding principles that underpin Australia’s oral health system; it also provides national strategic direction, including targeted strategies in 6 foundation areas and across 4 priority populations.

Australia’s 6 NOHP foundation areas are:

- Oral health promotion – all Australians have access to oral health promoting environments and to appropriate evidence-based information and programs that support them to make informed decisions about their oral health.
- Accessible oral health services – all Australians have access to appropriate oral health care in a clinically appropriate time frame.
- Systems alignment and integration – social, health and education systems work together to support healthy mouths and healthy lives.
- Safety and quality – oral health services are provided in accordance with the Australian Safety and Quality Goals for Health Care.
- Workforce development – the workforce for oral health is of an appropriate size and is appropriately trained and distributed.
- Research and evaluation – appropriate and timely data are available at both the population and service level for planning, monitoring and evaluation.

The 4 priority populations are the groups who experience the most considerable barriers to accessing oral health care and the greatest burden of oral disease:

- people who are socially disadvantaged or on low incomes
- Aboriginal and Torres Strait Islander (First Nations) people
- people living in regional and remote areas
- people with additional and/or specialised health needs.

Comprehensive and up-to-date data are needed to support the NOHP’s goal to improve the oral health of the Australian population and reduce the burden of poor oral health.

Key Performance Indicators

To monitor progress of the NOHP strategies, 26 core Key Performance Indicators were developed and have been reported on twice:

- Baseline data were reported in 2017, presenting data for the reporting period July 2014 – June 2016 (or as close as possible to this period). This report was published on the Council of Australian Governments (COAG) website in 2019 and, following the dissolution of COAG in 2020, can now be accessed via Trove (COAG, 2019).
- The AIHW produced a second performance monitoring report, published in 2020 (AIHW 2020), which presented data for the reporting period July 2016 – June 2018 (or as close as possible to this period).

These 2 reports highlighted the lack of routinely available national data to assess a number of indicators, and the particular difficulties encountered in assessing changes for people in the priority populations.

Table DD.2 provides a summary of the 26 indicators, their data sources and the frequency of collection.

Table DD.2: NOHP Key Performance Indicators

NOHP Key Performance Indicators topic area	NOHP Key Performance Indicator	Data source *(collection frequency)*
Our oral health – a national perspective	Caries experience in children Untreated caries prevalence Periodontitis prevalence Edentulism prevalence Inadequate dentition prevalence Mean number of missing teeth Potentially preventable hospitalisations	• National Child Oral Health Study 2012–14 *(survey conducted around every 10 years)* • National Study of Adult Oral Health 2004–2006 and 2017–18 *(survey conducted around every 10 years)* • National Dental Telephone Interview Survey 2013 *(survey conducted around every 3 years)* • State and territory health departments *(data collected routinely, supplied on request)* • AIHW Hospital Morbidity Database *(data collected routinely, reported annually)*
How oral disease impacts our wellbeing	People experiencing toothache Food avoidance due to dental problems People feeling uncomfortable with appearance of mouth and teeth	• National Dental Telephone Interview Survey 2013 *(survey conducted around every 3 years)* • National Study of Adult Oral Health 2017–18 *(survey conducted around every 10 years)*

NOHP Key Performance Indicators topic area	**NOHP Key Performance Indicator**	**Data source** *(collection frequency)*
Preventive strategies to reduce the risk of oral disease	Oral cancer relative survival rate Access to optimally fluoridated drinking water Daily brushing with fluoride toothpaste	• AIHW Australian Cancer Database *(data supplied annually)* • State and territory water authorities via state and territory health departments *(data supplied upon request)* • National Dental Telephone Interview Survey 2013 *(survey conducted around every 3 years)* • National Study of Adult Oral Health 2017–18 *(survey conducted around every 10 years)*
Behaviours that increase the risk of oral disease	Adults who smoke daily Free sugar consumption Adult alcohol consumption	• ABS National Health Survey *(survey conducted around every 3 years)*

NOHP Key Performance Indicators topic area	NOHP Key Performance Indicator	Data source *(collection frequency)*
Access to oral health services	People who have received an oral health check-up in the previous 2 years People who report avoiding or delaying visiting a dental practitioner in the last 12 months Children accessing oral health care through a government-funded oral health program Adults accessing oral health care in the public sector, by jurisdiction	• National Dental Telephone Interview 2013 *(survey conducted around every 3 years)* • National Study of Adult Oral Health 2017–18 *(survey conducted around every 10 years)* • ABS Patient Experience Survey *(survey conducted annually)* • State and territory health departments *(data collected routinely, supplied on request)* • Services Australia *(data collected routinely, extracted as needed)*
Safety and quality of oral health services	Private dental practices and services accredited to national safety and quality standards Patient experience visiting a dental professional	• Australian Commission on Safety and Quality in Health Care *(data supplied on request)* • ABS Patient Experience Surveys *(survey conducted annually)*

NOHP Key Performance Indicators topic area	NOHP Key Performance Indicator	Data source *(collection frequency)*
Oral health workforce	Newly registered dental practitioners, by division Registered clinically active dental practitioners Non-oral health VET sector enrolments successfully completing oral health units of competency Students enrolled in dental and oral health courses who have a rural background	• National Health Workforce Dataset *(data collected routinely, reported publicly via the Health Workforce Data Tool)* • National Centre for Vocational Education Research *(data supplied upon request)* • Department of Education and Training *(data supplied upon request)*

ABS = Australian Bureau of Statistics; VET = vocational education and training.

Source: AIHW 2020.

Other indicators

Alongside the NOHP, the Aboriginal and Torres Strait Islander Health Performance Framework monitors progress in First Nations people's:

- health status and outcomes
- determinants of health
- health system performance.

It reports on 68 measures across these 3 domains (tiers). Measure 1.11 Oral health in *Tier 1 – Health status and outcomes* describes the oral health of First Nations people. It highlights the main areas of improvement and those of continuing concern, aligning with the broader objectives of the NOHP.

Timely data from all sources mean that policy advisors can accurately assess the effectiveness of existing strategies and adjust them where necessary to deal with emerging oral health challenges. Without such data, it is hard to understand the oral health of the population and disparities in its oral health; it is also difficult to monitor progress, allocate resources effectively and target interventions at identified problems.

Scale of the data

The aim of the NOHP is to improve the oral health status of Australians – a challenging aim as there are no comprehensive national data sources from which to derive data on the status of Australians' oral health. Most of the available data on Australians' oral health status and their use of dental services is sourced from national population surveys and administrative data sets.

These and other data sources – such as the Australian Dental Association's annual consumer survey, which collects data on oral health – help to paint a clearer picture of the oral health status of Australians and their use of dental care services.

National population surveys

National population surveys are large-scale data collections that gather information on a country's population. They largely rely on self-reported data: individuals provide information about themselves through interviews, questionnaires or via online forms. These surveys aim to be representative by collecting data from a sample population that mirrors the demographic and geographic diversity of the broader population from which the sample is drawn. This is to ensure that statistical findings reflect the characteristics and experiences of the broader population.

ARCPOH surveys

The Australian Research Centre for Population Oral Health (ARCPOH) at The University of Adelaide regularly conducts surveys to monitor the oral health of Australians and their use of dental services. These surveys are considered to be representative of the Australian population.

Some ARCPOH surveys include a clinical examination component and are conducted on a 5-yearly cycle, alternating between adults and children. In this way, the data for each population group are updated about every 10 years.

- The National Survey of Adult Oral Health (NSAOH) was conducted in 1987–88, 2004–06 and most recently in 2017–18, with another planned for 2027.
- The National Child Oral Health Study (NCOHS) was first conducted in 2012–14 with the NCOHS 2023–2025 currently underway.

ARCPOH National Dental Care Survey

To complement the data from these surveys, ARCPOH also conducts the National Dental Telephone Interview Survey (NDTIS) – now called the National Dental Care Survey – about every 3 years; it is a population survey of self-reported oral health and use of dental services.

The first NDTIS was undertaken in 1994 and the most recent in 2021, with another tentatively scheduled for 2024. These surveys collect self-reported data on the oral health status of the Australian population – for example, on:

- the average number of decayed, missing or filled teeth
- Australians' use of dental services (such as the type of dental practices people visit and their visiting patterns).

ABS Patient Experience Survey

The ABS conducts the Patient Experience Survey annually. It collects information from people aged 15 and over on their experiences with selected aspects of the health system in the 12 months before their interview. This information includes patients' views and observations on the services they have received from dental professionals (such as their views on the accessibility of and barriers to services) as well as aspects of the patient–clinician interaction.

In the most recent Patient Experience Survey (ABS 2023):

- around 1 in 2 participants (52%) reported visiting a dental professional in the previous 12 months
- participants living in areas of least socioeconomic disadvantage were more likely than participants living in areas of most socioeconomic disadvantage to see a dental professional (65% compared with 42%)
- around 1 in 6 (18%) participants reported delaying or not seeing a dental professional when needed due to cost.

Limitations and challenges of national population surveys

These national population surveys are a valuable source of oral health data; however, they do have their limitations and can present various challenges. These drawbacks include:

- they do not provide data for small areas

- they demand a considerable amount of effort and resources, both in terms of coordination and data collection. As such, they may be conducted less often than would be considered ideal
- they may necessitate that participants attend appointments (for instance, surveys that include a clinical examination component like those conducted by ARCPOH), thus posing substantial logistical challenges
- they inherently rely on the willingness of respondents to participate, which can result in varying response rates, potentially introducing response bias
- they predominantly rely on self-reported data. This can be problematic when gathering clinical information about one's oral health status (for example, the extent of damage to teeth) and introduce inaccuracies into the data. Individuals might also struggle to recall the timing of dental visits, and a less than favourable visiting pattern may indicate an individual's poor overall understanding of their dental health.

Nevertheless, national population surveys remain an important tool for understanding Australia's oral health status. They are particularly well suited to gathering subjective insights, such as one's experience with dental services or how one feels about their own dental appearance.

Administrative data sets

Administrative data sets also play an important role in contributing to the oral health and dental care data landscape in Australia, complementing the information gathered through surveys.

They are collections of structured information, gathered and maintained by organisations (including Australian, state and territory governments) and are typically a by-product of providing a service. These data sets:

- offer a rich source of real-world data that can potentially cover a wide portion of the population – or at least a well-defined portion of it (based on eligibility for the service or program)
- can be de-identified and repurposed for analysis, research and policy evaluation, making them a valuable resource for data-driven decision-making
- if collected routinely and consistently, are a reliable resource for tracking trends and monitoring health-care use.

Like surveys, administrative data sets come with their own unique challenges and nuances that need to be considered. Some of the major national administrative health data sets and their limitations (in terms of yielding data on dental and oral health) are described below. They include:

- hospitals data
- health expenditure data
- Medicare Benefits Schedule data
- Pharmaceutical Benefits Scheme data.

Hospitals data

Data about dental services provided in hospitals are captured in the AIHW National Hospital Morbidity Database (NHMD) – a compilation of episode-level records from admitted patient clinical and administrative management systems in Australian hospitals. The data supplied include:

- demographic data about patients
- administrative details associated with the hospitalisation
- data on the diagnoses of the patients and the procedures they underwent in hospital.

The information is recorded in the hospital setting, compiled by state/territory health authorities and transformed into required formats (and so on). The AIHW then collates it for national reporting. The data captured in the NHMD are somewhat limited in providing a national picture, given that:

- most dental services are provided outside the hospital setting
- states and territories may differ in terms of which procedures are performed in hospital, rather than in alternative settings:
  - for example, extenuating clinical circumstances that might warrant hospital-based care may be considered by some but not all
- some dental procedures are performed in hospital emergency departments and are therefore not captured in the NHMD. While some information on these emergency presentations is captured in the National Non-Admitted Patient Emergency Department Care Database, the diagnosis recorded is not specific enough to identify most dental/oral health-related diagnoses.

Health expenditure data

Dental services expenditure data are derived from the AIHW Health Expenditure Database, a collation of more than 50 data sources that capture health spending by governments, individuals, private health insurers and other private sources in each financial year. This data set provides an indication of the financial contributions to dental services from different entities.

However, since data from some of the sources can be obtained only after a considerable time lag, it can take from 15 to 18 months after the end of the financial year to release the data.

Medicare Benefits Schedule data

The Medicare Benefits Schedule (MBS) contains details of attendances, tests and procedures that qualify for a Medicare Benefit under the *Health Insurance Act 1973* (Cwlth). The MBS data collection contains information on services that resulted in a payment of this benefit. The resultant data are a by-product of the administration of the Medicare 'fee-for-service' payment system by Services Australia.

Most general dental procedures do not qualify for a Medicare Benefit; however, the MBS data collection includes data for dental-related services provided by:

- approved dental practitioners (approved before 1 November 2004) in Category 4 – Oral and Maxillofacial Services
- dental practitioners registered in the specialty of orthodontics (limited services), registered dentists (limited services), and medical practitioners who are specialists in oral and maxillofacial surgery in Category 7 – Cleft Lip and Cleft Palate Services
- medical practitioners who are specialists in oral and maxillofacial surgery mainly in Category 1 – Professional Attendances (specialist attendances) and Category 3 – Therapeutic Procedures (surgical operations) of the MBS.

Pharmaceutical Benefits Scheme data

The Pharmaceutical Benefits Scheme (PBS) data collection contains information on prescriptions dispensed to Australians who hold a Medicare card, and to other eligible residents (as defined on the Schedule of Pharmaceutical Benefits) for whom a subsidy might be paid. This includes medicines prescribed by dentists (who can prescribe a restricted range of medicines – predominantly antibiotics and pain killers).

The database comprises information about PBS scripts and payments, patients, prescribers and dispensing pharmacies. It does not cover private prescriptions, over-the-counter purchases or off-label prescribing information.

It is not possible to quantify the number of prescriptions written by general practitioners for patients presenting with dental problems through this data source.

Extracting the data

This section explores the different arrangements that exist from which we can extract dental health data, providing an overview of the varied mechanisms for data acquisition.

How are dental services accessed in Australia?

Dental services are funded, and can be accessed, in a number of ways:

- privately
- through public dental clinics, depending upon eligibility
- through other funded dental programs; for example, the Child Dental Benefits Schedule, the Department of Veterans’ Affairs.

For people who purchased services privately, some may have had all or part of the costs of the service subsidised.

Publicly funded or subsidised dental health care

Government funding in the dental care sector not only improves accessibility of services but also creates opportunities to source valuable data for research and evidence-based policy development. Public dental care is available only to some Australians, usually people with a health-care card or Centrelink pensioner concession card (and their dependants).

When government funding is allocated to dental services, it often requires rigorous data collection and reporting to be done to ensure the investment is used effectively. A wide range of information can be required, including service usage data, costs, patient demographics and their oral health status. Yet, in Australia, the currently available data are fragmented and can lack comparability, given the different arrangements under which public dental services are provided across the states and territories.

Besides the general health administrative data sets outlined earlier in this article, there are also some dental-specific data sets compiled as a by-product of the administration and delivery of services.

Funding for public dental services

The Australian Government provides funding to states and territories to support the provision of public dental services, via the:

- Federation Funding Agreements
- National Health Reform Agreement
- Royal Flying Doctor Service
- Child Dental Benefits Schedule.

The states and territories provide the Australian Government with data on service use, the number of patients on waiting lists, average waiting times, Indigenous status, rural and regional status and the number of services provided by the private sector.

The AIHW compiles the Public Dental Waiting Times National Minimum Data Set annually. This data set enables reporting on the length of time that patients on a waiting list wait for public dental care in Australia. However, the data collated at the national level are limited as:

- public dental services are operated by state and territory governments, with eligibility for services and the organisation of services varying greatly across the jurisdictions; this affects the comparability of the data collected
- they capture only a minority of public dental care patients as the majority receive care through priority or emergency care arrangements and are not necessarily placed on a waiting list. Further, priority access arrangements can differ between jurisdictions.

The AIHW is currently working with the Department of Health and Aged Care and state and territory health departments to develop an alternative data set to capture more complete data about care provided through public dental services, including that offered under jurisdictional level incentives or programs (see the section titled ‘Bridging the gap and filling the holes’ for more information).

Child Dental Benefits Schedule

The Child Dental Benefits Schedule (CDBS) provides access to benefits for basic dental services to around 3 million eligible children. Services Australia administers the payment of benefits. These dental services include examinations, x-rays, cleaning, fissure sealing, fillings, root canals and extractions. They can be provided by public or private dental practitioners.

A child is eligible for these services if aged between 0–17 at any point in the calendar year, eligible for Medicare, and if either they or their caregiver receive an eligible Australian Government payment. Eligible children have access to a benefit cap of $1,095 (2024 cap) over a 2-calendar-year period. Around 1 in 2 children are eligible to receive services under the CDBS but, historically, only around 1 in 3 eligible children use the program.

In 2022–23, 5.2 million services were subsidised under the CDBS (Services Australia 2023).

Private health insurance

Individuals or families can purchase private health insurance to cover all or part of the cost of health care not covered by Medicare. For people who are eligible, private health insurance premiums are subsidised by the Australian Government via the Private Health Insurance Rebate. This government funding obliges the private health insurers to provide data to the government on what their funds were used for.

Private health insurance cover is generally divided into hospital cover, general treatment cover and ambulance cover. General treatment cover provides insurance against costs of treatment by ancillary health service providers, including dentists. The extent of cover depends on the type of policy purchased.

In 2022–23:

- 1 in 2 (50%) or around 13.2 million people had general treatment cover, excluding people with general treatment ambulance only cover (APRA 2023a)
- 50.0 million dental services were subsidised by private health insurance providers (APRA 2023b).

Box DD.1. General Treatment Dental data collection

The General Treatment Dental (GT-Dental) data collection contains de-identified unit record information relating to patients and general treatment dental services for which the private health insurer paid a benefit. Private health insurers report this information to the Department of Health and Aged Care at regular intervals. The collection contains de-identified unit record level data, with information related to patient demographics, procedure type, number of dental service items, charges, and benefits paid.

Privately funded dental health care

Privately provided dental services paid for wholly out-of-pocket by the individual present a distinct challenge for people who map the data landscape. It is inherently difficult to access data from these providers as there is no centralised repository for such information.

Not having comprehensive data from these providers is a major obstacle to fully understanding the nation's oral health status and use of dental services. In turn, this hinders the development of evidence-based policies and comprehensive research efforts in this sector.

Some general data about the Australian population's use of privately provided dental services are available, however, through national population surveys. In the future, more data may be made available in some way – for example, through reporting by sentinel dental practices.

Bridging the gap and filling the holes

Better data on oral health and dental service use can lead to better health outcomes for patients, reduced inequalities and an optimised oral health service. Outputs from the statistical analysis of data allow people with oversight of the health system to:

- develop evidence-based policy
- plan effective resourcing of the health system, resolving gaps in adequate care.

The AIHW is currently supporting the Department of Health and Aged Care with longer term public dental reform by identifying and developing a set of core public dental data for use at the national and jurisdictional level to accurately measure and describe dental service activity and recipients of services. Funding allocated to the AIHW for this activity is available to the end of June 2025.

This data set would likely enable some basic level of reporting on:

- the number and type of clinical dental services provided through public dental care programs
- demographic characteristics of clients receiving services
- information on the funding or administrative arrangements associated with these services.

The collection may also incorporate data needed to inform performance measures (such as waiting times) and support other measures of interest, along with data needed for routine reporting under funding or other arrangements.

The data eventually collected via the newly developed public dental national minimum data set will not only facilitate the measurement and reporting of public dental service activity but also serve as a valuable resource for identifying individuals in priority populations in the health-care system. This broadened data set will enable a nuanced understanding of eligibility criteria, incorporating factors such as age, pre-existing medical conditions, socioeconomic status and geographic location, to support more equitable and targeted public dental care interventions.

Regular check-ups are important

Collecting dental data routinely is a fundamental component of monitoring and improving overall oral health at the population level. Harmonising data collection methods, terminologies and reporting standards ensures consistency in data reporting between different providers, thereby creating a comprehensive and reliable data set to inform public health efforts.

Further reading

For more information on the oral health status of Australians and their use of dental care services see:

Oral health and dental care in Australia (AIHW web report)

National Oral Health Plan 2015–2024: performance monitoring report (AIHW web report)

Aboriginal and Torres Strait Islander Health performance Framework – Measure 1.11 Oral health

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Concussions in Australia over the last decade

Key messages

- In 2021–22, there were 17,700 Emergency department (ED) presentations and 10,800 hospitalisations for concussions.
- ED presentation concussion rates have increased by an average of 5% per annum over the past 8 years, but this is not translating to increased rates of hospitalisation.
- Falls were the leading cause of concussion hospitalisations (50%).
- As an activity undertaken at the time of the injury, sport was involved in just over 1 in 5 concussion hospitalisations, although this is likely an underestimate owing to under-reporting.
- Males and people aged 15–24 experience the highest rates of concussion. However, across certain sports (including combined rugby league and union codes, Australian Rules Football, soccer and touch football) females have higher rates of concussion based on participation estimates.

Introduction

There is rising global concern about concussions (see Box CON.1) and their long-term health effects. Especially within a sporting context, new research highlights the links between repeated concussions and permanent impacts on cognitive, behavioural and social functioning (Bannon et al. 2020; Chase et al. 2020; Walton et al. 2022).

With sport contributing substantially to the Australian identity, identifying and assessing the impacts of concussion on the sporting field is essential to prevent injury, optimise athlete performance and health, and reduce burdens on the health system.

Box CON.1: What is a concussion?

The definition of a concussion can vary between health care, academic and sporting contexts. Broadly, concussions are typically caused by a collision (with people or objects), resulting in an impulsive force to the head (ASC 2024). These forces result in a mild traumatic brain injury (Healthdirect 2022).

The AIHW National Hospital Morbidity Database reports information on diagnosis and external cause, using the International Statistical Classification of Disease and Related Health Problems, 10th revision, Australian Modification (ICD-10-AM; WHO 2019). For the purposes of this article, the term ‘concussion’ is used to encompass ICD-10-AM acute concussive injury codes S06.0 to S06.05. This includes diagnoses of concussion and loss of consciousness resulting from head trauma. Post-concussional syndrome (F07.2) is excluded from analysis, as it is not an acute injury code.

For ED records before 2018–19, codes from the Systemised Nomenclature of Medicine – Clinical Terms classification system were mapped to the corresponding ICD-10-AM equivalent codes.

A concussion is a type of traumatic brain injury (TBI). Across AIHW injury reporting, TBI encompassed ICD-10-AM intracranial injury codes S06.0 to S06.9 (AIHW 2021b). In 2021–22, concussions made up just under half of all hospitalised TBI cases (48%).

Numerous Australian sporting associations and academic institutions have invested substantial resources into improving player safety, including:

- injury surveillance research
- athlete educational programs
- return-to-play guidelines (AFL 2021; ASC 2024; Ignacy et al. 2021; Spiegelhalter et al. 2023).

An Australian Senate inquiry in 2023 explored concussions and repeated head trauma in contact sports (Senate Community Affairs References Committee 2023). However, data presented here show that sports are involved in just over 1 in 5 concussion hospitalisations in Australia.

It is important not to focus solely on the sporting context. Half of all concussion hospitalisations in 2021–22 were caused by falls, and a quarter by transport accidents (including while in a car, and on a motorcycle or bicycle). Sport in this report is classed as an activity, not a cause group (see Box CON.2). As such, a concussion hospitalisation involving sport will still have a separate cause assigned, such as a fall. Assessing concussions that occur both on and off the sporting field is necessary to minimise instances of both acute injury and long-term consequences of concussions (see Box CON.2).

Box CON.2: External cause and activity codes

Hospitals data have 2 fields relevant to determining the context of an injury.

1. External cause is the circumstance in which an injury has occurred, such as a fall or transport crash. All concussion hospitalisations had an external cause recorded; however, due to differences in state/territory data collection, no nationally comparable external cause data are available for emergency department presentations.
2. Activity codes describe what the person was doing at the time of injury – for example, sport or employment. A concussion that occurred during a given activity will have an accompanying external cause code.

Having as few as 3 concussions can contribute to cognitive decline in later life (Lennon et al. 2023); however, the number of reported cases of people suffering long-term effects from concussion is a very small proportion of reported concussion cases (QBI 2024). Sub-concussive impacts are considered potentially injurious despite the absence of symptoms (Daneshvar et al. 2023). Concussions have far-reaching impacts not only for the individual, but also for health systems and the wider community. It is estimated that over $50 million is spent on concussion-related hospital admissions across Australia's health system each year (Thomas et al. 2020) (see Box CON.3).

Box CON.3: ED presentations and hospitalisations

This article includes analysis of concussions recorded in either ED or hospital databases.

ED presentation – The term 'ED presentation' refers to an injury incident where a person visited an Emergency Department. An ED is a dedicated hospital area that administers emergency care to patients suffering from an acute medical condition or injury (AIHW 2005). A person may have an ED presentation without being admitted to hospital, depending on injury severity, hospital admission practices and if they left before the episode of care could be completed.

Hospitalisation – The term 'hospitalisation' refers to an injury incident where a person was admitted to hospital. A person may be admitted through an unplanned admission, a planned admission, a new episode of care within the same hospital stay, or a transfer from another hospital. To minimise double counting, transfer hospitalisations are excluded.

Data set limitations

Concussions are under-reported within both medical and sporting settings. Contributing factors include lack of education, different definitions of concussion, and a competitive sporting culture that promotes a ‘play on’ mentality (Leeds et al. 2022; Longworth et al. 2021; Senate Community Affairs References Committee 2023). The Australian Institute of Sport (2023) estimates that concussion under-reporting can be up to 82% across certain sports.

While research has mainly focused on concussion under-reporting in sport, Foster and colleagues (2019) suggest that a culture of concussion non-disclosure is not limited to athletes. Hence, numbers presented in this article are likely to be a substantial under-representation of the true numbers of concussions across Australia.

The data sets used in comparing sports have limitations. Not all ED presentation records have activity information, meaning that sport involvement across injuries cannot be completely determined. In hospitals, over half of concussion cases do not have any activity information recorded (54%), so findings related to activity at the time of injury should be interpreted with caution. In the sport context, it is important to take into account exposure, such as participation rates reported through AusPlay ™ – a large population tracking survey funded and led by the Australian Sports Commission. These rates are based on survey data, so are subject to sampling error. Consequently, rates of concussion per 100,000 participants should be treated as estimates.

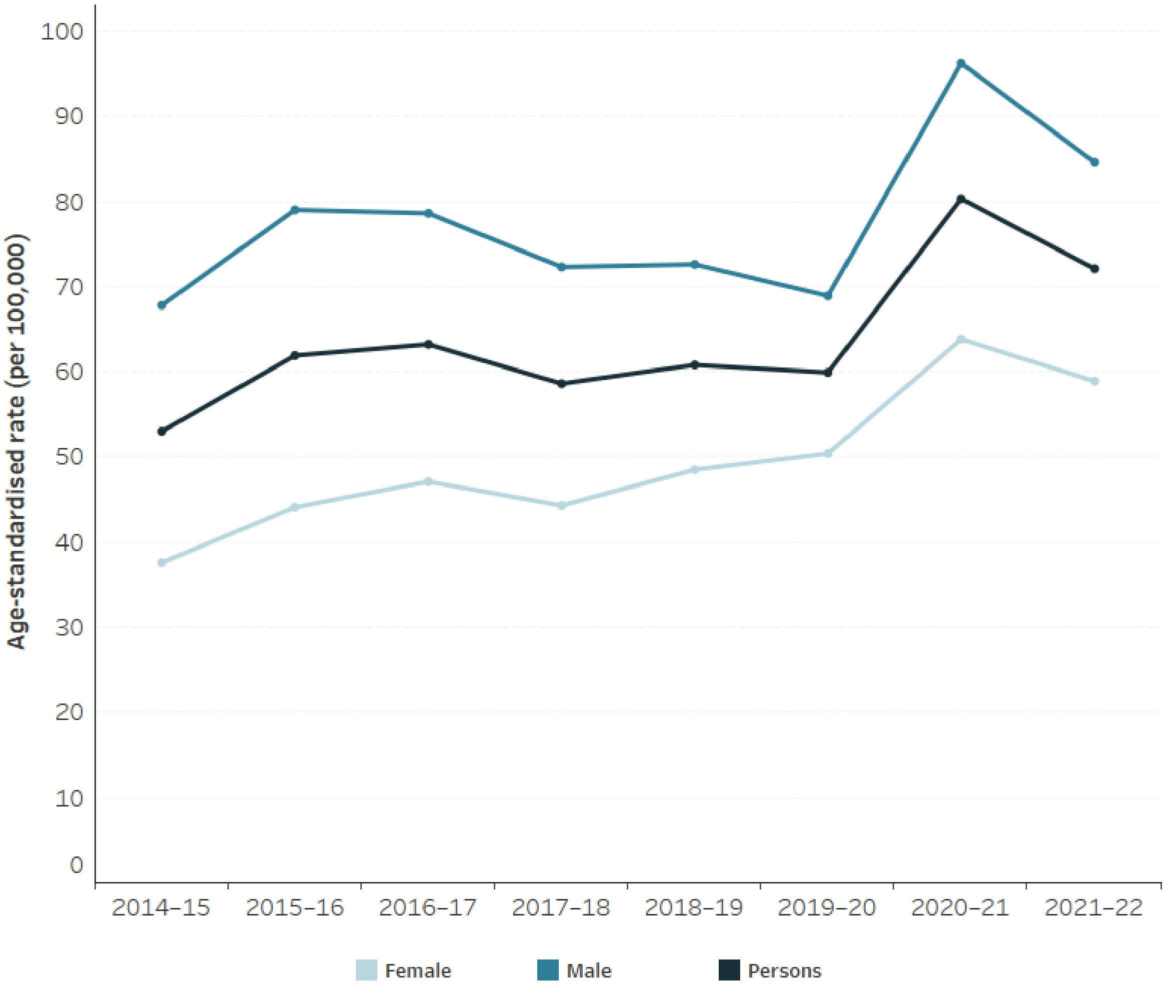
ED presentations for concussions on the rise, while hospitalisations decline

In 2021–22, there were 17,700 ED presentations for concussions (72 per 100,000 population). Between 2014–15 and 2021–22, ED presentation rates for concussions increased by an average of 5.4% per year. Notably in 2020–21, ED presentation numbers saw a 34% increase, following a period of stagnation (Figure CON.1). This increase is likely attributed, in part, to the easing of COVID-19 restrictions across Australia; however, it is still larger than expected relative to pre-pandemic trends. Total ED presentations increased by 6.9% in 2020–21 (AIHW 2023c).

Improved community awareness, as well as updated return-to-play guidelines for concussion, may be factoring into the rapid increase in concussion ED presentations (Thomas et al. 2020). Changing trends in triage categories could be reflecting this (see the section headed ‘What is the severity of concussions?’ later in this article). There have been no ICD coding changes to explain this phenomenon.

Figure CON.1: Rates of ED presentation for concussion are increasing over time

Age-standardised rates of concussion ED presentations, by sex, Australia, 2014–15 to 2021–22



https://www.aihw.gov.au

Source: AIHW National Non-Admitted Patient Emergency Department Care Database.

While ED presentations for concussions are on the rise, this is not being reflected in hospital admissions:

- In 2021–22, there were 10,700 concussion hospitalisations (42 per 100,000).
- Between 2012–13 and 2016–17, hospitalisation rates for concussions rose by an average of 6.4% per annum, from 41 to 53 per 100,000 population.
- Between 2017–18 and 2021–22, this trend reversed, with hospitalisations falling by an average of 3.2% per year (Figure CON.2). All injury hospitalisations also fell during this period (AIHW 2023e). COVID-19 is likely contributing to the volatility seen in Figure CON.2.

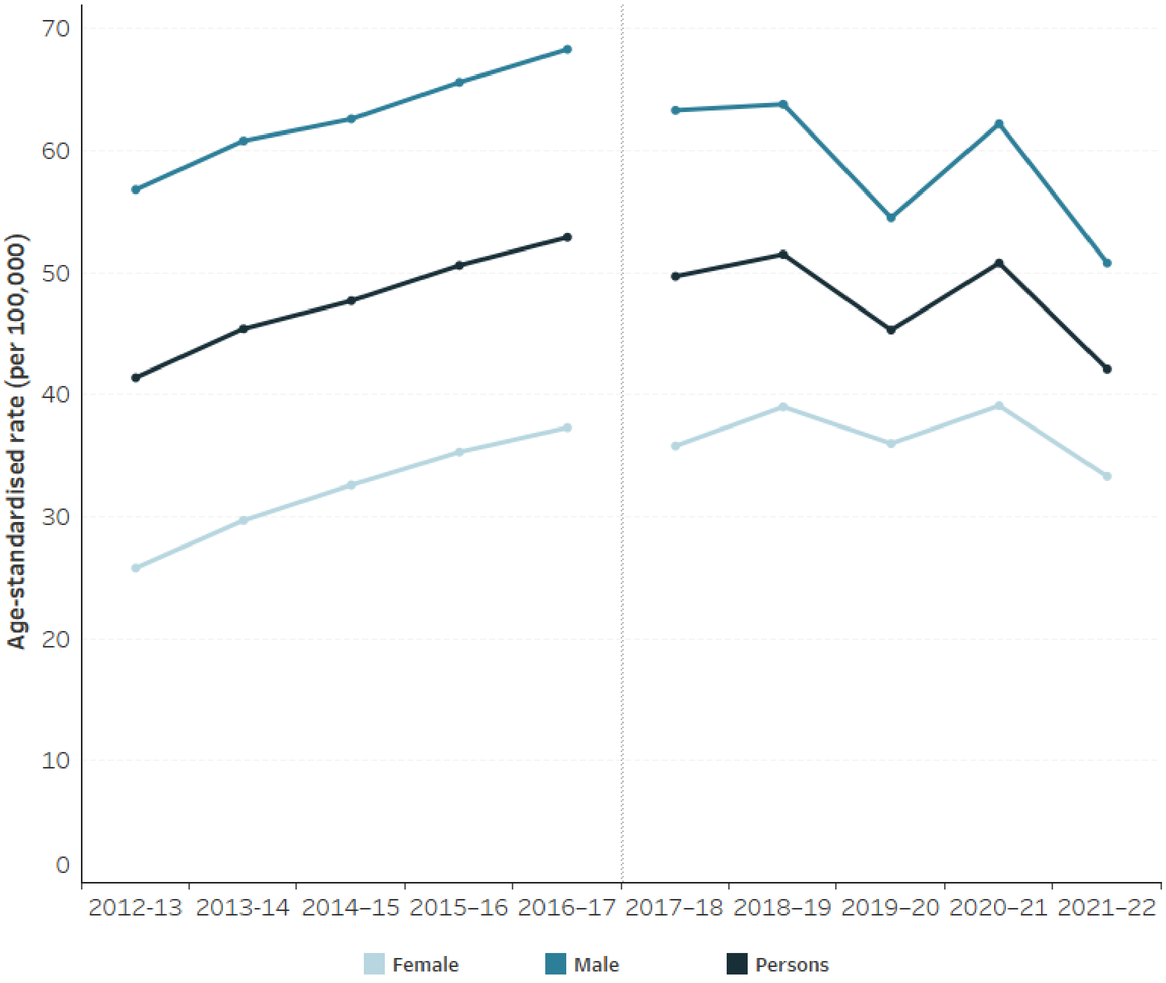
The Australian Institute of Sport and the Australian Medical Association Concussion in Sport Position Statement may have informed concussion management practices in EDs in stating that:

- most concussion symptoms resolve spontaneously, given appropriate management
- the main management approach is rest, without need for further medical intervention.

Changing trends in ED end status (see Figure CON.8) may be reflecting the application of this advice.

Figure CON.2: Rates of hospitalisation for concussion have fallen over the past 5 years

Age-standardised rates of concussion hospitalisations, by sex, Australia, 2012–13 to 2021–22



https://www.aihw.gov.au

Note: Hospitalisation data are divided into 2 time periods: 2012–13 to 2016–17, and 2017–18 to 2021–22. Comparing hospitalisations data for these 2 periods is not recommended due to a change in data collection methods between 2016–17 and 2017–18 (see *Injury in Australia* technical notes for more details).

Source: AIHW National Hospital Morbidity Database.

Males and people aged 15–24 have the highest rates of concussion

Males consistently have higher overall rates of injury than females (AIHW 2023e). Concussions are no exception and, in 2021–22, males:

- made up 60% of concussion hospitalisations and 59% of concussion ED presentations
- had the highest numbers and rates of concussion across all age groups. The key exception was women aged 65 and over, who have higher numbers and rates of concussion ED presentations.

Factors contributing to the higher rates of injuries among males could include the increased likelihood of:

- participating in risk-taking behaviours (Mollayeva et al. 2018)
- substance use/abuse (AIHW 2023a)
- occupational exposures and hazards (Safe Work Australia 2023).

Adolescents and young adults tend to be over-represented in concussions compared with all injuries, where rates of injury peak in older age groups (AIHW 2023e). People aged 15–24 had the highest rates of concussion ED presentations and hospitalisations (135 and 72, respectively, per 100,000 population) (see Figures CON.3 and CON.4).

Concussion among children

Developing brains are more vulnerable to concussion impacts, and children and adolescents appear to require longer periods of recovery time than adults (Manzanero et al. 2017; Parker et al. 2021). Younger age groups also have thinner skulls and less well-established neck muscles, both of which act as supporting structures to cushion the brain from impact (van Ierssel et al. 2021).

For ED presentations, boys aged 5–14 had the highest rates of concussion of any age group across the population (165 per 100,000) (Figure CON.3). Males aged 15–24 had the highest rate of hospitalisation for concussion, with 91 per 100,000 – nearly double the rate of their female counterparts (51 per 100,000) (Figure CON.4).

Figure CON.3: Children and young people have higher rates of concussion ED presentation

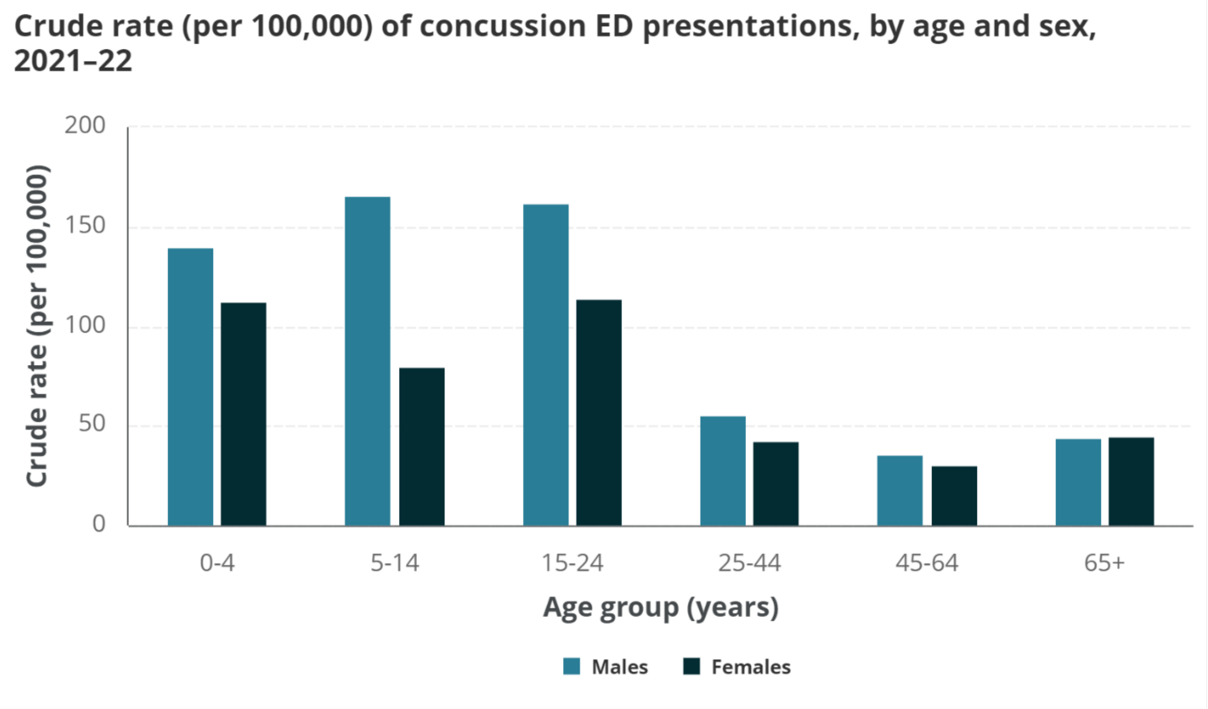
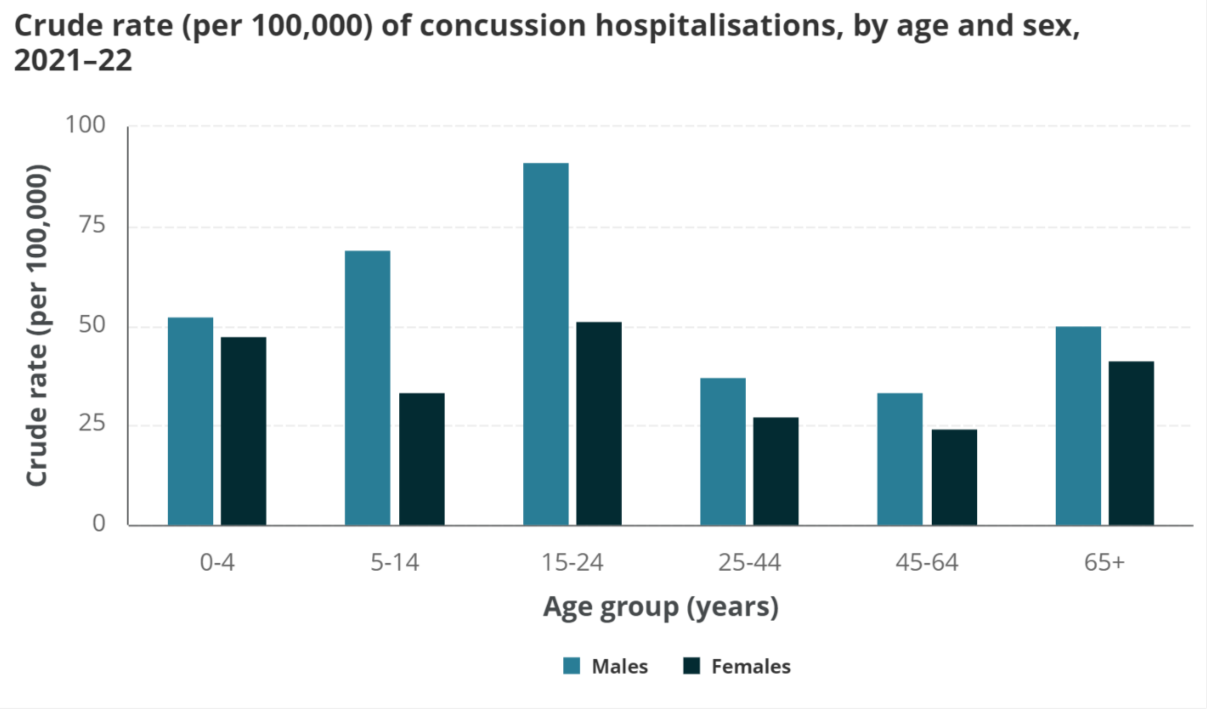


Figure CON.4: Children and young people have higher rates of concussion hospitalisation



Falls caused half of all concussion hospitalisations

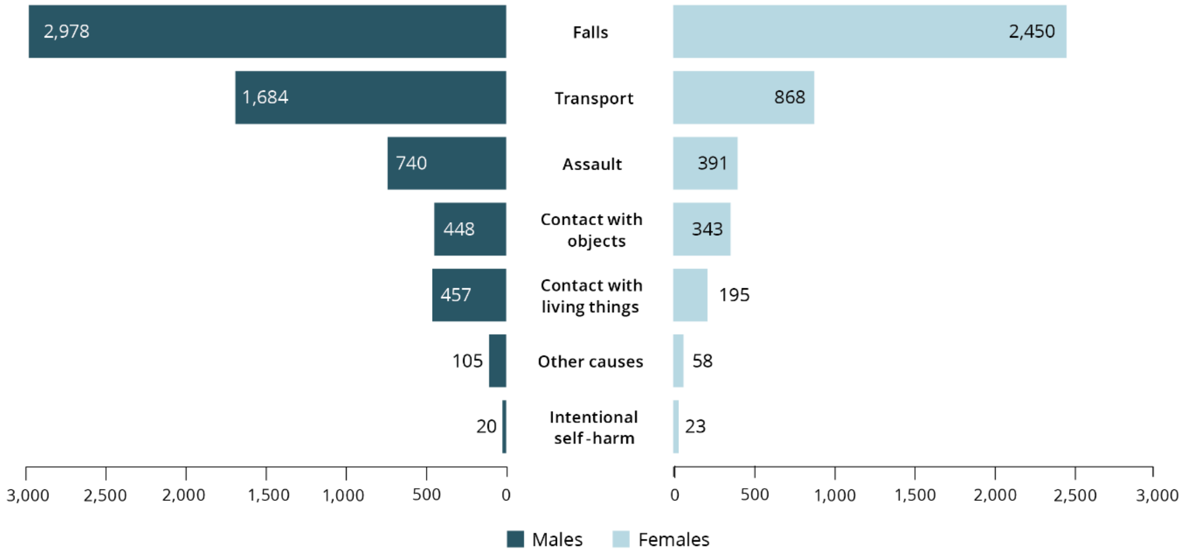
The leading causes (termed 'external causes' in hospital records) of concussion hospitalisations in 2021–22 were:

- falls (50%)
- transport crashes (24%)
- assault (11%) (Figure CON.5).

Separate to the cause of the injury, the activity undertaken at the time of the injury was also recorded in just over half of the injury cases. Sport is classed as an activity, not an external cause. For information on sports-related concussions, see the section headed '1 in 5 concussion hospitalisations involve sport' later in this article.

Figure CON.5: Falls are the leading cause of concussion hospitalisations

Number of concussion hospitalisations, by cause and sex, Australia, 2021–22



Notes

1. 'Other causes' includes *Drowning and submersion*, *Choking and suffocation*, *Accidental poisoning*, *Electricity and air pressure*, *Forces of nature*, *Overexertion*, *Other specified* and *Undetermined intent*.

2. For information on the grouping of external cause ICD-10-AM codes, see *Injury in Australia* technical notes.

Source: AIHW National Hospital Morbidity Database.

Falls

Falls caused the largest number of concussion hospitalisations (50%). This is similar to the pattern for total injuries, where falls are also the leading external cause of hospitalisations (43%) (AIHW 2023e). The most commonly specified types of falls were a fall:

- on the same level, including slipping, tripping, stumbling, or colliding with or being pushed by another person (53%)
- involving furniture (8.3%)
- on or from stairs or steps (6.4%).

Among hospitalisations for concussion caused by falls, the group aged 0–4 had the highest rate (42 per 100,000) followed closely by the 65 and over age group (39 per 100,000).

Transport crashes

Transport crashes are the second leading cause of concussion hospitalisations and the third leading cause of total injury hospitalisations (AIHW 2023h). Concussions made up around 4% of all transport injury hospitalisations (2,600) in 2021–22. Of these:

- nearly 3 in 10 (29%) were car occupants
- over one-quarter (27%) were pedal cyclists
- around one-fifth (19%) were motorcycle riders.

Assault

Assault is the third leading cause of concussion hospitalisations and the seventh leading cause of total injury hospitalisations (AIHW 2023e). Concussion hospitalisations made up around 6% of all assault injury hospitalisations (1,100) in 2021–22.

Males represented 65% of concussion hospitalisations related to assault. Where specified, females were more likely to have been assaulted by spouses or domestic partners (92%). Males were more likely to report being assaulted by an unknown person/s (86%).

Over one-third of all assault-related concussion hospitalisations did not have a perpetrator recorded. This information may be unavailable for a number of reasons, including because it was not:

- reported by, or on behalf of, victims
- documented in the hospital record (AIHW 2019).

Disclosure of the perpetrator in a hospital setting can be influenced by personal feelings such as fear or shame, insufficient recovery, insufficient privacy and time to disclose, and the extent of appropriate staff training and procedures that support disclosure.

Nearly 3 in 5 concussion hospitalisations involved a loss of consciousness

Loss of consciousness is an important factor in determining the severity of a concussion. Concussions involving a loss of consciousness have been shown to have poorer recovery outcomes than those with no loss of consciousness (Roy et al. 2020), though a large prospective cohort study of cognitive outcomes at one year follow up did not support an association (Schneider et al. 2022).

In 2021–22, 59% of concussion hospitalisations involved a loss of consciousness. Loss of consciousness (<30 minutes) (S06.02) was the most frequent principal diagnosis (4,500 diagnoses).

Males were more likely to have lost consciousness for any duration during a concussion incident than females (31 and 18 per 100,000). People aged 15–24 had the highest rate of loss of consciousness (40 per 100,000), followed by people aged 65 and over (34 per 100,000).

It has been estimated that loss of consciousness occurs in only around 10% of concussions in community sport football codes (Ractliffe et al. 2021). Of ED presentations, 28% of concussions involved a loss of consciousness. Comparatively, 59% of hospitalised concussion cases involved a loss of consciousness overall, and 51% of sports-related hospitalised concussion cases. This potentially represents people with more severe cases of concussion being admitted to hospital.

1 in 5 concussion hospitalisations involve sport

Of hospitalised concussion cases, 2,300 or 22% occurred while participating in sport or physical activity. The place where the injury occurred was specified for 74% of all concussion hospitalisations. Where specified, 17% of these occurred in a sports or athletics area (see Box CON.4).

Of the 2,300 concussion hospitalisations involving sport or physical activity:

- 1,600 were for males (69%)
- around 910 occurred while playing some form of rugby or football (including Australian Rules Football, rugby union, rugby league, soccer, and touch football) (39%)
- around 425 occurred while participating in a form of cycling (18%) (including BMX, mountain, road and velodrome cycling).

Box CON.4: Benefits of participating in sports and physical activity outweigh the health-care costs associated with injury

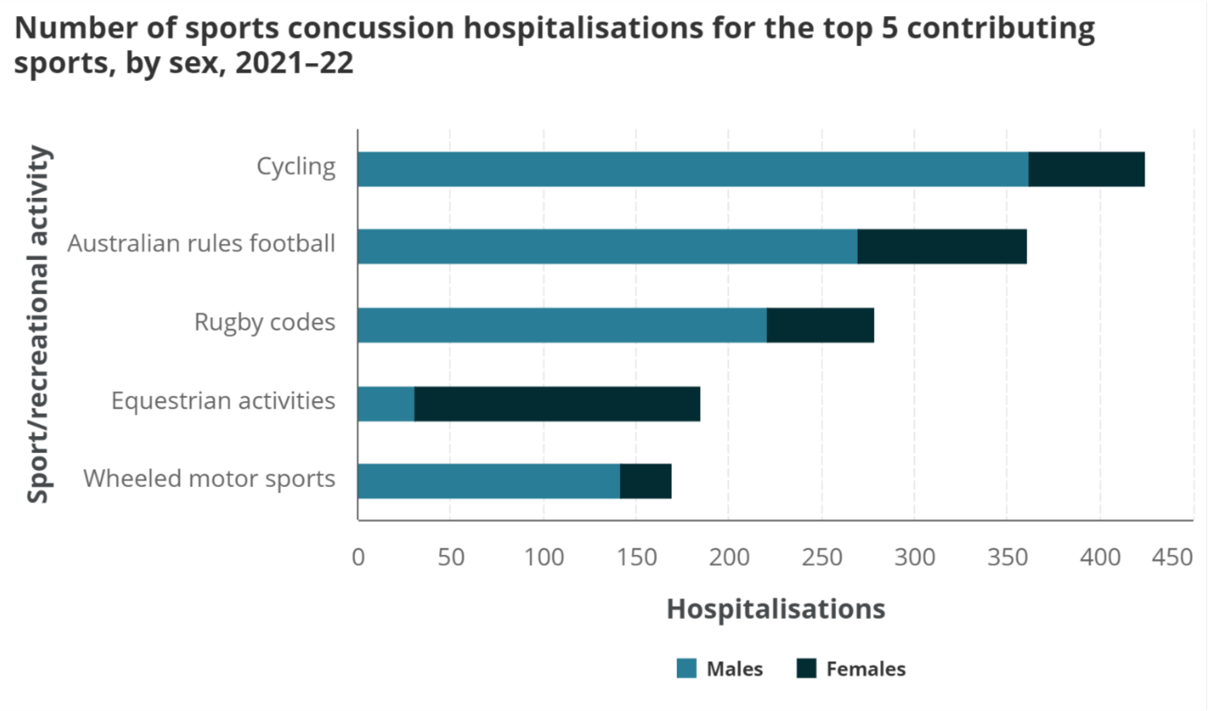
When evaluating the financial burden of sporting injuries including concussion, it is important to also consider the health benefits of sports and physical activity. Physical activity reduces the risk of developing various chronic health conditions. Further, in 2018–19, sport and physical activity had a net positive impact on the health system of $321 million, even when factoring in the costs of injury (AIHW 2023b). Minimising sports injuries, including concussions, should be the focus of prevention strategies, rather than avoidance of sport.

Similar to all concussion hospitalisations, younger age groups have the highest rates of hospitalisation. People aged 15–24 had the highest rate of concussion hospitalisations involving sport (27 per 100,000 population), followed by 5–14-year-olds (24 per 100,000). Children and adolescents have a higher risk of long-term brain injury from sports concussions than adults (Neelakantan et al. 2020), which often presents as learning difficulties and cognitive impairment while children are still in school (Lowry et al. 2019).

Cycling, whether as a sport or a mode of transport/recreation, was associated with the largest number of sports concussion hospitalisations (18%) (Figure CON.6). It was also the sport with the most concussion hospitalisations for males (360); for females, this was equestrian activities (150). This difference is similar to that seen in total sports injury hospitalisations (AIHW 2023d).

It is estimated that 13% of Australians aged over 15 participate in cycling, making it the fifth most popular sport/recreational activity (ASC 2023). This high participation rate, together with cyclists representing 1 in 4 injury hospitalisations from land transport crashes (AIHW 2023e), likely factors into the greater number of cyclist concussions.

Figure CON.6: Cycling was associated with the largest number of sports concussion hospitalisations



When evaluating the incidence of sports-related concussion, it is important to consider the popularity of the sport, or participation rates (AIHW 2023g). Every year, the AusPlay TM survey asks a sample of 20,000 Australians about their participation in sports and physical activity (ASC 2023).

Using these participant estimates for selected sports, those with the highest rates of concussion hospitalisation per 100,000 participants were:

- equestrian activities (53)
- rugby codes (49)
- wheeled motor sports (43) (Table CON.1).

Females have higher rates of concussion across contact sports

The rugby codes (covering both union and league) had the highest rates of concussion for females, with rates 1.6 times higher than for males (72 and 45 per 100,000 participants) (Table CON.1). This is consistent with research indicating that female athletes are more susceptible to concussion than males, and have a greater risk of poorer health outcomes. Factors influencing this may include:

- physiological differences (such as reduced neck strength)
- recent rapid increase of female participation in contact sports
- greater likelihood of reporting and seeking health services for concussions (AIS and AMA 2016; Di Battista et al. 2019; McGroarty et al. 2020).

Table CON.1: Rate per 100,000 participants aged 15 and over for sports with the highest rates of concussion hospitalisations, by sex, 2021–22

Sport	Sex	Concussion hospitalisations (number)	Australian participation rate (%)	Concussion hospitalisations (per 100,000 participants)
Equestrian activities	Males	24	0.3%	59
	Females	119	2.0%	52
	Persons	143	1.2%	53
Rugby codes	Males	132	2.8%	45
	Females	37	0.5%	72
	Persons	169	1.6%	49
Wheeled motor sports	Males	96	2.2%	41
	Females	18	0.2%	60
	Persons	114	1.2%	43
Australian Rules Football	Males	181	4.5%	38
	Females	60	1.3%	43
	Persons	241	2.9%	39
Roller sports	Males	49	1.4%	32
	Females	30	1.1%	24
	Persons	79	1.2%	29

Notes

1. Sports are ICD-10-AM activity codes mapped to AusPlay^{TM} sports categories following convention in *Sports Injury in Australia* Technical Notes.
2. Numerator counts are from the National Hospital Morbidity Database.
3. Denominator counts are estimates from the AusPlay^{TM} survey. (AusPlay^{TM} is a sample survey which may be subject to sampling error.) See *Sports Injury in Australia* Technical Notes for more information.

Sources: AIHW National Hospital Morbidity Database; AusPlay^{TM} survey results July 2021 – June 2022.

Falls and transport crashes are the leading causes of sports concussion hospitalisations

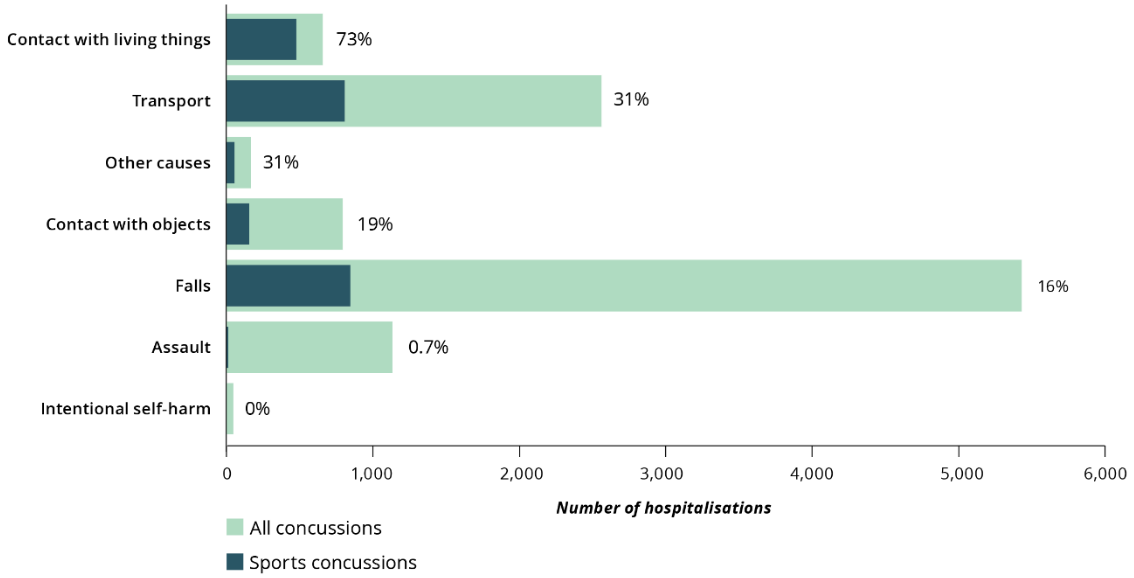
Similar to all concussion hospitalisations, the 2 leading causes of concussion hospitalisation while participating in sport were falls (36%) and transport (34%). Injuries caused by falls were present in 31 of the 34 sports identified through activity codes. Sports-related hospitalised concussion cases caused by transport mostly occur (94%) in transport-based sports across cycling, wheeled motor sports and equestrian activities.

Looking within cause groups, sports concussion hospitalisations made up most concussions caused by 'contact with living things'. Nearly three-quarters (73%) of concussions caused by contact with living things involved sport, which can include unintentional person-to-person contact (Figure CON.7).

Injuries involving a fall because of a collision with or pushing by another person (for example, during a rugby tackle) are included in the numbers of concussions caused by falls, not contact with living things. Of these 480 hospitalisations, 86% involved sport.

Figure CON.7: Sports were involved in the majority of concussions caused by contact with living things

Proportion of sports concussion hospitalisations compared with all concussion hospitalisations, by external cause, Australia, 2021–22



Note: 'Other causes' includes *Drowning and submersion*, *Choking and suffocation*, *Accidental poisoning*, *Electricity and air pressure*, *Forces of nature*, *Overexertion*, *Other specified* and *Undetermined intent*.

Source: AIHW National Hospital Morbidity Database.

What is the severity of concussions?

There are many ways the severity, or seriousness, of an injury can be measured. Severity metrics in this article compare concussions over time, and against all other head injuries – fractures, for example.

Box CON.5: What are severity metrics?

Severity metrics used in this article are:

Triage category: ED presentations are assigned 1 of 5 triage categories based on the urgency with which the patient requires medical care.

Waiting time: Triage categories have clinically appropriate waiting time cut-offs between the patient's being triaged and seen for medical assessment (NSW Health 2022). A patient is seen on time if they receive care within this time frame.

End status: Patients can leave the ED in different ways, for example, by being admitted to hospital, or when they 'Did not wait to be attended by a health care professional'. People admitted to hospital are likely to have more serious injuries.

ED triage trends are changing for concussion presentations

Between 2014–15 and 2021–22, the proportion of lower urgency concussion presentations (Semi-urgent or Non-urgent triage) increased (from 29% to 32%), while Urgent presentations fell (54% to 50%). The increase in lower urgency concussion ED presentations could be driven, in part, by increased public awareness of concussion.

Most concussion ED presentations are seen on time

Based on triage waiting time cut-offs, 58% of concussion ED presentations were seen on time (Table CON.2) in 2021–22 – a drop from the peak of 68% seen on time in 2014–15 and 2019–20. Concussions were less likely to be seen on time than all ED presentations, where 67% were seen on time in 2021–22, though this proportion, too, was down, from 74% in 2019–20 (AIHW 2021a, 2023c).

Concussion ED presentations were generally triaged as being more serious than other head injuries (including fractures, open wounds and superficial injuries). The most common triage category for concussions was Urgent (50%), while for other head injuries, it was Semi-urgent (49%).

Table CON.2: Number of concussion ED presentations, by triage category, Australia, 2021–22

Triage category	Clinically appropriate waiting time cut-off	Presentations	Per cent seen on time (%)	Per cent admitted to hospital (%)
Resuscitation	Immediate (within seconds)	429	99	80
Emergency	Within 10 minutes	2,795	68	50
Urgent	Within 30 minutes	8,778	53	27
Semi-urgent	Within 60 minutes	5,413	58	13
Non-urgent	Within 120 minutes	299	77	10
Total	Total	17,714	58	27

Source: AIHW National Non-Admitted Patient Emergency Department Care Database.

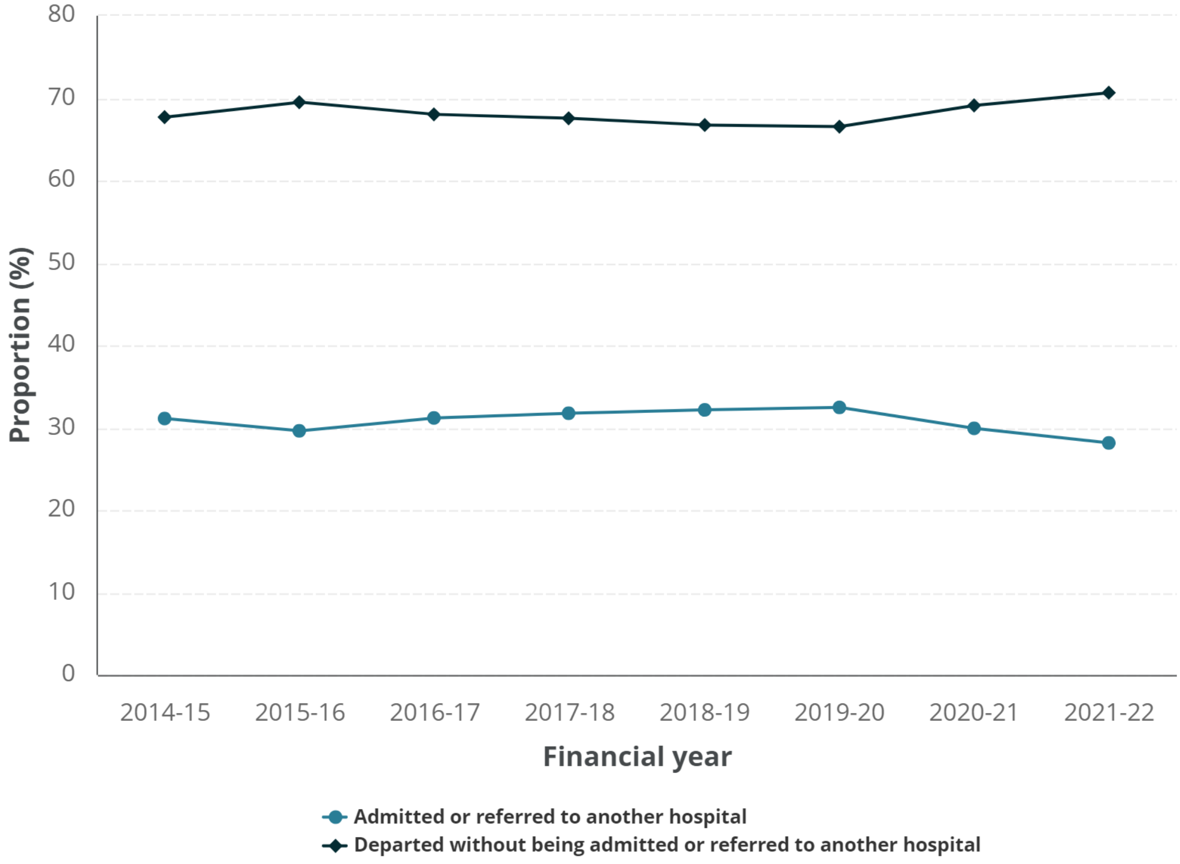
Fewer concussion cases are being admitted to hospital from ED

From 2019–20 onwards, the proportion of patients being admitted to hospital or transferred to another hospital from an ED fell by 4.3 percentage points, while patients who completed an episode of care and departed without being admitted or referred to another hospital increased by 4.1 percentage points.

This is the reverse of the trend between 2015–16 and 2019–20, where admissions and referrals increased by 2.8 percentage points, and non-admissions decreased by 3.0 percentage points. (Figure CON.8). This reinforces international research indicating that the COVID-19 pandemic saw a reduction in hospital admissions through EDs (Nourazari et al. 2021; Reschen et al. 2021).

Figure CON.8: Trends in ED end status are changing, with fewer concussion cases being admitted to hospital

Proportion of ED presentations, by end status 2014–15 to 2021–22



Graph excludes records with an end status of:

1. Did not wait to be attended by a health care professional
2. Left at own risk after being attended by a health care professional but before the non-admitted patient emergency department service episode was completed
3. Died in emergency department
4. Dead on arrival
5. Registered, advised of another health care service, and left the emergency department without being attended by a health care professional

Where to from here?

Monitoring the prevalence of concussions both on and off the sporting field remains a high priority in injury reporting. Under-reporting presents challenges in establishing the true causes, severity and health-care burden associated with concussions.

The AIHW is actively exploring linked data sets to expand the capabilities of injury surveillance beyond initial acute hospitalisations (AIHW 2023f). This approach would be useful in a concussion and sub-concussion context for progressive diseases that accelerate with repeated head injuries. Investigating the relationship between the number of hospitalised concussions, severity of hospitalisation, and recovery pathways would provide insights into the long-term health-care burden of concussions. An AIHW report on traumatic brain injury indicated the usefulness of larger scale applications of this data linkage approach (AIHW 2021b).

Analysing ED external cause data would assist with exploring factors contributing to the increase in ED presentations. External cause data are currently not consistently collected and/or provided by all jurisdictions to the AIHW. Improving collection to align with hospitalisations data would allow for greater analysis of ED injury presentations, which could identify potential avenues for targeted prevention.

The recent Senate inquiry into concussions and repeated head trauma in contact sports (Senate Community Affairs References Committee 2023) recommended that a national sports injury database be set up as a matter of urgency. The AIHW has begun this work, with funding from the Australian Sports Commission. Along with injury data from community sporting organisations, ED external cause data would be an essential part of this data collection.

Further reading

- Economics of sport and physical activity participation and injury (AIHW web report)
- Head injuries in Australia 2020–21 (AIHW web report)
- Health service use for patients with traumatic brain injury (AIHW web report)
- Injury in Australia (AIHW web report)
- Sports injury in Australia (AIHW web report)

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Electronic cigarette use (vaping) in Australia in 2022–2023

Key messages

- Results from the 2022–2023 National Drug Strategy Household Survey showed that the proportion of people using e-cigarettes daily in Australia has increased substantially, from 0.5% (an estimated 100,000 people) in 2016 to 3.5% (an estimated 700,000 people) in 2022–2023.
- The proportion of people smoking tobacco daily has fallen from 12% (an estimated 2.4 million people) in 2016 to 8.3% (an estimated 1.8 million people) in 2022–2023.
- The population groups most likely to be using e-cigarettes were different to those most likely to smoke tobacco between 2016 and 2022–2023:
  - Use of e-cigarettes is particularly high among younger people, with 9.3% of people aged 18–24 and 6.5% of people aged 25–29 using them daily in 2022–2023. Conversely, daily tobacco smoking is highest among people aged 40–49 (11%) and 50–59 (12%) in 2022–2023.
  - People living in the most disadvantaged socioeconomic areas are most likely to smoke tobacco, while people in the most advantaged areas are most likely to use e-cigarettes.

Introduction

Electronic cigarettes or vapes (referred to collectively as ‘e-cigarettes’) are personal vaping devices where people inhale aerosol rather than smoke. The inhaled aerosol usually contains flavourings and a range of hazardous chemicals; it may also contain nicotine, even if labelled ‘nicotine free’ (Department of Health and Aged Care 2023).

While the adverse effects of long-term e-cigarette use are currently unknown, there are well-documented short-term effects, including e-cigarette associated lung injury, cough, throat irritation and nausea. The adverse effects of using e-cigarettes that contain nicotine can also include inhalation toxicity (including seizures), nicotine dependence and increased heart rate and blood pressure (Banks et al. 2023).

The use of e-cigarettes (commonly referred to as vaping) was first identified in Australia around 2007, with evidence of use increasing since 2016 (AIHW 2024b; Wilkins et al. 2024).

This increasing use of e-cigarettes has occurred in an environment of steadily declining levels of tobacco smoking in Australia, a trend seen since the early 1990s (AIHW 2023).

Tobacco and e-cigarette control in Australia

The tobacco control measures of all Australian governments and public health organisations have been key to Australia's success in tobacco control. In recent decades, Australia has progressively implemented a comprehensive suite of tobacco control measures, including:

- increasing excise
- running social marketing campaigns
- introducing plain packaging
- issuing graphic health warnings
- prohibiting tobacco advertising and promotion
- providing support for people who smoke to quit (Department of Health and Aged Care 2024).

Work is ongoing, with new regulatory measures, public health campaigns and expansion of smoking cessation services being introduced in 2024 (The Hon. Mark Butler MP 7 December 2023).

In partnership with state and territory governments, the Australian Government is taking action to reduce e-cigarette use through stronger legislation, enforcement, education and support. These changes are being implemented over the course of 2024, with the intention of prohibiting non-therapeutic e-cigarettes in Australia. This effort has included:

- banning the importation of disposable single use e-cigarettes
- stopping the personal importation of e-cigarettes
- banning the importation of non-therapeutic e-cigarettes (that is, e-cigarettes not intended to help with quitting or reducing the use of regular cigarettes)
- imposing requirements on therapeutic e-cigarette importers and manufacturers, including compliance with minimum product standards.

A prescription is required to access e-cigarettes containing nicotine to help in stopping tobacco smoking. Further reforms are likely to be introduced later in 2024, including the introduction of pharmaceutical style packaging and quality and safety standards for all therapeutic e-cigarettes. See Vaping hub | Therapeutic Goods Administration (TGA) for more information.

Findings presented in this article

This article summarises select findings from the National Drug Strategy Household Survey (NDSHS) 2022–2023 on:

- use of e-cigarettes in Australia among people aged 14 and over
- comparisons between trends in e-cigarette use and recent trends in tobacco smoking.

It also compares e-cigarette use by older and younger age groups, and across socioeconomic areas.

The long-term impacts of e-cigarettes on the health of people who use them, and the impacts of policy measures aimed at reducing the use of e-cigarettes, require more data before both of these impacts can be fully understood.

Data on e-cigarette use were collected in late 2022 and early 2023, prior to the new restrictions coming into effect in 2024. At the time, in most jurisdictions, it was legal to sell and purchase e-cigarettes that did not contain nicotine, and to import and use e-cigarettes containing nicotine with a prescription.

E-cigarette use in Australia

How many people are using e-cigarettes in Australia?

E-cigarette use has increased substantially in recent years. In 2016, an estimated 100,000 (0.5%) people in Australia were using e-cigarettes daily (AIHW 2024a). By 2019, this number had doubled to an estimated 200,000 (1.1%) and, by 2022–2023, had increased to an estimated 700,000 (3.5%). In 2022–2023, almost half of people currently using e-cigarettes (49%) used them every day, and 68% at least weekly.

How many people are smoking tobacco in Australia?

Over the same period, consistent with the steady declines in smoking seen since 1991, the number of people smoking tobacco fell. An estimated 2.4 million (12%) people were smoking tobacco daily in 2016, but, by 2022–2023, that number had fallen to an estimated 1.8 million (8.3%). In 2022–2023, most of those people currently smoking tobacco did so every day (79%), and 90% smoked at least weekly.

Relationships between tobacco smoking and using e-cigarettes

Tobacco smoking and use of e-cigarettes have often been considered in the same context, either with use of e-cigarettes being an introduction to smoking, or by people using e-cigarettes to help them quit smoking. According to Australian guidance on the use of e-cigarettes to manage nicotine dependence (RACGP 2024), e-cigarette products that contain nicotine may improve quit rates for smoking cigarettes; however, there is currently not enough evidence for it to be prescribed as a first-line treatment. In contrast, evidence suggests that people who have never smoked tobacco who use e-cigarettes are around 3 times as likely to start smoking cigarettes as people who have not used e-cigarettes (Banks et al. 2022).

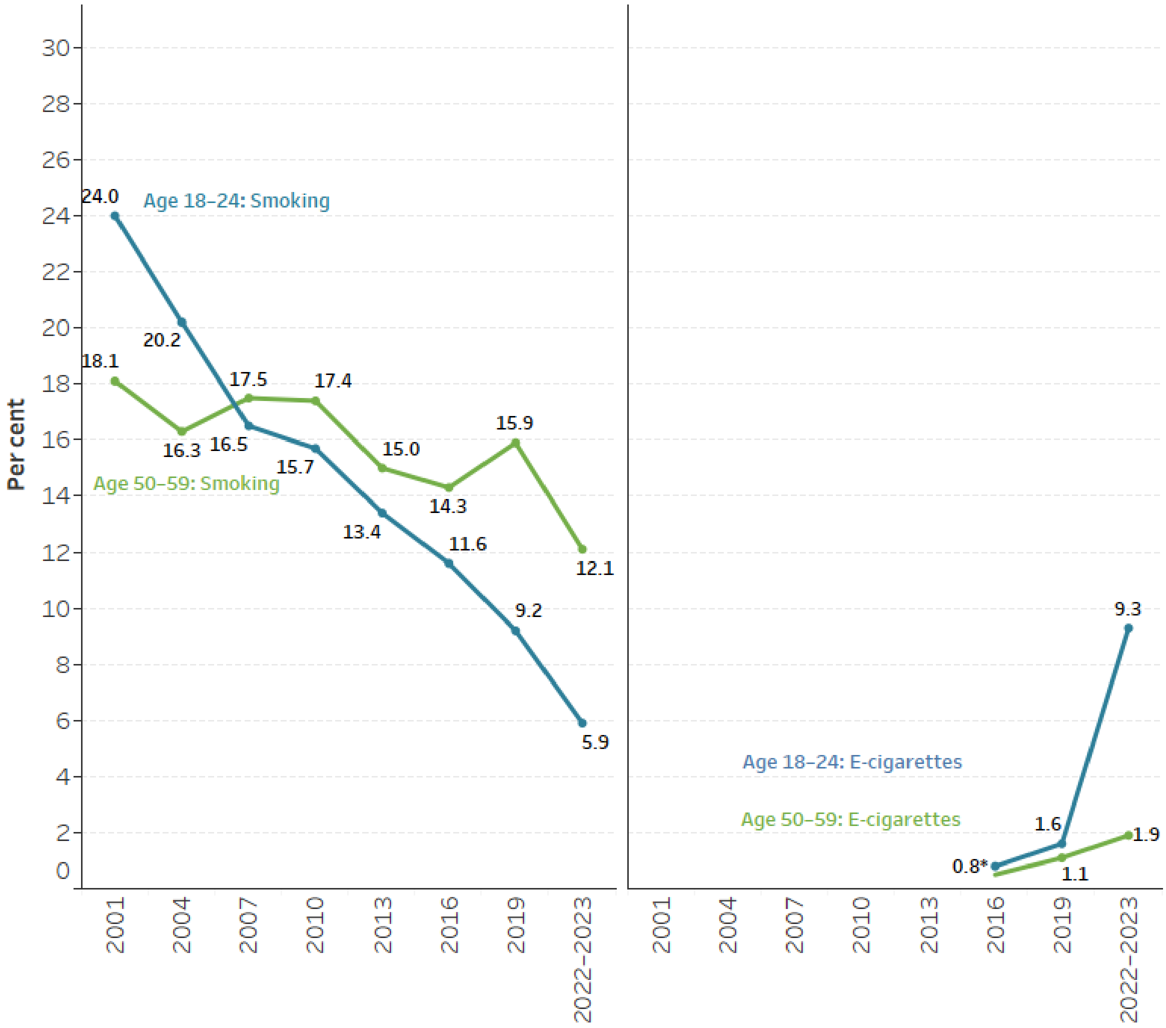
Point-in-time survey data such as from the NDSHS cannot be used to provide strong evidence on the use of e-cigarettes to help in stopping tobacco smoking or as a gateway to smoking. The NDSHS did show, however, that regardless of the potential relationships between tobacco smoking and use of e-cigarettes, the population groups most likely to be using e-cigarettes were different to those most likely to smoke tobacco.

E-cigarette use and tobacco smoking – by age group

Among people aged 14 and over in 2022–2023, older people were much more likely to smoke tobacco than younger people, but younger people were the most likely to use e-cigarettes. Figure V.1 shows smoking and e-cigarette use among 2 different age groups: people aged 18 to 24 (the most likely to use e-cigarettes) and people aged 50 to 59 (the most likely to smoke).

Figure V.1: While tobacco smoking is lower among people aged 18 to 24, e-cigarette use is increasing much faster among this age group than those aged 50 to 59

Daily tobacco smoking and daily e-cigarette use among people aged 18 to 24 and 50 to 59, 2001 to 2022–2023



Note: * Estimate has a Relative Standard Error between 25% and 50% and should be intrepreted with caution.

Source: NDSHS 2022–2023, AIHW.

https://www.aihw.gov.au

The results in Figure V.1 are examples of the broader trends seen in 2022–2023:

- Most age groups experienced a substantial decline in tobacco smoking between 2019 and 2022–2023, including people in both the 18 to 24 and 50 to 59 age groups.
- In contrast, while the use of e-cigarettes increased for most age groups over this same period, the increase was much more substantial among younger age groups. For the first time in 2022–2023, young adults aged 18 to 24 were more likely to use e-cigarettes daily than they were to smoke tobacco daily.

E-cigarette use and tobacco smoking – by socioeconomic area

In this article, the Index of Relative Socio-economic Advantage and Disadvantage (IRSAD) is used to classify individuals according to the socioeconomic characteristic of the area in which they live. It scores each area by summarising attributes of the population, such as income, educational attainment, unemployment rate, and jobs in skilled or unskilled occupations (ABS 2021).

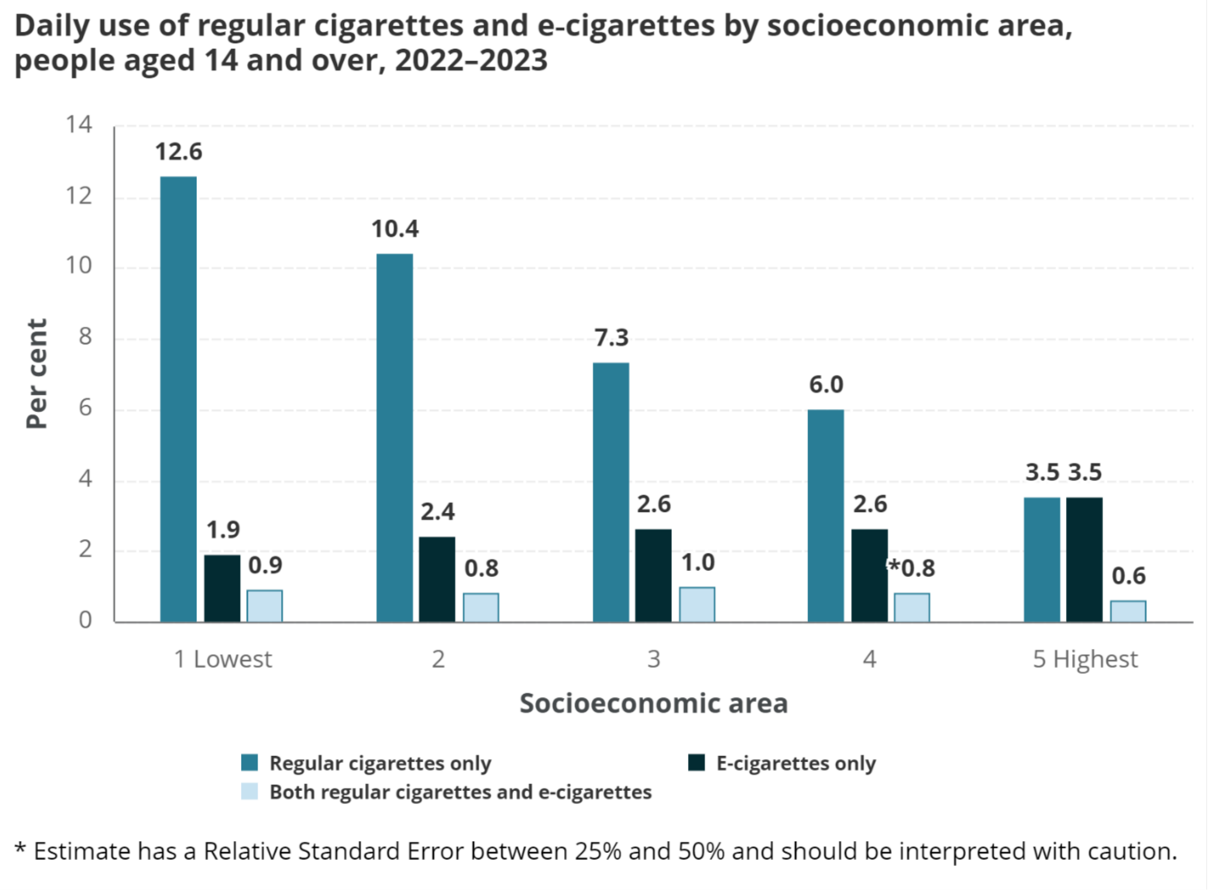
The areas are grouped into quintiles (fifths). The 20% of areas with the greatest overall level of socioeconomic disadvantage are described as the 'lowest socioeconomic areas'. The 20% of areas with the greatest overall level of socioeconomic advantage – the top 20% – are described as the 'highest socioeconomic areas'.

Note that the IRSAD reflects the overall or average level of advantage and 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 position.

People living in the most advantaged socioeconomic areas were the most likely to use e-cigarettes daily, while people in the most disadvantaged areas were the least likely to do so (Figure V.2). The trend is the opposite for tobacco smoking, however, which has been more common among people living in the most disadvantaged socioeconomic areas since before 2010, and less common among people living in the most advantaged areas (AIHW 2024c).

These trends show that use of e-cigarettes has been highest among groups that have been less likely to smoke tobacco since at least 2016.

Figure V.2: Use of tobacco cigarettes increased with socioeconomic disadvantage, while e-cigarette use increased with socioeconomic advantage



Source: NDSHS 2022–2023, AIHW.

Future focus

This article reviews the recent rise in e-cigarette use and the variations across age groups and socioeconomic areas before the restrictions on the marketing, importation, and supply of e-cigarettes were implemented in 2024. More data are needed in the future to examine the long-term impacts of these policy changes on both e-cigarette and tobacco use. Further information on the long-term effects of e-cigarette use on individual and population health is also required.

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Enhancing communicable disease monitoring in Australia through data linkage

Key messages

- Routine surveillance of communicable disease involves the systematic collection, analysis and interpretation of data; however, this process is less efficient, timely or complete than data linkage. Although complex, data linkage for communicable disease monitoring is of high value as it provides a rich 'person level' source of information.

  - For example, linked data can tell us if a person has been diagnosed with a communicable disease, been vaccinated, had a hospital admission, been provided a prescription for medication, or died.
- Understanding the full impact of COVID-19 on individuals and the health system in Australia was difficult during the height of the pandemic due to the complex data sharing arrangements between the national and state and territory jurisdictions.
- To assist with the COVID-19 vaccination rollout, data from the Australian Immunisation Register (AIR) was added to the Person Level Integrated Data Asset (PLIDA), which enabled surveillance of vaccine uptake by various population groups.
- The AIHW has developed the COVID-19 Register – a linked data asset – which can be used to develop a deeper understanding of the health outcomes and health service use of COVID-19 cases, inform patient care decisions, and monitor health system needs over time. The Register demonstrates the data sharing pathways and technical processes for communicable disease monitoring that can be applied to future communicable diseases of interest.

Introduction

Australia has a long history of population-based data linkage.

- Efforts from as early as the 1970s in Western Australia led to the creation of the Western Australian Data Linkage System in 1995 which linked up to 40 years of data from over 30 collections for a historical population of 3.7 million (Holman et al. 2008).
- In the mid-1980s, the AIHW commenced the national linkage of cancer registry and death data from cancer registries in Australian states and territories; this is one of the first examples of cross-jurisdiction data linkage in Australia (Smith and Flack 2021).

- The mid-2000s saw the establishment of the Centre for Data Linkage as well as state and territory data linkage units, such as the SA NT DataLink Consortium, which are supported through a variety of university and non-government entities (Boyd et al. 2012; Boyle and Emery 2017; Smith and Flack 2021).

Over the years, these linkage systems have helped to build national and cross-jurisdictional linkage of de-identified data from a diverse and extensive range of health data sets to support population-level research.

Data responses to COVID-19

COVID-19 emerged as a new disease in late 2019 and the World Health Organization declared it a pandemic in March 2020. As at May 2024, over 775 million cases have been confirmed globally, and 7 million deaths (WHO 2024). In Australia, there have been almost 12 million confirmed or probable COVID-19 cases, and more than 22,000 people have died from or with COVID-19 since the start of the pandemic to 29 February 2024 (ABS 2024; Department of Health and Aged Care 2024).

In response to the pandemic, state and territory health departments linked their communicable disease registers with other data holdings to inform jurisdictional decisions about public health action including contact tracing and the location of testing clinics (PHRN 2021). This data linkage at the state and territory-level promoted awareness of patient flow and health system demands, and continues to be used to understand the long-term impacts of COVID-19.

The COVID-19 pandemic demonstrated the need for strengthened national data infrastructure in Australia, such as linkable communicable disease registers, to support evidence-based public health policy and service planning decisions. Through a disease register and data linkage, the health service use and health outcomes of individuals affected by a particular disease can be monitored to assist with current and future planning and decision-making.

This article describes the development by the AIHW of the COVID-19 Register to understand health outcomes and health service use of people diagnosed with COVID-19. The discussion progresses through the following topics:

- the current status of communicable disease data sources in Australia
- Australia’s response to the COVID-19 pandemic
- an introduction to linked data, including the COVID-19 Register
- the current landscape on data sharing
- preliminary data findings from the COVID-19 Register
- future directions for communicable disease monitoring using linked data.

Communicable disease data in Australia

Communicable diseases are illnesses that spread between people. Some are fairly mild in impact, such as the common cold; others are of particular concern because they can cause serious illness (Department of Health and Aged Care 2023c).

National Notifiable Diseases Surveillance System data

In Australia, healthcare professionals are legally required to report certain diseases to state or territory authorities, including COVID-19. Every day, states and territories provide de-identified notification data about new cases of notifiable diseases to the Department of Health and Aged Care for inclusion in the National Notifiable Diseases Surveillance System (NNDSS) (Department of Health and Aged Care 2023d). The NNDSS is set up under the *National Health Security Act 2007 (Cwlth)* for the purposes of national communicable disease surveillance. Notifications, such as polymerase chain reaction (PCR) positive COVID-19 cases, come from various sources, including clinicians, hospitals and laboratories.

The NNDSS data are used to:

- identify national disease trends and outbreaks
- respond to potential outbreaks
- support quarantine activities
- allocate resources
- meet international reporting requirements
- track progress towards eradicating these diseases over time (Department of Health and Aged Care 2023d).

Other data for surveillance

States and territories use population-level communicable diseases data for surveillance purposes, including:

- for rapid, real-time decision-making to manage outbreaks
- in surveillance reports that outline the activity and severity of the communicable disease in the community.

Each state and territory has its own legislation, data management systems and outbreak responses. This diversity was reflected at the height of the COVID-19 pandemic in the often different rules among jurisdictions for isolation, quarantine and public health measures (such as mask mandates, and testing and reporting of Rapid Antigen Tests (RATs) and PCRs).

Additional complementary data, used together with communicable disease case information as part of national and jurisdictional surveillance activities include:

- waste-water surveillance of viral genetic material shed by infected asymptomatic and symptomatic individuals, which can be detected before clinical cases are identified (Department of Health, Western Australia 2023)
- mortality data, and data from the AIR for vaccination uptake, the Pharmaceutical Benefits Scheme (PBS) (for subsidised medications dispensed), hospital admissions records, and the National Medical Stockpile.

Surveillance systems

A range of other agencies already collect and collate communicable disease surveillance data that could be readily adapted to include surveillance of COVID-19 cases. Surveillance systems have been in hospitals and in primary health care services to monitor case severity and symptoms. Examples include:

- FluCAN – a hospital collection that collects influenza and COVID-19 hospital admission data
- Australian Sentinel Practices Research Network – a sentinel general practice surveillance system that collects the number of influenza-like illness presentations seen in participating practices each week
- FluTracking – an online syndromic surveillance system collecting community-level information on influenza-like illness that has since expanded to include COVID-19-like illness (Department of Health and Aged Care 2023a).

As well, new systems have been established where there were gaps:

- AusTrakka – developed to provide a national genomics surveillance platform for SARS-CoV-2 (the virus that causes COVID-19), with all state and territory public health laboratories uploading genomic sequences for nationally aggregated genomics analysis (CDGN 2022)
- Short Period Incidence Study of Severe Acute Respiratory Infection (SPRINT-SARI) – a hospital-based surveillance database that collects COVID-19 data from the majority of adult and paediatric Australian intensive care units (ANZIC-RC 2024)
- seroprevalence surveys – provide estimates on the total number of people who have been infected with SARS-CoV-2, including those infections that might have been missed (APPRISE 2022). For more information see the glossary.

Response to the COVID-19 pandemic

The systematic collection, analysis, and monitoring of data on COVID-19 was not readily available at the national level during the pandemic (Basseal et al. 2022).

Managing cross-jurisdictional outbreaks and painting a national picture on the impacts of COVID-19 on individuals and the health system was difficult during the height of the pandemic. The Australian Constitution does not authorise the Australian Government to legislate for public health responses and so any necessary action is at the state and territory government level. This situation presents challenges to data sharing, timely information exchange, and real-time analyses and evaluation (Basseal et al. 2022).

Nonetheless, facing and resolving these challenges is vital for informed and effective decision-making in a rapidly evolving public health emergency and beyond.

Responding to the need for national data, states and territories collaborated to provide daily aggregate COVID-19 case data to the National Incident Room (NIR) for the first 3.5 years of the pandemic. These efforts were the precursor to the addition of COVID-19 case data to the NNDSS. Data from the NIR and the NNDSS were useful for reporting national daily statistics on COVID-19 cases to the Australian public and for monitoring the impact of public health interventions and health service use.

Enhancing data sharing arrangements, standardised definitions and interoperability between data sources are imperative to improving Australia's response to future pandemics (Basseal et al. 2022; Shergold et al. 2022).

Introducing linked data

Data linkage is the process of identifying, matching, and merging records that correspond to the same person or entity from several data sets, to create a new combined data set. Linked data provide a valuable person-level source of information for health monitoring, beyond that available through routine disease surveillance and single data sources.

- For example, linked data can efficiently confirm if a person diagnosed with COVID-19 has had a hospital admission, been provided with a prescription for medication outside of hospital, been vaccinated, or died.

Some data are linked through the personal information from individuals within data sources (such as full name, date of birth, and address), which enables records to be matched and merged. This personal information is used only to link the data; it is not shared for any purpose. Other data can be linked through unique identifiers, with personal information not required.

Described below are 3 examples of linked data assets for COVID-19 monitoring.

AIR-PLIDA

To examine COVID-19 vaccine uptake and the real-world effectiveness of COVID-19 vaccines, data from the Australian Immunisation Register (AIR) were added to the Australian Bureau of Statistics' (ABS) PLIDA (formerly known as the Multi-Agency Data Integration Project (MADIP)). PLIDA combines information on health, education, government payments, income and taxation, employment, and population demographics over time (ABS n.d.).

This linked data asset, known as AIR-PLIDA, provided a source of surveillance during the vaccine rollout including vaccination rates by population characteristics such as occupation, cultural diversity, disability, and chronic health conditions (Department of Health and Aged Care 2023b; Welsh et al. 2023).

AIR-PLIDA data have shown that, between July 2021 and January 2022, there were groups in the population with lower levels of first dose vaccine uptake than the national average (Biddle et al. 2022). These groups included:

- Aboriginal and Torres Strait Islander (First Nations) people
- people who speak a language other than English
- non-citizens
- people with a core activity need for assistance
- people who were not employed
- certain occupation groups (technicians, labourers and trade workers).

These data provide helpful guidance on which population groups to target for further vaccination programs, as well as insight into socioeconomic variables that predicted vaccine uptake, which were previously unavailable from the unlinked data.

AIR-PLIDA continues to be used to provide insights into the effectiveness of vaccination and to guide recommendations on COVID-19 vaccination boosters (Liu et al. 2023).

Aged care

From March 2022, the AIHW worked with the ABS to link aged care data with AIR-PLIDA. This linkage, together with provisional mortality data from the ABS, provided information on rates of vaccination, population characteristics and deaths among residential aged care residents. The vaccination data assisted with efforts to improve low vaccination rates.

The AIHW also linked aged care data with Medicare data for the Department of Health and Aged Care, which improved responses to the needs of aged care services and recipients during the COVID-19 pandemic.

AIHW's COVID-19 Register

In April 2022, the Medical Research Future Fund funded the AIHW to establish a national linked data platform that integrated relevant existing health data sets. This initiative was taken to strengthen evidence-based public health and health system planning and management for current and future pandemics.

This linked data set, known as the COVID-19 Register, contains de-identified COVID-19 specific content data from the NNDSS linked to person level COVID-19 data received from state and territory disease registers. These data have then been linked to a range of administrative health data sets including:

- medication dispensing through the PBS
- health service use through the Medicare Benefits Schedule (MBS)
- hospital admission (including intensive care)
- aged care

- deaths
- vaccination through the AIR
- data from the National Disability Insurance Scheme (AIHW 2023).

The COVID-19 Register is a proof-of-concept initiative to provide government and approved researchers with a unique and more complete picture of the issues and experiences of Australians who have been diagnosed with COVID-19. It includes people who have not been diagnosed with COVID-19 as a control group.

The COVID-19 Register has been developed to include COVID-19 case data up to December 2022, with updated health data linked as it becomes available. For more information on the linkage method and high-level linkage results , see *COVID-19 Register: Linkage results*.

Research outcomes of using the COVID-19 Register

Outcomes of research using the COVID-19 Register have broad application. For example, understanding the:

- health outcomes after a COVID-19 diagnosis and the effectiveness of treatment options via linked data enables better targeting of treatments for newly diagnosed COVID-19 cases – including for specific population groups at higher risk of adverse health outcomes
- health service use of people diagnosed with COVID-19 helps to guide resource planning to meet the current and future needs of not only people diagnosed with COVID-19 but also future communicable diseases of interest.

Linkage protocols

As with other data held by the AIHW, the AIHW adheres to strong data governance arrangements including the internationally recognised Five Safes approach which guides the assessment and management of risks associated with data sharing and release. The AIHW applies the Separation principle which includes the physically separate storage of identifying and content information, and use of virtual secure access environments to ensure users only see the identifying or the content information they are approved to see.

The AIHW data linkage protocols mean AIHW linkage staff with access to personal identifiers and analytical data do not have access to the identifiers and analytical data at the same time for the duration of the project. Strict data output vetting is also conducted to check the data are confidentialised and suitable for release before the data leaves the secure access environment. For more information see: Five Safes Framework.

Further development

During 2024, the COVID-19 case data from the COVID-19 Register will be integrated with the AIHW’s National Health Data Hub (NHDH), which combines several data sets into a single enduring linked data system. The interoperability of the COVID-19 Register also allows for its future integration with PLIDA.

Current landscape on data sharing

The process of sharing data for national surveillance and monitoring is currently complex.

The COVID-19 Register has been developed within this data sharing landscape.

Where identified data or potentially re-identifiable data are involved (that is, personal information), the current arrangements for data sharing are subject to the *Privacy Act 1988 (Cwlth)*, including the Australian Privacy Principles contained in the Act. One of the following conditions must be met for the receipt, use and release of these data:

- consent is provided by each individual in the data set, or
- an authorised by law exception applies, or
- a waiver of consent pursuant to s. 95 of the Privacy Act is issued.

For state and territory data, additional processes and approvals are required to navigate their respective jurisdiction’s public health and privacy legislation.

The COVID-19 Register has been developed primarily through obtaining authorised by law exceptions, and waivers of consent through ethics approvals, noting that consent from individuals was not feasible in this instance, given the scale and routine nature of data collection.

Oversight of, and access to, the COVID-19 Register

An Advisory Board, consisting of senior executives from the AIHW and the Department of Health and Aged Care, oversees the COVID-19 Register project. Members of the Communicable Diseases Network of Australia (CDNA) also provide advice.

The Register can be accessed by approved researchers whose project proposal has been approved by the Register’s Advisory Group (comprising state and territory representatives). Researchers who wish to use the data need to ensure their research question/s falls under the approved uses, which include:

- epidemiological and statistical research
- service use and medication dispensing and patient journeys
- identifying groups or cohorts of interest
- monitoring, evaluation and data quality improvement.

COVID-19 case data and personal identifiers

While the NNDSS contains the COVID-19 content data for people diagnosed with COVID-19, such as date of notification and diagnosis method, it does not include identifiable personal information of people diagnosed with COVID-19 (such as name and address). These identifying data are needed for linking to link the COVID-19 case data with other health data sets. For this reason and purpose, the AIHW sought these personal identifier data from the respective state and territory disease registers.

The AIHW received a waiver of consent through the overarching AIHW ethics approval for the COVID-19 Register, which allowed it to receive the COVID-19 personal identifier data from each of the participating jurisdictions. However, before this could happen, a separate approvals process was required to meet the different public health legislative requirements of the states and territories. For some jurisdictions, this was effected through a waiver of consent via an additional ethics committee approval; while for others, separate processes were required.

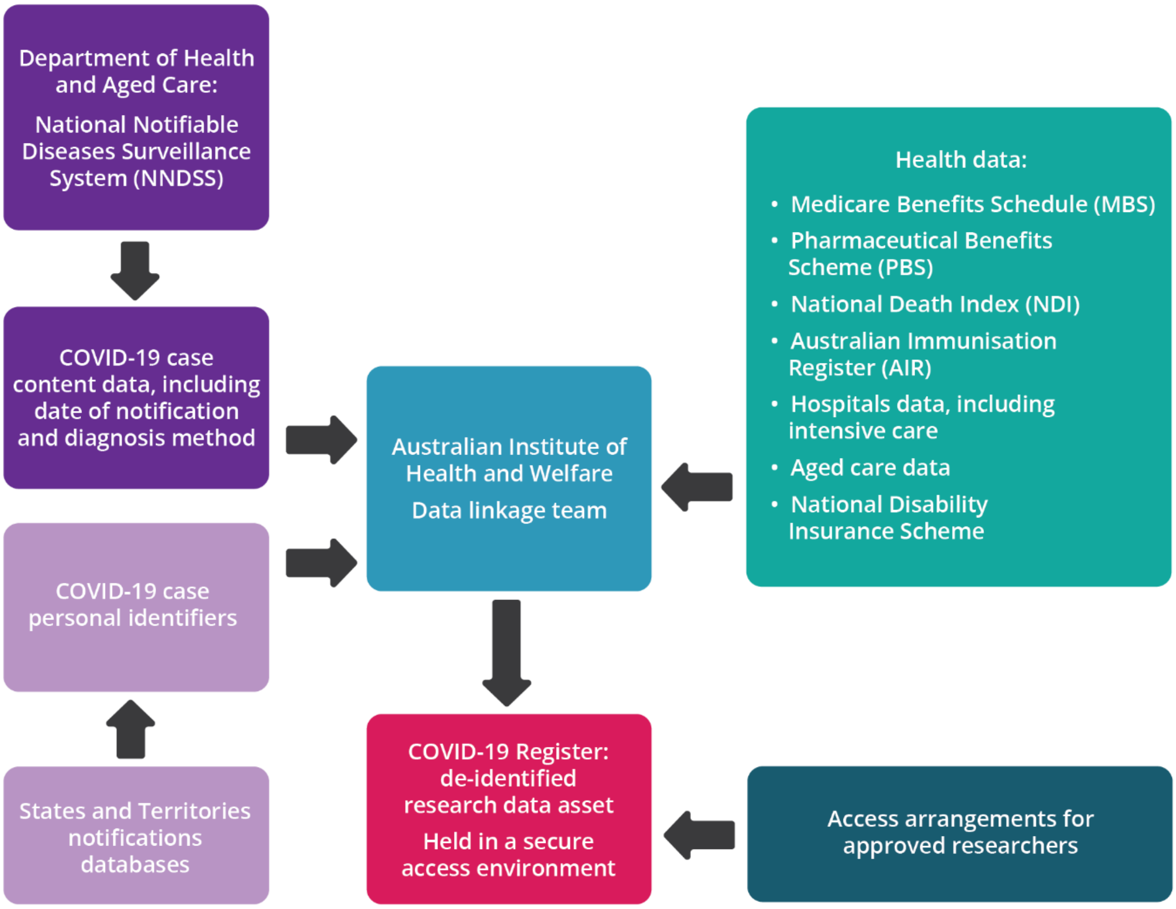
Health data sets

The health data sets in the COVID-19 Register were approved for data sharing through either a waiver of consent or authorised by law exception. The approach taken depended on current arrangements in place and the legal structures under which the data sets and collections were established.

Importantly, the Register does not contain any identifying information. The AIHW protects the privacy of an individual through a process of de-identification. This process involves removing identifying information (for example, a person's name, address or Medicare number) so that researchers are unable to tell to whom the information belongs. Only aggregate data can be released from the secure environment in which the data are held, and these data are checked by AIHW against rules for suppression and confidentiality to ensure that individuals cannot be re-identified. For more information see the arrangements discussed in Data governance.

The design of the COVID-19 Register is illustrated in Figure CD 1. The AIHW's data linkage team links COVID-19 case data from the state and territory communicable disease registers and the NNDSS with a range of health data. This linked data is presented as the COVID-19 Register, which is available in a secure environment to approved researchers. Linked deaths data are also provided back to the state and territory jurisdictions for incorporation into their notifications databases.

Figure CD 1: COVID-19 Register design



Department of Health and Aged Care:

National Notifiable Diseases Surveillance System (NNDSS)

COVID-19 case content data, including date of notification and diagnosis method

COVID-19 case personal identifiers

States and Territories notifications databases

Australian Institute of Health and Welfare

Data linkage team

Health data:

- Medicare Benefits Schedule (MBS)
- Pharmaceutical Benefits Scheme (PBS)
- National Death Index (NDI)
- Australian Immunisation Register (AIR)
- Hospitals data, including intensive care
- Aged care data
- National Disability Insurance Scheme

COVID-19 Register: de-identified research data asset

Held in a secure access environment

Access arrangements for approved researchers

Current and future projects

COVID-19 Register – a key role in disease monitoring

The AIHW has published initial findings using data from the first version of the COVID-19 Register. The report *Demonstrating the utility of the COVID-19 Register* explores potential analyses that could be conducted on the data using a subset of linked cases. The report explored deaths among people diagnosed with COVID-19, and health service use and prescriptions dispensed before and after a COVID-19 diagnosis.

Deaths

Existing surveillance systems can monitor how many people were dying from the acute effects of COVID-19, however, there has been limited information on long-term mortality patterns among people diagnosed with this disease. A program of work using linked data from the COVID-19 Register is underway to provide information on the extent to which deaths are associated with a prior COVID-19 diagnosis.

Health service use and prescriptions dispensed

The COVID-19 Register is also being used to examine health service use and prescriptions dispensed before and after a COVID-19 diagnosis, using claims data from the MBS and the PBS. The Register makes it possible to examine patient pathways after a COVID-19 diagnosis to determine if there are changes in the use of these 2 types of health service.

Future projects

Future research using the COVID-19 Register could further explore:

- the real-world effectiveness of vaccines
- the effect of different variants on individual health outcomes and the health system
- use of antivirals
- the impact of multiple COVID-19 notifications.

As well, the Register could explore how these outcomes vary across priority populations.

Several approved COVID-19 Register research projects are already underway. They focus, respectively, on:

- health and mortality outcomes for people living with dementia during the pandemic
- health outcomes following a COVID-19 diagnosis by population groups and vaccination status
- estimating COVID-19 expenditure and service use related to health and aged care.

Australian Centre for Disease Control

Establishing an Australian Centre for Disease Control (CDC) was an election commitment of the Australian Government. The centre's work would include ensuring ongoing pandemic preparedness, leadership through a federal response to future infectious disease outbreaks, and a focus on preventing communicable and non-communicable diseases.

Ongoing work to establish this stand-alone Australian CDC is centred on delivering 5 key objectives, namely to:

- increase independence and strengthen evidence-based and transparent decision-making to maintain trust
- improve national coordination of effort and efficiencies, with stronger partnerships, including across Australian Government agencies and between jurisdictions
- support national action through enhanced national capabilities, underpinned by the distinct and complementary roles and responsibilities of jurisdictions and the Australian Government
- enhance international connections
- increase and productively use resources to support preparedness and response across all jurisdictions, including nationally (Australian Centre for Disease Control 2024).

Progress to date

A joint Statement of Intent was reached during November 2023, receiving commitment from Commonwealth, state and territory governments to work together on the Australian CDC. Current work is progressing on the formal agreement (Australian Centre for Disease Control 2024).

On 1 January 2024, the first major establishment milestone was reached with the launch of the Interim Australian CDC within the Department of Health and Aged Care. Its key priorities continue to focus on leading a national response to prepare for future pandemics and to work to prevent communicable and non-communicable diseases.

The Interim Australian CDC is developing a data strategy to define the centre's role in developing and delivering a strategic approach to collecting, sharing, and using data in the Australian public health system. The strategy will describe strategies and processes for:

- establishing a new National Public Health Surveillance System
- optimising the use of linked data for communicable disease monitoring, including ways to streamline the current complex processes for data sharing.

The Department of Health and Aged Care continues to engage with counterparts in other agencies and international partners to leverage expertise and incorporate lessons into the final design of the Australian CDC. Alongside this, other consultation is ongoing and will support a phased approach to its establishment.

Conclusion

The COVID-19 pandemic in Australia has promoted discussion and planning on how to better respond to the current pandemic and assist with future planning. This includes investigating what is needed to ensure such responses are informed by data and evidence. Linking communicable disease data with a range of health and non-health data sets, will improve understanding of the impact of the disease on individuals and communities better than relying on a single data source.

The challenge in creating linked data to ensure responses to public health issues and pandemics are informed by the best data and evidence, is that current data sharing arrangements are complex to navigate. This includes navigating the requirements of the *Privacy Act 1988* and the different public health, privacy and data sharing legislation of the states and territories.

The COVID-19 Register provides a precedent for how these processes can be navigated and insights into the improvements that can be made to facilitate future monitoring of communicable diseases in particular, as part of the new stand-alone Australian CDC. The Register provides a foundation to improve medium, and longer-term health outcomes for COVID-19. Findings from research will provide information on vaccine effectiveness to help guide booster recommendations, better targeting of treatment options for people diagnosed with COVID-19, including for population groups at higher risk of adverse health outcomes, and resource planning to meet the current and future needs of people diagnosed with COVID-19 and future communicable diseases of interest.

The development of the COVID-19 Register aligns with the identified need for a system that will enhance Australia's monitoring of COVID-19 treatment and outcomes and response to future pandemics (Bennett 2023; Phelan et al. 2023). Integrating the COVID-19 Register with other national data assets will support future research and further Australia's commitment to pandemic preparedness.

Further reading

- *Demonstrating the utility of the COVID-19 Register* (AIHW report)
- Chapter 1 of *Australia's health 2022: data insights* The impact of a new disease: COVID-19 from 2020, 2021 and into 2022 (AIHW report)
- Chapter 2 of *Australia's health 2022: data insights* Changes in the health of Australians during the COVID-19 period (AIHW report)
- *COVID-19 linked data set: Linkage results* (AIHW report)

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Extreme weather related injuries in Australia over the last decade

Key messages

- There was an average of 912 injury hospitalisations related to extreme weather per year between 2012 and 2022. Counts exceeded 1,000 cases in 2013–14, 2016–17 and 2019–20. Similarly, crude rates of injury hospitalisation related to extreme weather, which averaged 3.7 per 100,000 people across the decade, rose above 4.2 per 100,000 people in 2013–14, 2016–17 and 2019–20.
- Extreme heat caused the most injury hospitalisations related to extreme weather over the last 10 years (78% or 7,104 hospitalisations – an average crude rate of 2.9 hospitalisations per 100,000 people).
- The highest number of recorded injury hospitalisations related to extreme weather (1,108, crude rate of 4.3 per 100,000 people) occurred during Australia's last El Niño year, 2019–20.
- On average, the rate of injury hospitalisation from bushfires is 1.6 times as high in El Niño years (0.44 per 100,000 people) as in La Niña years (0.27 per 100,000). While these rates may seem relatively small, they represent an undercount of injury hospitalisations related to extreme weather.
- The risk of hospitalisation due to extreme weather related injury increases with age, with nearly one-third of hospitalisations occurring in people aged 65 and over.

Introduction

Extreme weather events, such as heatwaves, bushfires and floods, can:

- cause acute injuries
- exacerbate chronic conditions
- alter the spread of infectious diseases
- adversely affect mental health and wellbeing.

Climate change is increasing the intensity, frequency and duration of these events (BOM and CSIRO 2022). The health impacts of climate change and extreme weather events vary across Australia, but changing weather and associated disease patterns leave Australians increasingly susceptible to adverse health impacts and pose challenges to the capacity of health services to adapt (Beggs et al. 2022).

Weather can increase the risk of injury in multiple ways. Extreme conditions or natural hazards can cause:

- acute physical injury and death
- subsequent injuries, such as drowning in floods

- increased risk of intentional self-harm and assaults from sustained adverse conditions (Corcoran and Zahnow 2021)
- increased injury risks associated with regular activities, such as heat stroke during sports.

There were 9,119 injury hospitalisations directly related to extreme weather between July 2012 and June 2022.

Importance of monitoring

As Australia adapts to a changing climate, monitoring the effects of extreme weather is of growing importance to public health in managing not only health impacts but also associated resource needs. Nonetheless, associating extreme weather conditions and health impacts can be challenging, as impacts can be direct and acute, or indirect, with delayed and/or longer term consequences.

Injury hospitalisations are only one of the health impacts of extreme weather conditions and related natural hazards; however, they can be an early indicator in monitoring morbidity, mortality and demands on the health-care system. Monitoring indicators such as this will be crucial in informing responses to the health impacts of climate change, such as when implementing the Australian Government’s National Health and Climate Strategy (Department of Health and Aged Care 2023).

Focus of this article

This article describes patterns in Australian hospitalisations for extreme weather related injuries between July 2012 and June 2022. It does not describe all weather related injuries or non-injury health conditions, and excludes ambulance call outs and general practice and emergency department presentations where no hospitalisation occurred. It presents a baseline for monitoring future changes in injury hospitalisations caused by extreme weather related conditions.

Specifically, it describes injury hospitalisations associated with 4 extreme weather conditions or related natural hazards (Table WI.1):

- extreme heat
- bushfires (a hazard associated with extreme heat)
- rain- and storm-related events, including high rainfall, floods and cyclones
- extreme cold.

Table WI.1: Numbers and rates of injury hospitalisations related to extreme weather between July 2012 and June 2022, and their ICD-10-AM codes

Weather condition	Number of injury hospitalisations	Average rate per 100,000 people per year	Principal diagnosis	External cause of injury relating to:
Extreme heat	7,104	2.9	E86 – Volume depletion L55 – Sunburn L56 – Other acute skin changes to ultraviolet radiation P74.1 – Dehydration of newborn T67– Effects of heat and light *or* T79.4 – Traumatic shock (including shock (immediate) (delayed) following injury) (including dehydration with shock)	X30 – Exposure to excessive natural heat *or* X32 – Exposure to sunlight
Bushfires	894	0.4	T20–T30 – Burns T58 – Toxic effect of carbon monoxide *or* T59.8 – Other specified gases, fumes, and vapours	X01 – Exposure to uncontrolled fire, not in building or structure *or* X30 – Exposure to excessive natural heat
Rain and storms	348	0.1	S00–T75, T79 – Injury, poisoning, and certain other consequences of external causes	X33 – Victim of lightning X36 – Victim of avalanche landslide and other earth movements X37 – Victim of cataclysmic storm *or* X38 – Victim of flood
Extreme cold	773	0.3	T33–T35 – Frostbite T68 – Hypothermia, *or* T69 – Other effects of reduced temperature	X31 – Exposure to excessive natural cold

Notes

1. All listed codes are ICD–10–AM (WHO 2019), and classifications experts and clinicians were consulted in the compilation of this list. X00 – Exposure to uncontrolled fire, in building or structure was intentionally not included.

2. An ‘injury hospitalisation’ refers to the index hospitalisation for a given injury case. Technical details around the selection of cases in this article are outlined in the AIHW web report Let’s talk about the weather: injuries related to extreme weather.

Source: AIHW National Hospital Morbidity Database.

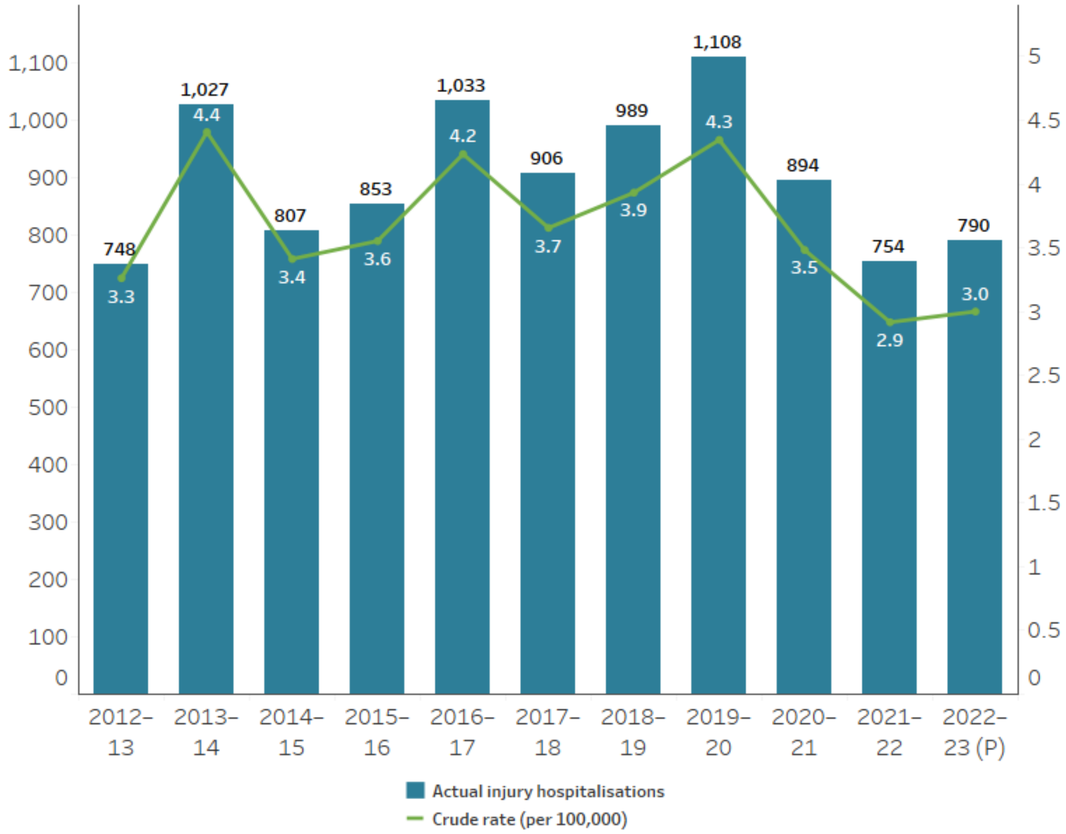
Hospitalisations related to extreme weather over time

From 1 July 2012 to 30 June 2022, there was an average of 912 cases per year of hospitalisations with evidence of injury related to extreme weather (crude rate of 3.7 per 100,000 people per year).

Hospitalisations due to injuries related to the 4 extreme weather conditions or associated natural hazards discussed in this article exceeded 1,000 cases (4.2 per 100,000 people) in 2013–14, 2016–17 and 2019–20 (Figure WI.1). However, 30 years of weather data would be needed before any trends could be discerned. Preliminary hospitalisation figures for 2022–23 indicate 790 hospitalisations, a crude rate of 3 per 100,000.

Figure WI.1: Injury hospitalisations related to extreme weather exceeded 1,000 cases in 2013–14, 2016–17 and 2019–20

Numbers and crude rates (per 100,000 people) of injury hospitalisations related to extreme weather across Australia, 2012–22



Source: National Hospital Morbidity Database.
https://www.aihw.gov.au

P = preliminary data.

Most injury hospitalisations occur over summer

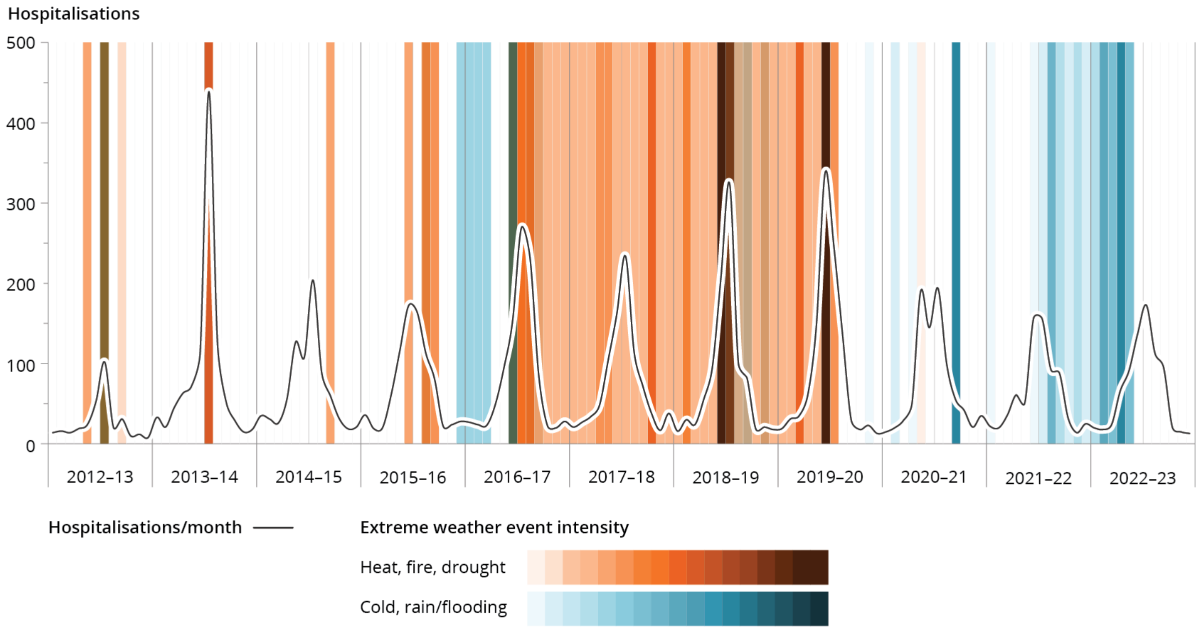
Most injury hospitalisations related to extreme weather occur between November and March of the next year (Figure WI.2). Extreme weather events can vary geographically but, in recent years, Australia has witnessed large multi-state extreme weather events, such as the:

- 2019–20 bushfires in Victoria, South Australia and New South Wales
- 2022 flooding across Queensland and New South Wales (BOM 2020, 2022a).

A variety of extreme weather events or natural hazards have occurred, often of prolonged duration or within short time frames of each other (Figure WI.2). Multi-state, sustained and sequential events can compound harm to human health and stretch available health and emergency management resources, highlighting the need for cohesive national approaches to mitigate the effects of extreme weather conditions (Beggs et al. 2022).

Figure WI.2: Most injury hospitalisations occur over summer

Number of injury hospitalisations related to extreme weather across Australia, and extreme weather event intensity, by month, July 2012 to July 2023



Note: BOM Special Climate Statements highlight notable climatological events, many of which (but not all) had substantial community impacts. They do not align perfectly with injuries; for example, a winter warm spell is unlikely to have major health impacts.

Source: AIHW National Hospital Morbidity Database and BOM Special Climate Statements.

Climate drivers affect injury hospitalisation patterns

Many factors influence Australia's weather. One of the largest drivers of annual variation is the El Niño–Southern Oscillation (ENSO) cycle (BOM 2021). El Niño is driven by warmer water surface temperatures in the central eastern Pacific Ocean, while La Niña occurs when the water surface temperatures are higher in the western Pacific. Both ENSO phases can occur in a calendar year.

In Australia, El Niño typically drives periods of:

- reduced rainfall
- warmer temperatures
- increased fire danger in south-east Australia.

La Niña is normally associated with:

- above average rainfall
- cooler daytime temperatures
- increased chance of tropical cyclones and flood events.

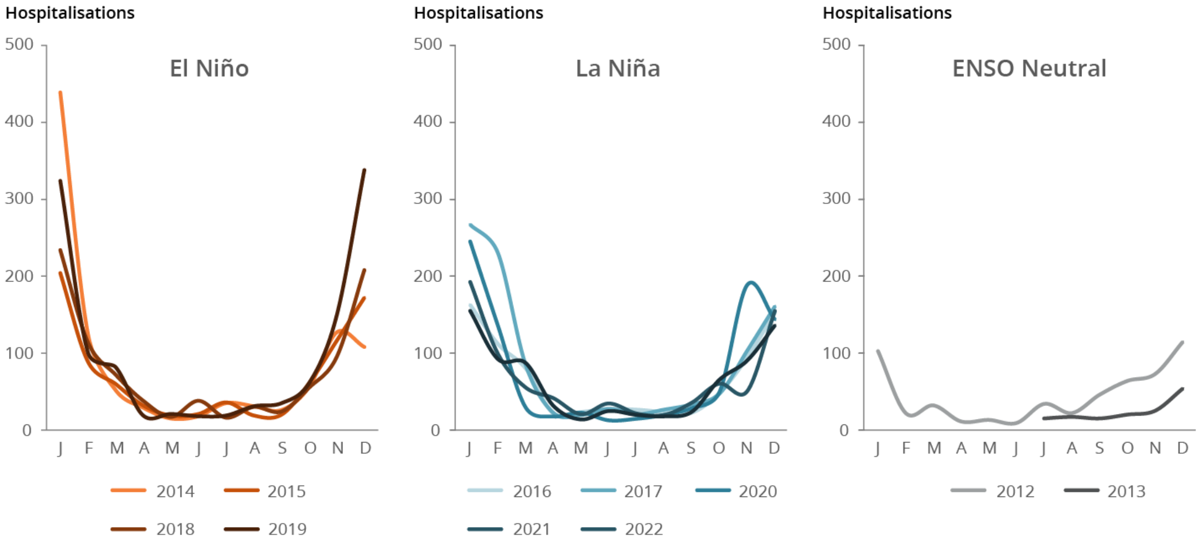
Extreme weather events leading to injury can occur in either phase of the ENSO cycle; however, some of these events are more likely under certain prevailing conditions.

Across Australia, more injury hospitalisations related to extreme weather were recorded for El Niño and La Niña years than for years with predominantly neutral ENSO drivers (Figures WI.3, WI.4; BOM 2024). In both El Niño and La Niña years, injury hospitalisations were predominantly recorded in summer.

- The highest number of recorded injury hospitalisations related to extreme weather (1,108 hospitalisations, crude rate of 4.4 per 100,000 people) occurred during Australia's last El Niño year (2019–20) (Figures WI.1 and WI.4) – 871 of these hospitalisations occurred between November 2019 and February 2020 (Figure WI.4).

Figure WI.3: Injury hospitalisations rise during El Niño and La Niña years

Injury hospitalisations related to extreme weather, by month, year and ENSO cycle, 2012–22



Source: Data sourced from the AIHW National Hospital Morbidity Database and the BOM ENSO Outlook alert system (BOM 2024).

Figure WI.4: Most injury hospitalisations occur during summer months across ENSO phases

Injury hospitalisations related to extreme weather, by month, year and ENSO cycle, 2012–2023

Source: Injury hospitalisation data sourced from the AIHW National Hospital Morbidity Database; the ENSO Outlook is from the BOM ENSO Outlook alert system (BOM 2024).

Most injury hospitalisations are due to extreme heat

Extreme heat was responsible for 78% of all injury hospitalisations related to extreme weather over the last 10 years (7,104 hospitalisations, an average number of 710 per year and an average crude rate of 2.9 per 100,000 people). Heatwaves are Australia’s most dangerous natural hazard in terms of loss of life (Coates et al. 2022; DAWE 2015).

Extreme heat events are occurring more often, earlier in the year, more intensely and for longer (BOM and CSIRO 2022; Steffen et al. 2014). The Bureau of Meteorology describes a heatwave as 3 or more days of unusually high temperatures for a location compared with the local climate and previous and expected weather (BOM 2022b). The Bureau also classifies heatwaves by intensity, using the excess heat factor, which warns how severe a heatwave will be for the local population to survive.

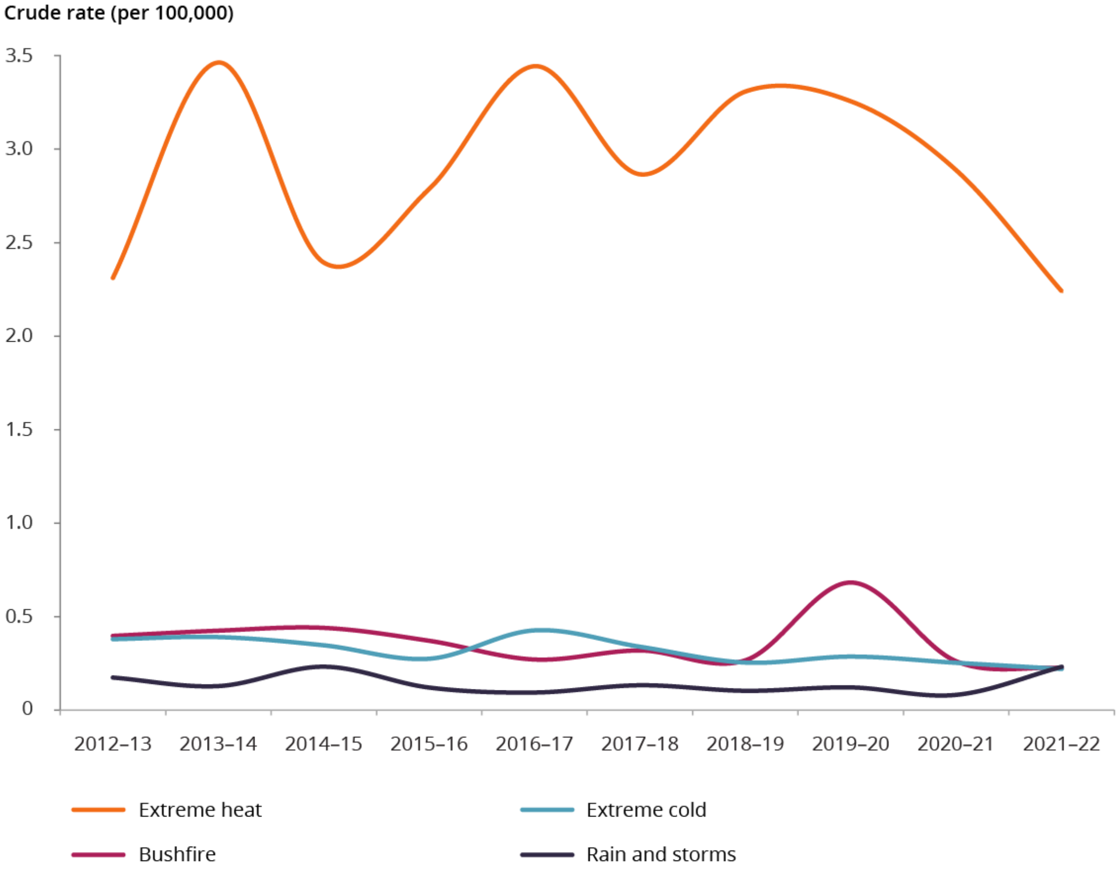
Exposure to prolonged or severe natural heat can result in physical conditions ranging from mild heat stroke to death (DEA 2023). High temperatures are also linked to irritability, fatigue and decreased performance, which can increase the risk of injury by affecting behaviour, such as operating vehicles and power tools (Xiang et al. 2014).

Across Australia, the rate of injury hospitalisation related to extreme heat exceeded 3 per 100,000 people in 2013–14, 2016–17, 2018–19 and 2019–20 (Figure WI.5). This rate remained consistently higher than hospitalisations due to any other hazard type between 2012 and 2022.

Excluding Tasmania, exposure to excessive heat was the most common cause leading to injury hospitalisation across states and territories. In Tasmania, it was the second most common cause, after extreme cold (AIHW 2023). Since 2000, heatwave deaths in Australia have been concentrated in events that largely affected Victoria and South Australia (Coates et al. 2022).

Figure WI.5: Extreme heat caused the most injury hospitalisations

Crude rates of injury hospitalisations related to extreme weather, by hazard type, 2012–22



Source: AIHW National Hospital Morbidity Database

Injury hospitalisations reflect only counts of direct impacts of heatwaves, with indirect health impacts, or lag effects, being potentially far greater and lasting longer (Steffen et al. 2014). Indirect impacts include worsening of pre-existing medical conditions, such as cardiac or renal disease, through effects such as:

- increased stress on the heart
- dehydration
- interactions of heat with certain medications (Zhang et al. 2022).

Other indirect consequences of heatwaves include those related to power outages (which disrupt air conditioning, and the refrigeration of food) and increased intoxication. Many indirect effects of heatwaves may not be captured by the existing hospital coding systems which inform this article.

Bushfires are a natural hazard related to hot and dry conditions

Australia is one of the most fire-prone countries in the world and the frequency of dangerous fire weather days conducive to extreme bushfires is increasing (BOM and CSIRO 2022).

Weather-related factors (including high temperatures, low humidity, lack of recent rain, and strong winds) can contribute to increased risk of bushfire danger. Bushfires also require a fuel load (which increases when vegetation dries out) and an ignition source, which can be either natural (such as a lightning strike) or human (such as discarded cigarettes, electrical faults or deliberate ignition).

Hence, bushfires frequently occur in conjunction with extreme weather events such as heatwaves, droughts or storm activity (when there may be lightning strikes and high winds).

Bushfires were responsible for 10% of all injury hospitalisations related to extreme weather over the last 10 years (894 hospitalisations, an average number of 89 per year and an average crude rate of 0.4 per 100,000 people per year) (Table WI.2). In 2019–20, there were 174 bushfire-related injury hospitalisations,107 more cases than in 2018–19, partly because of multi-state bushfires.

Table WI.2: Average annual rate of injury hospitalisations related to extreme weather (crude rates per 100,000 people), by ENSO pattern, 2012–13 to 2021–22

	Heat	Cold	Bushfires	Rain and storms	Total
El Niño	2.94	0.29	0.44	0.14	3.81
La Niña	2.86	0.31	0.27	0.14	3.57
Ratio – El Niño:La Niña	1.03	0.94	1.64	1.00	1.07

Source: AIHW National Hospital Morbidity Database.

Note: Data for 2 ENSO neutral years are excluded from this table. A ratio of more than 1 indicates higher injury hospitalisation rates due to a particular event during El Niño years compared with La Niña years. The closer the ratio is to 1, the less difference there is in rates between El Niño and La Niña years.

Injury reporting counts acute hospitalisations and deaths, which are only 2 of the more extreme health impacts of bushfires (AIHW 2020). Minor injuries may be treated without hospitalisation, while delayed or repeat presentations may occur from longer term health impacts.

The 2 most common injuries that result in hospitalisations related to bushfires are smoke inhalation and burns:

- Bushfire smoke inhalation leads to both acute and longer term health impacts (Rodney et al. 2021).
- Burns in bushfires can result from flames, radiant heat or ember attacks.

Hospitalisations for injury related to rain and storm events are difficult to measure

Rain and storm events are often interrelated. They include thunderstorms, cyclones and heavy or prolonged rainfall, which can lead to riverine or flash flooding and landslides.

Acute injuries

Intense or prolonged rainfall, floods and storms can directly cause various types of acute injuries, including:

- drowning (Peden et al. 2017)
- falls due to slippery surfaces or increased trip hazards
- contact with objects such as floating debris, submerged objects, trees or wind-borne objects (Way and Balogh 2022)
- bites and stings from displaced animals such as snakes (EPA Victoria 2022)
- burns, cardiac arrest and respiratory complications resulting from lightning strikes
- exposure to electric current from powerlines or water-affected electronic devices.

Indirect consequences

Indirect consequences include:

- injuries caused by transport-related accidents, including on land or water (Transport for NSW 2023)
- worsening of symptoms or death from non-communicable diseases such as cancer, cardiovascular diseases and diabetes owing to disruptions to health-care services (Ryan et al. 2015)
- communicable diseases from contaminated floodwaters (EPA Victoria 2022) or from spreading vector habitat following heavy rains (Pendrey and Martin 2023)
- injuries subsequent to displacement, clean-up activity and environmental upheaval caused by severe rains or storms.

Rain- and storm-related injuries are particularly challenging to identify in administrative hospital data since the external cause of injury may be recorded as transport or drowning (for example), rather than as being rain and storm related. Case counts for this type of injury potentially underestimate the number of hospitalisations more than for other types of injuries related to extreme weather.

There were 348 hospitalisations for rain- and storm-related injury recorded between 2012 and 2022 (4% of total, an average of 0.1 injury hospitalisations per 100,000 people per year across the decade). During 2021–22, Australia’s latest La Niña year, there were 60 hospitalisations for rain- and storm-related injury, which is:

- the highest number for any of the 10 years examined (10-year average was 35 injury hospitalisations)
- the equal highest crude rate per 100,000 people of the 10 years examined (0.2 in both 2014–15 and 2021–22).

Extreme cold hospitalisations are consistent over time

There were 773 injury hospitalisations (8% of total, 0.3 per 100,000 people) related to extreme cold recorded between July 2012 and June 2022 across Australia. Extreme cold hospitalisations were consistent over the past decade (Figure WI.5).

Vulnerability to injuries

Age, sex, occupation, poverty and pre-existing health conditions all make people more vulnerable to sustaining injuries related to extreme weather.

Vulnerable population groups

Certain population groups (depending on where they live and their access to resources) have a reduced capacity to avoid or reduce the impacts of extreme weather conditions; this places them at greater risk of injury related to extreme weather as well as other health consequences (Byrne et al. 2016; Peden et al. 2023; Tanner et al. 2013; Varghese et al. 2018).

Vulnerable occupations

People in occupations where large amounts of work occur either outdoors or in poorly ventilated environments are disproportionately exposed to natural hazards and extreme weather conditions, as are emergency service personnel required to enter areas where natural hazards have occurred (Fatima et al. 2021; Kjellstrom et al. 2016).

Urban heat island effect

As well, there is the urban heat island effect, likely to affect city inhabitants. This phenomenon occurs when heat is absorbed by building materials and surfaces such as bricks, roads, carparks and concrete and then radiated into the surrounding area. This effect increases the risk of injury hospitalisations related to extreme heat for people in cities (Steffen et al. 2014).

Vulnerability to extreme heat

Of hospitalised injury cases related to extreme heat in the 3 financial years from 2019 to 2022:

- 1 in 3 were for people aged 65 and over (37% or 793)
- 1 in 5 were for people aged 25–44 (22% or 478) (AIHW 2023)
- nearly twice as many were for males as females (1,434 versus 716).

This difference was most notable among people aged 25–44 and 45–64, where over twice as many males were hospitalised due to extreme heat as females. This may reflect the higher numbers of males in outdoor-based workforces, such as tradespeople and agricultural workers (Fatima et al. 2021).

Monitoring the impacts of extreme weather on Australia’s health

Monitoring the health impacts of climate change is important to inform policy responses, such as those outlined in the National Health and Climate Strategy (Department of Health and Aged Care 2023). This strategy commits to exploring options to develop a framework to monitor indicators of the health impacts of climate change.

The AIHW is actively working with national stakeholders to develop baseline reporting of key data and information on how climate and the environment affect the health of people in Australia – including the emerging area of surveillance of injuries related to extreme weather. This article presents baseline findings to inform future surveillance of such injuries. Improving surveillance over time is expected to lead, in turn, to improvements in detecting, preventing and preparing for the health impacts of extreme weather conditions across Australia.

Total injuries related to extreme weather – an underestimate

Information presented in this article on these findings, however, underestimates total injuries related to extreme weather for the following reasons:

- It is challenging to identify injury directly caused by weather in currently available hospital data sets. Available data do not preclude non-weather-related causes of injuries not related to weather. For example, hypothermia is counted where there is exposure to extreme cold, but this may include cases where the exposure was related to swimming.
- This article is limited to cases where it is reasonable to conclude injury was directly related to exposure to one of the 4 extreme weather conditions discussed (see Table WI.1).
- Only acute injuries where hospitalisation occurs are counted, excluding emergency department, general practitioner, or emergency service presentations.
- Causes of injury are multifactorial, but only the primary cause reported in hospital records is considered in this article. This means indirect injuries, for example, from road traffic accidents that occur due to adverse weather conditions, are excluded due to the primary external cause of injury being recorded as transport.

Conclusion

Injuries related to extreme weather mirror climate drivers, and are occurring across Australia, often affecting multiple states and territories at any one time. They disproportionately affect population groups such as the economically disadvantaged, older people, outdoor workers and people with pre-existing health conditions. They represent the 'tip of the iceberg' of the overall health impacts of a changing climate and are projected to contribute an increasing burden to Australia's health system over time.

Surveillance of injury caused by extreme weather is evolving as climate change continues to affect public health. Injury surveillance may provide early indicators of the broader impacts of extreme weather on Australia's health and health systems; however, challenges remain in accessing sufficiently detailed data to enable effective monitoring. Hospitalisations alone do not capture the full health impacts of extreme weather; hence, as already indicated, this article presents an underestimate of injuries related to extreme weather.

The AIHW is working alongside multiple stakeholders to improve the collection and reporting of injury-related hospitalisations and deaths. This is important both for monitoring injuries related to extreme weather and for preparing health systems to cope with future demand.

Further reading

- Let's talk about the weather: injuries related to extreme weather (AIHW web report)
- Injury in Australia (AIHW web report)
- Australian bushfires 2019–20 (AIHW publication [PDF 3.4 MB])
- Environment and health (AIHW web article)

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Improving Australia's dementia data for national action

Key messages

- Good policy decisions for people living with dementia rely on good data, but Australia still has some major dementia data gaps that the AIHW is helping to reduce in a National Dementia Data Improvement Plan 2023–2033.
- The biggest data gaps are not knowing the overall number of people who currently have dementia (dementia prevalence) or the number being newly diagnosed each year (dementia incidence).
- Planning services for people living with dementia is difficult without knowing who has been diagnosed with the condition. Similarly, evaluating which services are effective is challenging without being able to identify among people using a service who are living with dementia and who are not.
- The AIHW is undertaking a range of activities to improve dementia data, but these all depend on a commitment to high-quality and consistent data inputs that represent all the different people living with dementia in Australia.

Introduction

Almost everyone will be affected by dementia in some way over the course of their lives. According to a 2023 AIHW national survey of dementia awareness:

- 2 in 3 people had a family member or friend living with dementia
- 1 in 4 had cared for a family member or friend living with dementia (AIHW 2024).

Current estimates suggest that over 400,000 Australians are living with dementia; this number is expected to double in the next 35 years (AIHW 2023), meaning that dementia will be a part of the everyday lives of millions of Australians for years to come.

The commitment to action on dementia has been made. The Commonwealth is working with state and territory governments to develop a new, 10-year National Dementia Action Plan with clear and measurable objectives to improve outcomes for people living with dementia, their families and carers, including improving dementia data, maximising the impact of dementia research, and promoting innovation. It is anticipated that the Plan will be in place in 2024.

As dementia impacts more Australians, better data will increase our capacity to not only understand how many people need support but also to plan, resource and evaluate the services, initiatives and programs required to support them.

Better dementia data can lead to better lives, both for people living with dementia and, for their formal and informal carers. The needs of informal carers, including for respite, information, peer groups and income support, are urgent. But so too are the needs of the formal workforce who need to be supported with dementia-specific training, dementia-friendly working environments, and improved working conditions.

The final report of the Royal Commission into Aged Care Quality and Safety identified dementia care as an area for immediate attention (Royal Commission into Aged Care Quality and Safety 2021). Yet without robust data on how many people are living with dementia – and needing and accessing care– implementing the report's recommendations is challenging.

In September 2023, the AIHW released the National Dementia Data Improvement Plan 2023–33, outlining and prioritising data improvement activities to be undertaken over the next 10 years. A framework is now in place; the next step is to ensure that the plan's implementation remains a priority among the broader strategies in the Australian health, aged care and disability data landscape. The AIHW's National Centre for Monitoring Dementia (NCMD) is well positioned to take the lead on this work, but it cannot succeed alone. Improving Australia's dementia data will require long-term planning and commitment from multiple stakeholders at national, jurisdictional and local levels, across government, academic, research, not-for-profit, and corporate institutions.

What does this article include?

This article is a follow-up to Chapter 8 in Australia's health 2020: data insights 'Dementia data in Australia — understanding gaps and opportunities'. It presents a 'report card' on progress made with national data sources currently available to monitor dementia. It also describes what the NCMD is doing to work towards reducing remaining gaps and opportunities, including:

- working to understand the limitations of administrative data and advocating for changes to improve quality and consistency
- expanding the capabilities of individual administrative data sources by integrating them and creating enduring linked data assets
- evaluating alternative data sources and adding them to linked data systems where possible.

The aim of the AIHW's work is to understand who is living with dementia, where they are living, who is supporting them, what services they engage with and, what outcomes they experience, in order to evaluate:

- which services are helpful
- where there is unmet need
- whether specific types of people or communities are more heavily affected than others.

While not in scope for this article, preventing dementia and increasing dementia literacy are integral to reducing the impact of dementia. Increased awareness of what dementia is and where to go for support may increase the likelihood of people's being not only diagnosed at an appropriate time, but also able to access the support they need. Better data are needed, too, on dementia risk factors to inform targeted public health messaging and risk reduction strategies in the community (Anstey et al. 2020; Long et al. 2023). Further, while the focus of this article is on improving data about people living with dementia, better data are also needed to understand the experience of formal and informal carers of people living with dementia.

Dementia prevalence and incidence data remain elusive

To appropriately plan, provide and fund services to support people living with dementia it is necessary to know both:

- prevalence – the number of people with a condition at a given time.
- incidence – the number of people newly identified with a condition within a defined time period.

Prevalence allows appropriate planning for the overall number of services that will be required into the future, while incidence is important to inform diagnostic care pathways. Age-specific incidence is also an excellent indicator of whether public health prevention measures are working to delay dementia onset.

Measuring incidence and prevalence for dementia is particularly challenging as it is a complex syndrome, not a specific disease (see Box DEM.1) and the diagnostic process is not straightforward (for more information, see Clinical guidelines for dementia).

Box DEM.1: Barriers to identifying dementia in individuals

Dementia is not a single disease – rather a group of conditions that involve a decline in brain function over time. This decline happens differently for different people. Dementia can affect memory, speech, thinking, personality, behaviour and mobility.

Finding out who has dementia can be difficult because it can:

- be mistaken as a normal part of ageing
- be asymptomatic in its early stages
- take a long time to develop to a point where people seek support
- be feared or stigmatised so people deliberately avoid assessments
- affect different people in different ways so people and practitioners do not always see the signs or take the steps towards diagnosis.

Moreover, people living with dementia may not seek a diagnosis, even when it is affecting their lives and the lives of people around them. This means that many people may live (and die) with dementia without it ever being officially recognised or recorded (Lang et al. 2017).

All existing prevalence and incidence estimates have limitations

Current estimates for dementia prevalence and incidence in Australia, include reliance on data that are out of date, out of context, or self-reported.

Limitations of current prevalence data

The AIHW's national dementia prevalence rates are modelled from combining international prevalence rates with those for a single small-scale Australian study on younger onset dementia in Eastern Sydney (Withall et al. 2014) (for more information, see Dementia in Australia). This method is not ideal and risks underestimating or overestimating the true number of people living with dementia in Australia. This method also does not account for the impact and changes in risk and protective factors, and treatment and care pathways for dementia over time. Further, it does not account for over-representation of dementia in specific social or cultural groups.

Estimates for dementia prevalence can also be obtained from national data collected by:

- the Australian Bureau of Statistics (ABS), including from the Census of Population and Housing (the Census) conducted every 5 years
- the Survey of Disability, Ageing and Carers (SDAC) conducted every 3 to 4 years on a representative sample from the community and people in cared-accommodation, such as residential aged care facilities and hospitals (ABS 2021).

However, to date these estimates have been substantially lower than expected, compared with international prevalence rates (WHO 2021). Perhaps this is because they rely on self-report or proxy responses. Perhaps it is because the questions are new (dementia data were first collected in the SDAC in 2015 and in the Census in 2021) and are asked in the context of other competing health conditions.

Where possible, the NCMD collaborates with the ABS with the long-term goal of improving data collected to measure national dementia prevalence.

Limitations of incidence data

One development in measuring dementia incidence has been the establishment of the Australian Dementia Network (ADNeT) Clinical Quality Registry, which registers new cases of dementia at participating memory clinics and dementia diagnostic services. While still small in scale and non-mandatory, this resource has the potential to offer a measure of the number of people seeking a dementia diagnosis. It is, however, unlikely to reflect the overall incidence of dementia in Australia until data collection is expanded to be more nationally representative and include a wider range of clinical diagnostic pathways.

In the past, epidemiological studies of representative sample populations have been undertaken to estimate dementia incidence and/or prevalence at a national level. These have been more successful internationally in smaller geographical areas like the Netherlands (Ott et al. 1998) and the United Kingdom (Matthews et al. 2013) than in Australia.

Data collection for such studies is complex because people living with dementia are more likely to drop out of the long-term studies required to capture incidence data, and are often spread across community and institutional settings. Large-scale epidemiological studies, while highly valued for their robust findings, are also known to be costly, resource-intensive, and subject to bias and quality issues (Brayne and Davis 2012; Brayne and Moffitt 2022).

To have robust dementia prevalence and incidence data by 2033 is one of the 5 core goals of the National Dementia Data Improvement Plan. Working towards this goal, the NCMD is exploring the potential for routinely collected data and national data linkage assets to fill this gap.

Data gaps begin in primary health care

The AIHW's 2023 Dementia Awareness Survey (AIHW 2024) found that 90% of the people who said they would seek help for dementia symptoms would go to their general practitioner (GP). Data collected during GP visits would be an ideal source for capturing dementia incidence in Australia, if not for the fact that there are:

- known barriers to GP diagnoses (Casey et al. 2020, Lang et al. 2017)
- no standardised or systematic ways for GPs to document the diagnostic process even when they do undertake it.

This means that there are no national data sources for GP visits that contain information on dementia diagnoses, diagnosis dates, treatments, or care. The same is true for any visits to specialists to whom GPs may refer patients to, such as neurologists or geriatricians.

Pilot project to evaluate quality of dementia data from Primary Health Networks

This is a critical data gap that the NCMD, and the AIHW more broadly, have been working to rectify. A pilot project has been undertaken to evaluate the quality of dementia data that could be collected via Primary Health Networks (PHNs), as well as to test the governance, data transformation and data flow arrangements with PHNs providing the data. The overall aim is to develop a National Primary Health Care Data Collection that would become a principal source for identifying people diagnosed with dementia.

Routinely collected data cover some dementia data gaps

Without robust prevalence and incidence data sources, dementia researchers have had to become ‘data detectives,’ tracking traces of lives lived with dementia through administrative data designed for other purposes.

The AIHW’s current national prevalence estimate (based on a combination of prevalence rates from international studies and a small-scale Australian study) is that at least 400,000 people are living with dementia in Australia in 2024. Many of these people, but not all, will interact with health, disability or aged care services. During these interactions, dementia may be noted in their records, such as a reason for hospitalisation, or a health condition affecting their care needs when seeking aged care or disability support. But it may also go unnoticed or unreported.

The dementia data report card presented in Table DEM.1 outlines the major routinely or regularly collected data sources currently used to monitor dementia in Australia, including an indicator of whether these sources have improved, stayed stable, or deteriorated since first reported on in 2020.

Table DEM.1: Dementia data report card for routinely or regularly collected data sources currently used for monitoring dementia in Australia

Source	Dementia identified via	National coverage	Routine collection	Progress since 2020	Details
GP and specialists	Mention of dementia in practice management systems	⊗	✓	?	Data quality will be inconsistent across practices and practitioners, and individual-level data at a national level will take time to reach data maturity. The AIHW has conducted a proof-of-concept project obtaining aggregate and de-identified GP data from a sample of PHNs to inform the development of a National Primary Health Care Data Collection.
Pharmaceutical Benefits Scheme (PBS)	Four medications indicated for treatment of Alzheimer's Disease: Donepezil, Galantamine, Rivastigmine, Memantine	✓	✓	Stable	Only subsidised for people diagnosed with Alzheimer's Disease. Likely limited to people in earlier stages of dementia, of younger age and higher socioeconomic demographic (Welberry et al. 2020). May change if new medications or treatments for dementia management are approved and subsidised in the future.
Hospital admissions	International Statistical Classification of Diseases and Related Health Conditions, Australian Modification (ICD-10-AM) codes	✓	✓	⊕	Additional availability of supplementary chronic condition codes has increased dementia identifications. Remains subject to inconsistent coding, under-diagnosis and under-disclosure.

Source	Dementia identified via	National coverage	Routine collection	Progress since 2020	Details
	used for principal diagnosis, additional diagnosis, supplementary chronic condition codes				
Emergency department presentations	ICD-10-AM codes used for principal diagnosis, additional diagnosis	✓	✓	Stable	Minimal dementia identifications from this data source compared with others as often only one diagnosis recorded as most relevant to presentation, for example ‘fall’ rather than ‘dementia.’
Aged care assessments	Codes used to report health conditions	✓	✓	?	Improvement since 2020 in the availability of National Screening and Assessment Form data however, this is scheduled for replacement by the Integrated Assessment Tool, with limited information publicly available on plans for standardised assessment of health conditions, including dementia.
Residential aged care	Codes used to report mental and behavioural conditions	✓	✓	−	The Aged Care Funding Instrument (ACFI) was discontinued in October 2022 with its replacement, the Australian National Aged Care Classification (AN-ACC), no longer collecting health conditions, including dementia. The AIHW and the Department of Health and Aged Care are working together to resolve this new data gap.
Deaths	ICD-10 codes for underlying and	✓	✓	Stable	Changes in medical certification over time likely have an impact on trends (Adair et al. 2022).

Source	Dementia identified via	National coverage	Routine collection	Progress since 2020	Details
	associated cause of death				Deaths due to COVID-19 in the first years of the COVID-19 pandemic may have has an impact on coding of dementia deaths. People with dementia were more likely to die from COVID-19.
Australian Census 2021	Self-reported response option for new question (introduced in 2021) on presence of long-term health conditions	✓	Conducted every 5 years	⊕	Provides an additional source for measuring dementia prevalence in Australia (Dobson et al. 2023). Self-reporting may lead to underestimation so would benefit from validity studies. Extensive sociodemographic and geographic coverage could allow estimation of dementia prevalence in specific population groups and by smaller geography levels The AIHW is currently undertaking a project to examine people who self-reported as having dementia in the 2021 Census to see if they have dementia in other national administrative and survey data. Additionally, who has dementia recorded in other data sources but did not self-report as having dementia in the 2021 Census.
Survey of Disability, Ageing and Carers (SDAC)	Self-reported and proxy responses to questions on health conditions present and needs for assistance – for individuals and carers	Via a representative sample ✓	Conducted every 2–3 years	⊕	Additional questions have been added to the SDAC 2022, including whether dementia is diagnosed or suspected and age at diagnosis. Self-report still likely leads to underestimation.

Source	Dementia identified via	National coverage	Routine collection	Progress since 2020	Details
ADNet Clinical Quality Registry	Clinical diagnosis, as requirement for registry eligibility	⊗	Collects new cases	⊕	A new dementia-specific data source that could capture some clinical groups not identified elsewhere. Adheres to data standards outlined in a baseline minimum data set. Limited coverage expanding over time; participation is non-mandatory.
Dementia Support Australia	Clinical diagnosis of dementia, or suspicion of dementia, as requirement for service eligibility	✓	✓	⊕	A new dementia-specific data source that captures a clinical group that may not be identified elsewhere. Includes information on service support use as well as on behaviours and psychological symptoms of dementia (BPSD) and its impact. Only national data collection that includes the Neuropsychiatric Inventory, the gold standard for assessing BPSD.

Different data sources represent different people living with dementia

One of the main problems with single source administrative data is that they are not necessarily representative.

Not everyone living with dementia will interact with health, disability or aged care services. Further, dementia may not always be recorded for people who do. Studies in Australia and internationally have shown that pharmaceutical, hospitals, aged care assessment, residential aged care and deaths data all underestimate the number of people living with dementia (Cations et al. 2020; Gao 2018; Solomon et al. 2014; Stokes et al. 2020; Welberry et al. 2020; Xu et al. 2022).

Underestimates or biases with single source data

Both the number and type of people are underestimated in single source data:

- Some data sources, such as prescriptions data, are more likely to include a younger population living with dementia (for example, under 75 years) earlier in their symptom progression, because dementia medications are indicated at this age and stage rather than later.
- Other data sources, like assessments for entry into residential aged care, reflect an older population living with dementia (for example, 75 years and over), when the condition has progressed to requiring substantial care.

Using only one data source risks reaching wrong or biased conclusions about all people living with dementia in Australia because not everyone has been represented (Welberry et al. 2020).

National data linkage holds promise for better dementia data

When multiple administrative data sources are combined, and all the different service records that contain information on dementia for a person are linked, more people living with dementia in Australia can be identified. This is a way to overcome some of the bias inherent in single data sources and improve data on the overall number and type of people living with dementia who are represented (Wilkinson et al. 2018).

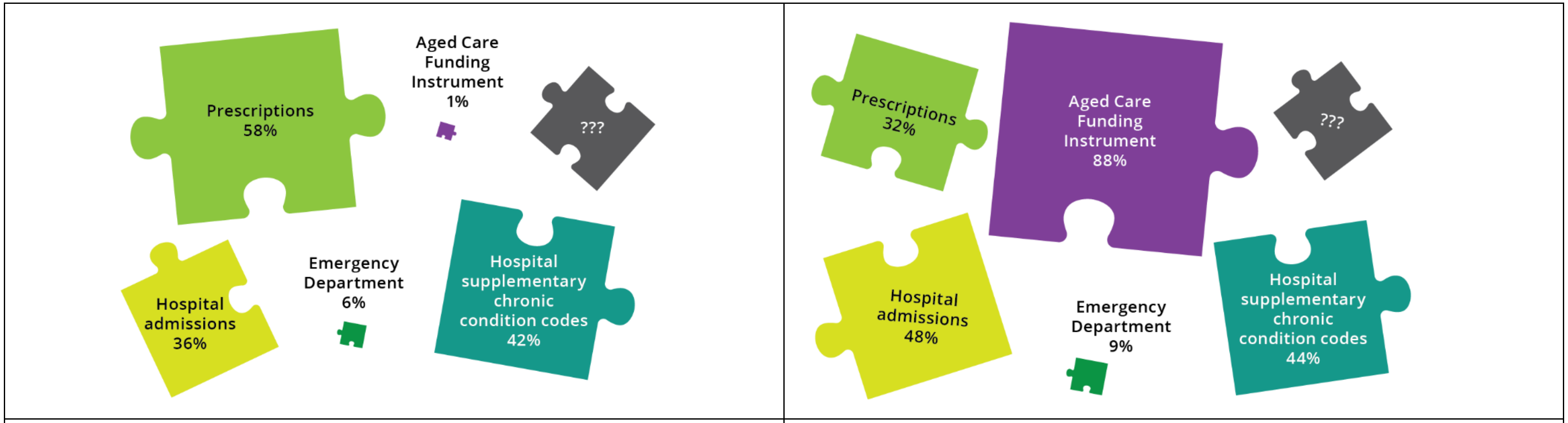
Putting together a puzzle – an apt analogy for dementia data detective work

Dementia data detective work using linked data can be likened to putting together pieces of a puzzle – where different data sources are collated to create one big picture that represents as many people living with dementia as possible. The size of the puzzle piece contributed by each data source may be bigger or smaller depending on the underlying population of interest:

- Figure DEM.1 presents an AIHW linked data example where, in a population aged 65 and over living in the community, PBS prescriptions data identify more people living with dementia (58% of the people identified as living with dementia in the community) than in a population of the same age living in permanent residential aged care (32% of the people identified as living with dementia in permanent residential aged care).
- Conversely, ACFI data play a tiny role in identifying people living with dementia in a community population (around 1% of all people identified as living with dementia in the community) but a massive role in identifying people living with dementia in residential aged care (88% of all people identified as living with dementia in permanent residential aged care).

Then, there is always a missing puzzle piece – representing people who have not engaged with the services offered by the included data sources (shown in black with question marks in Figure DEM.1). The size of this piece also varies depending on the sources included, but published literature suggests that it often represents around 20% of people living with dementia (Waller et al. 2017, Welberry et al. 2020).

Figure DEM.1: Example of dementia identification using linked data



Underlying population: age 65 and over living in the community

Underlying population: age 65 and over living in permanent residential aged care

Notes

1. Each data source identifies a different proportion of people living with dementia, and this varies depending on the underlying population characteristics.
2. For each population, percentages will not sum to 100% as dementia may be identified in multiple data sources for the same person.

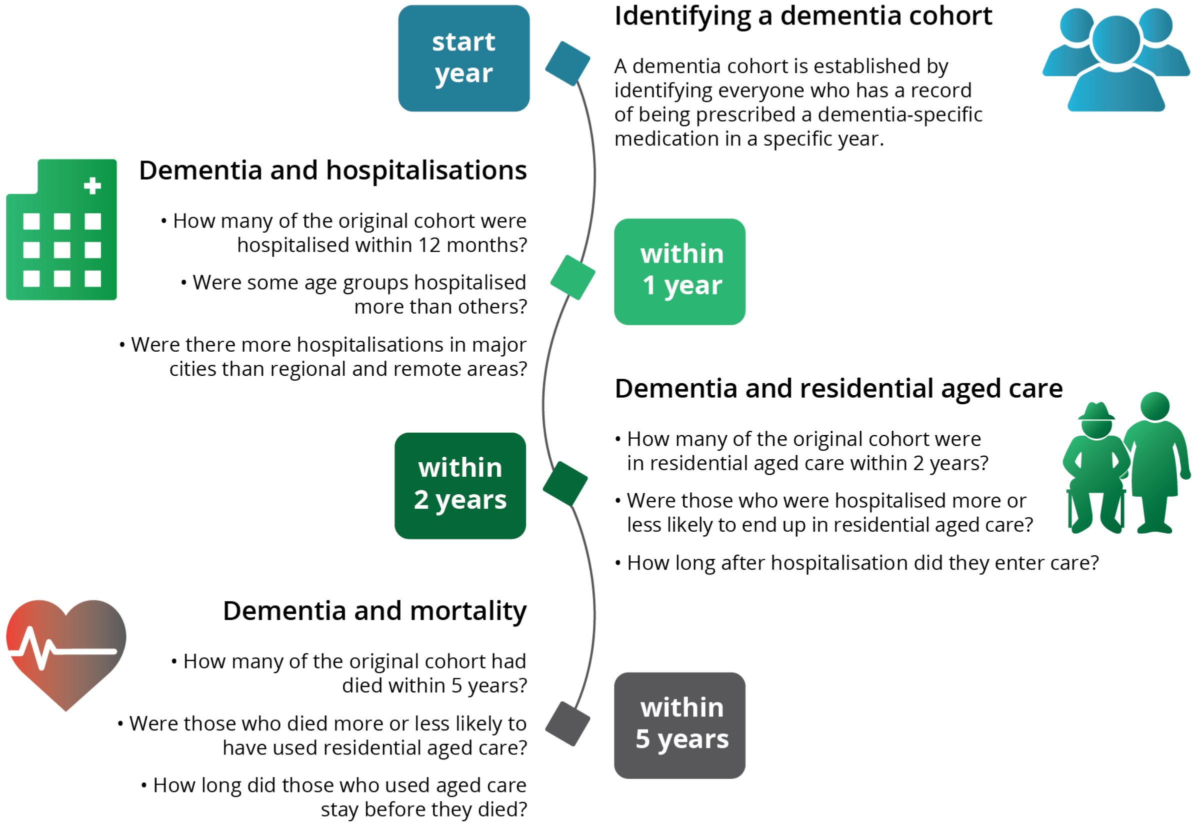
Source: AIHW analysis of all people in the National Health Data Hub linked data asset using services in 2020–2021.

At times it can be important to maximise the capability of linked data assets to identify people living with dementia by using all available data sources. This may be the case when using data linkage for modelling purposes:

- If inputs to the model only represent some of the people living with dementia (for example, only people identified via residential aged care assessments), outputs will be biased to the characteristics of these people (for example, people aged 75 and over with more advanced dementia and higher support needs).

However, there are circumstances where it might be of interest to isolate only a specific group of people within a linked data asset (for example, only people using dementia-specific medications) and then follow their service use and outcomes over time. An illustration of the questions that can be answered with this type of analysis is presented in Figure DEM.2.

Figure DEM.2: Example research questions that can be answered using linked health and aged care data



Identifying a dementia cohort

A dementia cohort is established by identifying everyone who has a record of being prescribed a dementia-specific medication in a specific year.

Dementia and hospitalisations

- How many of the original cohort were hospitalised within 12 months?
- Were some age groups hospitalised more than others?
- Were there more hospitalisations in major cities than regional and remote areas?

Dementia and residential aged care

- How many of the original cohort were in residential aged care within 2 years?
- Were those who were hospitalised more or less likely to end up in residential aged care?
- How long after hospitalisation did they enter care?

Dementia and mortality

- How many of the original cohort had died within 5 years?
- Were those who died more or less likely to have used residential aged care?
- How long did those who used aged care stay before they died?

As shown in Figure DEM.2, there are a myriad of opportunities for data linkage projects that extend well beyond providing an alternative for prevalence measurement.

Investment in linkage paves the way for improved data

If the road to improved dementia data relies heavily on linked data, there is still some work to do to make the ride a little smoother. For instance:

- ethics and governance required for data linkage projects can hinder the timely use of data.
- the process of linking data is time and resource intensive – combined with the expenses of secure data environments, this can result in prohibitive oncosts.

Current initiatives for data linkage

Acknowledging these roadblocks, the AIHW is currently focused on more enduring approaches to data linkage, and is a key player in initiatives such as the National Disability Data Asset (NDDA) and the Australian National Data Integration Infrastructure (ANDII).

The AIHW is also investing in a data linkage system to benefit the wider research community. A key component of this is the National Health Data Hub (NHDH) – an extension and expansion of what was the National Integrated Health Services Information data asset – that will be interoperable with the ANDII and available to external researchers.

Streamlining ethics and governance processes for the NHDH is a priority for the AIHW. As our data linkage matures and grows, methods and processes are continually being refined and becoming more familiar. Over time, stakeholders and data custodians are gaining confidence as they see their data being appropriately used to produce outputs of national importance, including reports on:

- younger onset dementia
- geographical variation in health service use for people living with dementia
- transitions to residential aged care after hospital for people living with dementia.

For more information on the NDDA and the ANDII, see Australia's health data landscape in *Australia's health 2024: data insights.*

Consistency in data collections supports long-term health policy goals

Whether used in linkages or as stand-alone data sources, almost all of the administrative data used to identify people living with dementia in Australia are collected for other reasons – most often in the course of providing essential health and aged care services. This means that the information collected may not always meet data requirements and may change over time.

- One example of this is the collection of information about people living in residential aged care. Until recently, data on health conditions were collected during aged care funding assessments for people living in permanent residential aged care, via the Aged Care Funding Instrument (ACFI). In October 2022, the ACFI was replaced by the Australian National Aged Care Classification (AN-ACC) to shift the funding focus from a person's health conditions to their functional capacity as a result of those conditions. While a person's cognition is assessed under AN-ACC, their health conditions, including their dementia status, are no longer recorded.

Not collecting the health conditions of people living in permanent residential aged care has wide-reaching consequences. For dementia data, the number of people living with dementia in this population is now unknown. There is now also one less data source for identifying dementia in linked data assets, which lowers the validity of analyses of outcomes for people living with dementia in permanent residential aged care. In the data example in Figure DEM.1, 23% of the population living with dementia in permanent residential aged care would not have been identified without the ACFI.

Dementia is not the only health condition disproportionately affecting permanent aged care residents. This new data gap will compromise monitoring and surveillance of the health of this vulnerable population in Australia.

While aged care funding assessment data are not collected specifically for monitoring health conditions, additional information collected alongside assessments would provide high coverage (as everyone who enters permanent residential aged care is assessed). The AIHW is therefore exploring avenues with the Department of Health and Aged Care to maximise this opportunity for best practice data collection.

Having national dementia data available and reported regularly in key monitoring areas by 2033 is one of the 5 core goals of the National Dementia Data Improvement Plan.

Specifications solidify ongoing data requirements

Consistent and consolidated data specifications underlie the quality, reliability and usefulness of all dementia data. Efforts must be made to ensure that data collections measure and report the same concepts in the same ways, ideally using the same (or equivalent) names, labels and values. For this to occur, agreement about what each data item means is required among organisations that collect and report data relating to people living with dementia. This may sound simple in theory but can be challenging in practice.

There has been a lot of recent movement in this direction:

- For dementia-specific data, a Dementia National Best Practice Data Set was endorsed in October 2022, recommending how basic items related to dementia could be standardised for dementia data collections.
- The next phase is to support a broad range of organisations – including primary health, hospital, and aged care service providers – in taking these recommendations

and then monitoring their use in practice, incorporating refinements as agreed and necessary.

For aged care data, the AIHW and the Department of Health and Aged Care have partnered to deliver:

- an Aged Care Data and Digital Strategy to drive system-wide improvement
- associated minimum and best practice data sets that set the standards for what and how data should be collected to improve aged care data quality in stages.

When endorsed and implemented in routine data collection, these specifications will facilitate the provision of consistent information about the number, characteristics and service use of people with dementia across different data sources.

Enforcing the collection of specific data items is difficult without any mandating authority; it requires co-ordination and commitment across sectors. Work between government and industry organisations to support data entry standards such as FHIR (Fast Healthcare Interoperability Resources) is a promising development towards ensuring that the digital architecture is in place to facilitate the exchange of quality and consistent health care data more broadly. Having such standards in operation should support future sharing of dementia data.

Harmonised dementia data collected across sources is one of the 5 core goals of the National Dementia Data Improvement Plan for 2033.

Data linkage capacity can still be strengthened

There are ways to maximise opportunities afforded by linked data assets. Some require additions to existing linkages; others involve improving the quality of existing data.

Adding dementia-specific data sources

One way to increase the number of people identified as living with dementia in linked data is to include dementia-specific data sources in the assets themselves. The AIHW has been working on a pilot project to include data in the NHDH from people living with dementia who are registered with either:

- the Australian Commonwealth Government funded national behavioural support service programs of Dementia Support Australia (approximately 90,000 people) or the ADNet Clinical Quality Registry (approximately 2,500 people).

When these data are incorporated, we will not only have a means to assess the validity of dementia identification via routine data sources, but also have a richer understanding of the treatment and support pathways available to people living with dementia, and the impact these have on overall outcomes (such as entering permanent residential aged care).

Having dementia data within wider national linkages is one of the 5 core goals of the National Dementia Data Improvement Plan for 2033.

Targeting data collection and linkage in priority populations

One of the largest dementia data gaps is among people in special interest populations who are historically under-represented in routine data, such as:

- Aboriginal and Torres Strait Islander (First Nations) people
- people from culturally and linguistically diverse (CALD) backgrounds
- people from the lesbian, gay, bisexual, trans, queer, and intersex (LGBTQI+) community.

Dementia prevalence and caregiver strain can be higher in these populations and there can be cultural barriers to accessing support, both for people living with dementia and their carers (Gilbert et al. 2022; Lo Giudice et al. 2016; Radford et al. 2019).

In First Nations, CALD and LGBTQI+ populations, monitoring prevalence and incidence at a national level can be challenging in terms of measuring both the numerator (how many people are living with dementia), and the denominator (the total population at risk).

There are known issues when reporting First Nations data, including sensitivity around disclosure of Indigenous status and large proportions of missing values for this field in administrative data collections. LGBTQI+ people have been invisible in Australian data collections until recently, and Australia still has a long way to go in accurately reflecting this community. Australia is also lagging in capturing data on CALD populations, currently relying on rudimentary proxies such as country of birth and language spoken at home. There is still work to do in the field of ethnicity identification to improve Australia's dementia data for CALD community groups (FECCA 2015; Low et al. 2019).

In many cultures, including those of Australia's First Nations people, dementia is thought of differently than it is in a clinical or service delivery context. Methods of data collection historically used in government and research settings in Australia may not be appropriate in some cultural contexts. There is much to be learned from other cultures about supporting people living with dementia, so it is imperative to take the time and find the ways to listen (Antoniades et al. 2022; Bradley et al. 2020).

Engaging with cultural groups that have been systematically marginalised in Australian history requires sensitivity, a willingness on both sides to consult and collaborate, and real commitment to the principles of co-ownership and co-design.

Meanwhile, maximising data linkage opportunities to include data sources that are working to improve their collection of information on First Nations people, people from CALD backgrounds and LGBTQI+ people, such as the Census and the ABS's Person Level Integrated Data Asset, is one way to increase our understanding of how dementia affects these groups and their engagement with health and welfare services.

These are not the only population groups that would benefit from improved data collection and linkage either – other priority populations include veterans, people with disability, people with childhood dementia and homeless people.

One of the 5 core goals of the National Dementia Data Improvement Plan is that by 2033 we will have improved dementia data in priority population groups.

Standardising dementia identification in routine data

Another avenue to improve and standardise data on people living with dementia is to include dementia flags in administrative data– a specific field that indicates whether a person is known to be living with dementia, either represented as:

- a simple yes or no, or,
- (preferably for measuring incidence and prevalence) a date of first identification or diagnosis, if that data became available.

This flag could be added at the point of data collection and might then be beneficial for people living with dementia when they engage with services – for example, ensuring that their dementia status is known during a hospital admission so that clinicians can better manage their experience. Alternatively, it could be added retrospectively when deidentified data collections are prepared for use.

Currently, there are no specific dementia flags in routine data sources and linkages. Their inclusion could ensure that people living with dementia receive the care they need, and/or that the same people are being identified as living with dementia for all dementia monitoring and research projects. While there would be many hurdles to overcome to implement dementia flags, a similar recommendation was made for disability data as a result of the recent Disability Royal Commission, and the Commission's final report discusses merits and barriers to implementation.

Undertaking studies that validate linkage-derived prevalence and incidence

Even with regular supply of high-quality data, data linkage assets such as the NHDH will still under-represent the population living with dementia in Australia, as illustrated by the missing puzzle piece in Figure DEM.1 (Chow et al. 2022). This is because, at present, they include only the population that engage with the specific services included in the linkage.

An Australian validation study showed that linked data can capture 77% of the population expected to be living with dementia according to global estimates (Welberry et al. 2020), noting that capture rates vary according to age, as some age groups will be more likely to interact with specific services than others.

The AIHW, in collaboration with The University of Queensland, is currently undertaking a similar validation of dementia identified via linked data in Australia, as opposed to the gold standard of clinical diagnosis in a study cohort. The aim is to use findings from this study:

- to improve dementia incidence estimates
- better understand where the weaknesses lie in ascertaining dementia cases via data linkages. Understanding this is important as analyses of health and service use of people living with dementia will be inaccurate if dementia cases have been missed and wrongly allocated to non-dementia comparison groups.

Given known issues with the under-identification of dementia using self-reported data (McGrath et al. 2021), the AIHW is also currently using linked data to examine the capture of self-reported dementia in the 2021 Census compared with dementia records in other national administrative and survey data.

Being able to link and validate these data sources against each other brings us ever closer to true estimates of dementia prevalence and incidence in Australia. It also shines a light on data sources where dementia ascertainment may not be as robust. This allows us either to apply caution when interpreting findings from analyses that use these sources, or to invest resources in activities that improve quality and reduce bias – one of which may be regular validation.

Reduce, reuse, recycle can apply to data collection

Minimising waste is important in terms of data collection too, especially in health and aged care service delivery settings where resources are often stretched. Expanding existing data to enable reporting of dementia – with the strategic view to 'collect once, use often' – is another improvement opportunity for dementia data.

- For example, residential aged care quality indicators have been collected since 1 July 2019 and have expanded in scope over time; they now include 11 indicators across clinical, health, and wellbeing domains. Although these are reported at aggregate levels – and the data are used as input to the star ratings that provide information on providers' quality of care at a facility level – the data are collected by assessing each individual in care. If there were a consistent collection of these records at the individual level, and it were possible to access these de-identified data along with the dementia status of the individual, this would open a whole new suite of possibilities for understanding the residential aged care experience of people living with dementia in Australia. The potential for individual-level aged care data is explored further in Chapter 8 of Australia's welfare 2023: data insights – 'Measuring quality in aged care: what is known now and what data are coming'.

This is not an isolated example of where innovations in the collection, distribution and configuration of data already being collected could hold potential for dementia monitoring and reporting. Similar opportunities also lie in greater use and application of artificial intelligence to analyse big data such as those generated through clinical care, as shown in recent examples using natural language processing to extract dementia data from electronic medical records (Ienca et al. 2018; Maclagan et al. 2023; Oh et al. 2023).

Dementia action needs data-informed decisions

Dementia is a serious and growing health and aged care issue in Australia. It has a substantial impact on the health and quality of life of people living with the condition, as well as on their family and friends and the wider community.

Implementing some of the dementia data improvement activities outlined in this article should assist in reaching the ambitious goals of the National Dementia Data Improvement Plan 2023–33. Embracing future data and technological advancements will also be essential, both to ensure that data are future proofed, and to minimise the impact of data collection on the people dedicated to caring and supporting people living with dementia.

Reducing the impact of dementia relies on co-ordinated, ongoing efforts by governments and local communities to act as needed to improve outcomes for people living with dementia and their carers. This action must be informed by a strong evidence base, the foundation of which is improved dementia data.

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The ongoing challenge of chronic conditions in Australia

Key messages

- Australians are living longer than ever before, but chronic conditions continue to have a considerable impact – 91% of the non-fatal burden of disease is related to them.
- There are many challenges in living with chronic conditions – some expected, such as the demand on Australia's health-care system and the impact of climate change, and some unexpected, such as the COVID-19 pandemic.
- To cope with the growing burden of chronic conditions, it will be critical to continue to focus on prevention and health promotion, and to harness data to identify inequalities and monitor progress.

Introduction

Over the last century, Australia has made great improvements in health. Advances in infectious disease control, disease screening, diagnosis and treatment have dramatically reduced mortality rates and improved the quality of life for many people living with chronic disease.

Today, Australians are living longer than ever before, with children born in 2023 expected to live into their 80s (AIHW 2023a). However, just over one-tenth of their lives will be spent with ill health, and the burden of chronic conditions remains high. Around 6 in 10 Australians are estimated to live with a long-term health condition (AIHW 2024a).

Chronic conditions thus present a key challenge for individuals, governments and society as a whole. The causes are varied and complex. A person's health and wellbeing are affected not only by individual characteristics and behaviours, such as genetics and lifestyle, but also by the world around them and their opportunities throughout life (Box CC.1).

The impact of chronic conditions is widespread. Individuals with chronic conditions often have complex health needs and require services from all levels of the health system. Living with or caring for someone with a chronic condition can also affect a person's social and economic circumstances, creating additional barriers to earning an income, participating in education, and/or socially engaging in communities. Australia's ageing population presents an additional challenge through the increased demand for services to care for and support people living with chronic conditions.

From the vantage point of almost a quarter of the way through the 21st century, this article explores how Australia is living with chronic conditions. It considers some of the challenges Australia may face in the future, namely:

- the demands on the health system
- the risks of communicable disease outbreaks, such as COVID-19
- the increasing impact of climate change and commercial determinants of health.

The article also highlights the value of prevention and early detection, and the importance of data in identifying inequalities and monitoring progress to improve the lives of all Australians.

Box CC.1: What are chronic conditions?

Also referred to as chronic diseases, non-communicable diseases or long-term health conditions, chronic conditions are generally characterised by their long-lasting and persistent effects. Chronic conditions are not usually immediately life threatening but tend to develop gradually, becoming more common with age. Once present, they often persist throughout a person's life and require long-term management.

In comparison, infectious diseases are caused by infectious agents (bacteria, viruses, parasites and fungi and their toxic products) and often cause acute or short-term illness. Many infectious diseases are also communicable diseases, meaning they can be passed from one person or animal to another. In some cases, infectious diseases can lead to longer term illness, or may be considered chronic conditions.

For example, HIV is an infectious disease; however, it can be treated as a chronic condition in Australia, given the availability of effective medicine. For more information on infectious disease in Australia, see Infectious and communicable diseases.

The changing story of Australia's health

> *'The nature of disease changes with the nature of societies.'*
>
> Egger 2017

The health of Australians today is considerably different from what it was a century ago. While people born today are expected to live, on average, into their 80s, those born in the early 1900s were expected to live to around age 55 (AIHW 2022b). The 20th century saw improvements to living conditions, infection control, and advancements in medicine that led to overall lower death rates and longer life expectancy at all ages.

From infectious diseases to chronic conditions

Until the 1930s, infectious and parasitic diseases caused at least 10% of all deaths each year, with death rates from these diseases being highest among the very young and very old (Jain 1994). Infectious disease control measures and childhood immunisation led to substantial declines in mortality from tuberculosis, polio, diphtheria, tetanus, whooping cough, measles, mumps and rubella. Between 1907 and 2020, deaths from infectious diseases fell by 98% – from 320 per 100,000 deaths to 6.9 per 100,000, after accounting for differences in age structure (known as ‘age-standardised rates’; see Glossary) (Figure CC.1). As a result, Australia experienced a health transition from more infectious diseases to more chronic conditions (Beaglehole and Bonita 1997).

The rise and fall of cardiovascular disease deaths

In the early part of the 20th century, cardiovascular disease was the fourth most common cause of death in Australia after pneumonia, tuberculosis and diarrhoeal disease, and was more common than cancer (Cumpston 1989). As fewer people died from infectious diseases, deaths from cardiovascular diseases increased rapidly, aligning with an ageing population structure (ABS 2002). By the mid-20th century, cardiovascular diseases accounted for more than half of all deaths, not only in Australia but also in most of the industrialised nations (Braunwald 1997).

After rising for several decades to a peak in 1968, deaths from cardiovascular disease dropped considerably over time – a decline of 85%, from 830 per 100,000 deaths in 1968 to 125 per 100,000 in 2022, after accounting for differences in age structure. This large fall represents a public health success. It can be attributed to both prevention and treatment; namely, a combination of:

- reductions in risk factor levels
- improvements in detection and secondary prevention
- advances in treatment and care (AIHW 2022b).

Changing mortality due to other chronic conditions

As Australians are living longer, other chronic conditions have appeared among the leading causes of death. Crude mortality rates (‘crude rates’; see Glossary) from cancer have steadily increased over the last 50 years, although age-standardised rates – generally steady between 1970 and 2000 – have since fallen. This may be due, in part, to the ageing of the Australian population and to an increase in the average age at death due to cancer over this period. Increased and earlier detection through cancer screening has likely also played a role for certain cancers. For example, cervical cancer mortality has halved since the National Cervical Screening Program was introduced in 1991 (AIHW 2023i) – read more in ‘Story from the data - Cervical cancer prevention, screening, and the path to elimination’ .

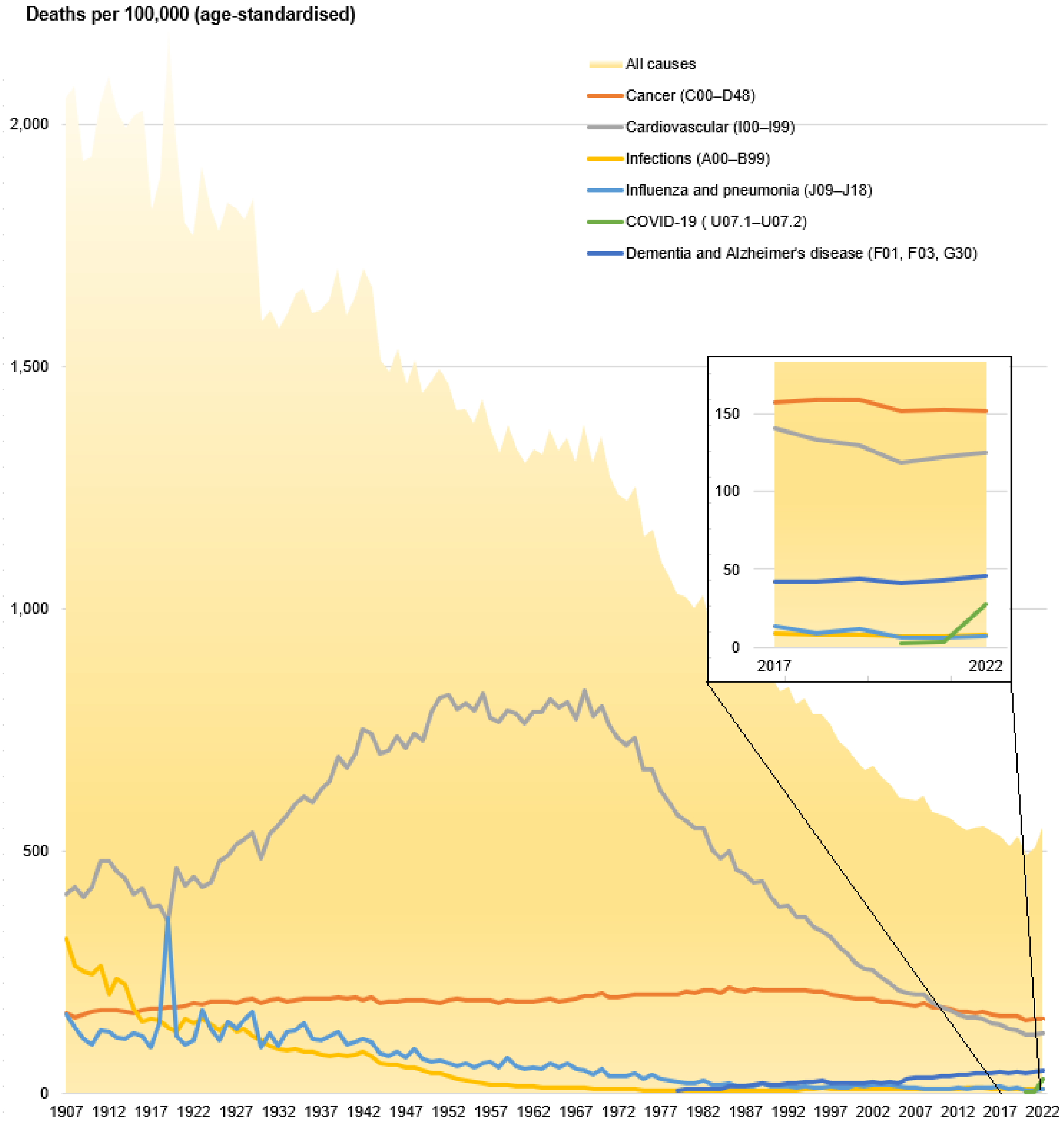
Dementia has also emerged as a leading cause of death, accounting for 9.0% of all deaths in 2022 (AIHW 2024b). Overall, chronic conditions contributed to 90% of all deaths in 2022 (AIHW 2024a).

Resurgence in infectious disease deaths due to COVID-19

Deaths due to infectious diseases remained low until the COVID-19 pandemic, which saw COVID-19 become the third leading cause of death in 2022. This was the first time in over 50 years that an infectious disease has been in the top 5 leading causes of death in Australia – since 1970, in fact, when influenza and pneumonia were the fifth leading causes (ABS 2023a).

Figure CC.1: While overall mortality has fallen dramatically, leading causes of death have shifted from infectious disease to chronic conditions

Age-standardised mortality rates (per 100,000 population), by selected broad cause of death, 1907–2022



Notes

1. Age-standardised to the 2001 Australian Standard Population.

2. Changes in mortality rates are also influenced by data improvements and changes to coding practices over time.

3. Data on deaths from dementia and Alzheimer's were not available before 1979 due to coding practices. Coding changes and variations in certification practices have likely resulted in an increase in deaths coded to dementia and Alzheimer's since around 2006.

Source: AIHW 2024b.

Australians are living longer, but still with ill health

On average, Australians are now living longer than ever before, with life expectancy at birth reaching 81.3 years for males and 85.1 for females born in 2023 (AIHW 2023a). As well as living longer, Australians are, on average, spending more years lived in full health – also referred to as the health-adjusted life expectancy (HALE). Between 2003 and 2023, males gained 3.2 years in life expectancy and 2.2 years in HALE. The corresponding gains for females were 2.1 years in life expectancy and 0.8 year in HALE.

Despite these gains, the average time spent in ill health also increased by 1.0 year for males and 1.3 years for females, resulting in little change in the proportion of life spent in full health in recent decades (AIHW 2023a).

Burden of disease

The impact of living with disease and injury on the population as a whole can be further explored through the burden of disease. Burden of disease is a measure that combines the years of healthy life lost from living with illness and injury (non-fatal burden, or years lived with disability) with years lost to dying prematurely (fatal burden, or years of life lost) to estimate total health loss (total burden, or disability-adjusted life years, or DALY).

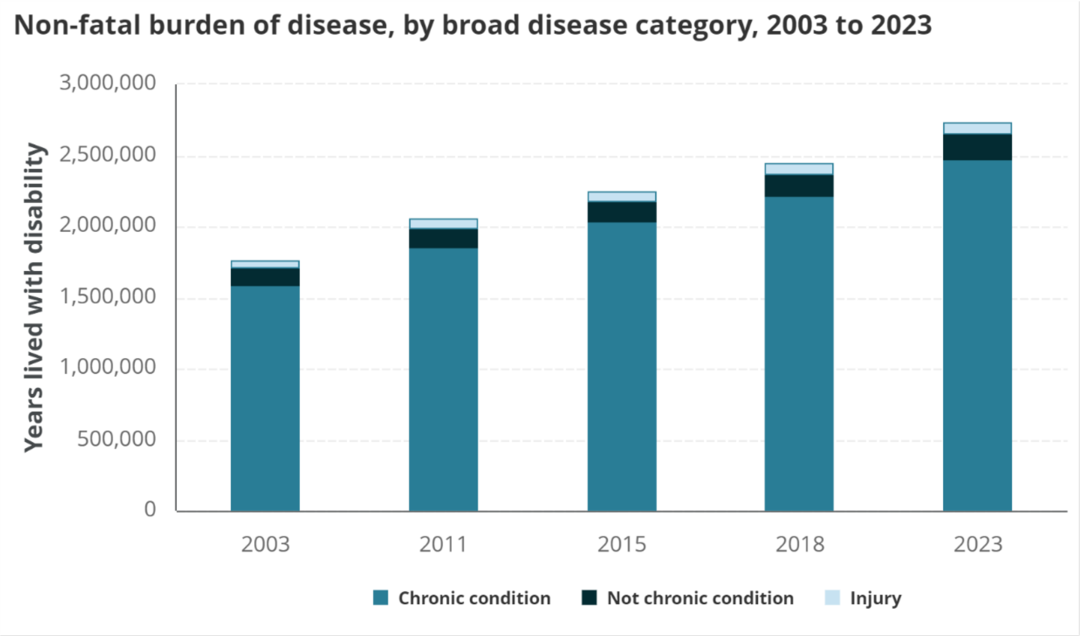
In 2023, Australians lost an estimated 5.6 million years of healthy life in total disease burden (AIHW 2023a). Over the last 20 years, although there was a 27% fall in the rate of fatal burden, the rate of non-fatal burden rose by 6.3%, after adjusting for population ageing (AIHW 2023a).

Majority of burden of disease due to chronic conditions

Chronic conditions make up an overwhelming proportion of the burden of disease – 91% of non-fatal burden and 78% of fatal burden in 2023. This proportion has remained stable over time, but population growth and ageing have led to an increase in the burden overall.

- The years lived with disability due to chronic conditions rose from 1.6 million in 2003 to 2.5 million in 2023 (Figure CC.2a). In the same period, the years of life lost due to chronic conditions rose from 1.7 million to 1.9 million (Figure CC.2b).
- By disease group, cancer remains the leading cause of premature death in Australia, contributing to one-third (33%) of the fatal burden in 2023 (AIHW 2023a). This is followed by cardiovascular disease, though the proportion of fatal burden due to cardiovascular disease has fallen over time – from 27% of fatal burden in 2003 to 19% in 2023.
- The leading causes of ill health between 2003 and 2023 were mental and substance use disorders (26% of the non-fatal disease burden in 2023), followed by musculoskeletal disorders (23%) (AIHW 2023a).

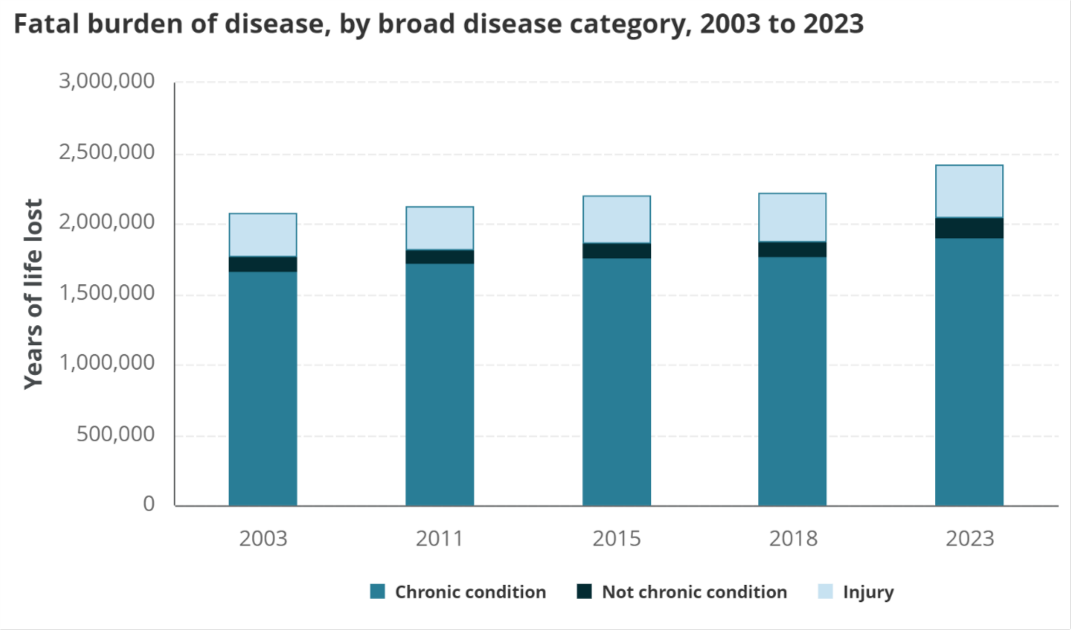
Figure CC.2a: An overwhelming majority of Australia's non-fatal burden of disease is due to chronic conditions



Source: AIHW analysis of the Australian Burden of Disease Study Database 2023.

Figure CC.2b: A large proportion of Australia's fatal burden of disease is due to chronic conditions

Fatal burden of disease, by broad disease category, 2003 to 2023



Source: AIHW analysis of the Australian Burden of Disease Study Database 2023.

Many Australians are living with multiple conditions

Many people experience multimorbidity; that is, they have 2 or more chronic conditions at the same time. The Australian Bureau of Statistics’s (ABS’s) National Health Survey presents self-reported data on 10 selected chronic conditions that are common, that pose significant health problems, and that have been a focus of ongoing public health surveillance (ABS 2023b):

- arthritis
- asthma
- back problems
- cancer
- chronic obstructive pulmonary disease
- diabetes mellitus
- heart, stroke and vascular disease
- kidney disease
- mental and behavioural conditions
- osteoporosis.

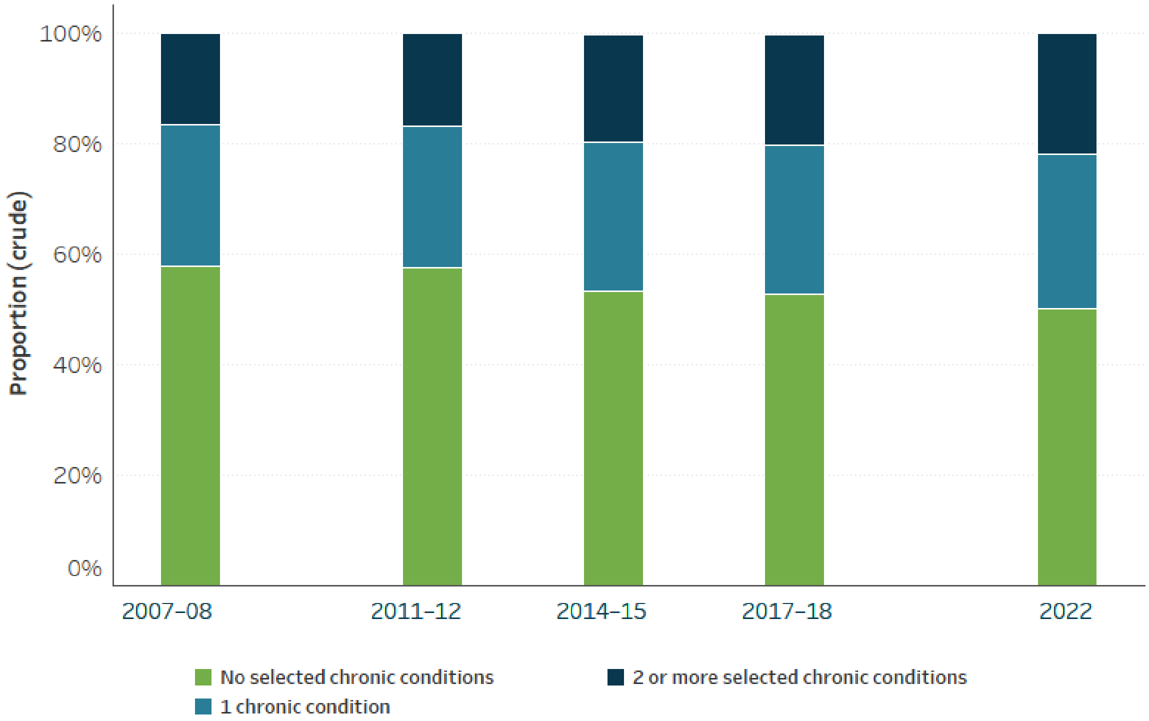
In 2022, the National Health Survey estimated that more than 1 in 5 Australians were living with multimorbidity, based on these selected chronic conditions. Of the population with at least one of these conditions, 44% were estimated to experience multimorbidity. However, the prevalence of multimorbidity varies considerably by the type of chronic condition – 87% of people with chronic obstructive pulmonary disease (COPD) and 85% of people with cardiovascular disease experience multimorbidity.

The prevalence of multimorbidity has gradually increased in recent years, even after adjusting for changes in the population age structure over time (Figure CC.3). The proportion of the population with multimorbidity has also increased at a greater rate than the proportion with one chronic condition only – up 33% from 2007–08, compared with an 18% increase for a single condition.

For more information, see Multimorbidity.

Figure CC.3: The proportion of Australians living with 2 or more chronic conditions is growing

Crude proportion (per cent) of Australians living with selected chronic conditions, 2007–08 to 2022



Notes

1. Data are self-reported.

2. Selected chronic conditions are arthritis; asthma; back problems (dorsopathies); cancer (malignant neoplasms); COPD; diabetes mellitus; heart, stroke and vascular disease; kidney disease; mental and behavioural conditions; and osteoporosis. Includes people with a current health condition that has lasted, or is expected to last, for 6 months or more – except for people reporting diabetes mellitus and/or heart, stroke and vascular disease (which are included irrespective of whether the condition is current and/or long term). Multiple conditions belonging to the same condition type (such as mental and behavioural conditions) are treated as the one condition. For example, a person with anxiety and depression (and no other chronic condition) is treated as having one selected chronic condition.

Source: ABS 2023d.

https://www.aihw.gov.au

Chronic conditions represent a complex interplay of one's individual health and environment

The factors that influence a person's health and wellbeing, including their likelihood of developing chronic conditions, are varied and complex. These factors, known as determinants of health, may be either a risk or protective to a person's health. Strengthening those determinants that are protective and minimising those that are a risk can:

- reduce the risk of developing a chronic condition
- ease symptoms for those already living with chronic conditions
- improve a person's quality of life overall.

At the highest level, health determinants include broad features of society, such as social cohesion and inclusion, commercial practices and environmental factors. These interact with and influence mid-stream factors, such as socioeconomic characteristics, health behaviours, working conditions, psychosocial and safety factors, and downstream biological factors, such as body weight, blood glucose and blood pressure – which have the most direct impact on health. Not only can all of these factors influence health, but also a person's health can influence health determinants, such as through the ability to earn income or access social support.

While positive health behaviours can contribute to good health, individuals have little to no control over many determinants of health:

- Age, sex and genetics all influence health and one's predisposition to chronic conditions.
- People living with chronic conditions may be at greater risk of adverse effects during extreme weather events, which are increasing in frequency, intensity and duration due to climate change. These adverse effects may occur directly (such as the impact of bushfire smoke on people with respiratory conditions) or indirectly (through reduced access to medication, treatment and preventive health screening).
- Broader aspects of society also play a role; for example:
    - cultural acceptance of alcohol and binge drinking
    - proximity to commercial outlets for tobacco, alcohol and discretionary foods
    - advertising of these products (Livingston 2011; Livingston et al. 2023; Schultz et al. 2021).

For more information on health determinants and how they affect health, see What are determinants of health?.

Modifiable risk factors

In 2018, up to 38% of the total burden of disease in Australia was estimated to be preventable by reducing exposure to 40 risk factors (such as tobacco use, overweight and obesity, dietary risks, and high blood pressure) (AIHW 2021a).

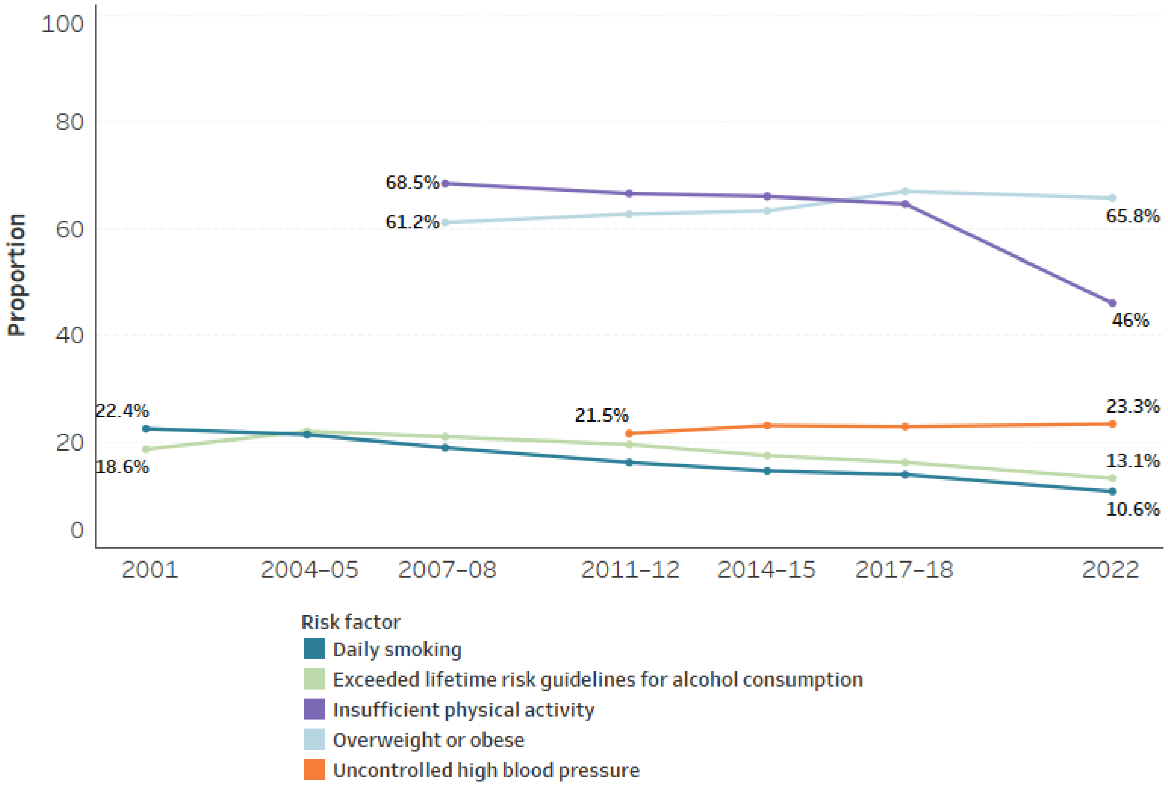
In recent decades, some improvements have been made in areas such as insufficient physical activity, and harmful alcohol consumption (Figure CC.4). However, the proportion of adults living with overweight and obesity continues to rise, driven largely by a rise in the proportion of adults living with obesity, which is the higher risk category. New risk factors also emerge over time.

While the proportion of the population who smoke daily is steadily declining, the proportion currently using e-cigarettes has increased from 1.2% in 2016 to 7.0% in 2022–2023 (AIHW 2024e).

These trends are similar even after accounting for differences in the age structure of the population over time.

Figure CC.4: Insufficient physical activity, daily smoking and risky alcohol consumption decreasing, while overweight and obesity increasing

Trends in selected risk factors, 2001 to 2022



Notes

1. Data are self-reported.
2. Data on Daily smoking, Exceeded lifetime risk guidelines for alcohol consumption, Overweight or obese and Uncontrolled high blood pressure are sourced from ABS 2023d. Data on these risk factors include responses from people whose sex at birth is male, female or a term other than male or female.
3. Data on insufficient physical activity are sourced from AIHW 2024f. Due to small numbers and the need to protect privacy, data on insufficient physical activity does not include responses from people who reported sex at birth as a term other than male or female.
4. See Glossary for full definition of each risk factor.

Sources: ABS 2023d; ABS 2024f.

https://www.aihw.gov.au

All is not equitable: some people experience avoidable differences in health outcomes

While many factors are monitored individually, it is important to take a holistic view to properly understand the role of health determinants.

The Australian population is diverse, and the story of chronic conditions is not the same for all. There is a close relationship between people's health and the circumstances in which they grow, live, work, play and age. A complex interaction between the circumstances of certain groups of Australians and the health determinants outlined in the previous section can contribute to avoidable differences in risk factor prevalence and health outcomes.

The amount of burden attributable to the 40 selected risk factors was higher for all risk factors as the level of socioeconomic disadvantage increased. The greatest relative difference in burden rate was for tobacco use (people living in areas of most disadvantage had 3.0 times the age-standardised rate of people living in areas of least disadvantage), followed by intimate partner violence and high blood plasma glucose (both 2.5 times) (AIHW 2021a). In terms of disease burden:

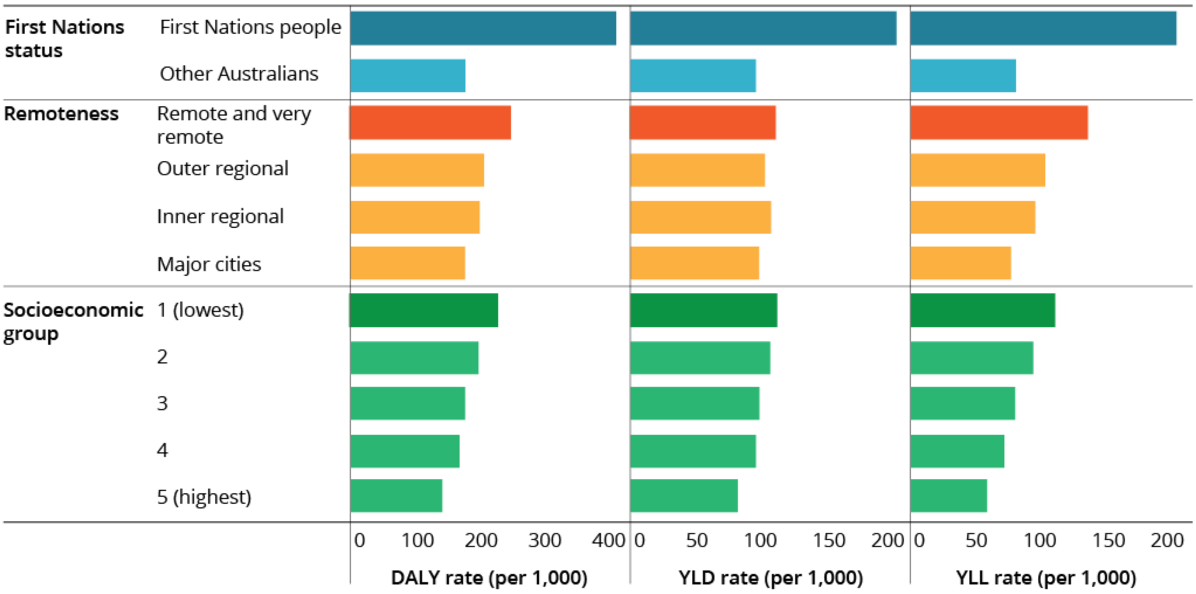
- The burden of disease among First Nations people is 2.3 times that of other Australians (Figure CC.5).
- People living in rural and remote areas and people living in the lowest socioeconomic areas also often experience higher rates of disease burden than other Australians.

These factors can build on each other, resulting in even greater inequality. For instance, First Nations people living in *Remote* areas experience a greater disease burden than First Nations people living in *Major cities* (AIHW 2022a).

These results illustrate the interconnectedness of health behaviours and determinants, both upstream and downstream, and how focusing on social determinants of health can improve health outcomes.

Figure CC.5: First Nations people, people living in *Remote and very remote* areas and people living in lower socioeconomic areas experience greater disease burden than their counterparts

Variation in burden of disease rates by population group, 2018



DALY = disability-adjusted life years; YLD = years lived with disability; YLL = years of life lost

Note: Rates are age standardised to the 2001 Australian population.

Sources: AIHW 2021a, 2022a.

Barriers to equitable health outcomes

Barriers to achieving equitable health outcomes may include difficulties in accessing services due to work or carer obligations, physical distance, affordability, and having insufficient knowledge to confidently navigate the health system. Many of these barriers are interlinked with the determinants of health.

- People from culturally and linguistically diverse backgrounds often face interconnected health and social disadvantages and greater challenges when navigating the health-care system (AIHW 2023e).
- For First Nations people, cultural identity, family and kinship, Country and caring for Country, knowledge and beliefs, language, participation in cultural activities and access to traditional lands are key determinants of health and wellbeing, and a lack of culturally appropriate care is a barrier to seeking health care.
- People with disability, older people and people in prisons also face unique barriers to achieving good health.

For more information, see the following AIHW web articles or reports:

- Rural and remote health
- Health and wellbeing of First Nations people
- Health of people with disability
- Health of older people
- Health of people in prison
- Chronic health conditions among culturally and linguistically diverse Australians, 2021

More chronic conditions means more use of health services

Not all chronic conditions are preventable. Even with prevention efforts and favourable determinants, many Australians will eventually be diagnosed with a chronic condition. Given this, the focus must shift to how to best manage chronic conditions and optimise quality of life.

Primary care

Australia’s health system provides care for people with chronic conditions through a complex mix of health professionals and service providers. Primary care is often a person’s first contact with the health system and plays a key role in preventing, detecting, diagnosing and managing chronic conditions. Primary health care providers often refer individuals to specialist services that provide expert care for particular body systems or conditions, and to diagnostic services such as radiology and imaging.

Despite the lack of comprehensive national primary care data, the available data show that chronic conditions make up a substantial proportion of general practice activity:

- In 2022–23, 60% of people (10.2 million) who visited a general practitioner (GP) in the last 12 months had a long-term health condition (ABS 2023c).
- In 2022–23, almost 1 in 6 (16%; 4.1 million) Australians claimed a Chronic Disease Management service – that is, a set of Medicare items available to people with chronic or terminal illness to help organise their care and manage complex care needs across multiple health-care providers (AIHW 2024d).

Overall, Australians are seeing a GP more often. The use of Medicare-subsidised GP services per person is increasing – both in total volume and in the average number of visits per person (Figure CC.6), even after accounting for the ageing population (Box CC.2; AIHW 2023h). The peak of service use in 2021 can be attributed to attendances to assess suitability for the COVID-19 vaccine and the increased availability of telehealth services during this period; however, the GP attendance rate has been steadily increasing since the early 2000s (AIHW 2023h).

The use of GP Enhanced Primary Care services – a range of services, many of which are aimed at preventing, diagnosing or managing chronic conditions – is also increasing. Part of this growth can be attributed to new Medicare items being introduced, thereby increasing the number of services available. Still, the increasing uptake of these services demonstrates a need for this care, and illustrates the growing volume of care being provided for more complex health needs, including chronic conditions, in the general practice setting.

Box CC.2: Australia's changing population

Understanding the changing nature of the Australian population is key to understanding the story of chronic conditions in this country.

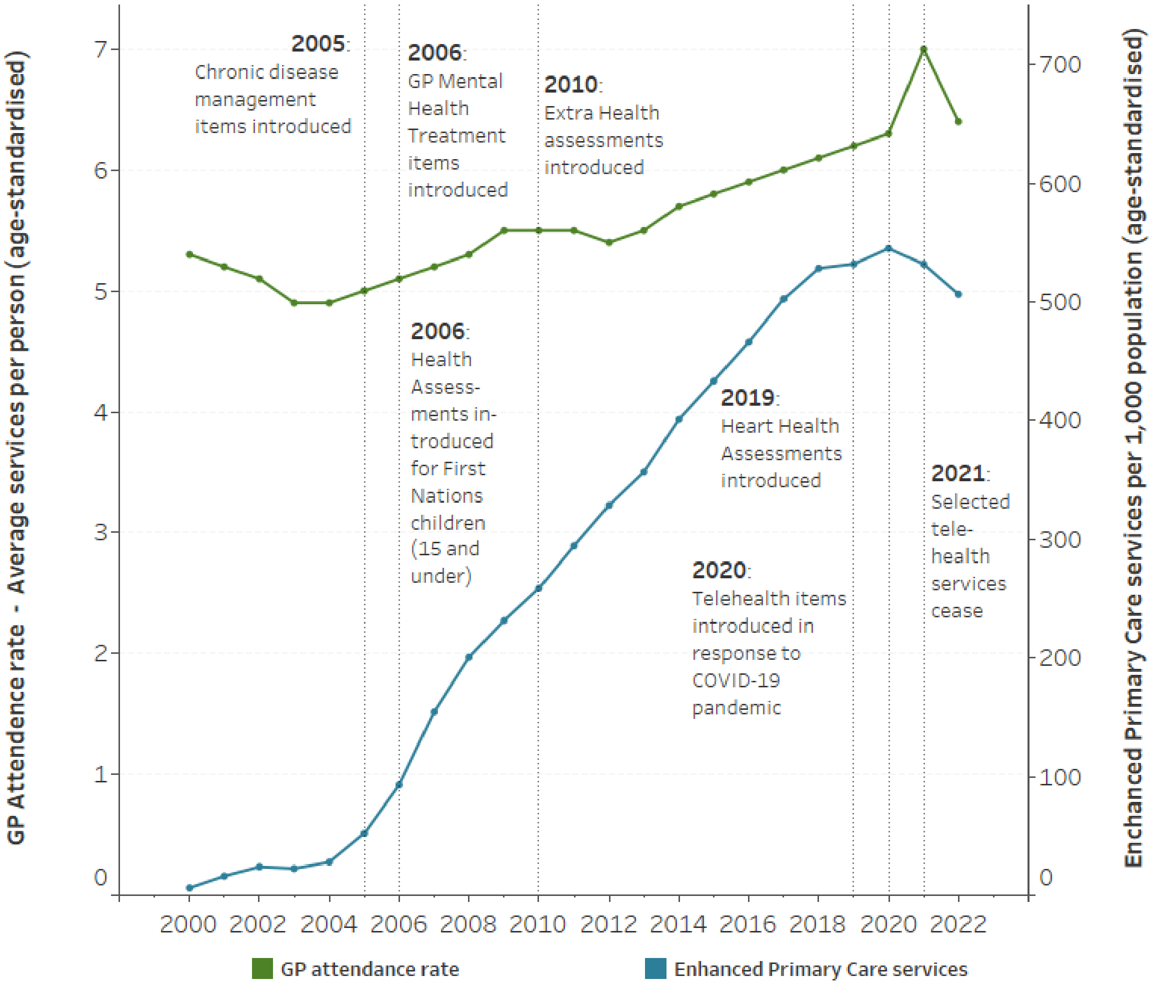
Over the last 50 years, it has doubled, from 13.1 million in 1971 to 26.2 million in 2022 (ABS 2021a). Before the turn of the century, much of this growth was due to natural increase – births minus deaths. From 2005–06, overseas migration was the main driver of growth – until the COVID-19 pandemic when international border restrictions in 2020–21 saw the first net outflow of migrants since World War II. By 2034, Australia's population is projected to reach 30.9 million (AIHW 2024g).

Declining fertility and lower mortality mean the Australian population is ageing. While the arrival of younger overseas migrants has offset this in part, the median age of the population has increased by more than 10 years in the last 5 decades, from 27.5 in 1971 to 38.3 in 2023. With age being a common and unavoidable risk factor for many chronic conditions, a population who are older and living longer will continue to create pressures for treating and managing ill health in Australia.

For further information on Australia's population, see Profile of Australia's population.

Figure CC.6: Increase in average yearly GP visits per person and in use of services related to detecting and treating chronic conditions

Age-standardised patterns in GP services, 2000 to 2022



Notes:

1. Age-standardised to the 2001 Australian Standard Population.

2. GP attendances include both non-hospital and in-hospital GP presentations, as well as services rendered by a practice nurse or an Aboriginal and Torres Strait Islander Health Practitioner on behalf of a GP (Medicare Broad Type of Service Groups 101, 102, 103 and 110). GP attendances related to the assessment of patient suitability for the COVID-19 vaccine were also included.

3. Enhanced Primary Care services refer to the Medicare Broad Type of Service Group 102. This group includes services such as health assessments, medication management reviews, the creation and review of treatment plans, and the coordination of care for people living with complex health conditions who require multidisciplinary, team-based care from a GP and at least 2 other providers. This group contains hundreds of items and changes over time as new items are introduced and discontinued. These item changes impact the trend of Enhanced Primary Care services over time.

Sources: AIHW 2023h; AIHW analysis of Services Australia 2023.

https://www.aihw.gov.au

New models of primary care

A lot of work is being done on new models of care in general practice to promote continuity of care and provide more accessible services.

For example, from 1 October 2023, a new model in primary care began called *MyMedicare*. This model enables a patient to voluntarily identify a general practice and practitioner as their regular care team; it aims to encourage continuity of care to improve health outcomes (Department of Health and Aged Care 2023a).

New Medicare Benefits Schedule (MBS) items and incentive payments have been linked to *MyMedicare* registration progressively from November 2023 to help practices provide care that responds to patient needs. There are potential opportunities to draw on the nurse and allied health workforces to support the medical workforce in managing patients with chronic conditions and in encouraging access to multidisciplinary teams to keep patients well – and out of hospital.

As at 10 April 2024, around 1.0 million patients and 5,800 practices had registered for *MyMedicare* (Department of Health and Aged Care, personal communication, 17 April 2024). This represents around 3.9% of Australians and 91% of general practices.

Hospital care

Hospitals are another integral part of Australia's health system, providing advanced and complex care. At the end of a person's hospital stay, information is collected on the reason chiefly responsible for the hospitalisation (known as the principal diagnosis, see Glossary), as well as other conditions determined to affect patient care (known as additional diagnoses, see Glossary). Based on a list of over 100 chronic conditions from the Australian Burden of Disease study (ABDS), analysis of the principal and additional diagnosis data estimated that chronic conditions are associated with:

- more than half (55%) of all hospitalisations
- nearly three-quarters (74%) of all bed days – the time spent in hospital receiving care.

In 2021–22, 6.4 million hospitalisations were related to chronic conditions; 4.0 million of these (63%) had a chronic condition as the principal diagnosis. After accounting for differences in the population age structure over time, the rate of chronic condition hospitalisations in the last decade has slightly increased, mirroring the trend seen for all hospitalisations (Figure CC.7).

Emergency department care

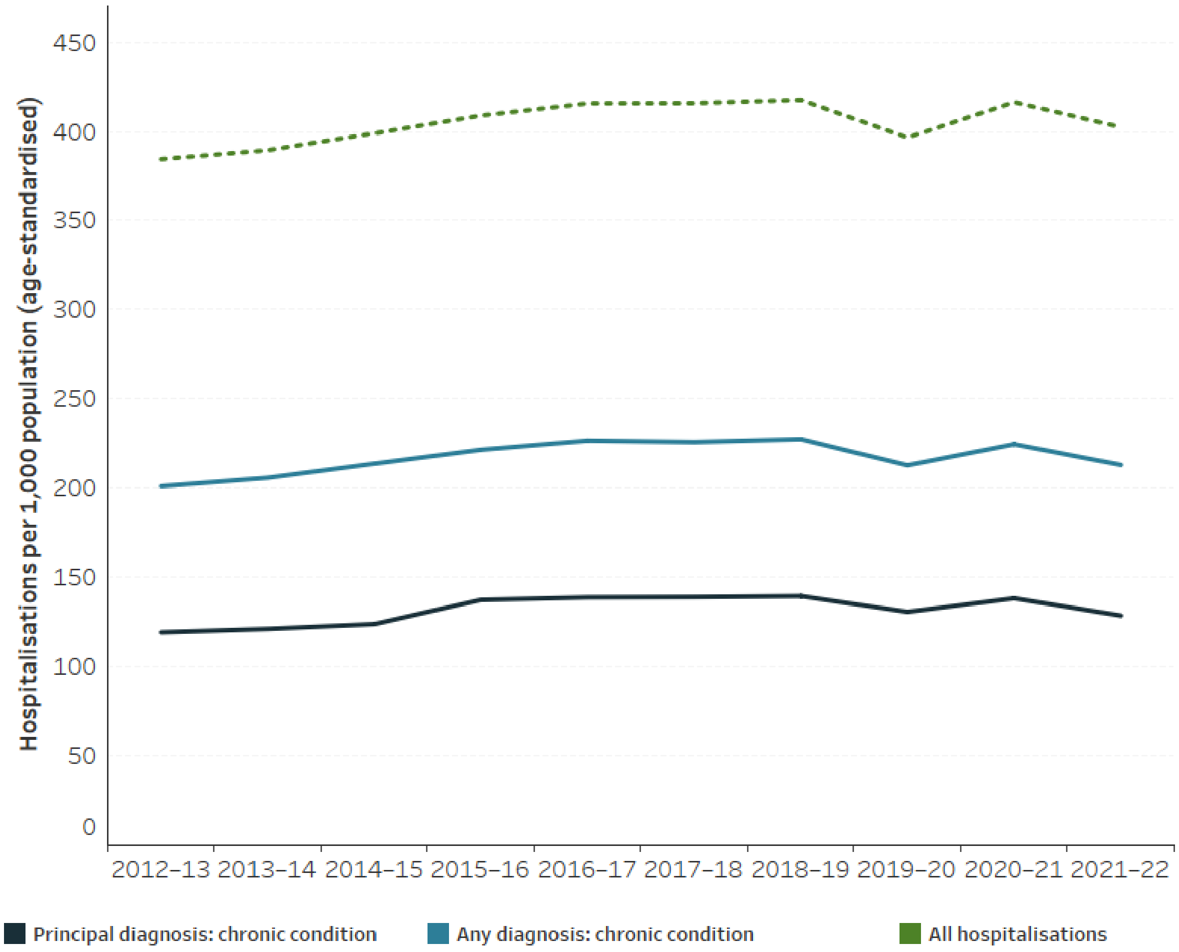
Emergency departments (EDs) treat acute and urgent illnesses and injuries, and have a key role in managing patients with chronic conditions. At the end of an ED visit, information is collated on the main reason for attendance (principal diagnosis) as well as up to 2 coexisting conditions or complaints (additional diagnoses).

Between 2018–19 and 2022–23, around 1 in 6 (16%) ED presentations were associated with chronic conditions each year (based on a list of over 100 conditions from the ABDS). These presentations include, for example, the acute and life-threatening episodes of chronic conditions such as heart attacks and strokes, as well as illness or injury caused or exacerbated by a chronic condition.

It is likely, however, that the true proportion of ED presentations related to chronic conditions is much higher, as patients may present only with symptoms and require further testing to receive a diagnosis. Pain in the throat and chest, and abdominal and pelvic pain were the 2 most common reasons for seeking care in an ED in 2022–23; together, they represented 9.6% of total presentations and possibly included patients with undiagnosed cardiovascular disease, respiratory disease or gastrointestinal disorders (AIHW 2023g).

Figure CC.7: There has been a gradual increase in hospitalisations for chronic conditions over time

Patterns in hospitalisations, 2012–13 to 2021–22



Source: National Hospital Morbidity Database 2012–22.
https://www.aihw.gov.au

What does the future hold for chronic conditions in Australia?

This question is difficult to answer. Studying the history of chronic conditions and patterns in the data helps to identify trends and best practices for enhancing the health of Australians. However, this only gives us some understanding, as new challenges can emerge rapidly and unpredictably.

Expectations of Australia's health-care system are high

Australia's health-care system (both primary care and hospital systems) continues to provide high-quality treatment, care and support to people living with chronic conditions, with a high cost to the economy. Expectations to keep people well, and participating in work, education and communities are high.

A strong health-care workforce is key

Australia's health-care workforce is expected to respond to emerging health issues quickly, and this sees it operating under increasing pressures to achieve positive outcomes for the individual patient and the health-care system. While overall health workforce numbers are trending in the right direction, its accessibility depends very much on the distribution of its members in areas where they are most needed (AIHW 2022c).

Coordinated care across multiple providers and systems

As the proportion of people living with 2 or more chronic conditions continues to rise, so, too, does the need for services from multiple providers, across multiple systems,including health, aged care, disability, education and social services. Evidence suggests that people with multiple conditions benefit from coordinated care to improve health and wellbeing, and that this results in a better individual experience of the health system (Australian Health Ministers' Advisory Council 2017).

Poorer experiences for some

The system sometimes works well; however, not all patients have the same health-care experience. Poorer experiences and outcomes are reported for some of Australia's priority population groups, such as First Nations people, people living in rural and remote Australia, people with disability, and culturally and linguistically diverse Australians (Khatri and Assefa 2022). This is of particular concern given the higher rates of chronic disease burden experienced by these population groups (see the section earlier in this article headed 'All is not equitable: some people experience avoidable differences in health outcomes').

Future challenges

Looking ahead, chronic conditions such as mental illness (particularly depression and anxiety), dementia and chronic liver disease (see Box CC.3) are emerging as some of the fastest growing chronic conditions. This is while the level of more 'familiar' chronic conditions, such as type 2 diabetes, cardiovascular disease, arthritis and asthma, remains high. It is expected in the future that more Australians will have multiple chronic conditions, due to the common risk factors and disease pathways that chronic conditions share.

Box CC.3: An 'unseen' chronic condition: non-alcohol fatty liver disease

Chronic liver disease was the ninth leading cause of fatal burden in Australia in 2023 and, when combined with liver cancer, was the fifth leading cause of fatal burden (AIHW 2023a). Non-alcoholic fatty liver disease (NAFLD) is currently the most common form of chronic liver disease worldwide (Wong et al. 2023), and the number of people living with this condition has increased markedly in Australia over the past 2 decades (Clayton-Chubb and Roberts 2023). A recent study in regional Victoria estimated the prevalence of NAFLD to be almost 40% (Vaz et al. 2023) and showed that it had increased significantly over the last 15 years, particularly for women.

The prevalence of NAFLD has been shown to increase parallel to the prevalence of obesity, which, in turn, has been closely linked to unhealthy environments contributing to unhealthy diets and insufficient physical activity (see Figure CC.4 for Australia's trend in obesity). A study in Australia has projected the prevalence of NAFLD to increase by 25% between 2019 and 2030 (Adams et al. 2020).

As survival rates improve for other other diseases, such as cardiovascular disease, diabetes and cancer, previously 'hidden' chronic conditions like NAFLD are becoming more visible. It therefore remains important to monitor these emerging diseases, to enable health policy to evolve, and the health system to respond in a timely manner.

Ongoing impact of COVID-19

The COVID-19 pandemic illustrated that there are challenges that could threaten the ability of Australians and the health-care system to cope with the future burden of chronic conditions.

During the COVID-19 pandemic, a range of public health interventions were put in place to help contain the spread of the virus that causes COVID-19. While governments and public health officials tried to balance the benefits of these interventions with the potential harm they caused, some unintended consequences were observed, including:

- worsening wellbeing across a range of indicators, including life satisfaction, psychological distress and loneliness – especially among young people, people with low education, and people with low income (Biddle et al. 2022)

- delays to seeking primary care, with almost 10% of people aged 15 and over reporting having delayed or missed needed health care from a GP due to COVID-19 (ABS 2021b)
- interruption of non-urgent elective surgery in various jurisdictions at different times during the pandemic because of disruptions to the delivery of hospital services due to rising COVID-19 case numbers and hospitalisations (AIHW 2021c)
- disruption of national cancer screening programs, with fewer screenings for BreastScreen and the National Bowel Cancer Screening Program (AIHW 2023c, 2023d) and likely also fewer screenings for the National Cervical Screening Program (AIHW 2023i).

Long COVID

Long COVID or post-acute COVID-19 is a new chronic condition that has emerged since the start of the COVID-19 pandemic in 2019; it is estimated to affect between 5–10% of COVID-19 cases. Long COVID refers to the long-term symptoms that some people experience after they have had a COVID-19 infection (Department of Health and Aged Care 2024). Common symptoms can include fatigue, cough, breathlessness, joint or muscle pain, chest pain, change in sense of taste or smell, anxiety and/or low mood (Health Direct 2023). Several studies have reported increased health-care use and costs as well as patient reports of limitations on their daily activities and a reduced quality of life (AIHW 2022d).

Climate change

Climate change is an example of a current challenge that is predicted to have increasing negative impacts on people living with chronic conditions and on people at risk of developing chronic conditions in Australia. People living with physical and mental chronic conditions are particularly vulnerable to the effects of extreme weather events, natural disasters and poor air quality.

As a consequence of climate change, the intensity and frequency of heatwaves and drought – and the number of days with fire weather conditions – have increased and are projected to continue increasing (BOM and CSIRO 2020). The health impacts of these events are also likely to increase (Beggs et al. 2019; WHO 2018) and disproportionately affect priority populations, such as people with chronic conditions, First Nations people, and people living in rural and remote Australia. Excessive heat can exacerbate existing health conditions, such as heart disease, diabetes, kidney disease and mental and behavioural conditions (AMA 2015).

In December 2023, the Australian Government launched Australia's first National Health and Climate Strategy (Department of Health and Aged Care 2023b). The strategy outlines the government's vision for 'healthy, climate-resilient communities, and a sustainable, high-quality, net zero health system,' and identifies whole-of-government actions over 5 years to achieve this.

Ageing population

The Australian population continues to experience increased life expectancy; it is also an ageing population. With age a common and unavoidable risk factor for many chronic conditions, more pressure will be placed on the health-care and aged-care systems to manage and treat people living with chronic conditions. Already, there is pressure to improve the connection between these 2 systems to ensure that the complex needs of older people living with chronic conditions can be met.

In 2020–21, there were 19,600 hospitalisations for older people waiting for residential aged care (Productivity Commission 2023). Almost 1 in 10 (9.8%) of these 'aged care type' patients waited 35 days or longer in hospital, suggesting that barriers are preventing the smooth transition of patients between hospital and aged care.

Also, given the complex interaction between determinants and disease, some people are more likely than others to develop more chronic conditions as they age, making them more vulnerable.

Role of health promotion and prevention

To cope with the growing burden of chronic conditions, prevention and promoting health across the life-course for all Australians must be a priority in the conversation.

The National Preventive Health Strategy 2021–2030 (Department of Health 2021) provides a platform for an overarching, long-term approach to prevention in Australia. To achieve its aims and assess progress being made into the future, the strategy requires:

- long-term investment
- implementation of preventive health actions
- continual monitoring of targets.

In the second half of 2024, the AIHW will be releasing a report monitoring the targets and aims outlined in the strategy.

Australia – a global leader in some areas

Australia has already been a global leader in some aspects of prevention – namely, for tobacco control and the pathway to cervical cancer elimination (see the section later in this article headed 'Story from the data - Cervical cancer: prevention, screening, and the path to elimination'). It is also known to have one of the most robust and comprehensive immunisation systems in the world (AIHW 2022b). It shares these success stories with the rest of the world but the question remains: what will the next success story be in preventing chronic conditions?

Australia will need to ensure it retains an appropriate focus on preventing new and/or emerging risks. For example:

- e-cigarettes – to counter the increased marketing and use of these in recent years, particularly among young people, Australian governments are implementing a range of new regulatory and non-regulatory measures (for more information on recent trends in vaping, see <Electronic cigarette use (vaping) ein Australia in 2022–2023>)
- obesity – long-standing challenges remain in halting the growing number of people living with obesity (which is linked to many chronic conditions, including type 2 diabetes, coronary heart disease and dementia) without increasing weight stigma.

Increasing importance of data and monitoring of chronic conditions

To understand where the burden of chronic conditions is heading in Australia, we need to continue to use the rich data at our disposal to create information that can be used to guide Australia's health and other social systems towards a future where all Australians can live healthier and longer lives.

There is a growing volume of information generated by the health system, but how best to harness that information is an ongoing challenge. Opportunities exist to improve the management and dissemination this information, with the support of technical advancements, ensuring it is accessible, timely, relevant, accurate and actionable to:

- more accurately predict disease
- monitor the uptake and impact of effective treatments
- enable evidence-based decisions to be made (see the section later in this article headed 'Story from the data – Understanding type 2 diabetes in Australia').

It is vital that we continue to monitor chronic conditions across the disease spectrum, including health determinants and prevention, disease prevalence and multimorbidity, health service use and outcomes. The AIHW's Australian Centre for Monitoring Population Health is one such vehicle for monitoring, which brings together the latest data and information on the health of Australians. We need to continue to do this across all priority population groups and in a way that will identify emerging threats, issues and success stories so that Australia's health system can be flexible and adapt to whatever the future may hold.

Box CC.4: Stories from the data

Monitoring of chronic conditions as a whole is integral to understanding the health of Australians at a broad level. However, as is seen in mortality trends across the 20th and 21st centuries (Figure CC.1), marked differences exist in trends for individual conditions. These are underpinned by etiological differences, and result in wide variation in the population groups affected, the type and level of care needed, and the opportunities for public health intervention.

This article includes 2 examples which show how the targeted collection and analysis of robust data can reveal the story of chronic conditions, and provide a compass to guide future health policy and care:

Story from the data – Cervical cancer: prevention, screening, and the path to elimination
Story from the data – Understanding type 2 diabetes in Australia

Story from the data - Cervical cancer prevention, screening, and the path to elimination

While communicable disease and chronic disease are often considered separately, they are linked through the nature of disease. People with chronic conditions are often at higher risk of communicable diseases. Conversely, some communicable diseases can lead to chronic conditions, leaving individuals with life-long conditions long after the acute stage of the illness has passed.

This nexus presents an opportunity: a better understanding of communicable disease can improve the understanding, detection and even prevention of chronic conditions. One such example is the connection between human papillomavirus (HPV) and cervical cancer.

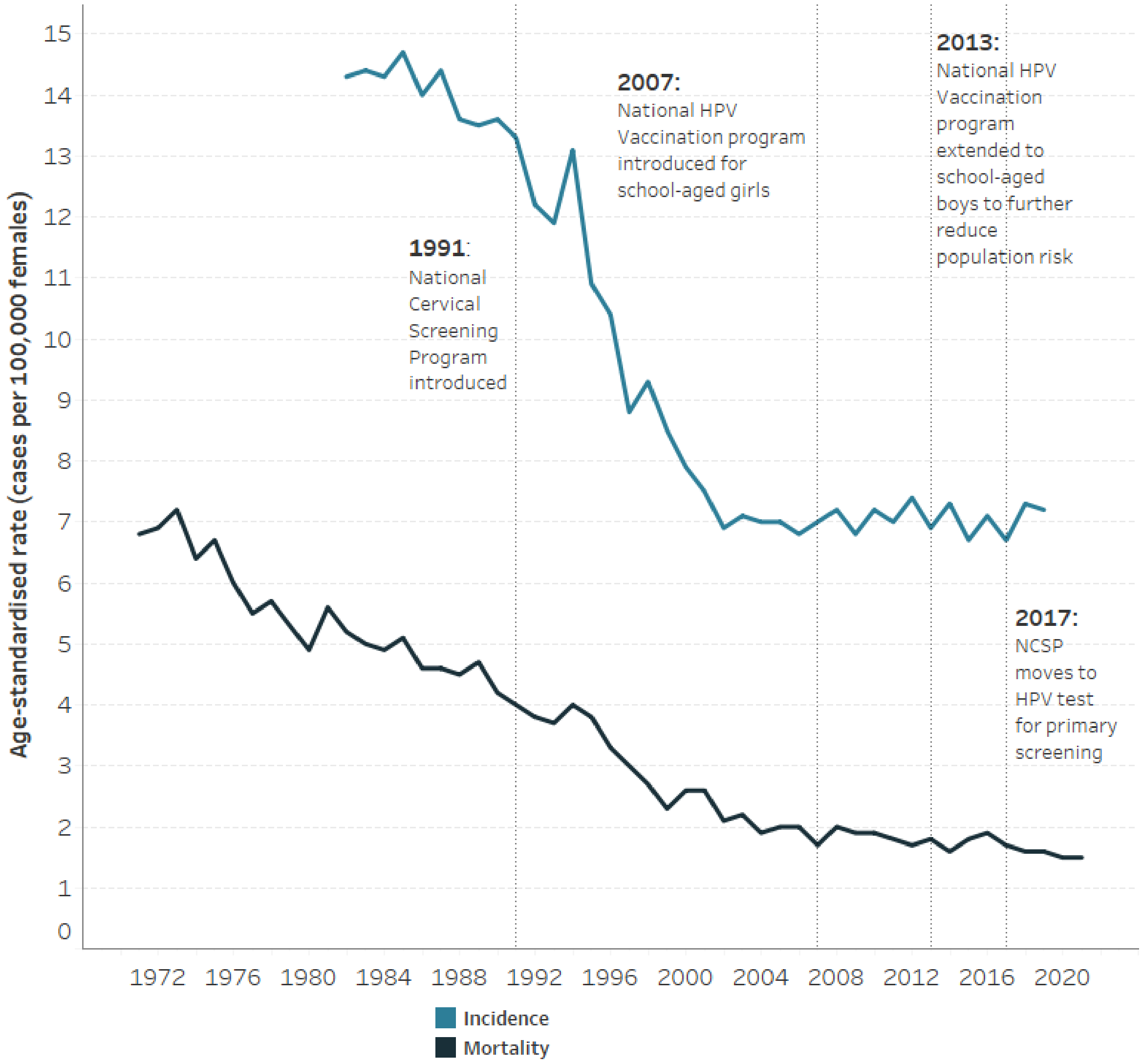
Incidence of cervical cancer trending downwards

In 2019, 945 new cases of cervical cancer were diagnosed in women of all ages in Australia – an incidence rate of 7.2 new cases per 100,000 women in the population (AIHW 2023b). This rate has been trending down in recent decades, due in large part to the role of screening and prevention (Figure CC.8). Since 1991, the NCSP has operated to reduce cervical cancer cases, illness and deaths by detecting precancerous cervical abnormalities before any potential progression to cervical cancer.

Opportunistic cervical screening has been conducted in Australia since 1960 – and falls in incidence and mortality rates for cervical cancer were evident before the NCSP was introduced (AIHW 2023i). But the NCSP has proved to be a highly successful public health initiative, having halved cervical cancer incidence and mortality in Australia since it was introduced in 1991.

Figure CC.8: Cervical screening halved cervical cancer incidence and mortality

Age-standardised cervical cancer incidence and mortality rates with milestones for key prevention initiatives, 1971–2021



Source: AIHW 2023b
https://www.aihw.gov.au

Human papillomavirus is a highly contagious virus. Some types of HPV are oncogenic (cancer-causing). Infection with an oncogenic HPV type can potentially lead to several types of cancer, including cervical cancer.

Successful prevention and screening initiatives

Understanding the role of HPV in cervical cancer subsequently led to 2 major public health developments in Australia:

- the introduction of a national HPV vaccination program in April 2007. Vaccination against HPV is Australia's primary prevention strategy against cervical cancer. In 2020, 80.5% of females and 77.6% of males aged 15 were fully immunised against HPV (NHMRC Centre of Research Excellence in Cervical Cancer Control 2022)
- a change in the screening test for the NCSP. Previously, the NCSP involved 2-yearly Pap tests to detect precancerous changes to cervical cells. From December 2017, Australia shifted to using a Cervical Screening Test, which tests for the presence of oncogenic HPV. Screening for HPV in the first instance can identify those who may be at risk of cervical cancer earlier than Pap tests, and is required only every 5 years.

Cervical screening remains a vital secondary prevention strategy against cervical cancer for both HPV-vaccinated and unvaccinated individuals. In 2018–2022, 77% of the eligible population of females aged 25–74 participated in the NCSP (AIHW 2023i).

On track for elimination, but challenges remain

As a result of screening and vaccination efforts, Australia has the potential to become the first country in the world to eliminate cervical cancer (Department of Health and Aged Care 2023c). Modelling predicts that the incidence of cervical cancer in Australia will drop to fewer than 4 new cases per 100,000 women by 2035 (the World Health Organization's elimination threshold) (Hall et al. 2019).

Challenges remain, however, with cervical cancer incidence higher among First Nations women, women living in *Very remote* areas and women living in lower socioeconomic areas (AIHW 2023i). This situation mirrors lower levels of HPV vaccination and screening participation in these populations. Self-collection of a screening sample, as opposed to practitioner-collection, is one initiative used to encourage screening participation in the under-screened population. Self-collection became available to all participants in cervical screening from July 2022.

Nevertheless, the success story of HPV and cervical cancer demonstrates the power of medical research, vaccination and screening, and is a promising example for the future of chronic conditions in Australia.

Story from the data – Understanding type 2 diabetes in Australia

Type 2 diabetes is often referred to as a global epidemic (Zimmet 2017) and is a leading cause of morbidity and mortality worldwide. It is the most common form of diabetes, generally occurring in adulthood. In some cases, it can be prevented or delayed. It is often associated with risk factors such as physical inactivity, poor diet, obesity, and tobacco smoking. Genetic and family-related factors also pose a risk.

Type 2 diabetes was the 11th highest cause of disease burden in Australia in 2023, and the fifth leading cause among men aged 65–84. It was associated with 9.3% of all hospitalisations in 2020–21 (1.1 million hospitalisations) and contributed to just over 6.5% of all deaths in 2021 (11,200 deaths) (AIHW 2023f).

Prevalence of diagnosed type 2 diabetes more than doubled between 2000 and 2021

According to National Diabetes Services Scheme data, the proportion of people in Australia living with diagnosed type 2 diabetes (known as ‘prevalence’; see Glossary) was 4.6% in 2021. This proportion has more than doubled from 2.1% in 2000; however, there has been a disproportionate increase in prevalence among older age groups (Figure CC.9a). The greatest increases are seen in the older age groups, with a 4-fold increase among people aged 85 and older, from 4.3% in 2000 to 18% in 2021.

Incidence of diagnosed type 2 diabetes declined between 2000 and 2021

Between 2000 and 2021, the rate of new type 2 diabetes diagnoses (known as ‘incidence’; see Glossary) declined overall in Australia. The greatest changes were seen among those aged 55–69 and 70–84, with incidence halving – from 871 and 776 cases per 100,000 population in 2000, to 425 and 352 cases per 100,000, respectively (Figure CC.9b).

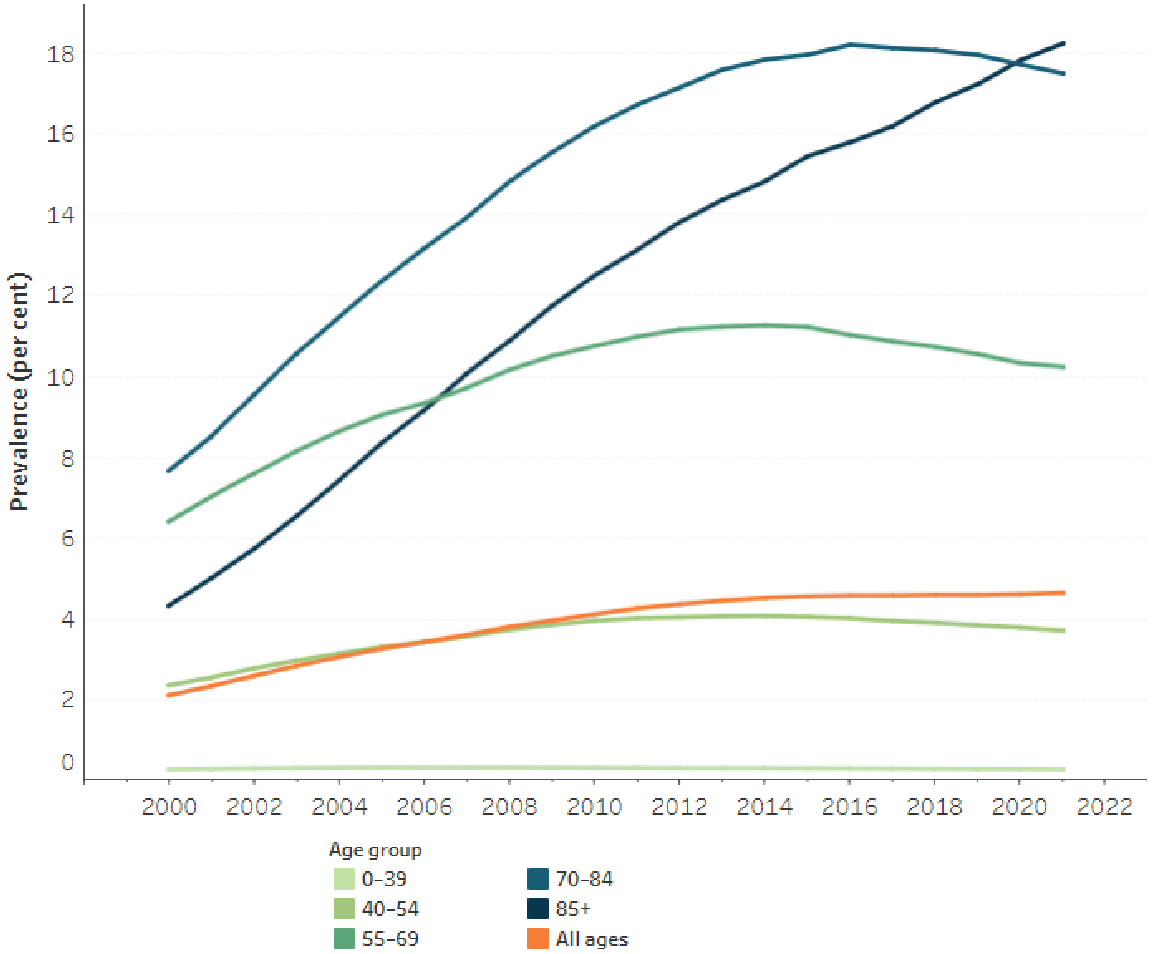
Global trends

Although the incidence of type 2 diabetes continues to increase globally (Khan et al. 2020), a number of other high-income countries have also reported a declining trend, (Magliano et al. 2021). The exact cause of this downwards trend is unknown. Some contributing factors may be improved preventive measures such as screening, increased awareness and educational programs leading to behavioural changes and/or risk factor modification (Magliano et al. 2019).

It will be important to continue to monitor the incidence of type 2 diabetes going forward and to ensure that this downwards trend is experienced across all population groups and small geographic areas of Australia.

Figure CC.9a: Type 2 diabetes prevalence continues to grow among older Australians

Crude prevalence rates for type 2 diabetes, by age group, 2000–2021



Notes:

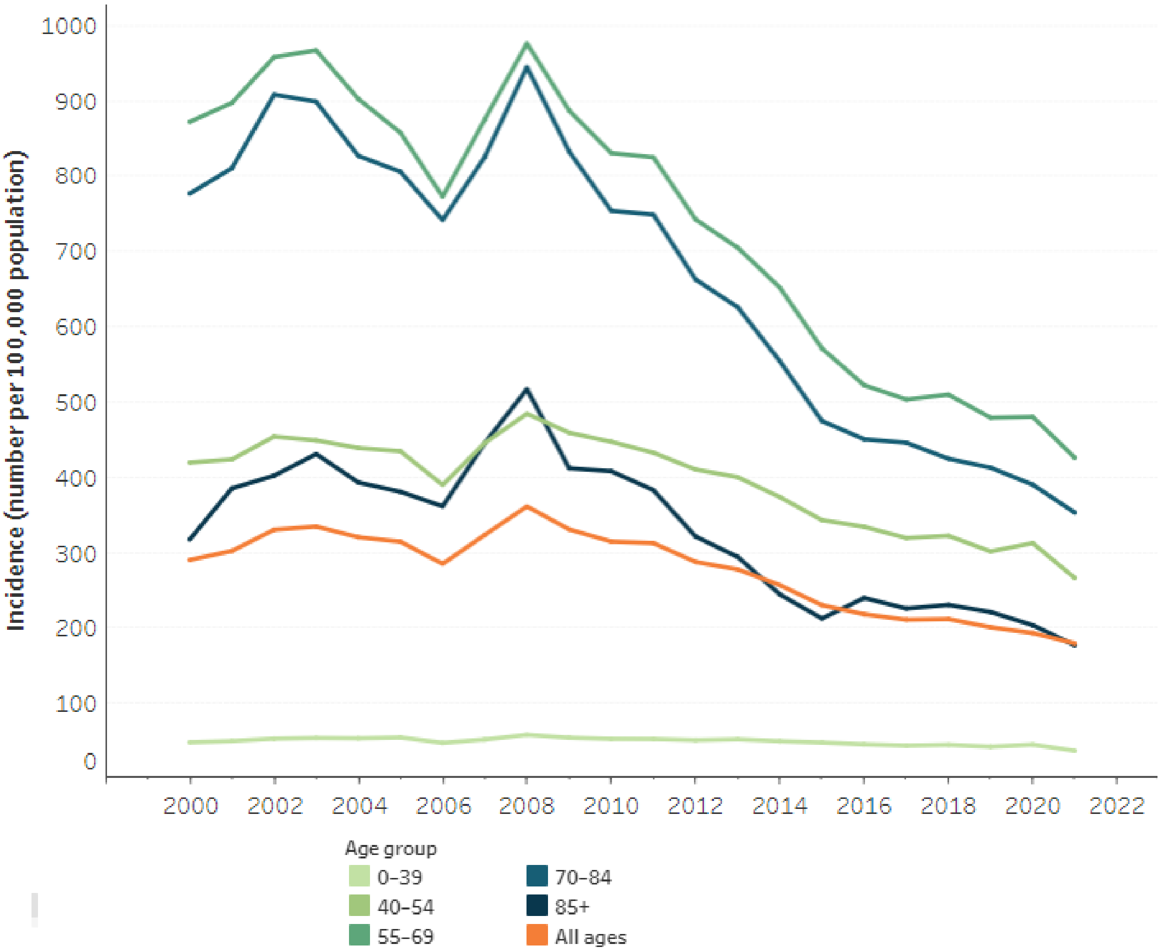
1. Age standardised to the 2001 Australian Standard Population.
2. Includes persons with missing or unassigned information on age and/or sex.

Source: AIHW analysis of linked National Diabetes Services Scheme and Australasian Paediatric Endocrine Group state based registers.

https://www.aihw.gov.au

Figure CC.9b: Fewer new cases of type 2 diabetes each year since 2008

Crude incidence rates for type 2 diabetes, by age group, 2000–2021



Notes:

1. Age standardised to the 2001 Australian Standard Population.

2. Includes persons with missing or unassigned information on age and/or sex.

Source: AIHW analysis of linked National Diabetes Services Scheme and Australasian Paediatric Endocrine Group state based registers.

https://www.aihw.gov.au

Differences exist across Australia

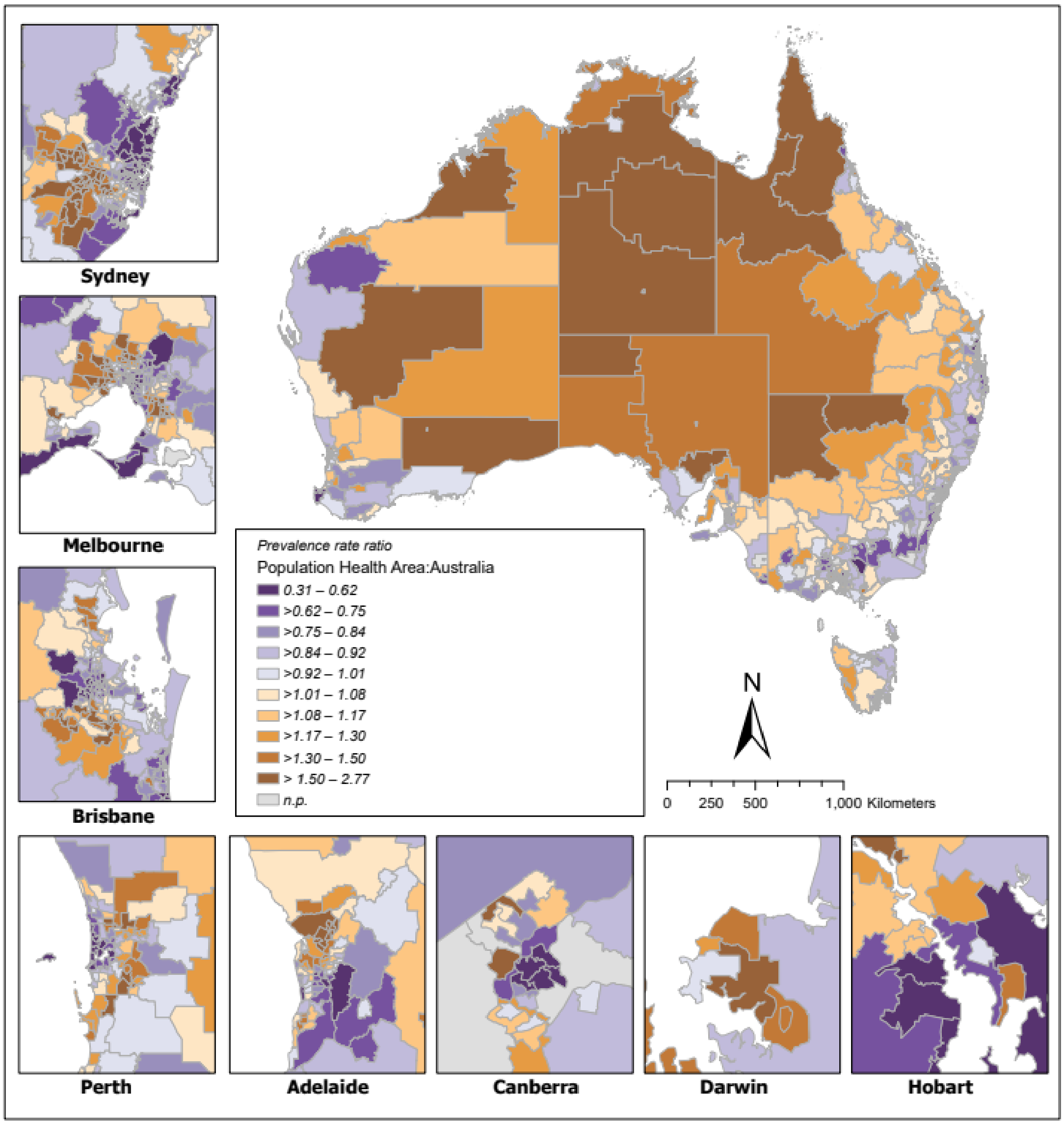
While national trends provide a broad picture, the story is not the same for all Australians. In 2021, the AIHW combined online geospatial interactive mapping technology with national health data on chronic conditions, including type 2 diabetes (AIHW 2021b). The geospatial dashboards present disease prevalence, hospitalisation and death rates alongside profiles of health and selected population characteristics by geography.

While the analysis found that 5.9% of Australian adults were living with diagnosed type 2 diabetes, this prevalence varied between 0.7% and 14.2% when split by Population Health Area (see Glossary) (Figure CC.10). Compared with their respective state/territory average, the areas with the highest age-adjusted rates generally displayed less favourable health risk profiles and had higher proportions of the population living in socioeconomically disadvantaged areas.

Similar results were found for hospitalisations and mortality, where the areas recording the highest age-adjusted rates were mostly located in regional or remote areas. These areas had higher proportions of First Nations people and people living in socioeconomically disadvantaged areas than other parts of their state/territory.

Figure CC.10: Prevalence of type 2 diabetes varies considerably by location

Age-standardised rate ratios for type 2 diabetes prevalence, by Population Health Area, people aged 18 and over, 2018



PHA = Population Health Area.

Note: The age standardised prevalence rate ratios compare the type 2 diabetes prevalence rate in an area with the national average, adjusted for differences in age structure.

Source: AIHW 2021b.

Geospatial analysis enhances understanding

Interactive mapping identifying which chronic conditions and their risk factors are most common in a local region can help health professionals to sharpen their focus on preventing or managing them earlier. Combining this with service use data and various time intervals creates even greater opportunities. For example, the AIHW's recent release of weekly health service use data by geographic area enables research on the impact of environmental events (in particular, bushfire) that are highly localised and time specific (AIHW 2024c).

Innovative analysis and reporting of data will be a key tool in continuing to monitor chronic conditions in Australia, and to equip health professionals, policy advisors, researchers and support services with customised insights to inform and develop timely, evidence-based prevention strategies and support services for those living with chronic conditions.

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Size and sources of the health gap for Australia’s First Nations people 2017–2019

Key messages

- A large part of the ‘health gap’ – disparities in many health outcomes seen between Aboriginal and Torres Strait Islander (First Nations) people and non-Indigenous Australians – can be attributed to differences in the social determinants and health risk factors between First Nations people and non-Indigenous Australians: to close this gap, these differences need to be resolved.
- Analyses of survey data from 2017 to 2019 for adults aged 18-64 show that almost two-thirds (65%) of the observed gap on a composite health measure is explained by a set of 11 selected factors, broadly classified into 2 groups: social determinants of health (5 factors) and health risk factors (6). (One-third of the gap still remains unexplained, though, beyond the contributions of all factors considered in the modelling.)
- The differences between First Nations and non-Indigenous people on the combined set of 5 social determinants explain around 35% of the health gap. Among these, the largest effects are due to differences in employment status and hours worked (contributing to 14% of the health gap), equivalised household income (13%) and highest level of school attainment (8.9%).
- The differences on the combined set of 6 health risk factors explain around another 30% of the health gap. Among these, the largest effects are due to differences in current smoking status (contributing to 13% of the health gap) and overweight and obesity status (11%).
- If First Nations adults were to have the same average levels as non-Indigenous adults on just 3 of these critical factors (that is, the same average equivalised household income, same average employment rate and hours worked, and same average smoking rate), the health gap would be reduced by more than one-third from what is seen in the data – from a 24 to around a 14 percentage point gap.
- The health gap seen in the 2017–19 surveys has fallen slightly (by 2.9 percentage points) from that observed in a similar earlier AIHW study (which used the same methodology to analyse data from 2011–13 surveys) – from an adjusted health gap of 26.9 percentage points in 2011–13 to 24.0 percentage points in 2017–19.

Note: The analyses used in this report are updates of previous work by the AIHW on sources of the health gap report, using the 2012–2013 Aboriginal and Torres Strait Islander Health Survey. Like for the previous analyses, we are not able to estimate the potential role of other factors contributing to the gap, such as differences in access to health services, and discrimination, for which data were not available in the surveys used. The effects of these other factors are part of the 35% of the overall health gap that remains unexplained after accounting for the role of the factors used in this analysis.

Introduction

Health at the individual level is influenced by a range of interconnected social, economic, and environmental factors. These include:

- home, school, workplace and community environments
- experiences of social institutions and systems
- education
- economic stability
- access to health care (Braveman and Gottlieb 2014; CSDH 2008; Taylor et al. 2016).

Certain improvements made but the ‘health gap’ remains

Over the past 2 decades, some health and social indicators – such as smoking prevalence and year 12 attainment – have improved (AIHW 2023b; Productivity Commission 2023a, 2023b); however, substantial disparities remain in many health outcomes between First Nations and non-Indigenous Australians (AIHW 2023a; PM&C 2020). This is referred to as the ‘health gap’.

Much of the understanding of the health gap is based on observed differences between First Nations people and non-Indigenous Australians in factors widely recognised as key determinants of health (Biddle 2012; Mackenbach 2015; Marmot 2011; Shepherd et al. 2012). These include differences in:

- the social determinants of health – on average, levels of education, employment, income and housing quality are lower among First Nations people than among non-Indigenous Australians (AHMAC 2017; AIHW 2023a)
- health risk factors – on average, rates of smoking are higher, levels of physical activity are lower, and the risk of high blood pressure is greater among First Nations people than among non-Indigenous Australians (AHMAC 2017; AIHW 2023a)
- access to appropriate health services – First Nations people are more likely than non-Indigenous Australians to report difficulty in accessing affordable health services that are close by (AIHW 2015). First Nations people also face additional barriers to accessing health services due to cultural reasons, such as language problems, discrimination and cultural appropriateness (AIHW 2023a).

This article estimates the contributions made to the health gap between First Nations people and non-Indigenous Australians by exploring differences in 2 groups of health determinants: socioeconomic factors (such as education and household income) and health risk factors (such as smoking status and body mass index, or BMI). It updates a previous analysis done using 2011–13 data – reported in Chapter 6.7 in *Australia’s health 2018* (AIHW 2018) – and attempts to answer 2 main questions:

- If we adjust for demographic and geographic differences between First Nations people and non-Indigenous Australians, how large is the health gap, and how much of it can be explained by differences in social determinants and health risk factors?
- If First Nations people and non-Indigenous Australians had similar demographic, geographic, socioeconomic and health risk factor profiles, how much of the health gap would remain?

Measuring and analysing the health gap

To measure the health gap, we construct a composite good health score using 3 components:

- self-assessed health rating
- number of long-term health conditions
- a measure of emotional well-being based on the Kessler Psychological Distress scale (see Box FN.1).

Based on this score, people in each survey were categorised as being either in good health or not, based on a cut-off value. The health gap was then defined as the difference in the proportion of First Nations people and non-Indigenous Australians considered to be in good health.

This health gap was then analysed in 2 stages:

- First, a logistic regression model was used to estimate the association between good health and selected demographic, geographic, socioeconomic and health risk factors for each population group.
- Second, a decomposition method related to average differences across 2 subgroups was applied to the regression model results to estimate:
  - the size of the health gap
  - how much of it could be explained by differences in individual social determinants and health risk factors between First Nations and non-Indigenous people
  - how much of the gap remained unexplained.

The analysis used data on people aged 18–64 from 2 large nationally representative sample surveys conducted by the Australian Bureau of Statistics (ABS):

- the 2018–19 National Aboriginal and Torres Strait Islander Health Survey (NATSIHS) (ABS 2019)
- the 2017–18 National Health Survey (NHS) (ABS 2018).

While more recent NHS data are now available, the next round of the NATSIHS is still in progress.

The final sample of individuals for these analyses consisted of around 4,230 First Nations and 9,430 non-Indigenous working-age adults (aged 18–64). This age group was chosen for 2 reasons:

- Firstly, certain explanatory variables of interest in these surveys, such as blood pressure status and exercise participation, were available only for people aged 18 and over.
- Secondly, people aged 65 and over were excluded because employment status is best defined for people younger than the typical retirement age.

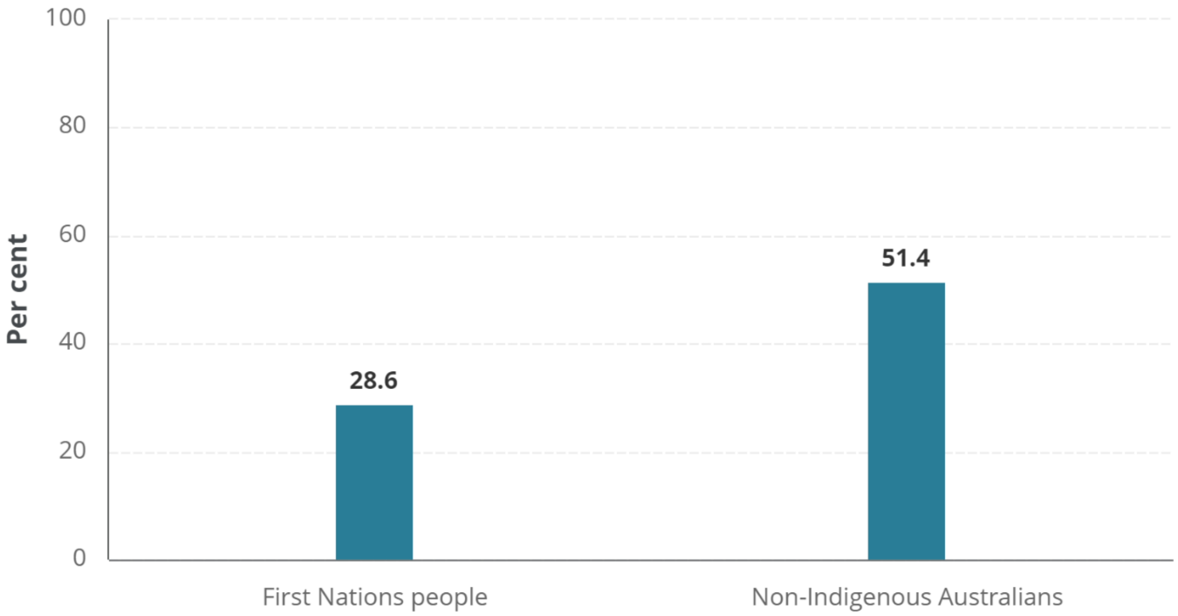
Note that the health gap defined and analysed in this article (see Box FN.1) differs from the gaps in life expectancy and underlying mortality between non-indigenous and First Nations people that feature in formal reporting in the National Agreement on Closing the Gap – July 2020 and other AIHW reports (AIHW 2022a, 2022b).

Size of the health gap

In 2017–2019, just under 3 in 10 (29%) First Nations people aged 18–64 were considered to be in good health compared with more than 5 in 10 (51%) non-Indigenous Australians in this age group (Figure FN.1). This implies an overall 'health gap' of 22.8 percentage points (pp) between the proportion of First Nations and non-Indigenous adults assessed to be in 'good health', using the composite good health score (Box FN.1).

Figure FN.1: The ‘health gap’ between First Nations and non-Indigenous Australians is 23 percentage points

Proportion of people aged 18–64 considered to be in good health, by Indigenous status, 2017–19



The good health measure used for this report is described in the next section.

Source: AIHW analysis of ABS NATSIHS 2018–19 and ABS NHS 2017–18.

After accounting for differences in average age, sex, marital status, remoteness and state/territory of residence between First Nations and non-Indigenous survey respondents, adjusted health gap was slightly higher at 24.0 pp. This gap has fallen slightly, by 2.9 pp, from 26.9 pp, which was the adjusted health gap previously reported using the same composite good health score for 2011–13 data (AIHW 2018).

How is ‘good health’ measured?

The ‘good health’ indicator used in this analysis was based on a good health score with 3 components:

- self-assessed health score, ranging from 1 (poor) to 5 (excellent), where a higher score indicates better health
- emotional distress score, based on responses to the Kessler–5 psychological distress scale, ranging from 0 to 20, where a lower score indicates better health
- morbidity score, based on the number of self-reported selected long-term health conditions, ranging from 0 to 21, where a lower score indicates better health.

Box FN.1 describes how the composite good health score was derived from these measures. This method is consistent with that used in previous AIHW analyses of the health gap, using data from 2004–08 (AIHW 2014b) and 2011–13 (AIHW 2018). For further information about the good health score, see Technical notes.

Box FN.1: Calculating the composite good health score

$$good\ health\ score = self\ assessed\ health - morbidity\ score - \left(\frac{emotional\ distress\ score - 2}{2}\right)$$

$$good\ health\ indicator = Yes, if\ good\ health\ score\ is\ 3\ or\ higher$$
$$No, otherwise$$

For consistency and comparability, both the measurement of the composite good health score and the cut-off value of 3.0 for the good health indicator are adopted from the previous AIHW analysis of the health gap which used the 2011–13 data (AIHW 2018).

Examples

Person A has ‘very good’ self-assessed health, hypertension and an emotional distress score of 1. Their good health score is:

$$good\ health = 4 - 1\ - \left(\frac{1-2}{2}\right) = 3.5$$

Because the score is greater than 3, Person A meets the definition of good health.

Person B has ‘good’ self-assessed health, osteoporosis, diabetes and an emotional distress score of 4. Their good health score is:

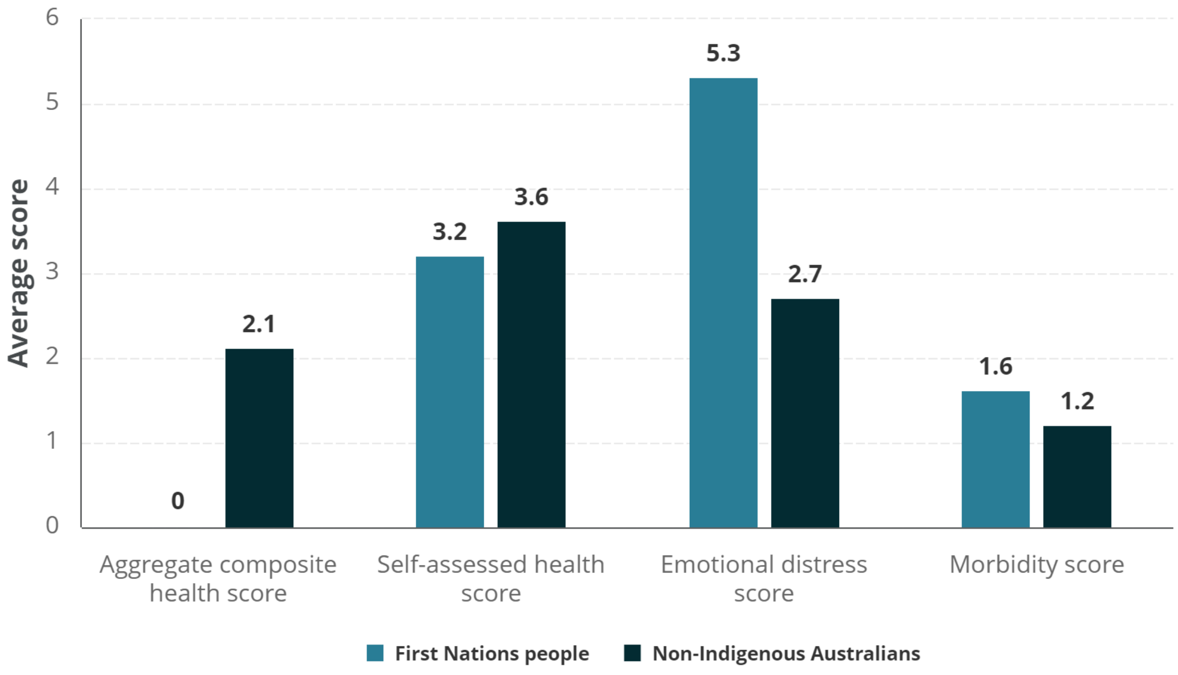
$$good\ health = 3 - 2\ - \left(\frac{4-2}{2}\right) = 0$$

Because the score is less than 3, Person B is not in good health.

Note: the good health score computed as above can be a negative number.

Figure FN.2: First Nations people score lower on the aggregate composite good health and the self-assessed health component, and higher on the emotional distress and morbidity components

Average score for aggregate composite good health and its sub-components by Indigenous status, persons aged 18–64, 2017–19



Survey respondents for whom any of the regression variables are missing were excluded from the estimation sample. These average scores are based on the actual sample of individuals used in regression models estimated so may not be representative of the overall population of persons aged 18–64 in these 2 surveys, given the large number of variables used in the models.

Source: AIHW analysis of ABS NATSIHS 2018–19 and ABS NHS 2017–18.

What were the findings?

The average of each of the sub-component scores for First Nations and non-Indigenous Australians is shown in Figure FN.2.

Consistent with the previous analysis of data from 2011–13 (AIHW 2018), First Nations people were found to have:

- lower average values for both composite good health and self-assessed health scores
- higher average values for the emotional distress and morbidity scores.

The largest difference in the average sub-component scores was for the emotional distress score, where the average score for First Nations people (5.3) was almost twice that for non-Indigenous Australians (2.7). The average value for the composite good health score was 0.0 for First Nations people and 2.1 for non-Indigenous Australians in 2017–19.

Sources of the health gap

The Oaxaca-Blinder decomposition technique (Blinder 1973; Oaxaca 1973) – as extended for non-linear models (Yun 2004; Powers et. al 2011) – was used to estimate how much of the health gap could be explained by differences in social determinants and health risk factors discussed below. (For further details on this decomposition methodology, see Technical notes.) Some other studies applying this method to analyse health gaps or health inequalities for other countries are Allen et al. (2022) and Lhila and Long (2012).

The aggregate decomposition results are presented in Figure FN.3. The percentage values reported in this figure for the explained component of the health gap are in reference to the adjusted health gap of 24.0 pp in 2017–19 (as reported in the previous section of this article). This adjustment already accounts for the differences between the First Nations and non-Indigenous populations on several demographic and geographic factors.

Hence, the contributions of other factors reported in this section can be treated as additional effects net of the small adjustment to the heath gap due to demographic and geographic factors alone.

Almost two-thirds of the health gap is explained by 11 factors

The results show that almost two-thirds (65%) of the health gap is explained by 11 selected factors (Figure FN.3), broadly classified into 2 groups: social determinants (5 factors) and health risk factors (6) (see Figure FN.4 for a list of the 11 factors).

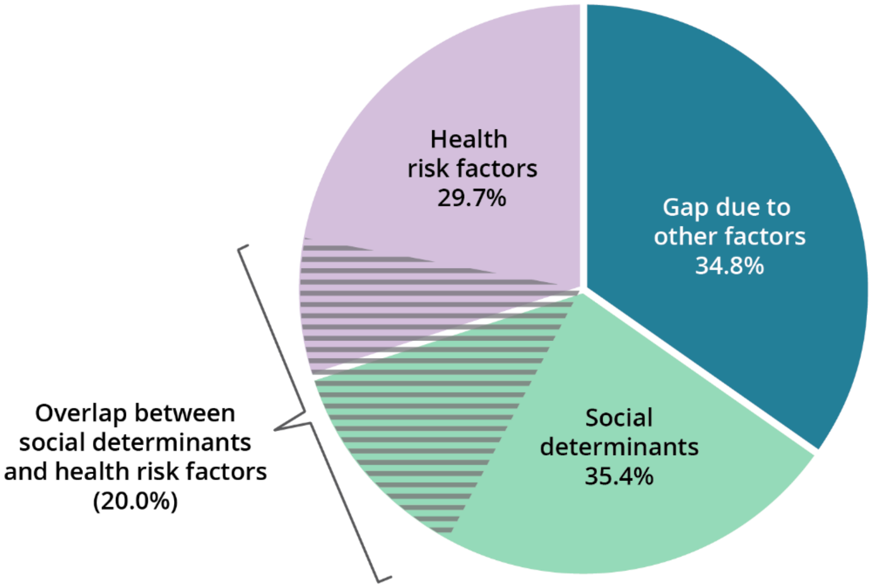
Combined, social determinants explain slightly more than one-third (35%) of the health gap, and the selected health risk factors account for another 30%. An estimated 20% of the total health gap can be attributed to the overlap, or interactions, between the social determinants and health risk factors. This is because the 2 sets of factors influence each other. The overlap between these 2 sets of factors is indicated by the fact that the combined total contribution of both set of factors to the health gap in the full model results presented in Figure FN.4 is less than the sum of the contributions of the social determinants only (in a model that includes only the social determinant factors) and the contributions of the health risk factors (in a model that includes only the risk factor variables).

One example of how an important social determinant of health varies between First Nations and non-Indigenous people is year 12 attainment, which is more than 2 times higher among non-Indigenous people aged 18-64 (65%) than among First Nations people of the same age (30%). This difference is a part of the overall 35% of the health gap explained in total by the 5 social determinant variables included in the regression model.

Among the health risk factors, there is also a large difference in the proportion of First Nations people aged 18–64 who are current smokers (50%) compared with non-Indigenous persons (18%); this difference is a part of the overall 30% contribution in total of the 6 health risk factors included in the model.

Figure FN.3: Over 35% of the health gap could be explained by differences in social determinants and about 30% by differences in health risk factors between the First Nations and non-Indigenous people

Proportion of the adjusted health gap explained by differences in social determinants and health risk factors between First Nations people and non-Indigenous Australians aged 18–64, 2017–19



Note: Gap due to other factors refers to the component of the gap unexplained by differences in the factors included in this study. This reflects the fact that the available data do not provide a complete picture of the differences between the First Nations and non-Indigenous populations.

Source: AIHW analysis of ABS NATSIHS 2018–19 and ABS NHS 2017–18.

Removing the differences in selected factors could reduce the gap

Our analysis indicates that the adjusted health gap would be reduced from 24.0 pp to 8.3 pp if First Nations working-age adults had the same average values for the 11 selected factors as non-Indigenous working-age adults. Most of the 15.6 pp reduction would come from social determinants (8.5 pp), and a 7.1 pp reduction from health risk factors.

In other words, 45% of First Nations working-age adults would have been assessed as being in good health if they had had the same average values as non-Indigenous adults for the 11 selected factors (in addition to demographic and geographic factors). This figure is well above the 29% of First Nations adults in good health from the current survey results (Figure FN.1).

More than one-third of the gap remains unexplained

While differences between First Nations and non-Indigenous Australians across the 11 selected factors explain 65% of the health gap, around 35% is left unexplained by this analysis. This unexplained component reflects the fact that the available data sources provide an incomplete picture of the differences between the 2 populations. Moreover, this ‘picture’ may possibly include the effects of factors that contribute to good health that are not available in the survey data analysed. Factors contributing to this unexplained component of the health gap may include:

- access to culturally appropriate and high-quality health-care services relative to need, which is of crucial importance for First Nations health outcomes (AHMAC 2017; AIHW 2014a, 2015)
- connection to Country and language (Mitrou et al. 2014)
- effects of structural disadvantage and of racism and discrimination that First Nations people face in Australian society (Durey et al. 2023; Marmot 2011).

These factors were not sufficiently captured by the available survey data used in this analysis.

Furthermore, the analysis we present can account for relationships between health status and the social and health risk factors only at one point in time (2017–19). The unexplained component may also therefore include:

- the cumulative effects of early life events on current health
- the effects of different social determinants and risk factors that applied at other points in time
- the effects of other factors that are intrinsically difficult to measure in a survey that records information at one point in time.

The potential important role of cumulative effects on current health status should be further investigated with panel data or survey data linked to a time series of administrative data in order to better understand which aspects of unfavourable early life events broadly persist over the life cycle, and which have a better chance of being remedied over time.

Social determinants have the greatest effect on the health gap

Among factors considered in this study, differences in employment and hours worked contributed most to the overall health gap (14%), followed by differences in equivalised household income (13%) and highest level of school education (8.9%) (Figure FN.4).

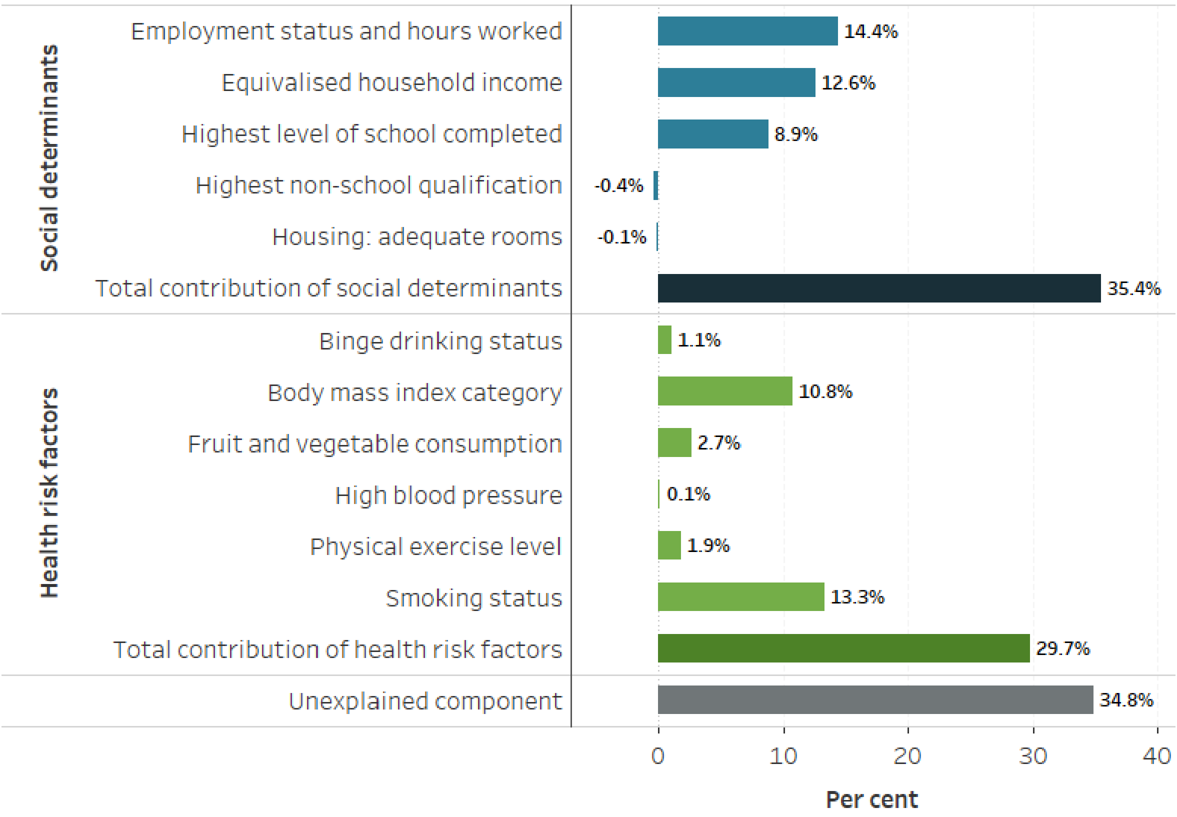
Among the health risk factors, differences in smoking status made the greatest contribution to the health gap, at 13%, followed by overweight and obesity status (11%).

Together, employment/hours worked, household income, and smoking status account for 40% of the total health gap, which represents 62% of the total contribution made by the 11 selected factors.

If First Nations adults were to have the same average levels as non-Indigenous adults of just these 3 factors (that is, same average equivalised household income, same average employment rate and hours worked, and same average smoking rate), the health gap would be reduced by more than a third – from 24 pp to around 14 pp.

Figure FN.4: Employment and hours worked, equivalised household income, smoking status and BMI category are among the individual factors that contribute most to the health gap

Contribution of individual social determinants and health risk factors to the adjusted health gap (as a percentage of the total adjusted health gap) between First Nations people and non-Indigenous Australians aged 18–64, 2017–19



Note: The contribution of a variable to the gap can be either positive or negative. A positive contribution means that the predicted gap would be lower than the actual gap if the 2 subgroups had the same levels of that explanatory variable. A negative contribution means that the predicted gap would be higher than the actual gap if the 2 subgroups had the same levels of that explanatory variable. A negative contribution also helps to 'explain' the gap in the sense that, were it not for the differences observed on that variable, the actual health gap would have been higher. The 2 negative contributions shown in this graph, however, are small and not statistically significantly different from zero.

Source: AIHW analysis of ABS NATSIHS 2018–19 and ABS NHS 2017–18

https://www.aihw.gov.au

How do the key factors affect good health?

This section focuses on the 5 factors that contribute most to the explained health gap between First Nations and non-Indigenous adults in this analysis. Overall, the full set of the 11 socioeconomic and health risk factors explain around 65% of the gap (with 35% of the gap unexplained by the model estimated).

These following 5 factors alone account for 92% of that 65% explained gap:

1. employment status and hours worked
2. smoking status
3. household income level (equivalised)
4. overweight and obesity status
5. highest level of school completed.

The results are presented of logistic regression modelling a person's odds of being in good health, depending on the presence or absence of these 11 factors. The results obtained were the first steps from which the contributions to the gaps were estimated, with the analysis carried out separately for the sample of First Nations and non-Indigenous adults. This section also highlights differences in results between these 2 subpopulations.

This analysis estimated an odds ratio (OR) of a person's being in good health for each factor – that is, the odds that a person would be in good health if exposed to a specific factor (for example, if they were a current smoker) compared with the odds of being in good health if they were not exposed to that factor (not smoking).

How to interpret the value of the estimated odds ratio for each factor

An OR value of:

- **1 (or close to 1)** means the factor has little or no effect on the odds of a person's being in good health, compared with a person in the reference group
- **greater than 1** means the factor increases the odds of a person's being in good health, compared with a person in the reference group. This implies a positive association between that factor and the good health measure
- **less than 1** means the factor decreases the odds of a person's being in good health, compared with a person in the reference group (a negative association between the factor and the good health measure).

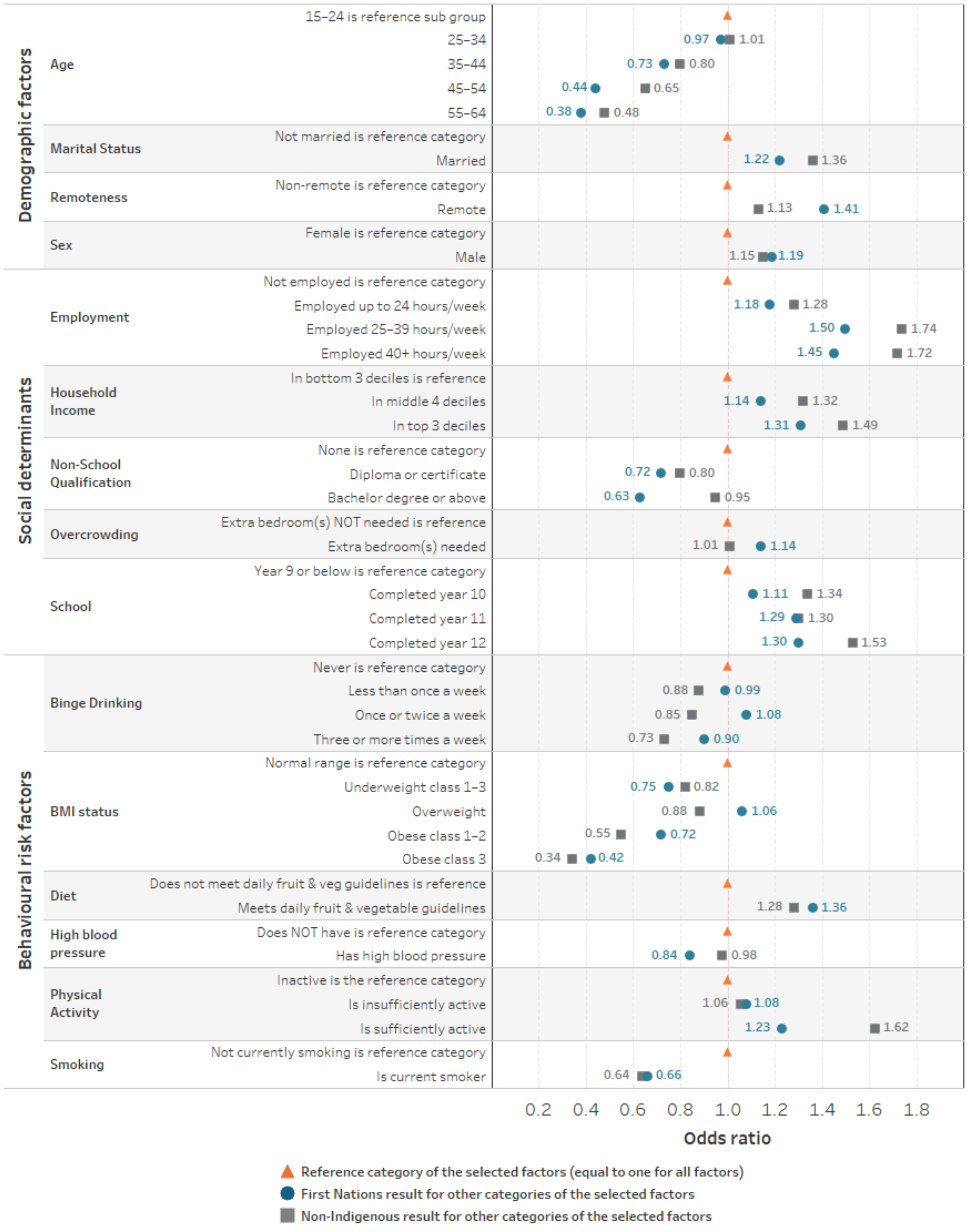
Note that the odds of being in good health is not the same as the probability of being in good health, although these concepts are related – a factor that leads to increased odds also increases the probability.

For some factors described in the sections that follow, the same factor statistically significantly increases the odds of being in good health for non-Indigenous adults, but not for First Nations adults. This may be an effect of the statistical model (considering the smaller sample size of First Nations adults, and there being inherently more non-Indigenous adults than First Nations adults in ‘good health’ in the reference categories used to calculate the ORs). However, some of these differences in the estimated results in the models by Indigenous status form part of the unexplained component of the health gap.

The results for the estimated ORs for the 5 factors mentioned earlier (that contribute most to the explained gap) are shown in Figure FN.5 and are summarised in the sections that follow.

Figure FN.5. The main factors that significantly affect the odds of being in good health for First Nations people are being a current smoker, and being obese (risk factors) and working for at least 25 hours per week (protective factor)

Estimated odds ratios and 95% confidence intervals for key factors related to good health, by Indigenous status, people aged 18–64, 2017–19



Notes:

1. The data visualisation in this chart includes the 95% confidence intervals (CI) for the odds ratio estimate reported for each variable/factor category, apart from the Reference category. The 95% CI are reported separately for the odds ratio by Indigenous status. The two values shown for the range of the 95% CI represent the lower and upper level of the odds ratio estimate for that factor. A larger CI range indicates a lower level of precision of the estimate, and a smaller CI range a higher precision. The 95% CI range is also used to determine statistical significance of the estimate: if it does not overlap 1, it can be inferred that the odds ratio estimate is statistically significantly different from one at the 5% significance level.
2. Odds ratio results reported in above figure are for selected variables/factors used in the regression model. Other variables in the model include State of residence (results not shown).

Source: AIHW analysis of ABS NATSIHS 2018–19 and ABS NHS 2017–18.
https://www.aihw.gov.au

Employment and household income

Being employed (for at least 25 hours per week) was statistically significantly and positively associated with good health.

- The odds of being in good health for people who were employed were 1.5 and 1.7 times as high as the odds for people not employed (for First Nations and non-Indigenous adults, respectively).
- Working fewer than 25 hours per week compared with not being employed was statistically significantly and positively associated with good health only among non-Indigenous adults.

Levels of equivalised household income were not statistically significantly associated with good health for First Nations adults; however, this could be partly due to the small survey sample size of First Nations adults in the top 3 equivalised household income deciles. Among non-Indigenous adults, being in the middle 4 and top 3 equivalised household income deciles was associated with 1.3 and 1.5 times the odds of being in good health, respectively, relative to the bottom 3 deciles.

Smoking status

Being a current smoker, compared with not being a smoker, statistically significantly reduced the odds of being in good health (0.6–0.7 times the odds) for both First Nations and non-Indigenous adults.

Highest level of school completed

Both First Nations and non-Indigenous adults who completed a higher level of secondary schooling had greater odds of being in good health.

- For First Nations adults, a higher level of schooling statistically significantly increased the odds of a person’s being in good health *only* if they completed year 12 (1.3 times the odds, compared with the reference category of having completed year 9 or below).
- Non-Indigenous adults had statistically significantly increased odds of being in good health if they completed any year of schooling above year 9 (1.3–1.5 times the odds).

Overweight and obesity status

Being obese (having a BMI greater than 30) statistically significantly reduced the odds of being in good health, compared with adults in the normal weight range (BMI 18.50–24.99), among both First Nations and non-Indigenous adults.

Being in the class III obese category (BMI >40.00), statistically significantly reduced the odds of being in good health (0.42 and 0.34 times the odds) for both First Nations and non-Indigenous adults, respectively, relative to people with normal range BMI.

Being in the overweight but not obese range (BMI 25.00–29.99) statistically significantly reduced the odds of being in good health only for non-Indigenous adults.

What has changed since 2011–13?

Compared with the previous analysis of data from 2011–13 (AIHW 2018):

- the overall size of the adjusted health gap has reduced by 2.9 pp, from 27 pp to 24 pp
- the unexplained component of the adjusted health gap has reduced, by 12 pp, from 47% to 35%, largely due to a substantial increase of 11 pp in the proportion of the health gap explained by health risk factors (which rose from 19% to 30%)
- the proportion explained by social determinants has increased, but only by 1 pp, from 34% to 35% (Table FN.1).

Among the health risk factors, BMI and smoking status had the largest change in contribution to explaining the health gap. The proportion of the health gap explained by:

- BMI has increased by 3.6 pp, from 7.2% to 10.8%
- smoking has increased by 3.3 pp, from 10.0% to 13.3% (Table FN.1).

The increased contributions of these 2 factors – BMI and smoking – in explaining the health gap is consistent with the increased difference in the smoking and obesity rates between First Nations and non-Indigenous adults between these 2 time periods:

- In 2011–13, 50.5% of First Nations adults aged 18-64 were current smokers compared with 21.8% of non-Indigenous adults (a difference or gap on smoking rates of 28.7 pp).
- This difference in smoking rates of 28.7 pp increased to 32.4 pp in 2017–19 (with about the same percentage – 50.4% – of First Nations adults being smokers, but a lower proportion (18%) of non-Indigenous adults being smokers, compared with 2011–13).
- There was a similar increase in the difference (or widening of the gap) in the obesity rate between First Nations and non-Indigenous adults between 2011–13 and 2017–19.

Table FN.1: Health gap analyses: summary comparison of changes between 2017–19 and 2011–13 analyses

	2017–19	2011–13
Health gap adjusted for demographic and geographic factors (percentage points)	24.0	26.9
Proportion of adjusted health gap explained by differences in social determinants (%)	35.4	34.4
Proportion of adjusted health gap explained by differences in health risk factors (%)	29.7	18.8
Proportion of adjusted health gap due to other factors (%)	34.8	46.8
Largest individual contributors to the adjusted health gap (proportion of adjusted gap explained) (%):		
Employment status	14.4	12.3
Equivalised household income	12.6	13.7
Smoking status	13.3	10.0
BMI category	10.8	7.2
Highest level of schooling completed	8.9	8.7

Note: Gap due to other factors refers to the component of the gap unexplained by differences in the factors included in this study. This reflects the fact that the available data do not provide a complete picture of the differences between the 2 populations.
Source: AIHW analysis of ABS NATSIHS 2018–19 and ABS NHS 2017–18; AIHW (2018).

What does this mean?

The results clearly show the need to examine the key factors behind the overall health gap. Our findings highlight the areas where there is substantial potential for current and emerging targeted policies to reduce health disparities between First Nations and non-Indigenous Australians.

The focus should be on the 5 key areas that contribute to the health gap by:

- boosting rates of year 12 completion
- increasing employment
- increasing weekly hours of work
- reducing smoking prevalence
- reducing obesity rates.

Furthermore, improving one factor, such as education, can indirectly improve other health outcomes through its effect on other factors such as employment and smoking status. It is also worth noting that adult (age 25–64) employment and year 12 attainment are both current Closing the Gap targets, and maternal smoking is a supporting indicator for the healthy birthweight target.

What is missing from the picture?

Access to affordable and culturally appropriate health services are likely to explain a considerable proportion of the health gap between First Nations and non-Indigenous Australians. Health service access was not included in this analysis, however, due to a lack of available data in the surveys used.

Although the analysis in this article uses data from well-designed health surveys conducted by the ABS, the variables used to create the 'good health' measure at the centre of this analysis are derived from self-assessed/self-reported data. There are some known limitations of self-reported data in providing an accurate picture of objective health, and analysis of self-reported measures alone is not sufficient to inform health policy. This analysis could be extended with additional measures that reflect objective health status if they are available in suitable future data collections or using linked data.

As well, the surveys used for this analysis are of a cross-sectional nature which capture only a snapshot of information at one particular time. They do not account for the cumulative effects on health that arise from early life events. Furthermore, this analysis looked only at the gap in health status of working age adults (aged 18–64); results may substantially differ for other age groups, particularly among children and people aged over 64.

Finally, this analysis did not consider any cultural determinants of health for First Nations Australians, or the effect on them of experiencing structural disadvantage, racism and discrimination. It is strongly recognised that cultural determinants are important for the health of First Nations people but these factors were not sufficiently captured by the available survey data to be used in this analysis.

Also, the Oaxaca-Blinder decomposition technique used in this article requires that the same set of factors or variables be modelled for both population subgroups; hence, the effects of factors unique to the health outcomes of First Nations peoples cannot be evaluated through this technique.

Further reading

More information on the previous analysis of the sources of the health gap (which used 2011–13 data) can be found in Chapter 6.7 in *Australia's health 2018* – Size and sources of the Indigenous health gap, accessed 4 March 2024.

An even earlier AIHW health gap analysis which used different methods to analyse 2004–08 data can be found in the Feature article in *Australia's health 2014* - The size and causes of the Indigenous health gap, accessed 4 March 2024.

More information on First Nations people's access to health services relative to need is available in the *Aboriginal and Torres Strait Islander Health Performance Framework report*, accessed March 4 2024.

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Technical notes: Size and sources of the health gap for Australia's First Nations people 2017-2019

Notes on the good health score sub-components

The level of self-assessed health status in both the 2018–19 National Aboriginal and Torres Strait Islander Health Survey and the 2017–18 National Health Survey is reported in 5 categories. For this analysis, these categories were assigned a score from 5 to 1, corresponding to 'excellent', 'very good', 'good', 'fair' and 'poor', respectively.

Morbidity score

The morbidity score is based on the widely used Charlson Index (Charlson et al. 1987). It sums the number of conditions reported by a respondent but ignores the weighting factor usually associated with the severity of the condition (which was not reported in these surveys). The long-term health conditions used to generate this morbidity score include cancer; and conditions of the circulatory, respiratory, nervous, endocrine, urinary and musculoskeletal systems. The morbidity score ranged from 0 to 21.

Emotional distress score

The emotional distress score was calculated as the sum of individual Kessler-5 scores, measuring how often respondents reported feeling nervous, without hope, restless or jumpy, 'everything was an effort', and 'so sad that nothing could cheer them up', in the 4 weeks before the survey. The score for each response was scaled from 0 (none of the time) to 4 (all the time) and summed over the 5 responses, resulting in emotional distress scores that ranged from 0 to 20.

Methodology for estimating the sources of the health gap

Overview

The decomposition methodology used in this analysis consisted of 2 steps:

1. modelling the factors that contribute to good health, separately for First Nations people and for non-Indigenous Australians, using logistic regression with the same set of explanatory or independent variables

2. applying the Oaxaca-Blinder decomposition technique, which uses the estimated model results from the first step above, to estimate how much of the average gap in good health between First Nations people and non-Indigenous Australians can be explained by differences in these explanatory variables between these 2 population subgroups.

A logistic regression model is estimated in the first step because the dependent variable of interest, good health, is a binary indicator variable with a value of 1 (good health) or 0 (not in good health). Although this variable is binary at the level of an individual survey respondent, when averaged over each population subgroup, it represents the average probability of being in good health among that subgroup.

The Oaxaca-Blinder decomposition is a technique originally developed to study labour market discrimination (Blinder 1973; Oaxaca 1973) based on a linear regression estimated in the first step. This method has been extended to include decomposition of non-linear model results, such as the logit regressions in this article (Jann 2008, Powers et. al 2011).

The extensions of the Oaxaca-Blinder decomposition have also been commonly used to investigate health inequalities (for example, Allen et al. 2022; Kalb et al. 2014; Rahimi and Nazari 2021; Sajadipour et al. 2022). This method was also used in the previous AIHW analysis of the health gap between First Nations people and non-Indigenous Australians using 2011–13 data (AIHW 2018).

The key analytical insight from the Oaxaca-Blinder technique is that it can break down, or decompose, the average difference in any outcome measured over 2 population subgroups (such as difference in the proportion of First Nations people and non-Indigenous Australians in good health) into 2 components (Jann 2008):

1. An explained component: the portion of the difference between the 2 population groups that can be attributed to observable differences in the explanatory variables used in the model of good health. An example of this would be the difference in smoking rates between First Nations people and non-Indigenous Australians, and this is expected to contribute to the health gap between them.
2. An unexplained component: the proportion of the difference which cannot be explained by observable differences in the explanatory variables used in the model. For example, the effect of living in a remote area on good health may be different for First Nations people and non-Indigenous Australians.

The ‘explained component’ of the average difference represents the estimate of how much the overall good health gap would be reduced if both population groups had the same average values for the explanatory variables. The ‘unexplained component’ represents the difference in good health between the 2 population groups that would remain even when they had the same average values for the explanatory variables used in the model for good health.

The overall average gap can therefore be expressed as:

Total average gap = Explained component + Unexplained component

However, there is not a unique way to represent the above breakdown. Alternative representations have been proposed (Jann 2008, Fortin et al. 2010), and some of these are described further in this appendix. In the analyses for this article, we chose an interpretation that evaluates the explained component using the regression estimates for the non-Indigenous sample. In this specific context, it is reasonable to treat the relationships between health and the explanatory variables estimated for the majority non-Indigenous population as the expected relationship in the whole population.

The Oaxaca-Blinder decomposition technique also allows for a detailed decomposition where the contribution of each single explanatory variable to the aggregate explained and unexplained effects can be computed. There are procedures to ensure that the contribution of each single variable in explaining the overall gap add up to the total explained component, even when the decompositions are based on a non-linear regression model, as is the case here with the use of logistic models (Powers et al. 2011).

For this analysis, the Oaxaca-Blinder decomposition method was carried out using the Stata 17 statistical software (StataCorp 2021) and the specific non-linear implementation of this method developed by Jann (2008). Further details of the Oaxaca-Blinder decomposition method – including the adjustments required when the underlying regression model estimated in the first step is non-linear – are given in the next section.

Decomposition methodology

In a linear regression framework, where an outcome of interest, Y_i measured for an individual *i* who can be in either of 2 subgroups, A or B, is modelled as having the same set of explanatory variables (*X*s) but with a different set of coefficients (β) that determine the effects of those explanatory variables, the underlying model can be represented as:

$Y_i = \boldsymbol{\beta}^A X_i + e_i^A$ if individual *i* belongs to Group A Eq. (1.1)

$Y_i = \boldsymbol{\beta}^B X_i + e_i^B$ if individual *i* belongs to Group B Eq. (1.2)

(where X represents the set of explanatory variables, $\boldsymbol{\beta}^A$ and $\boldsymbol{\beta}^B$ represent the set of estimated regression coefficients for the set of *X*s that apply respectively for individuals in Group A and B, and e_i^A and e_i^B are the individual error terms in the estimated regression model).

Then, making use of the property that the estimated regression line always goes through the point representing the average of the Y and X data values, the difference in the average value of *Y* between the 2 groups can be expressed in terms of the estimated coefficients (β) and the average values of the *X* variables.

That is:

$$Difference\ in\ mean\ value\ of\ Y = \overline{Y^A} - \overline{Y^B} = \boldsymbol{\beta^A}\overline{X^A} - \boldsymbol{\beta^B}\overline{X^B} \qquad Eq.(2)$$

(where $\overline{Y^A}$ and $\overline{X^A}$ represent the average values of *Y* and *X* within Group A, and similarly $\overline{Y^B}$ and $\overline{X^B}$ within Group B).

The relationship of Eq. 2 shows that the difference (or gap) in the average value of the outcome of interest between the 2 groups can be represented fully in a regression model context in terms of the estimated parameters, $\boldsymbol{\beta}^A$ and $\boldsymbol{\beta}^B$, and the average values of the data, $\overline{X^A}$ and $\overline{X^B}$, for the 2 groups. If $\boldsymbol{\beta}^A$ equals $\boldsymbol{\beta}^B$ and $\overline{X^A}$ equals $\overline{X^B}$ then the average gap, as an accounting relationship, must always be equal to zero.

This relationship in Eq. 2 provided the insight, proposed initially (and independently) in Oaxaca (1973) and Blinder (1973), that when the average gap is non-zero, that gap can be further broken down (decomposed) into 2 separate components:

(i) one representing the difference in the average values of the *X* variables between the 2 groups, and

(ii) the other representing the effects of differences in the estimated coefficients ($\boldsymbol{\beta}^A$ and $\boldsymbol{\beta}^B$).

Component (i) is interpreted as the 'explained' (E) part of the gap (or also as the 'Endowment' effect) because it relates to the effects due to the difference in the X values. Intuitively, if the 2 groups had the same average levels of the explanatory variables, or the same endowments, that part of the gap would not exist.

On the other hand, the second part of the gap that arises from differences in the estimated coefficients (β) does not usually have a logical explanation. It is not easy to explain why the regression coefficients on the same variable will differ between 2 subgroups. So, this component is conventionally labelled as the 'unexplained' (U) or 'coefficients' component of the overall gap.

There are alternative ways to carry out these further decompositions of the average gap into the explained (E) and unexplained (U) components. Two of the commonly used representations of the E and U components are as follows:

$$Gap = E_1 + U_1 = \left(\overline{X^A} - \overline{X^B}\right)\beta^A + \overline{X^B}(\beta^A - \beta^B) \qquad Eq.(3.1)$$

$$Gap = E_2 + U_2 = \left(\overline{X^A} - \overline{X^B}\right)\beta^B + \overline{X^A}(\beta^A - \beta^B) \qquad Eq.(3.2)$$

In Eq. 3.1, the explained component E_1 evaluates the difference in the *X* bars using the coefficients estimated for Group A. In Eq. 3.2, the explained component E_2 evaluates the difference in the *X* bars using the coefficients estimated for Group B.

This choice, however, is not always arbitrary. It can be based on the underlying context of the *Y* variable that is the outcome of interest. In a general framework that seeks to understand the differences between 2 groups on a specific variable of interest, it may be more reasonable to assign one of the 2 groups as the reference group whose coefficients should be interpreted as the 'norm' or the 'baseline' version of the relationships between the *X* variables and the *Y* outcome. If so, it is appropriate to then use that group's coefficients as the benchmark for evaluating how much of the overall gap in the *Y* outcome would be changed if the 2 groups had the same level of the *X* explanatory variables.

In the specific context of explaining the gap in health outcomes between First Nations and non-Indigenous Australians, it is more reasonable to take the relationship observed for this article are based on the decomposition represented by Eq. 3.1 where (if we assign Group A to represent non-Indigenous Australians, and Group B to represent First Nations people) the effect of the $\left(\overline{X^A} - \overline{X^B}\right)$ difference in endowments is evaluated using β^A – the estimated coefficients for non-Indigenous Australians.

To check the robustness of our decomposition result that treats the non-Indigenous group as the reference group, we also estimate the decomposition into the explained and unexplained components, using a third alternative based on the regression coefficients from a pooled sample of both First Nations and non-Indigenous people in the 2 health surveys. If the estimated coefficients from a pooled regression model (estimates from a single model for both groups) is given by β^*, Eq. 3.3 below is an equivalent decomposition to Eq. 3.1 and 3.2:

$$Gap = E_3 + U_3 = \left(\overline{X^A} - \overline{X^B}\right)\beta^* + \left[\overline{X^A}(\beta^* - \beta^A) + \overline{X^B}(\beta^* - \beta^B)\right] \qquad Eq.(3.3)$$

The explained component E_3 evaluates the effect of the difference in the X variables using the pooled coefficients β^*. In this derivation, the unexplained component U_3 now consists of 2 separate sub-components, which reflect how each of β^A and β^B differ from the pooled β^*.

Non-linear decompositions

The decomposition formulae noted above (in Equations 2 to 3.3) are based on a linear regression model as specified in Equation 1.

In the specific context of analysing the sources of the gap in health outcomes between First Nations and non-Indigenous Australians, the estimated model is a logistic regression model based on classifying whether an individual is in good health or not.

The decomposition results for non-linear regressions, such as in a logistic model, have a similar structure to the linear derivations above into an explained and unexplained component. But the actual derivations of the E and U components are a bit more complex and depend on the *X* values for the whole sample of individuals and not just the average values of the *X*s represented by $\overline{X^A}$ and $\overline{X^B}$.

The equivalent non-linear decomposition of equation 3.1 is (Powers et. al 2011):

$$Total\ mean\ gap = \underbrace{\left\{\overline{F(X_i^A\beta^A)} - \overline{F(X_i^B\beta^A)}\right\}}_{E} + \underbrace{\left\{\overline{F(X_i^B\beta^A)} - \overline{F(X_i^B\beta^B)}\right\}}_{U}$$

(where X_i^A denotes the i^{th} observation in Group A and X_i^B denotes the i^{th} observation in Group B; and where in the case of a logit model, $\overline{\mathrm{F(X_i\beta)}}$ denotes the average of the logistic cumulative distribution function evaluated at each $(\mathrm{X_i\beta})$ for the relevant groupings, as follows):

$$\overline{F(X_i^A\beta^A)} = \frac{1}{N_A}\sum_{i=1}^{N_A} F\left(X_i^A\beta^A\right)$$

$$\overline{F(X_i^B\beta^A)} = \frac{1}{N_B}\sum_{i=1}^{N_B} F\left(X_i^B\beta^A\right)$$

$$\overline{F(X_i^B\beta^B)} = \frac{1}{N_B}\sum_{i=1}^{N_B} F\left(X_i^B\beta^B\right)$$

(where N_A and N_B are the total number of observations in Group A and Group B, respectively).

In implementing the Oaxaca-Blinder technique in this article to decompose the average health gap between First Nations and non-Indigenous working age persons, Group A represents non-Indigenous people and Group B represents First Nations people in the above formulae.

See Powers et al. (2011) for further detailed descriptions and statistical bases of the non-linear interpretation of the Oaxaca-Blinder method, including for logistic regression models. However, standard statistical packages, such as STATA routinely derive the equivalent decompositions for non-linear models; and the results in this article are derived using the specific STATA 17 command *Oaxaca.do* with the logit option as described in Jann (2008).

Detailed non-linear decompositions

If there are *K* different explanatory variables in the regression model, the average gap can be further decomposed into the contribution made by each explanatory variable to the total E effect and to the total U effect, as represented below by E_k and U_k, respectively:

$$Total\ mean\ gap = E + U = \sum_{k=1}^{K} E_k + \sum_{k=1}^{K} U_k$$

For non-linear decompositions, there are additional relationships that each of E_k and U_k *can* be related to the aggregate E and U effects, through a weighted sum procedure:

$$\begin{aligned} Gap &= E + U \\ &= \sum_{k=1}^{K} E_k + \sum_{k=1}^{K} U_k \end{aligned}$$

$$= \sum_{k=1}^{K} W_{\Delta_{x_k}} \times E \; + \; \sum_{k=1}^{K} W_{\Delta_{b_k}} \times U$$

$$where\ the\ sum\ of\ weights\ is\ equal\ to\ 1, i.e. \sum\nolimits_k W_{\Delta_{x_k}} = \sum\nolimits_k W_{\Delta_{b_k}} = 1.$$

For example, to derive the contribution of the k_{th} variable to the total explained gap in a non-linear model, the derivations are as follows (Powers et. al 2011):

$$E_k = W_{\Delta_{x_k}} \times E$$

$$where\ W_{\Delta_{x_k}} = \frac{\left(\overline{X_k^A} - \overline{X_k^B}\right)\beta_k^A}{\sum_{k=1}^{K}\left(\overline{X_k^A} - \overline{X_k^B}\right)\beta_k^A}$$

Decomposition accounting and model fit R Square statistic

Finally, this is a clarifying note. In both the linear and non-linear versions of the Oaxaca-Blinder decomposition of the average differences into an explained and unexplained component, the average gap is fully accounted for. The E and U terms, by definition, equal the difference in the average of the Y values (Y bar); that is, 100% of the gap is accounted for, so as to speak, by including the unexplained component that arises from the differences in the β^A and β^B. This represents an accounting identity. However, such an accounting for the sources of the difference in the mean values between 2 groups in a regression framework has nothing to do with the quality of the model fit, or explanatory power of the underlying regression models for the 2 subgroups, which are usually represented by the R Square statistics.

The R Square for a regression model represents what proportion of the overall variance in the *Y* variable in an estimation regression sample is explained by the *X* variables. This use of the ‘explained proportion’ related to the R Square statistic should not be confused with the ‘explained component’ (E) of the Oaxaca-Blinder decomposition.

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Use of Medicare services and pharmaceuticals by mental health patients in Australia over the last decade

Key messages

- Between 2012 and 2021, growth in the use of mental health related services and mental health prescriptions was highest for females and those under 25 years of age.
- Mental health consumers living in *Least disadvantaged* areas or in *Major cities* had higher use of both mental health and non-mental health services and prescriptions than consumers in more disadvantaged or remote areas.
- Most mental health consumers accessed at least one of their mental health services (83%) or prescriptions (91%) through a General Practitioner.
- *Antidepressants* were the most frequently dispensed mental health prescription, while prescriptions of *Psychostimulants, agents used for ADHD and nootropics*, had the largest increase.

Introduction

This article presents an overview of the demographics and use patterns of mental health consumers who accessed clinical services (both mental health and non-mental health) and prescription medications provided through the Medicare Benefits Schedule (MBS) and Pharmaceuticals Benefits Scheme (PBS) over the period 2021 to 2021 (see Box MH.1).

- MBS mental health related services are provided by psychiatrists, other medical practitioners (for example, paediatricians), General Practitioners (GPs), psychologists, and other allied health professionals (for example, accredited mental health social workers). They are delivered across different settings, including in hospital, consulting rooms and at home.
- The PBS provides a variety of mental health related medicines prescribed by GPs, psychiatrists, other medical practitioners and nurse practitioners.

People with mental illness can also access a range of non-mental health related services provided through MBS and/or PBS to meet their health care needs.

It should be noted that mental health consumers may also access a range of health services which are not within the scope of the MBS or PBS. These include specialised admitted hospital psychiatric care, specialised community mental health services, and mental health services funded by Primary Health Networks.

The rationale for considering non-mental health service and medications is based on the fact that people with mental illness, in particular long-term serious illness, are more likely to have comorbid physical conditions (AIHW 2023d). Of the 22% of Australians aged 16–85 that reported a mental disorder in the last 12 months, around 40% also reported a long-term physical health condition (ABS 2023).

Specification of the analysis can be found in the Technical Notes.

This article has 4 sections. They are on mental health consumers' use of:

1. MBS mental health related services
2. MBS non-mental health services
3. PBS mental health related medicines
4. PBS non-mental medicines.

In summary, the analysis found that the number and type of MBS and PBS services accessed by mental health consumers were influenced by a variety of factors, such as age, sex, socioeconomic status, and remoteness.

This article uses the terms *mental health consumer* and *population rate*. These are defined below:

mental health consumer: a person who accessed at least one MBS or PBS mental health services within the reporting period (2012–2021 or 2017–2021 for this article).

population rate: a rate calculated as the number of consumers who accessed MBS or PBS services divided by the Estimated Resident Population for the relevant year. It is presented as a percentage (%) in this article, equivalent to the number of consumers per 100 population.

Box MH.1: About Medicare services and pharmaceuticals

Australia's health system is a complex mix of funders, service providers and health professionals across the Australian Government, state and territory governments and the non-government sector (AIHW 2022c). Medicare is Australia's universal health insurance scheme which subsidises the cost of medical and health services, providing patients with services and medicines at a reduced cost via a government rebate or subsidy. The MBS lists many medical and allied health services; the PBS and the Repatriation Pharmaceutical Benefits Scheme (RPBS) list a range of prescription medicines (AIHW 2023c).

People experiencing mental illness can access a variety of Medicare-subsidised mental health specific services and/or prescription medicines. Included as a subset of all mental health related services is the initiative *Better Access to Psychiatrists, Psychologists and General Practitioners through the Medicare Benefits Schedule* (Better Access), which provides Medicare rebates to eligible people to access needed mental health services. During the emergency phase of the COVID-19 pandemic in 2020, the Australian Government made a range of changes to the MBS items. For example, the number of Better Access Medicare-subsidised psychological therapy sessions were doubled from 10 to 20 per year (Department of Health and Aged Care 2022a) and the availability of telehealth sessions were expanded (Department of Health and Aged Care 2022b).

This article focuses only on Medicare-subsidised services and PBS pharmaceuticals to provide a snapshot of the findings and does not represent or reflect Australia's entire health system. For example, Medicare-subsidised services have greater use in high socioeconomic areas and *Major cities* due to the location of health practitioners (AIHW 2023a, 2023b). However, for some settings and sectors mental health services have a higher population rate of services accessed in more remote areas compared with *Major cities*, such as state and territory specialised community mental health care, emergency departments and admitted patient care in hospital (AIHW 2022a, 2022b, 2023d).

If a service or medicine is not covered by Medicare or the PBS, the data is not included in this article. For the purpose of the analysis and ease of presentation, both PBS and RPBS data are aggregated and reported as PBS findings.

MBS mental health related services

Box MH.2: MBS Mental health related services data analysis

For the purposes of this article, mental health MBS consumers are categorised into 4 groups according to the number of services, or level of service usage, over the year:

1. *Low*: one mental health related service per year
2. *Low–Medium*: 2–5 mental health related services per year
3. *Medium–High*: 6–15 mental health related services per year
4. *High*: 16 or more mental health related services per year.

These groupings have been selected for presentation purposes and are not based on the types of services accessed nor on demographic or clinical factors related to consumers.

Details of the mental health services included in this section are outlines in the Technical Notes. The Better Access MBS items include treatments, mental health plans, reviews, and other activities.

In 2021, there were about 14 million MBS mental health related services (an average of 5.0 services per consumer) compared with about 8 million (an average of 5.1 services per consumer) in 2012. In 2021, about 11% (2.8 million) of the estimated Australian population accessed MBS mental health related services, an increase from about 7% (1.6 million) in 2012.

Between 2019 and 2021, there was a steady increase of MBS mental health consumers in the *High* service use group and minor changes in the other groups (Table MH.1). In the

High service use group, there were 73,000 consumers in 2019, increasing to 158,000 in 2021. This increase may have been driven by the range of changes made to the MBS in response to the COVID-19 pandemic, including the increase in the number of Better Access sessions provided – from a maximum of 10 to 20 treatment sessions per year (Department of Health and Aged Care 2022a) (see Better Access Evaluation Final Report for more details on Better Access services).

Table MH.1: Rate of MBS mental health consumers per 100 population in each service usage group, 2019 to 2021

Service usage group	2019	2020	2021
Low	34.1	34.3	35.3
Low–Medium	37.9	36.8	35.9
Medium–High	25.2	24.5	23.2
High	2.7	4.4	5.6

Note: Percentages may not total 100% due to rounding.

Source: MBS data (sourced from the Department of Health and Aged Care).

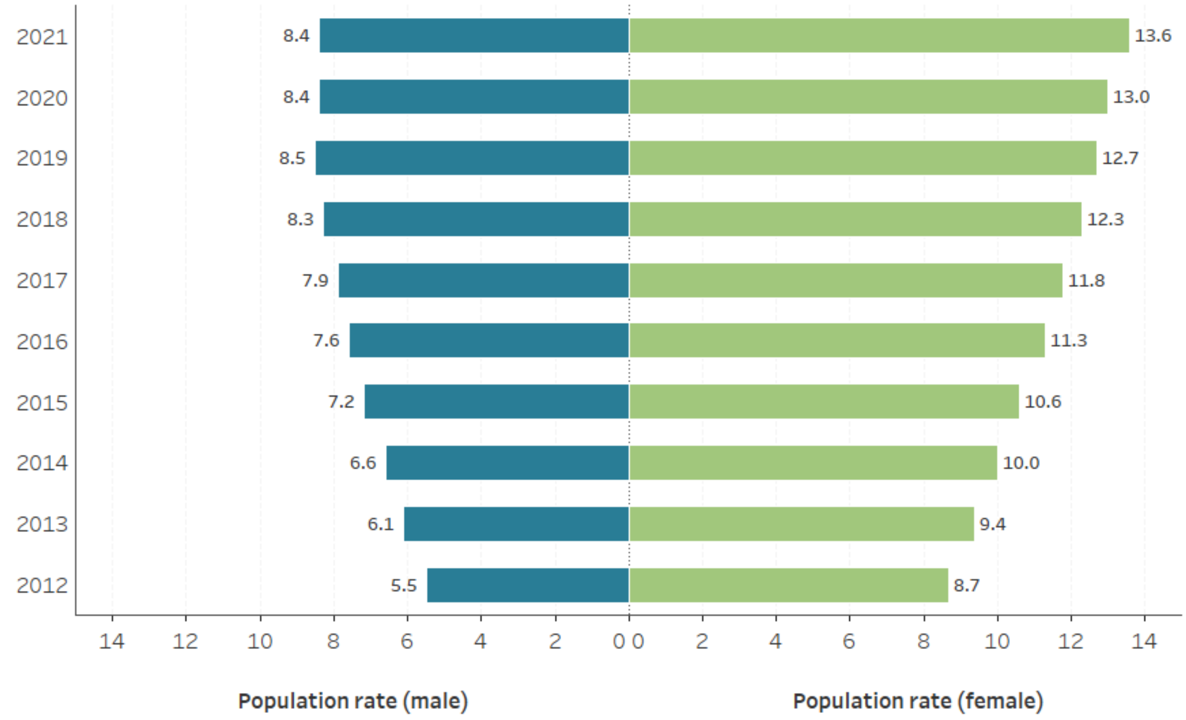
Females are more likely to use MBS mental health services

Female MBS mental health consumers had a higher rate of service use than males across all service usage groups and years. In 2021, females made up around 60% of consumers in the *Low* and *Low–Medium* service use groups, 65% in the *Medium–High* group and 71% in the *High* group.

The proportion of females who accessed MBS mental health services grew from 8.7% in 2012 to 14% in 2021. For males the proportion increased from 5.5% in 2012 to 8.4% in 2021. The rate for males remained relatively stable from 2019 to 2021 (Figure MH.1).

Figure MH.1: Females had a higher population rate than males and more consistent growth from 2012 to 2021

MBS mental health consumer population rate (%) by sex, 2012 to 2021

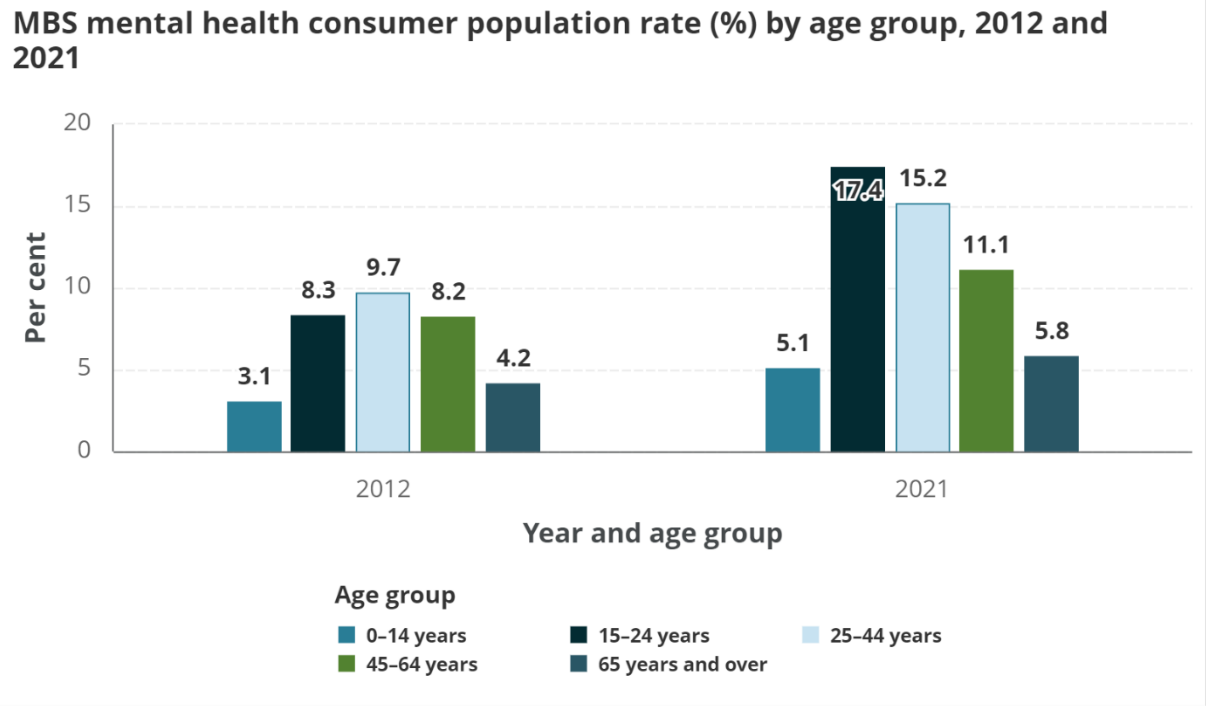


Source: MBS data (sourced from the Department of Health and Aged Care)
https://www.aihw.gov.au

Largest growth for MBS mental health service use has been for young people

The use of mental health services has shifted over time for younger people. In 2021, consumers aged 15–24 had the highest population rate for service use (17%), increased from 8.3% in 2012 (Figure MH.2). They also had the largest percentage increase (111%) in the number of MBS mental health consumers from 2012 to 2021.

Figure MH.2: The highest population rate was for people aged 15–24 in 2021



Source: MBS data (sourced from the Department of Health and Aged Care).

Between 2012 and 2019, the population rates (% of the population) for service use steadily increased across all age groups; however, there were differences across age groups between 2019 to 2021. The population rate dropped from:

- 5.3% to 5.1% for the 0–14 age group
- 11.3% to 11.1% for the 45–64 age group
- 6.2% to 5.8% for the 65 and over age group.

On the other hand, the age groups 15–24 and 25–44 showed sustained growth for service use over this period, from 14.4% to 17.4% and from 14.2% to 15.2%, respectively.

Major cities had the highest use of MBS mental health service use

About three-quarters (74%) of MBS mental health consumers accessing services resided in *Major cities* and *Inner regional* areas (similar to the overall distribution of the Australian population). Generally, the percentage of MBS mental health related services among the populations of *Major cities* and *Inner regional* areas were similar for each service use group and the total overall; in each category of greater remoteness, however, the population rate decreased for each service use group and the total overall.

- For example, in 2021, in *Major cities* and *Inner regional* areas, MBS mental health consumers comprised 11% of the population, compared with 8.7% in *Outer regional*, 5.8% in *Remote* and 3.3% in *Very remote* areas. This is due, in part, to MBS mental health services being more readily available in *Major cities,* based on the distribution of the health workforce. For instance, mental health workforce data for 2021 indicated that there were:

  - 19 psychiatrists per 100,000 population in *Major cities* compared with 2 in *Very remote* areas
  - 142 psychologists per 100,000 population in *Major cities* compared with 20 in *Very remote* areas (AIHW 2023f).

The population rate of service users increased for all remoteness areas from 2012 to 2021. Although *Remote* and *Very remote* areas had the lowest rates, they had the largest increases relative to 2012; namely from:

- 3.1% of the *Remote* population in 2012 to 5.9% in 2021
- 1.5% of the *Very remote* population in 2012 to 3.3% in 2021.

This may be due to increased awareness of mental health issues, assistance in rural and remote communities (Department of Health 2019a) and the introduction of Better Access telehealth services in 2017 (Department of Health 2019b).

MBS mental health consumers in least disadvantaged areas had the highest service use

People residing in areas of lower disadvantage had the highest rate of MBS mental health consumers, with the rate decreasing with increasing disadvantage. In 2021, the population rate (% of the population) in least disadvantaged areas were 14% compared with 9.1% for the most disadvantaged areas. This difference has grown over time, with the population rate for the:

- least disadvantaged areas increasing by 5 percentage points from 9.1% in 2012
- most disadvantaged areas increasing by only 3 percentage points from 6.2% in 2012 (Figure MH.3).

Box MH.3: Socio-Economic Indexes for Areas analysis

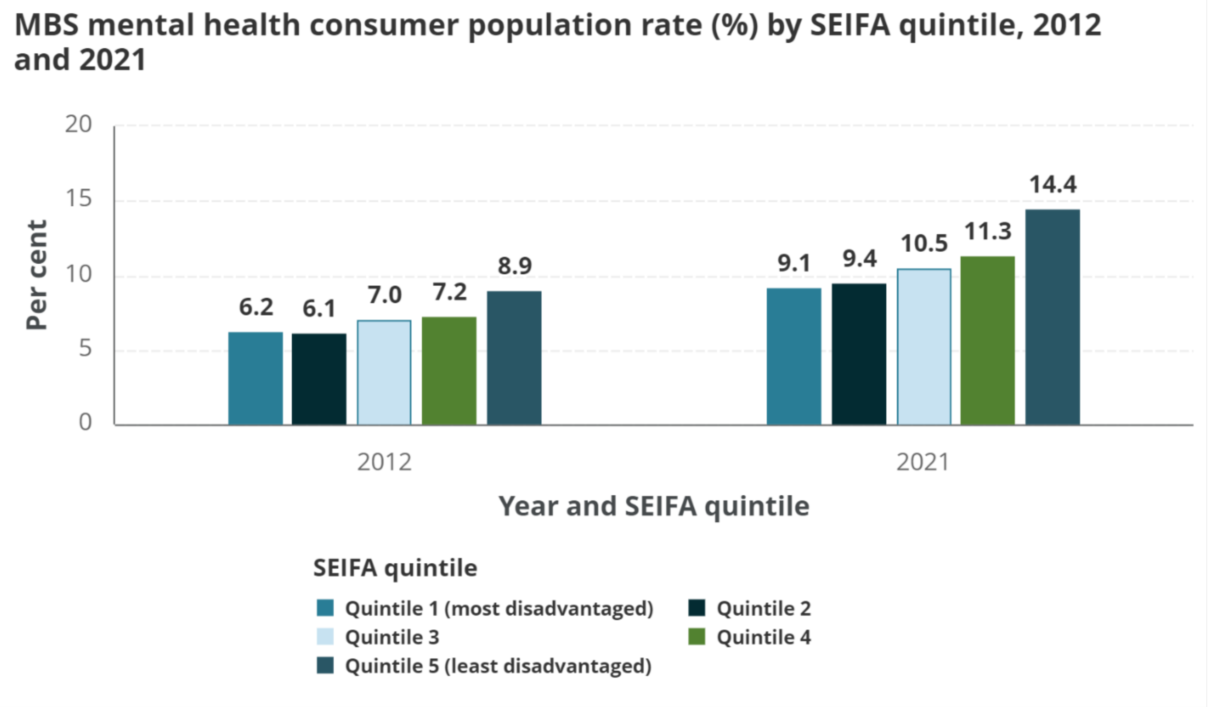
The Australian Bureau of Statistics calculates Socio-Economic Index for Areas (SEIFA) Index of Relative Socioeconomic Disadvantage (IRSD) scores, accounting for social and economic indicators of advantage and disadvantage (such as education, occupation, employment, income, families, and housing). These scores are used to summarise the socioeconomic conditions of a geographical area.

The SEIFA IRSD indexes are assigned to areas. SEIFA scores are determined by dividing the Australian areas into 5 equally sized groups (called quintiles), ranging from the most disadvantaged to the least disadvantaged.

For more information on SEIFA, see Socio-Economic Indexes for Areas (SEIFA), Australia (ABS 2021).

Between 2012 and 2019, the population rate for MBS mental health consumers grew steadily for all socioeconomic areas. From 2019, people in the 2 least disadvantaged areas had a stronger increase in the population rate than people in the most disadvantaged areas, where it remained steady.

Figure MH.3: The least disadvantaged areas had a higher population rate than the most disadvantaged areas



Source: MBS data (sourced from the Department of Health and Aged Care).

General practitioner services are used by the largest number of MBS mental health consumers

In 2021, 83% of MBS mental health consumers had one or more services from a GP; with GPs having the largest increase in consumer numbers for mental health services – an 80% growth from 1.3 million in 2012 to 2.3 million in 2021. GPs are often the first point of contact for people seeking mental health care services; they provide consumers with mental health services, prepare mental health treatment plans and/or refer consumers to other health professionals (AIHW 2023f).

Between 2019 and 2021, the number of consumers receiving services from psychiatrists grew 15%, from 419,000 to 480,000 consumers each year, compared with the growth for:

- GPs – an increase from about 2.26 million to 2.33 million consumers
- other psychologists – an increase from about 728,000 to 742,000 consumers
- clinical psychologists – a decrease from 545,000 to 541,000 consumers.

Despite slower or no growth in the number of consumers receiving services from other psychologist and clinical psychologists during this period, these providers had strong growth in the number of services delivered (21% and 25% increase, respectively), compared with a 3% increase for GPs and a 9% increase for psychiatrist services.

More MBS mental health consumers are using telehealth to access services

While videoconference telehealth consultations have been available for some mental health MBS services for many years, the proportions of consumers who used telehealth increased markedly from 2020 to 2021 – from 1.3% in 2020 (34,100 consumers) to 36% in 2021 (1,010,000 consumers). This large increase was due to the broad introduction of teleconference services and videoconference services in response to the COVID-19 pandemic.

The number of MBS mental health consumers accessing face-to-face services fell from about 2.7 million in 2019 to 2.6 million in 2021.

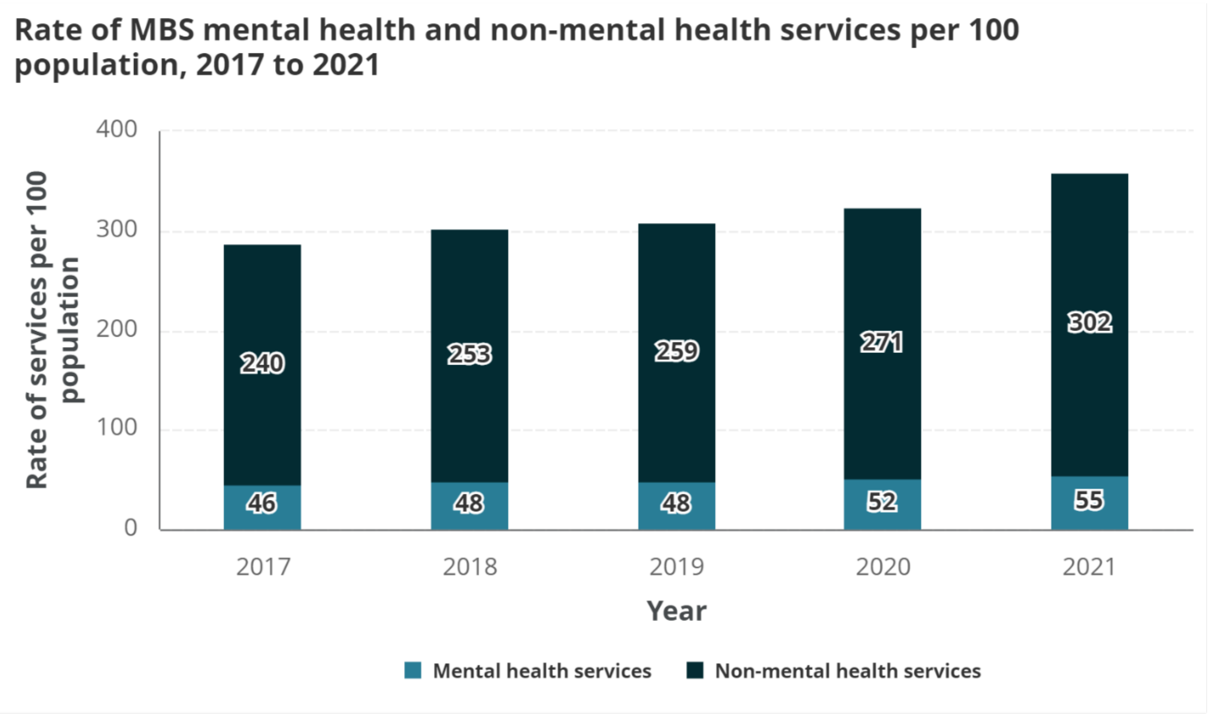
MBS non-mental health related services

Almost all (98%) MBS mental health consumers accessed one or more MBS non-mental health service during 2017 and 2021. The number of mental health services accessed by mental health consumers increased from:

- 46 services per 100 population in 2017 to 55 in 2021 for mental health services
- 240 services per 100 population in 2017 to 302 in 2021 for non-mental health services (Figure MH.4).

In considering the use of non-mental health specific services it should be noted that GPs may choose to treat a patient for a mental health issue using a general consultation MBS service item. As such, it is likely that there are some non-mental health services where mental health may have been one of the conditions managed, or the main condition managed.

Figure MH.4: Between 2017 and 2021, the rates of MBS mental health and non-mental health services per 100 population increased each year



Source: MBS data (sourced from the Department of Health and Aged Care).

Older mental health consumers had the highest median number of non-mental health services

Between 2017 and 2021, the median (see glossary) number of non-mental health services increased with age, from 8 services per year for consumers aged 0–14 to 40 services for people aged 65 and older. Overall, females had a higher median number of services (21 per year) than males (13). For most age groups, females had a higher median number, except for consumers aged 65 and older where both sexes had a median number of 40 services per year.

The largest difference between the sexes was in the 25–44 age group, where females had a median number of 21 services compared with 12 for males. One factor that may affect these findings is the use of services related to reproductive health care.

Major cities had the highest use of MBS non-mental health services

The proportion of MBS mental health consumers who accessed non-mental health services was lower in *Remote* and *Very remote* areas than in less remote areas.

- For example, in 2021, the broad type of non-mental health service with the highest proportions of patients were unreferred GP attendances and pathology tests which were accessed, respectively, by 98% and 84% of mental health consumers in *Major cities* compared with 96% and 77% of consumers in *Remote* and *Very remote* areas.

The largest percentage point difference was for specialist attendances, which were accessed by 41% of mental health consumers in *Major cities*, compared with 27% in *Remote* and *Very remote* areas. Practice nurse services was the only broad type of service accessed by a higher proportion of mental health consumers in *Remote* and *Very remote* areas (13%, compared with 9% for Major cities).

MBS mental health consumers in the least disadvantaged areas had the highest use of MBS non-mental health services

In 2021, the non-mental health rate for mental health consumers ranged from 403 services per 100 population for the least disadvantaged areas, to 254 services for the most disadvantaged areas (for information on SEIFA see Box MH.3).

In 2021, consumers in the most disadvantaged areas had the highest population rate of receiving *GP* (98%) and diagnostic imaging (52%) services. However, consumers in the most disadvantaged areas had the lowest rate for receiving operations (18%) and optometry (32%) services, compared with other areas.

PBS mental health related use

Box MH.4: PBS mental health related prescriptions data analysis

Mental health consumers included in PBS analysis

In this article, PBS mental health consumers are defined as people dispensed one or more mental health related prescriptions during the year. Consumers are categorised into 4 prescription groups according to the number of prescriptions dispensed by health professionals over the year.

Prescriptions are counted for each medication and repeat dispensed to a consumer (see more details in the Technical Notes).

1. *Low*: 1–2 prescriptions per year
2. *Low–Medium*: 3–8 prescriptions per year
3. *Medium–High*: 9–15 prescriptions per year
4. *High*: 16 or more prescriptions per year.

These groupings have been selected for presentation purposes and are not based on the types of prescriptions accessed, nor demographic or clinical factors related to consumers.

Statistics used to categorise mental health consumers in this article are related to the number of medications dispensed, not the number of prescriptions written for the consumers by a health professional. Medications dispensed during hospital admissions are not included.

Results from use of one medication are not directly comparable with those from another due to variability in the nature of mental illness, including its acuity and duration. It is not possible to describe what a good outcome is for a particular medication, as the same number of prescriptions could reflect totally different outcomes, depending on the specific medications (for example, the difference between long-term/ongoing medications and one-off prescriptions).

Medication groups included in PBS analysis

The analysis in this article includes 5 Anatomical Therapeutic Chemical (ATC) classification medication groups:

- *antipsychotics* (ATC code N05A)**:** drugs used to treat symptoms of psychosis (a severe mental disorder, characterised by loss of contact with reality, delusions and hallucinations), which are common in conditions such as schizophrenia, mania and delusional disorder
- *anxiolytics* (ATC code N05B)**:** drugs prescribed to treat symptoms of anxiety
- *hypnotics and sedatives* (ATC code N05C)**:** hypnotic drugs used to induce sleep and treat severe insomnia. Sedative drugs are prescribed to reduce excitability or anxiety
- *antidepressants* (ATC code N06A)**:** drugs used to treat the symptoms of clinical depression and other conditions
- *psychostimulants, agents used for ADHD and nootropics* (ATC code N06B)**:** drugs used to treat the symptoms of clinical depression and other conditions. Agents used for Attention Deficit Hyperactivity Disorder (ADHD) and to improve impaired cognitive abilities (nootropics) (AIHW 2023c; WHO Collaborating Centre for Drug Statistic Methodology 2023).

Consumers who were dispensed more than one medication type were counted once for each type; therefore, the sum of consumers by medication type may be larger than the total number of PBS mental health consumers.

In 2021, 18% of the Australian population had at least one mental health related prescription dispensed under the PBS, an increase from 15% in 2012.

Between 2012 and 2021 the:

- population rate of PBS mental health consumers per 100 population in the *Medium–High* and *High* prescription groups increased from 3.9% and 1.9% in 2012, respectively, to 6.1% and 2.6% in 2021 (Table MH.2)
- population rate in the *Low* and *Low–Medium* groups remained relatively stable (Table MH.2)
- median number of prescriptions dispensed for consumers increased from 6 to 8 per person per year.

Table MH. 2: Rate of PBS mental health consumers per 100 population in each prescription dispensed category, 2012, 2016 and 2021

Prescription dispensed category	2012	2016	2021
Low	4.5	4.8	4.4
Low–Medium	4.8	4.5	4.9
Medium–High	3.9	5.1	6.1
High	1.9	2.2	2.6

Note: Percentages may not total 100% due to rounding.

Source: PBS/RPBS data (sourced from the Department of Health and Aged Care).

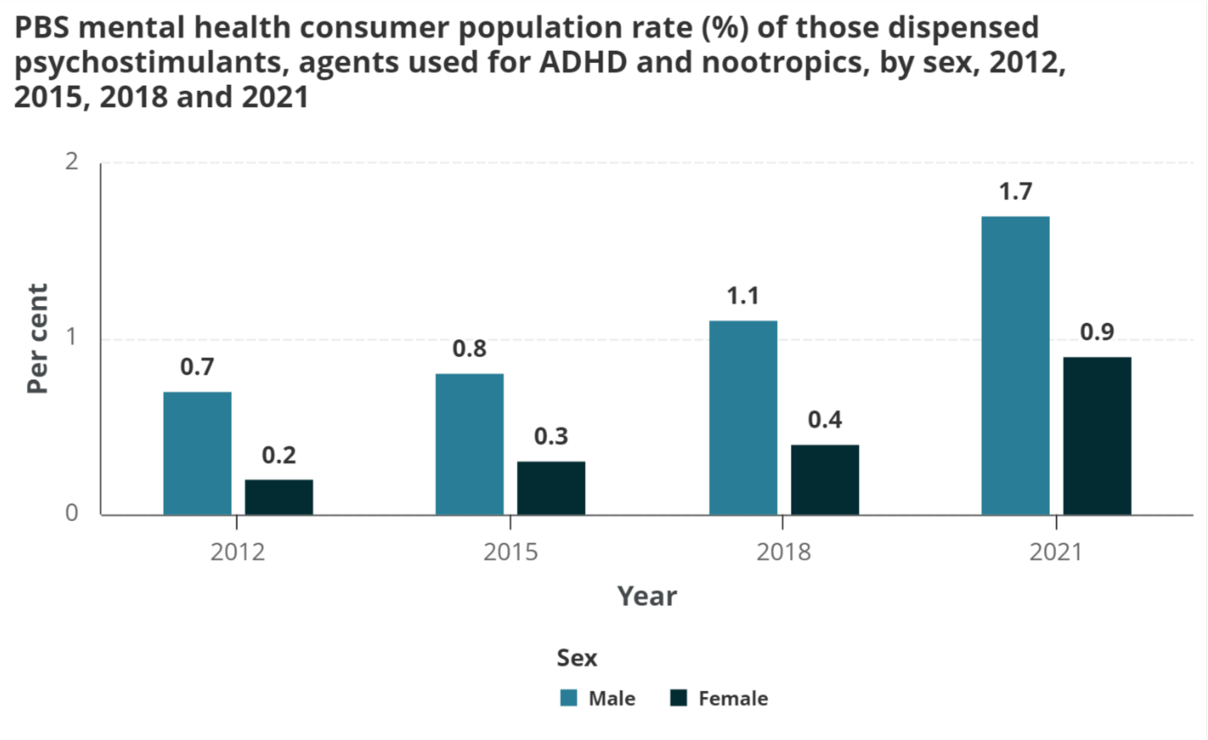
Over half of PBS mental health consumers were females

In 2021, females made up 60% of PBS mental health consumers who were dispensed mental health related prescriptions – a similar proportion to that between 2012 to 2020. Between 2012 and 2021, the rate of the male population who were dispensed prescriptions increased from 12% to 15%, while for females it increased from 18% to 21%. Between 2017 and 2021, females were dispensed a median of 8 mental health prescriptions each year compared with 7 for males.

In 2021, 0.9% of females and 1.7% of males were dispensed *psychostimulants, agents used for ADHD and nootropics* – an increase from 0.2% of females and 0.7% of males in 2012 (Figure MH.5). While still representing relatively small numbers, the increases for both sexes could be related to a range of factors including:

- increase awareness about ADHD and associated symptoms, which may have resulted in increased demand for treatment (including prescription of *psychostimulants*).
- as well, changes in the ADHD diagnosis criteria, and the impact of the COVID-19 pandemic, may have affected prescribing rates over time.

Figure MH.5: The population rate (%) of male and female PBS mental health consumers who were dispensed *psychostimulants, agents used for ADHD and nootropics* continually increased from 2012 to 2021



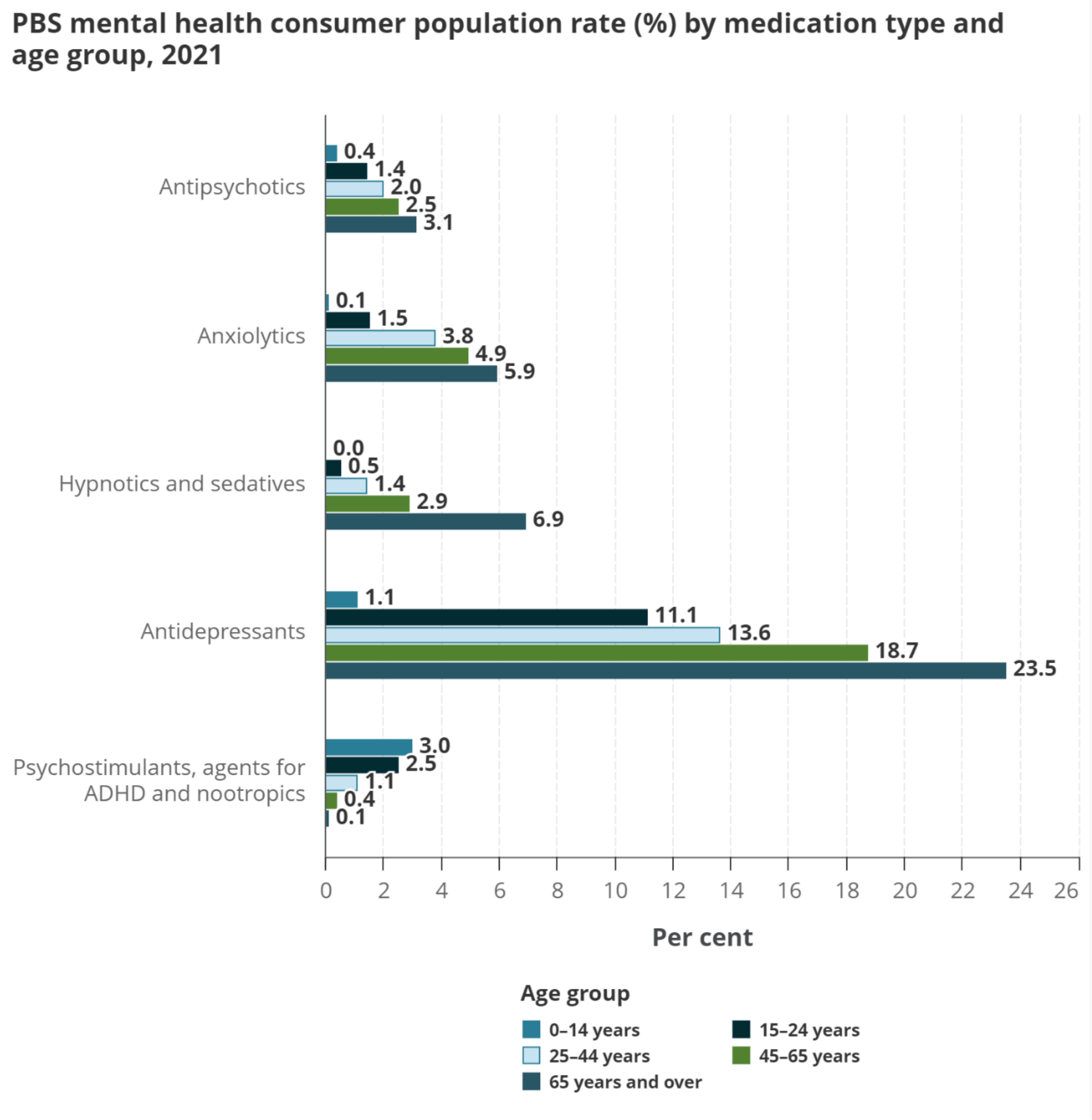
Source: PBS/RPBS data (sourced from the Department of Health and Aged Care).

Use of PBS mental health prescriptions grew most for young people

In 2021, the population rate of PBS mental health consumers who were dispensed a medication was 4% of people aged 0–14, more than double the rate in 2012 (2%). Young people aged 15–24 had the next largest rate rise relative to 2012, increasing from 8% in 2012 to 14% in 2021. Older age groups had slower growth or even decreases during the period.

In 2021, 14% of the population were dispensed *antidepressants*, the highest rate for all mental health related medications. The rates of *antidepressant* consumers ranged from 1% of the 0–14 age group up to 24% of the 65 and over age group. For the 0–14 age group, the highest rate was for consumers dispensed *psychostimulants, agents used for ADHD and nootropics* (3%) (Figure MH.6).

Figure MH.6: Antidepressants were the most commonly dispensed prescription, for mental health consumers aged 15 years and over

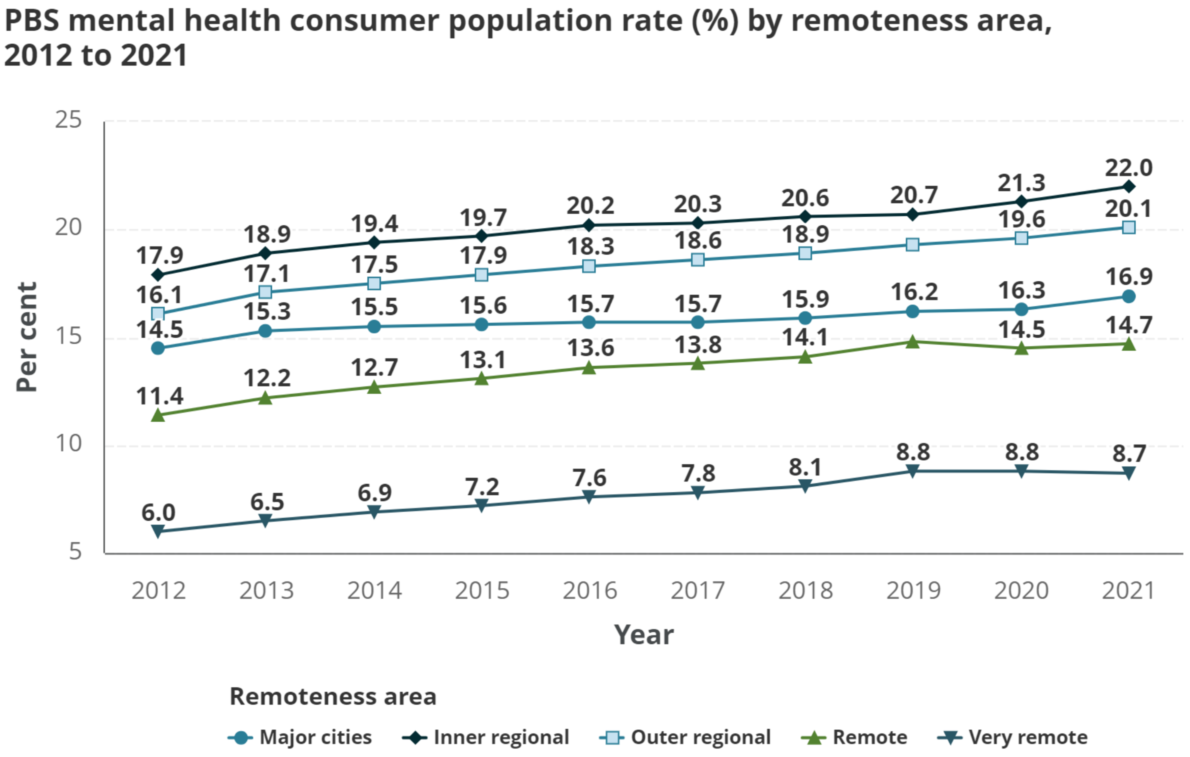


Source: PBS/RPBS data (sourced from the Department of Health and Aged Care).

Remote and *Very remote* areas had the lowest rates of PBS mental health consumers

In 2021, the population rate of PBS mental health consumers who were dispensed prescriptions was highest in *Inner regional* areas (22%), compared with *Outer regional* areas (20%), *Major cities* (17%), *Remote* areas (15%) and *Very remote* areas (8.7%). This pattern was similar for each year from 2012 to 2021 (Figure MH.7).

Figure MH.7: Between 2012 and 2021, Inner regional areas had the highest population rate of PBS mental-health related prescription consumers, while Very remote areas had the lowest



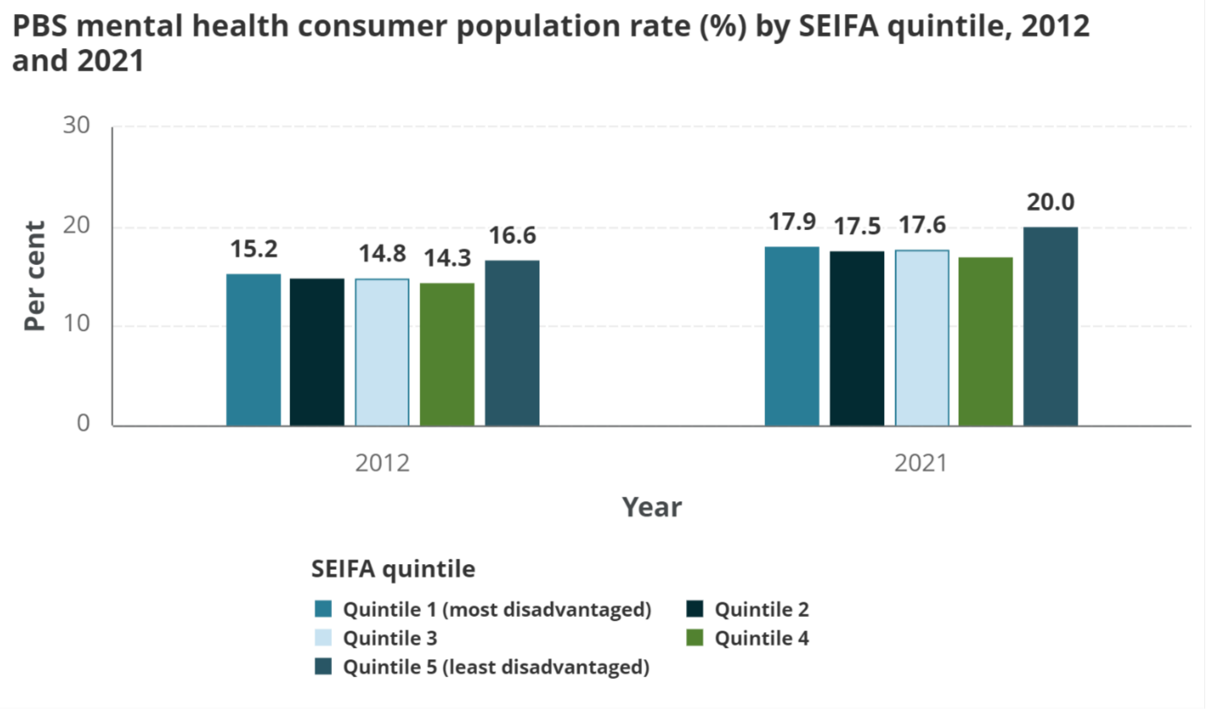
A percentage of the Australian Government subsidy on pharmaceuticals in remote First Nations communities is funded through the Aboriginal Health Services program, where drugs are supplied directly to consumers and hence are not included in the PBS data. Therefore, figures presented for Remote and Very Remote areas may be considered an underestimate where there are relatively larger First Nations populations.

Source: PBS/RPBS data (sourced from the Department of Health and Aged Care).

Least disadvantaged socioeconomic areas had the highest population rate of PBS mental health consumers

In 2021, the *least disadvantaged* areas (quintile 5) had the highest population rate of PBS mental health consumers (20%), followed by *most disadvantaged* areas (quintile 1) (18%) (Figure MH.8). Between 2012 and 2021, the rate of PBS mental health consumers increased across all socioeconomic areas. Several factors, such as access to services, health-seeking awareness and behaviour, and ability to pay for services, contribute to the differences across the areas.

Figure MH.8: The population rate (%) of prescriptions dispensed to mental health patients increased in all socioeconomic areas each year



Source: PBS/RPBS data (sourced from the Department of Health and Aged Care)

Antidepressants are the highest used medication by PBS mental health consumers

PBS mental health consumers who were dispensed *antidepressant* prescriptions were the largest medication group (77% of the total PBS mental health consumers in 2021). The annual number of *antidepressant* consumers increased by more than one million people from 2.4 million in 2012 to 3.6 million in 2021.

Consumers dispensed *psychostimulants, agents used for ADHD and nootropics* were the smallest group of PBS mental health consumers (327,000 in 2021), but had the highest relative growth in consumer numbers, more than tripling from 107,000 in 2012.

In 2021, the most frequent combination of dispensed medications were:

- *antidepressants* with *anxiolytics* (339,000 consumers)
- *antidepressants* with *antipsychotics* (189,000)
- *antidepressants* with *hypnotics and sedatives* (176,000).

The majority of PBS mental health consumers received prescriptions from general practitioners

In 2021, 4.2 million consumers (91% of the total PBS mental health consumers) were dispensed prescriptions from GPs (Note that consumers may receive prescriptions from multiple provider types during a reporting period). In 2021, 9% of consumers were dispensed prescriptions by psychiatrists, 4% by paediatricians, 6% by other specialists, and 4% by other provider types.

In 2021, around three-quarters of PBS mental health consumers who received prescriptions from GPs, psychiatrists and paediatricians were dispensed multiple prescriptions per year, compared with only around a third from other medical specialists and a fifth from other providers.

The strongest growth in consumers was among those dispensed prescriptions by paediatricians – an increase of 157%, from 72,234 in 2012 to 185,786 in 2021. This relates to the strong growth for young consumers aged 0–14 and 15–24 who were dispensed prescriptions for *antidepressants* and *psychostimulants, agents used for ADHD and nootropics* (see the section 'Use of PBS mental health prescriptions grew most for young people').

PBS non-mental health related use

Between 2017 and 2021, PBS mental health consumers who were in the higher mental health prescription groups had a higher median number of non-mental health prescriptions dispensed. There was a median of 7 non-mental health prescriptions dispensed within the *Low* group to 27 in the *High* group. This is likely associated with some consumers having more complex health care needs, requiring both mental health and non-mental health medications (AIHW 2023e).

Male PBS mental health consumers aged 65 and over had the highest median number of non-mental health prescriptions

Between 2017 and 2021 there was a trend for higher median numbers of non-mental health prescriptions with increasing age. In the younger age groups, males had the same or lower median numbers of non-mental health prescriptions as females. Comparatively, males in the 65 and over age group had a higher median number of non-mental health PBS prescriptions (43) than females (40).

PBS mental health consumers living in *Inner regional* and *Outer regional* areas accessed the most non-mental health prescriptions

Consumers in *Inner regional* and *Outer regional* areas had higher median numbers of non-mental health prescriptions (13) than in *Major cities* (11) and *Remote* and *very remote* areas (10).

PBS mental health consumers living in the most disadvantaged areas dispensed highest number of non-mental health prescriptions

There was a trend for higher median numbers of non-mental health prescriptions dispensed with increasing disadvantage of each socioeconomic group.

- For example, people living in the *most disadvantaged* areas were dispensed a median of 15 PBS non-mental health prescriptions compared with 9 for the *least disadvantaged* areas. This pattern likely reflects the 'social gradient of health', characterised by associations between socioeconomic disadvantage and greater likelihood of chronic health conditions (AIHW 2022c).

Conclusion

This analysis shows that over the reporting period from 2012 to 2021 there is variability in mental health consumer characteristics and patterns of service use among those who accessed both mental health and non-mental health services subsidised through the MBS and PBS.

A range of factors can influence who, what, where and how these services are provided and accessed, as well as the impact of and response to the COVID-19 pandemic. The type and volume of the health services can vary for consumers, depending on their care needs, which can also alter due to changes in acuity and duration of conditions over time. Patterns of service use differ with the needs of consumers and the availability and ability to access services due to financial and/or geographical factors.

It is important to continue to understand the consumer profiles, growth trends and use patterns in this area to deliver better services and meet further needs.

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Technical notes: Use of Medicare services and pharmaceuticals by mental health patients in Australia over the last decade

MBS data

Calendar year data are used from:

- 1 January 2012 to 31 December 2021 for MBS mental health use (10 years)
- 1 January 2017 to 31 December 2021 for MBS non-mental health use (5 years).

Mental health consumer population:

- People who received at least one mental health related service during the reporting period.

MBS mental health services include:

- Better Access (BA) services, which are a sub-category of all mental health services. Services that count towards the BA quotas include:
    - psychological therapy services provided by eligible clinical psychologists
    - focused psychological strategy services provided by eligible general practitioners (GPs), registered psychologists, social workers and occupational therapists.
- Better Access to psychiatrists, psychologists and GPs initiative, which provides Medicare rebates for up to 10 individual sessions and up to 10 group mental health treatment sessions per calendar year
- in response to the COVID-19 pandemic, from 9 October 2020 until 31 December 2022, 20 individual sessions were available each calendar year per person
- all the other Medicare-subsidised assessment, treatment, and review services specific to mental health outside of the BA initiative including:
    - services for eating disorder treatments since 2019
    - psychological therapy services to people affected by bushfires in the 2019–20 financial year.

MBS mental health consumers were categorised into 4 groups according to their level of service usage each year:

- *Low*: 1 relevant service
- *Low–Medium*: 2–5 relevant services
- *Medium–High*: 6–15 relevant services
- *High*: 16 or more relevant services.

PBS data

Calendar year data are used from:

- 1 January 2012 to 31 December 2021 for PBS mental health use (10 years)
- 1 January 2017 to 31 December 2021 for PBS non-mental health use (5 years).

The article reports findings for all dispensed prescriptions (subsidised and under co-payment threshold) for mental health related medications for PBS mental health consumers.

Subgroups of consumers were also analysed according to the Anatomical Therapeutic Chemical (ATC) classification of the dispensed medication:

- antipsychotics (N05A)
- anxiolytics (N05B)
- hypnotics and sedatives (N05C)
- antidepressants (N06A)
- psychostimulants, agents used for attention-deficit hyperactivity disorder and nootropics (N06B).

PBS mental health use:

- Prescriptions are counted for each medication and repeat dispensed to a patient. For example:
    - if a clinician issued an *anxiolytic* prescription in 2020 that could be filled 6 times (that is, one initial supply and 5 repeats) and a person was dispensed the medication 4 times in 2020, that person is recorded as receiving 4 prescriptions of *anxiolytics* in 2020
    - if this person was then dispensed one of the 2 remaining repeat supplies in 2021, they are recorded as receiving one prescription of *anxiolytics* in 2021. Dosage information and prescriptions for initial or repeat medication supplies that were not dispensed are not included in the data.

PBS mental health consumers were categorised into 4 groups according to the number of prescriptions dispensed:

- *Low*: 1–2 prescriptions per year
- *Low–Medium*: 3–8 prescriptions per year
- *Medium–High*: 9–15 prescriptions per year
- *High*: 16 or more prescriptions per year.

The category names are not based on any clinical definition or consensus of what constitutes ‘low’ or ‘high’ medication use and are purely for categorisation within the context of the data used for this report.

Using nowcasting and projections for statistical understandings in health

Key messages

- Nowcasting can provide reliable, up-to-date estimates of the current health burden.
- Projections can indicate future health trends.
- Reliable estimates depend on stable historical trends and assumptions about the impact of future policies and practices.

Introduction

A current picture of the health of Australians is important when developing health policy and when planning health services. Investment decisions for specific treatment facilities, workforce planning, and evaluation of health policy rely not only on an accurate measure of current disease burden (including new cases, prevalence and mortality), but also on a reliable indication of the burden that might be expected in the future.

The more recent and complete data are, the more likely they will provide a reliable picture of today. Recent data combined with time series data provide information about today, while enriching an understanding of the journey to this point.

It is not uncommon, though, for the most recent data to be several years old. The reasons for this are many and varied:

- Some surveys that provide the main source of data for certain health conditions are conducted only every few years.
- For some annual data collections, such as hospital admissions and cancer incidence data, the time it takes to collect, code, collate and validate the data so they are suitable for analysis can contribute to reporting delays.

With such data, the journey can be understood – but what about the understanding of today?

A number of techniques are used to provide more timely data, including:

- using ‘preliminary’ or ‘fast-tracked’ data that is subject to change
- imputing data based on similar population groups to fill data gaps
- undertaking large-scale data linkages across a wide range of existing datasets which provide valuable information but can require considerable time and expense to obtain necessary approvals.

Nowcasting and projections are feasible and oft-used techniques that use understandings from the journey to provide a possible picture of not only today but also future health needs.

This article briefly explores why the most recent data in some collections can be several years old. It uses examples from the cancer reporting program and the Australian Burden of Disease Study to show how projecting both to the current period (nowcasting) and the future can provide statistical health understandings about today and beyond. It also discusses the limitations of this approach when unforeseen events, such as the COVID-19 pandemic, occur. (See Box NP.1 for definitions of key terms used in this article).

Box NP.1: Key terms used in this article

burden of disease: An estimate that measures the impact of living with illness and dying prematurely.

cancer incidence: The number of new cases of cancer diagnosed in a given year.

cancer mortality: The number of deaths that occurred during a given year for which the underlying cause of death was recorded as cancer.

cancer prevalence: The total number of people alive at a specific date who have ever been diagnosed with cancer.

cancer survival: The probability of being alive for a given amount of time after a diagnosis of cancer.

nowcast: A term to describe a forecast of statistics to the **current year**, based on past trends and knowledge of current events.

projection: A term to describe a forecast of statistics **into the future**, using past trends and assumptions about future events.

What are nowcasting and projections?

Nowcasting may be described as a forecast for today.

- For example, where the most recent data are several years old, historical trends can be examined, and then knowledge and assumptions about events that may influence the continuation of these trends to the present day applied, to create statistics for the current period.

While similar in concept to nowcasting, projections use historical trends and assumptions about the future to indicate how things may look in the years to come.

There are 2 key questions to consider in deciding whether to nowcast data:

- Are the most recent statistics available sufficiently relevant to today?
- If not, can a reliable estimate for today be produced?

Suitability of data

Not all data are suitable to nowcast or project. Producing a reliable estimate of current health burden depends on stable trends in disease data, coupled with knowledge or reliable assumptions of current policies and practices that may affect these trends.

Diseases that have volatile trends with the potential to change quickly (such as infectious diseases) are difficult to accurately nowcast, as are diseases or conditions for which there are known changes in detection or treatment patterns that will influence the trend.

Diseases with slow moving and stable trends – such as cancer, diabetes, chronic kidney disease and cardiovascular disease – are much more suited to nowcasting.

In addition, estimates of future health burden depend heavily on stable trends in demographic data (such as for population growth and ageing), as well as assumptions of future trends.

Limitations of nowcast or projected data

Of course, nowcast or projected data do have limitations. Determining current or future health burden involves some uncertainty, as it is virtually impossible to derive a perfect prediction. The further the actual data are from the point of the projection, the greater is the opportunity for inaccuracies to compound, and the more prone the projection is to changes in the environment, which may affect its reliability. Regular updates of nowcast and projected data help to minimise the impact of these changes.

It is important to indictate the reliability of nowcast and projected estimates. Rounding and prediction intervals help the user to understand the level of certainty associated with the estimate.

AIHW practice

The AIHW uses nowcasting and projections in several products, including for its cancer reporting program and burden of disease estimates. This article provides a brief description of the rationale, methods and limitations for both cancer and burden of disease nowcasting.

Using nowcasting in cancer reporting

Cancer statistics released annually by the AIHW in Cancer data in Australia include those for incidence, mortality, survival, risk and prevalence. Most of these statistics are sourced from the Australian Cancer Database.

Why doesn't the AIHW publish more timely cancer data?

Australian cancer data have among the highest quality and most complete population coverage in the world. Although the data are not available until around 3.5 years after the reporting period, this time-lag is consistent with reporting standards around the world.

There are several reasons for this time-lag:

- It takes considerable time for the jurisdictional cancer registries to receive and then enter cancer incidence and mortality data from notifiers (including hospitals; pathology laboratories; and the Registries of Births, Deaths and Marriages) and to follow up with notifiers and other authorised people to ensure important information about the cancer is correct.
- Further time is then required to compile the jurisdictional data into the national dataset (including undertaking data harmonisation and quality checks) and to create the range of cancer-related statistics made available to the public.

What cancer data are nowcast?

In 2012, the AIHW started producing publicly available year-to-date (nowcast) statistics on cancer incidence (the number of new cases of cancer diagnosed in a given year) and mortality (the number of people who die from cancer in a given year) to meet the needs of stakeholders, including policy advisors, researchers and the general public. Nowcast prevalence statistics (the number of people alive who have previously been diagnosed with cancer) will be publicly released for the first time in 2024.

These estimates support day-to-day service delivery by providing a valuable indication of how many cancer cases are expected to be diagnosed and treated, while changing (particularly increasing) trends help to identify emerging areas of need.

Actual data still needed too

Nowcasting does not negate the need for timely and accurate actual data on cancer. For instance, nowcast data are unable to predict unusual events – such as cancer clusters or other unexpected increases; as such, they are unsuitable to monitor interval cancers for screening programs or other service delivery and research where greater data accuracy is needed.

Survival rates are a key cancer statistic, but the AIHW does not produce nowcast or projected estimates for cancer survival as the most recent statistic is generally considered to provide a reasonably relevant indication of survival to today. Also, it is uncertain whether survival can be projected sufficiently well to provide an informed estimate for today.

Cancer incidence nowcasting

Given the apparent need for nowcasting, can a reliable estimate be calculated?

In general, cancer incidence rates change gradually over time. There may be some volatility in rates between years, but there is often a trend that sees incidence moving in a general direction (for example, see Figure NP.1 to view trends for all cancers combined).

To nowcast cancer incidence, the AIHW uses a linear regression method which looks at the last 10 years of incidence rates. Based on these rates, the AIHW then estimates current incidence rates by 5-year age-group and sex for a mutually exclusive list of over 350 cancer sites and types – which forms the building blocks for all incidence statistics. These building blocks are aggregated to report by various cancer groups and total cancer incidence.

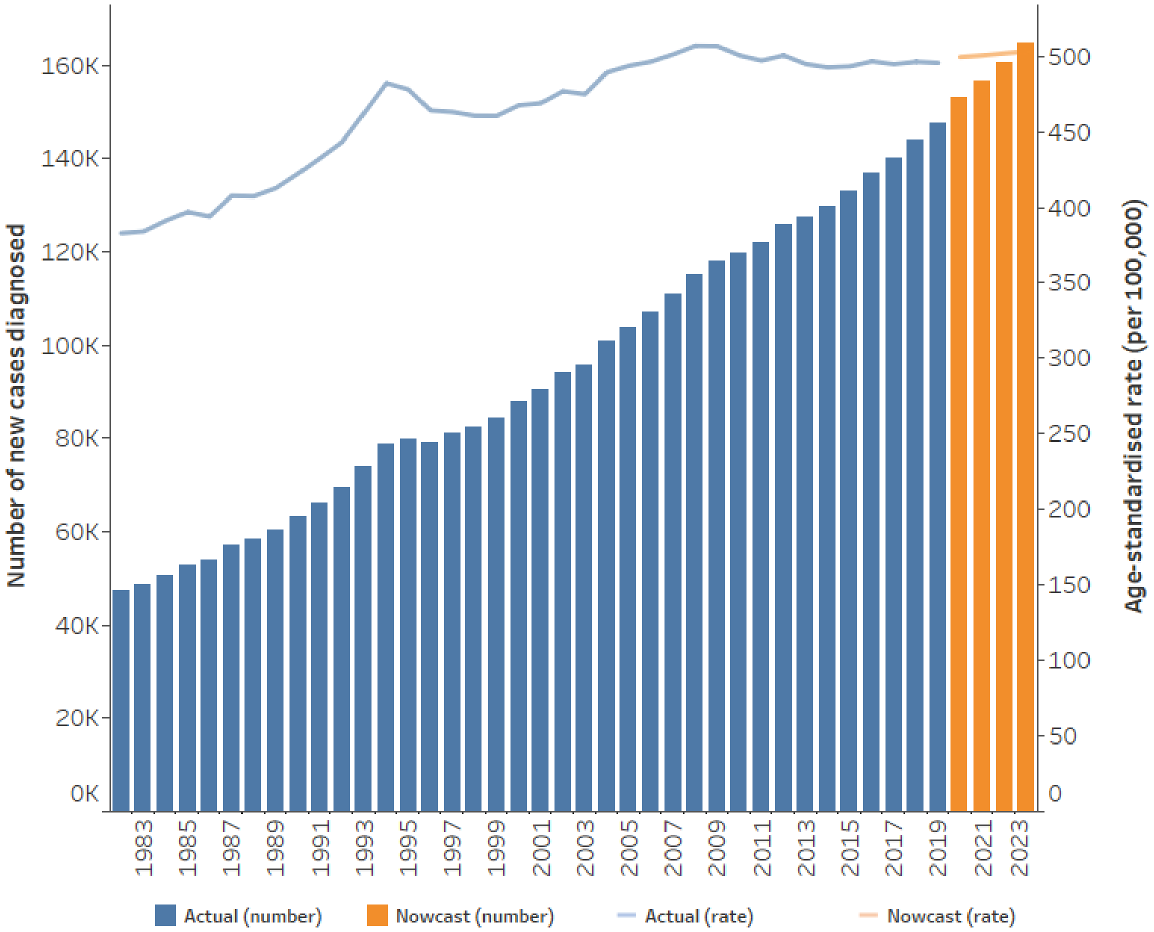
Full methods for nowcasting cancer incidence are described in Cancer data in Australia.

- For example, in 2019 there were 147,600 cases of cancer diagnosed with an associated rate (age-standardised to the 2001 Australian Standard Population) of 496 cases per 100,000 people. Using nowcasting methods, 164,700 new cases are expected to be diagnosed in 2023, with an estimated age-standardised rate of 503 cases per 100,000 people (AIHW 2023b).

The nowcast figures help to paint a picture of cancer today that may otherwise be hard to gauge from the most recent actual data. Similarly, the small degree of change in age-standardised rates indicates that, based on recent trends, the rates for all cancers combined are relatively stable, even though the number of cases is increasing.

Figure NP.1: Cancer incidence and rates are suitable to nowcast

Cancer cases and age-standardised incidence rates, persons, Australia



Notes:

1. Actual data are provided between 1982 and 2019. Nowcast data are provided from 2020 to 2023.
2. Age-standardised rates are expressed as per 100,000 population and standardised against the 2001 Australian Standard Population.

Source: Australian Cancer Database 2019; AIHW 2023b.
https://www.aihw.gov.au

Prostate cancer – an exception for nowcasting

There is one exception to this methodology. Incidence rates for prostate cancer have been highly volatile as new detection methods have been introduced, making them unsuitable as a basis for nowcasting.

Instead, nowcast prostate cancer incidence statistics use the actual incidence rates for the most recent year – rather than the most recent 10 years – applied to the relevant populations by age.

Long-term cancer incidence projections

Nowcasting incidence uses linear regression; however, there is a limit on how many years into the future it is considered appropriate to forecast cancer incidence counts and rates.

Within the AIHW's cancer data program, nowcast cancer incidence rates are also referred to as short-term projections. Cancer incidence rates projected out to 10 years in the future (around 13–14 years beyond the actual data) are referred to as long-term projections.

To use linear regression for long-term projections would be to suggest that the cancer trends will continue to move in the same direction for this length of time. For many cancers, the cancer incidence trends indicate that this may not be a realistic assumption. For longer term cancer projections, the AIHW uses the NordPred software package to project cancer incidence. This is a specially designed cancer incidence projection program written by Harald Fekjær and Bjørn Møller at the Cancer Registry of Norway, which takes account of the impacts of individual ageing, general societal changes and different birth cohorts.

The longer the time between the last actual data and the projection, the greater the risk that new trends will emerge that projections cannot accurately account for. Changes to existing trends will affect the reliability of the estimate to some extent.

While we produce nowcast estimates for many cancers and for many age groups, long-term projections only include the total number of cancer cases (that is, not disaggregated by age group) for those cancers with sufficient case numbers to support a projection with a degree of certainty. We elect not to provide detailed long-term estimates (such as by age group) for long-term projections because of the greater volatility of the finer-level data.

Cancer mortality nowcasting

The process to nowcast cancer mortality estimates is similar to that used for cancer incidence, but with fewer obstacles to overcome.

- Firstly, the most recently available mortality data are closer to the year of data release (2 years). This shorter projection interval means there is less chance of unexpected changes in trends.
- Secondly, unlike incidence (which can be subject to sudden spikes related to changes in diagnosis techniques or the introduction of screening programs), changes in cancer mortality trends are often more gradual. This is the case for prostate cancer, where the issues that affected trends in prostate cancer incidence (making them unsuitable for nowcasting) did not affect trends in prostate cancer mortality in the same way; thus, nowcasting of prostate cancer mortality can continue to use linear regression.

Methods are being explored for long-term projections of cancer mortality; however, the AIHW is not currently producing these.

Cancer prevalence nowcasting

The 2024 release of the AIHW publication will include nowcast prevalence statistics. Cancer prevalence is the number of people alive at a set point in time who have been diagnosed with cancer within a certain period.

- For example, 10-year prevalence of lung cancer for 2024 is the number of people alive as at 31 December 2024 who were diagnosed with lung cancer within the preceding 10 years.

Prevalence is a function of incidence, mortality and survival, and projecting cancer prevalence is consequently more complex. A simplified explanation of how nowcast estimates for cancer prevalence are calculated is to apply survival rates to the number of people diagnosed with cancer to derive the number projected to be alive at the set point in time. Actual incidence data are used where available, and incidence projections are used where they are not. While short-term cancer incidence projections can be used to estimate the number of people diagnosed (as previously mentioned), cancer survival is not projected.

Full methods for cancer prevalence nowcasting will be provided with the data release in 2024.

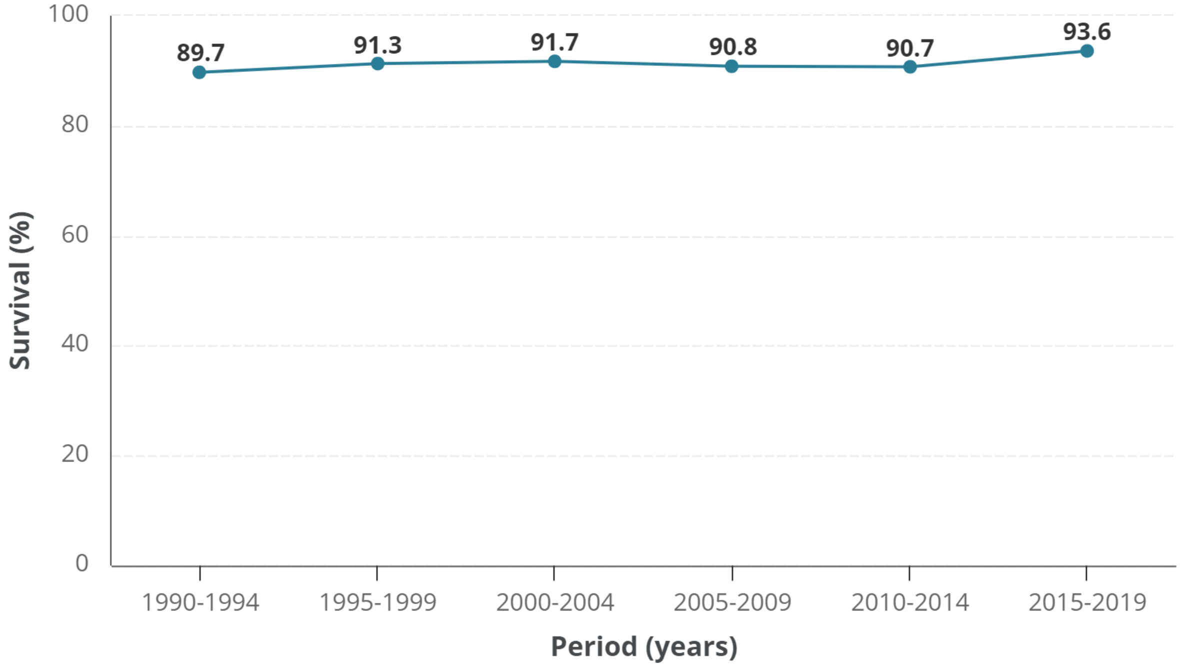
Why isn’t cancer survival nowcast?

As previously noted, the most recent survival statistic is generally considered to provide a reasonably relevant indication of current cancer survival. Also, it is uncertain whether survival can be projected sufficiently well to provide an informed estimate for today.

- For example, consider the 5-year survival of melanoma of the skin (Figure NP.2). For many years, the survival rate of melanoma of the skin was relatively stable; however, in the latest period (2015–2019), there has been an increase in survival. The question for the forecast would be: will survival continue to increase at the same rate or does the most recent survival represent only a step in increased survival? Without understanding the nature of the increase, it is difficult to know whether the rate will continue to increase or stabilise.

Figure NP.2: Without understanding the reason for a change in trend, cancer survival is difficult to nowcast

5-year relative survival rates for melanoma of the skin, persons, Australia



Relative survival is calculated with the period method, using 5-year periods from 1990–1994 to 2015–2019. For more information on survival calculations, see the "Using the data" and "Technical Notes" pages within the Cancer Data in Australia - external site opens in new window web report.

Accounting for COVID-19 in cancer projections and nowcasting

The most recent nowcast cancer incidence and projections include years during which Australia was affected by COVID-19; however, the latest actual cancer data are from before the pandemic. The impact of COVID-19 on cancer incidence and the potential for it to affect mortality have been speculated, but actual national data are not yet available for analysis.

- For example, the impacts of COVID-19 restrictions on breast and cervical screening activity (AIHW 2021) and on cancer diagnostic and therapeutic services for breast, colorectal, lung, prostate and skin cancers (Cancer Australia 2021) have been well documented. The impacts on these services may subsequently affect incidence and mortality for these cancers from 2020 onwards.

As well, changes in the population structure due to COVID-19 may also have an impact on future cancer estimates.

- For example, in 2022, there were just under 10,000 deaths from COVID-19, with a median age at death of 86 (ABS 2023). As cancer is predominantly a disease of older people, it is likely that a proportion of the population who died from COVID-19 may, had they lived longer, been diagnosed with cancer, with a smaller proportion dying from cancer. This will result in a potentially lower number of actual cases and deaths from cancer in 2022 than is expected from the existing trends.

The purpose should always be considered when developing projections and nowcast statistics. When projecting cancer incidence for years impacted by COVID-19, we have not attempted to account for the potential influence the pandemic may have had on cancer incidence trends. For a start, the information base was insufficient to do so; and the resulting projections may not have fulfilled their intended purpose – to provide an indication of cancer incidence within Australia. COVID-adjusted projections would focus on the timing of cancer diagnoses (as diagnosis of cancer may be delayed during lockdown and possibly made in a later year), muddying the general trends and overall volume of cancer incidence. In producing a more complex set of projections, we would fail to meet the purpose of these projections and nowcast figures.

Difficulty of nowcasting different types of cancer

A single, consistent and easily replicated method of nowcasting is used for cancer, due to the large number of different types of cancer that must be nowcast.

Over time, various ways of projecting cancer statistics have been tested. Each method has apparent strengths and weaknesses.

- For linear regression, it can take time to factor in emerging trends and there is more opportunity for inaccuracies where rates move more quickly.
- For the prevalence projections, there are risks associated with projecting incidence rates combined with being unable to reliably estimate survival rates.

Prostate cancer incidence rates

The worst case scenario for cancer incidence nowcasting and projections is where a cancer's rates can dramatically rise and fall over a relatively short period. This happened, for instance, with prostate cancer incidence rates and the events are discussed in more detail in *Cancer in Australia 2021*. Use of standard linear regression was considered inappropriate for nowcasting prostate cancer incidence as historical trends were not sufficiently stable, but the need for an estimate remained.

In this case, rather than not provide a nowcast estimate for this cancer, the most recent rates were held constant and only population growth (which is known) applied. Essentially, the nowcast estimate for prostate cancer incidence can be interpreted as 'if rates remain the same, the number of prostate cancer cases would be…'.

There were 23,000 cases of prostate cancer in 2019 (the most recent actual data); by 2023, it is estimated that there will be 25,500 cases (AIHW 2023b). This large change with stable rates highlights the impact that population growth (particularly for older age groups) has on case numbers for a cancer such as prostate cancer, which often occurs at older ages where population growth is faster and incidence rates are higher.

Using nowcasting in burden of disease

The Australian Burden of Disease Study (ABDS) is a powerful resource to help understand the health of Australians over time and provides estimates of the disease burden for specific reference years since 2003. Information on burden of disease and injuries is important for monitoring population health and provides an evidence base to inform health policy and service planning. It is used to monitor progress against relevant targets in the National Preventative Health Strategy 2021–2030.

Data informing the ABDS

The data that informs the ABDS come from many different sources, including epidemiological studies, health surveys, hospital admissions, large government administrative datasets (such as the Pharmaceutical Benefits Scheme and the Medicare Benefits Schedule) and other state and national data sets, including the National Mortality Database (deaths) and the Australian Cancer Database.

These data, which vary in both currency and completeness, are used in complex models for each disease or injury to estimate the burden from living with and/or dying from a disease or injury in a specific year. For each iteration, the reporting (or reference) year is determined based on the availability of the most recent data for key data sources. Where data are not available for the reference year, simple modelling techniques are used to provide estimates for the reference year.

Benefits of nowcasting for burden estimates

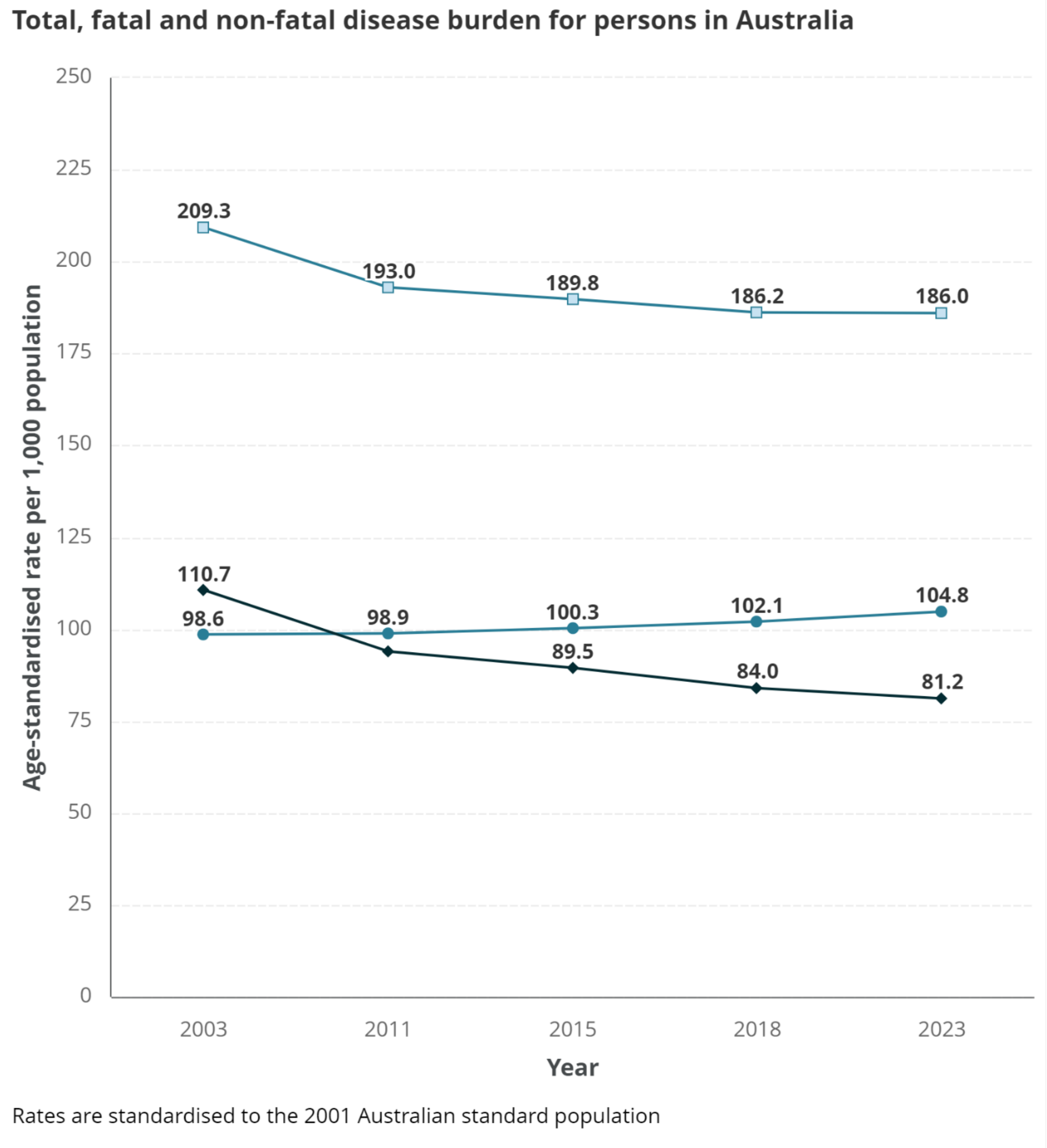
The complex methods for deriving estimates (which can take between 2 and 3 years), together with the availability of recent data, lead to delays in releasing timely national burden estimates.

- For example, the ABDS 2018 was released in 2021 based on data for the 2018 reference year. The 3-year gap between the reference year and the year of publication makes the estimates appear to be outdated and less relevant, especially so when rapid changes or major events occur in the interim, such as the COVID-19 pandemic.

Nowcasting offered an opportunity to overcome these issues. In 2022, a new approach was adopted whereby burden estimates from the most recent reference year (2019) for each disease or injury were modelled forward to the year of publication (2022), taking known impacts of the COVID-19 pandemic into account where possible, to produce annual estimates (AIHW 2022). This same approach was taken in 2023 to produce 2023 disease burden estimates (AIHW 2023a).

Figure NP.3 shows the resultant total, fatal and non-fatal disease burden from specific time points nowcast to 2023. This shows the expected continued decline of overall disease burden by 11%, driven by a strong expected decline (27%) in fatal burden and countered by an expected increase (6.3%) in non-fatal burden.

Figure NP.3: Burden of disease estimates are suitable to nowcast



Source: AIHW 2023a.

As burden of disease estimates are modelled numbers rather than 'actual' measures of disease or injury, projections to the publication year enable:

- changing age structures, healthcare needs and environmental landscapes in Australia to be accounted for
- a timely snapshot of the health challenges in Australia to be provided without substantially impacting the validity of the estimates
- more frequent and timely monitoring of progress against relevant targets in the National Preventative Health Strategy 2021–2030.

How burden estimates are nowcast

For each disease or injury, the most recent data, supplemented by information gleaned from expert consultation and from published literature, are combined with trend analysis from past years (assuming that the trend will continue) to determine the current burden. Where necessary, the reference period used to inform the trend is restricted where data are considered inappropriate for use in trend analysis.

Methods used

Two regression models are used to accommodate different annual patterns of disease:

- Where a decreasing trend is detected, the Poisson (log-linear) regression (which assumes that rates changed at a constant per cent annually) is applied.
- Where an increasing trend is detected, the simple linear (ordinary least-squares) regression (which assumes a constant fixed amount of change) is applied.

Where no change is detected, the most recent rates are assumed to apply to today's population.

Further information on the methods used are available in the Technical Notes for the Australian Burden of Disease studies 2022 and 2023.

Accounting for COVID-19 in burden of disease nowcasting

The COVID-19 pandemic presents an important consideration for the selection of appropriate models given its impacts on the input data sources available, the health system or the disease/injury itself.

For some diseases that were affected by COVID-19, estimates for 2020 are not included as that was not a typical mortality year, and morbidity was influenced by many factors, including, for example, the pandemic restrictions and the pause on non-essential surgeries. Other years may be excluded where data are considered inappropriate for use in trend analysis, such as due to coding changes, or where data in early years are not robust.

- For example, disease estimates that would otherwise rely on health surveys or screening data sources were likely to be affected due to restrictions and lockdowns in reference years following the onset of the COVID-19 pandemic. Therefore, selected regression models needed to consider factors beyond indicators of best fit and incorporate an assessment of appropriateness in considerating the pandemic data environment.

While the impact of COVID-19 on other diseases and injuries could not be fully accounted for due to limited evidence and data availability, nowcasting of 2023 burden rates – including and excluding COVID-19 (direct burden) – showed that total burden rates would have been lower in 2023 than in 2018 without COVID-19 (AIHW 2023a).

Future directions for nowcasting and projections

Improving the timeliness of data presented in our reports continues to be a strategic focus of the AIHW. Timeliness of data reporting is also monitored as a performance indicator in AIHW annual reports.

This article, which provides examples of nowcast and projected estimates from 2 key AIHW reporting areas – cancer and burden of disease – presents a valuable discussion on the usefulness and considerations of now-casting and projections in AIHW reporting.

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Nordpred software package (n.d.), Cancer Registry of Norway.

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External reviewers

Thanks to the following experts for reviewing articles of this report.

Reviewer	Article
Professor Leon Flicker – Western Australian Centre for Health and Ageing, The University of Western Australia	Improving Australia’s dementia data for national action
Dr Heidi Welberry – Centre for Big Data Research in Health, UNSW Sydney	
Dr Rowena Mobbs – Faculty of Medicine, Health and Human Sciences, Macquarie University	Concussions in Australia over the last decade
Dr Amy Peden – Senior Research Fellow, School of Population Health, UNSW Sydney	Patterns of extreme weather related injuries in Australia over the last decade
Professor Rosemary Korda – National Centre for Epidemiology and Population Health, Australian National University	Enhancing communicable disease monitoring in Australia through data linkage
Associate Professor Bette Liu – National Centre for Immunisation Research and Surveillance, Sydney Australia	
Lucy Westerman – Executive Officer, Australian Chronic Disease Prevention Alliance	The ongoing challenge of chronic conditions in Australia
Tracey Johnson – Chief Executive Officer, Inala Primary Care; Deputy Chair	
Eithne Irving – Deputy CEO and General Manager, Australian Dental Association	Australia’s dental data landscape
Professor Matthew Spittal – Melbourne School of Population and Global Health, University of Melbourne	Use of Medicare services and pharmaceuticals by mental health patients in Australia over the last decade
Professor Peter Butterworth – National Centre for Epidemiology and Population Health, Australian National University	
Professor Hayden McRobbie – School of Medicine and Health, University of New South Wales	Electronic cigarette use (vaping) in Australia in 2022–2023
Associate Professor Christopher Stevenson – School of Health and Social Development, Deakin University	Using nowcasting and projections for statistical understandings in health

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Abbreviations

ABDS	Australian Burden of Disease Study
ABS	Australian Bureau of Statistics
ACS	acute coronary syndrome
ADHD	Attention Deficit Hyperactivity Disorder
AIR	Australian Immunisation Register
ANDII	Australian National Data Integration Infrastructure
ARCPOH	Australian Research Centre for Population Oral Health
ATC	Anatomical Therapeutic Chemical
Australian CDC	Australian Centre for Disease Control
BMI	body mass index
CALD	culturally and linguistically diverse
CDBS	Child Dental Benefits Schedule
CDNA	Communicable Diseases Network of Australia
CI	confidence interval
COPD	chronic obstructive pulmonary disease
COVID-19	coronavirus disease of 2019
CSIRO	Commonwealth Scientific and Industrial Research Organisation
DALY	disability-adjusted life years
ED	emergency department
GP	general practitioner
HALE	health-adjusted life expectancy
HPV	human papillomavirus
ICD-10-AM	International Statistical Classification of Disease and Related Health Problems,10th revision, Australian Modification
IRSAD	Index of Relative Socio-economic Advantage and Disadvantage
IRSD	Index of Relative Socioeconomic Disadvantage
LGBTIQ+	lesbian, gay, bisexual, trans/transgender, intersex, queer and/or other sexuality

MaCCS	Maternity Care Classification System
MBS	Medical Benefits Schedule
NAFLD	non-alcoholic fatty liver disease
NATSIHS	National Aboriginal and Torres Strait Islander Health Survey
NCSP	National Cervical Screening Program
NDDA	National Disability Data Asset
NDSHS	National Drug Strategy Household Survey
NDSHS	National Drug Strategy Household Survey
NDTIS	National Dental Telephone Interview Survey
NHDH	National Health Data Hub
NHMD	National Hospital Morbidity Database
NHS	National Health Survey
NLP	natural language processing
NNDSS	National Notifiable Diseases Surveillance System
NOHP	Australia’s National Oral Health Plan 2015–2024
OR	odds ratio
PBS	Pharmaceutical Benefits Scheme
PCR	Polymerase chain reaction
PHRN	Population Health Research Network
PLIDA	Person Level Integrated Data Asset
pp	percentage points
RAT	Rapid Antigen Test
RPBS	Repatriation Pharmaceutical Benefits Scheme
SEIFA	Socio-Economic Indexes for Areas
STEMI	ST-segment elevation myocardial infarctionTBI traumatic brain injury
YLD	years lived with disability
YLL	years of life lost

Glossary

Aboriginal and Torres Strait Islander: In most data collections, a person who identified themselves, or was identified by another household member, as being of Aboriginal or Torres Strait Islander origin. For a few data collections, information on acceptance of a person as being Aboriginal and Torres Strait Islander by a First Nations community may also be required. See also **First Nations people**.

activity code: A code denoting what a person was doing at the time of their injury resulting in hospitalisation.

acute: A term used to describe something that comes on suddenly and is often brief, intense and severe.

additional diagnosis: A condition or complaint either coexisting with the **principal diagnosis** or arising during the episode of hospitalisation or attendance in an emergency department.

adjusted health gap: The estimated gap in the proportion of First Nations people and non-Indigenous Australians considered to be in good health, after adjusting for differences in age, sex, marital status, state/territory and remoteness of residence between these 2 subpopulations.

admitted patient: A patient who undergoes a hospital's formal admission process.

age structure: The relative number and percentage of people in each age group in a population.

age standardisation: A method to remove the influence of age when comparing rates between population groups with different **age structures**. This method is used as the rate of many diseases vary strongly (usually increasing) with age, and so, too, can service use; for example, hospitalisations – a population group with an older age structure will likely have more hospitalisations. The age structures of different populations are converted to the same 'standard' structure, and then the relevant rates, such as hospitalisations, that would have occurred within that structure are calculated and compared.

age-standardised rates: Rates that enable populations that have different age structures to be compared. The age structures of the different populations are converted to the same 'standard' structure, and then the rates that would have occurred with that structure are calculated and compared. Rates can be expressed in many ways – for example, per 100,000 per population years, per 100,000 population and per 1,000 population.

Alzheimer's disease: A degenerative brain disease caused by nerve cell death resulting in shrinkage of the brain. A common form of **dementia**.

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.

arthritis: A group of disorders for which there is inflammation of the joints, which can then become stiff, painful, swollen or deformed. The 2 main types of arthritis are osteoarthritis and rheumatoid arthritis.

asthma: A common, chronic inflammatory disease of the air passages that presents as episodes of wheezing, breathlessness and chest tightness due to widespread narrowing of the airways and obstruction of airflow.

back 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.

behaviours and psychological symptoms of dementia (BPSD): Refer to a range of non-cognitive symptoms common among people with dementia. These include – agitation, anxiety, apathy, depression, hallucinations or delusions, insomnia, risky behaviour, resistive behaviour, verbal aggression and wandering.

burden of disease (**and injury**)**:** The quantified impact of a disease or injury on a population, measured using the **disability-adjusted life years (DALYs)**.

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

cancer incidence: The number of new cases of cancer diagnosed in a given year.

cancer mortality: The number of deaths that occurred during a given year for which the underlying cause of death was recorded as cancer.

cancer prevalence: The total number of people alive at a specific date who have ever been diagnosed with cancer.

cancer survival: The probability of being alive for a given amount time after a diagnosis of cancer.

cardiovascular disease/condition: Any disease of the cardiovascular system, namely the heart (cardio) or blood vessels (vascular). Includes angina, heart attack, stroke and peripheral vascular disease. Also known as circulatory disease.

caries: Bacterial disease that causes the demineralisation and decay of teeth and can involve inflammation of the central dental pulp.

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

cervical screening test (**CST**)**:** A human papillomavirus (HPV) test with partial genotyping and, if the HPV test detects oncogenic HPV, liquid based cytology (LBC).

chronic conditions/diseases: A diverse group of diseases/conditions, such as heart disease, cancer and arthritis, which tend to be long lasting and persistent in their symptoms or development. Although these features also apply to some **communicable diseases**, the term is usually confined to non-communicable diseases.

communicable disease: An **infectious disease** or illness that may be passed directly or indirectly from one person to another.

comorbidity: In relation to an index disease/condition, any additional disease experienced by a person while they have the index disease. The index and comorbid disease/condition will change depending on the focus of the study. Compare with **multimorbidity**.

concussion: A mild traumatic brain injury typically caused by a collision (with people or objects) resulting in an impulsive force to the head (ICD-10-AM acute concussive injury codes S06.0 to S06.05).

condition (**health condition**)**:** A broad term that can be applied to any health problem, including symptoms, diseases and various risk factors (such as high blood cholesterol, and obesity). Often used synonymously with disorder.

COVID-19 (Coronavirus disease 2019): an infectious disease caused by the SARS-CoV-2 virus.

crude rate: A rate derived from the number of events recorded in a population during a specified time period, without adjustments for other factors such as age (compare with **age-standardised rates**).

current use of ecigarettes: A term describing people who reported using **electronic cigarettes** daily, weekly, monthly or less than monthly.

currently smoke: A term describing people who reported smoking tobacco daily, weekly or less than weekly.

daily smoking: A term describing people who reported smoking tobacco at least once a day (includes manufactured [packet] cigarettes, roll-your-own cigarettes, cigars or pipes). Excludes chewing tobacco, electronic cigarettes (and similar) and smoking of nontobacco products.

daily use of e-cigarettes: A term describing people who reported using **electronic cigarettes** daily.

data linkage: Bringing together (linking) information from 2 or more data sources believed to relate to the same entity, such as the same individual or the same institution. This linkage can provide more information about the entity. In certain cases, it can provide a time sequence, helping to tell a story, show pathways and perhaps unravel cause and effect. The term is used synonymously with record linkage and data integration.

dementia: General term for disorders, such as Alzheimer’s disease or vascular dementia, characterised by worsening mental processes. Symptoms include impaired memory, understanding, reasoning and physical functioning.

dental services: Preventive, diagnostic and restorative services provided by registered dental professionals.

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.

determinant: Any factor that can increase the chances of ill health (risk factors) or good health (protective factors) in a population or individual. By convention, services or other programs that aim to improve health are usually not included in this definition.

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

disability-adjusted life year (**DALY**)**:** A year (1 year) of healthy life lost, either through premature death or, equivalently, through living with disability 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.

do not smoke: A term describing people who reported never smoking tobacco, or smoking tobacco previously but not currently (ex-smoking).

e-cigarette: refer to **electronic cigarettes.**

electronic cigarettes: Devices where people inhale vapour rather than smoke. The inhaled aerosol usually contains flavourings and may also contain nicotine. Also called e-cigarettes or vapes.

emergency department (ED) presentation: An injury incident where a person visited an emergency department (see **emergency department (ED)**).

emergency department (ED): A dedicated hospital area that administers emergency care to patients suffering from an acute medical condition or injury.

end status: The status of the patient at the end of the non-admitted patient emergency department service episode, as represented by a code.

ENSO, El Niño and La Niña: El Niño–Southern Oscillation and climate drivers declared by the Bureau of Meteorology, based on oceanic temperatures and currents in the Pacific Ocean.

ever use of e-cigarettes: A term that describes people who have used electronic cigarettes at least once in their lifetime.

exceeded lifetime risk guidelines for alcohol consumption: Based on the Australian Bureau of Statistics National Health Survey. Where a person’s reported average daily alcohol consumption was determined to exceed the National Health and Medical Research Council 2009 guideline 1 for the consumption of alcohol, which recommends no more than 2 standard drinks per day to reduce the lifetime risk of harm from alcohol-related disease or injury.

ex-smoking: A term that describes a person who has smoked at least 100 cigarettes or equivalent tobacco in their lifetime but does not smoke at all now.

external cause: The environmental event, circumstance or condition given as the cause of injury, poisoning and other adverse effect.

external cause: The event, circumstance or condition given as the cause of injury, poisoning and other adverse effect.

fatal burden: The quantified impact on a population of premature death due to disease or injury. Measured as **years of life lost** (**YLL**).

First Nations people: People who have identified themselves, or have been identified by a representative (for example, their parent or guardian), as being of **Aboriginal and/or Torres Strait Islander** origin.

general practice: A medical practice that includes fully-qualified **general practitioners (GPs)**.

general practitioner (GP): A medical practitioner who provides comprehensive and continuing care to patients and their families in the community.

genomic sequence: a process to decipher the genetic material found in an organism or a virus to enable tracking of a virus.

genomic surveillance: the process of collecting genomic sequence data from representative populations to detect new variants and monitor trends.

good health: An indicator variable (either 'yes' or 'no') based on a composite good health score with 3 sub-components: self-assessed health, emotional distress and morbidity. See the section in the article 'Size and sources of the health gap for Australia's First Nations people 2017–2019' headed '*How is 'good health' measured*?' and the accompanying technical note '*Notes on the good health score sub-components*'.

health outcome: A change in the health of an individual or population due wholly or partly to a preventive or clinical intervention.

health: Term relating to whether the body (including the mind) is in a well or ill state. With good health, the state of the body and mind are such that a person feels and functions well and can continue to do so for as long as possible.

health-adjusted life expectancy: The average number of years that a person at a specific age can expect to live in full health; that is, taking into account years lived in less than full health due to the health consequences of disease and/or injury.

heatwave: An event said to occur when maximum and minimum temperatures are unusually hot over 3 or more days compared with the local climate and past weather.

hospital: A health-care facility established under Australian, state or territory legislation as a hospital or a free-standing day procedure unit and authorised to provide treatment and/or care to patients.

hospitalisation: An episode of hospital care that starts with the formal admission process and ends with the formal separation process. An episode of care can be completed by patients being discharged, transferred to another hospital or care facility, or dying, or by a portion of a hospital stay beginning or ending in a change of type of care (for example, from acute to rehabilitation). The term is synonymous with admission and separation.

immunisation: A procedure designed to induce immunity against infection by using an antigen to stimulate the body to produce its own antibodies. See also **vaccination**.

incidence: The number of new cases (of an illness or event, and so on) occurring during a given period. Compare with **prevalence**.

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.

infectious disease: A disease or illness caused by an infectious agent (bacteria, viruses, parasites and fungi and their toxic products). Many infectious diseases are also **communicable diseases**.

informal carer: A person who provides unpaid assistance or supervision to someone – usually family and friends – who needs help because of disability, physical or mental health condition, end-of-life health condition or old age, with assistance being ongoing, or likely to be ongoing, for at least 6 months. In the Australian Bureau of Statistics Survey of Disability, Ageing and Carers, informal assistance may include instances where small amounts of money, or payments for expenses incurred, are paid to the carer by the person whom they care for, or where assistance is received from family or friends who are living in the same household, whether or not the carer is paid.

injury hospitalisation: An incident where a person is admitted to hospital with injury as the main reason. If a single incident led to an admission in more than one hospital, the incident has only been counted once in data reported in this article. The term 'case' is synonymous with 'injury hospitalisation'.

insufficient physical activity: Based on AIHW analysis of the National Health Survey, insufficient physical activity is when a person's reported physical activity did not meet Australia's Physical Activity and Sedentary Behaviour Guidelines (2014). Physical activity includes walking for fitness, recreation, or sport; walking to get to or from places; moderate exercise; and vigorous exercise (multiplied by 2) recorded in the week prior to interview. Guidelines vary by age.

- For people aged 18-64: did not complete 150 minutes of moderate to vigorous activity (where vigorous activity is multiplied by 2) on 5 days or more per week.
- For people aged 65 years and over: did not complete 30 minutes or more of moderate to vigorous intensity activity (where vigorous activity is multiplied by 2) on at least 5 days each week.

International Statistical Classification of Diseases and Related Health Conditions (ICD): The World Health Organization's internationally accepted classification of diseases and related health conditions. The tenth revision (ICD-10) is used in Australia for recording the causes of death on a Medical Certificate of Cause of Death. The Australian modification (ICD-10-AM) is currently used in Australian hospitals to record diagnoses and procedures for admitted patients.

life expectancy: The average number of years that a person at a particular age can be expected to live, assuming that age-specific mortality levels remain constant.

median: The middle number of a sorted list of numbers (either ascending or descending).

Medicare Benefits Schedule (**MBS**) **data collection:** The MBS data collection contains information on services that qualify for a benefit under the *Health Insurance Act 1973* (Cwlth) and for which a claim has been processed. The database comprises information about MBS claims (including benefits paid), patients and service providers. MBS claims data are an administrative by-product of the Services Australia administration of the **Medicare** fee-for-service payment system.

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)** lists the Medicare services subsidised by the Australian Government. The schedule is part of the wider Medicare Benefits Scheme (Medicare).

Medicare-subsidised services: Services listed in the **Medicare Benefits Schedule** that resulted in a payment of **Medicare** benefit.

mental health consumer: A person who accessed at least one **Medicare Benefits Schedule** or **Pharmaceutical Benefits Scheme** mental health services within a given period of time.

mental illness (or **mental health disorder**)**:** A clinically diagnosable disorder that significantly interferes with an individual's cognitive, emotional or social abilities. The term covers a spectrum of disorders that vary in severity and duration, including **anxiety disorders**, affective disorders (such as **depression**), psychotic disorders and substance use disorders.

metadata: Information about how data are defined, structured and represented. It makes data files meaningful by describing the information captured in data, and how it is measured and represented.

morbidity: The ill health of an individual, and levels of ill health in a population or group.

mortality: The number or rate of deaths in a population during a given time period.

multimorbidity: The presence of 2 or more chronic diseases/conditions in a person at the same time. Compare with **comorbidity**.

musculoskeletal disorder/condition: One of a group of conditions, along with arthritis and other conditions, that affects the bones, muscles and joints. Other conditions include **back problems**, juvenile arthritis, osteoarthritis, osteopenia, osteoporosis (low bone density) and rheumatoid arthritis.

never smoked: A term that describes a person who had smoked fewer than 100 cigarettes or the equivalent tobacco in their lifetime.

non-fatal burden: The quantified impact on a population of ill health due to disease or injury. Measured as **years lived with disability (YLD)**, which is also sometimes referred to as years of healthy life lost due to disability.

nowcast: A term to describe a forecast of statistics to the current year based on past trends and knowledge of current events.

oral health: The health of the mouth, tongue and oral cavity; the absence of active disease in the mouth.

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.)

overweight or obese: Based on the Australian Bureau of Statistics National Health Survey, overweight or obese is when a person's body mass index (calculated by dividing the person's weight (in kilograms) by their height (in metres) squared) was 25 or over (overweight) or 30 or over (obese).

Pap test: A shortened term for the **Papanicolaou smear –** a procedure to detect cancer and precancerous conditions of the female genital tract – which is the screening test of the National Cervical Screening Program. During a Pap test, cells are collected from the transformation zone of the cervix – where the squamous cells from the outer opening of the cervix and glandular cells from the endocervical canal meet. This is where most cervical abnormalities and cancers are detected. For conventional cytology, these cells are transferred onto a slide, and sent to a pathology laboratory for assessment. Collected cells are then examined under a microscope to look for abnormalities.

permanent residential care (**aged care**)**:** Care provided to a person in an Australian government-approved aged care home, including accommodation (bedding and other furnishings, meals, laundry, social activities), personal care (bathing, showering, toileting, dressing, eating, moving about), and nursing and allied health services if required.

Pharmaceutical Benefits Scheme (PBS): A scheme through which the Australian Government subsidises the cost of a wide range of prescription medicines. Most prescriptions for General Schedule medicines (Section 85) are dispensed through community pharmacies, but the PBS is also available through eligible public hospitals to patients on discharge, and day patients. Several drugs are also distributed under alternative arrangements where these are considered more appropriate (Section 100).

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 on 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.

Population Health Areas (**PHAs**)**:** A combination of whole Statistical Areas Level 2s (SA2s) and multiple aggregates of smaller SA2s. (A Statistical Area is a geographical classification defined by the Australian Bureau of Statistics; there are 4 levels of Statistical Areas, Level 1 to 4, assigned according to increasing size and population.) This level of geography (a PHA) maintains much of the value of the SA2 geography, while ensuring that, by aggregating smaller population SA2s, relatively few areas need to have data suppressed. The Public Health Information Development Unit from Torrens University developed PHAs in collaboration with state and territory health agencies. PHA updates occur after each government Census, in line with changes to the Australian Statistical Geography Standard. For more information, see Population Health Areas.

potentially preventable hospitalisations (**PPHs**): Hospital separations for a specified range of conditions where hospitalisation is considered to be largely preventable if timely and adequate care had been provided through population health services, primary care and outpatient services.

The PPH conditions are classified as vaccine preventable, chronic and acute. Respective examples include influenza and pneumonia, diabetes complications, chronic obstructive pulmonary disease, and dental and kidney conditions. The rate of PPHs is currently being used as an indicator of the effectiveness of a large part of the health system, other than hospital inpatient treatment.

prescription: An authorisation issued by a medical professional for a patient to be issued with a particular medication.

prevalence: The number or proportion (of cases, instances, and so forth) in a population at a given time. For example, in relation to cancer, refers to the number of people alive who had been diagnosed with cancer in a prescribed period (usually 1, 5, 10 or 26 years). Compare with **incidence**.

primary health care: Services delivered in many community settings, such as 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.

Primary Health Networks (PHNs): Independent primary health care organisations that commission services and are operated by not-for-profit companies, informed by clinical councils and community advisory committees. They were established on 1 July 2015 by the then Department of Health.

principal diagnosis: The diagnosis established, after study, to be chiefly responsible for occasioning an episode of admitted-patient care. 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).

projection: A term to describe a forecast of statistics into the future using past trends and assumptions about future events.

psychosocial: A term that describes involvement of both psychological and social factors.

remoteness classification: A classification that divides each state and territory into 5 classes of remoteness based on their relative accessibility to goods and services (such as to general practitioners, hospitals and specialist care) – as measured by road distance. These regions are defined as remoteness areas by the Australian Statistical Geography Standard in each Census year. The 5 Remoteness Areas are *Major cities*, *Inner regional*, *Outer regional*, *Remote* and *Very remote.* See also **rural**.

respite care: An alternative care arrangement for dependent people living in the community, which give people – or their carers – a short break from their usual care arrangements.

rural: A term that describes geographic areas outside urban areas, such as towns and cities. In this report, ‘rural and remote’ encompasses all areas outside Australia’s *Major cities* according to the remoteness classification of the Australian Statistical Geography Standard. In many instances, the term ‘rural and remote’ is used interchangeably with the term ‘regional and remote’.

separation: The formal process by which an admitted patient completes an episode of care either by being discharged, dying, transferring to another hospital or by changing type of care.

seroprevalence surveys (serosurveys): surveys that estimate the percentage of a specific population that has been **infected** with a pathogen through serological testing. They can tell us about the total number of people who have been infected, including those infections that might have been missed.

socioeconomic areas: Areas defined according to the Index of Relative Socio-Economic Disadvantage or the Index of Relative Socio-economic Advantage and Disadvantage. These indexes are is part of the Socio-Economic Indexes for Areas (SEIFA), a set of indexes created by the Australian Bureau of Statistics from Census data that aims to represent the socioeconomic position of Australian communities and reflect the overall or average level of disadvantage of the population in an area. The SEIFA does not show how individuals living in the same area differ from each other in their socioeconomic group.

syndromic surveillance system: Used to identify illness clusters before diagnoses are confirmed and reported to public health agencies, initiating a rapid response.

telehealth: Health services delivered using information and communication technologies, such as videoconferencing or through other communication technologies.

triage category: A category used in the emergency departments of hospitals to indicate the urgency of a patient's need for medical and nursing care. Patients are triaged into 1 of 5 categories on the Australasian Triage Scale. The triage category is allocated by an experienced registered nurse or medical practitioner.

uncontrolled high blood pressure: Based on the Australian Bureau of Statistics National Health Survey, uncontrolled blood pressure is when a person's measured systolic blood pressure was 140 mmHg or more, or diastolic blood pressure was 90 mmHg or more, whether or not the person was taking blood pressure medication.

vaccination: The process of administering a vaccine to a person to produce immunity against infection. See **immunisation**.

Vapes: refer to **electronic cigarettes.**

waiting time: The time between when a patient in an emergency department is triaged and when they are seen for medical assessment. A patient is seen on time if they receive care within this timeframe.

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.

years lived with disability (**YLD**)**:** A measure calculated as the prevalence of a condition, multiplied by a disability weight for that condition. YLD represent non-fatal burden. Sometimes referred to as **years of healthy life lost due to disability** (**YLD**).

years of life lost (**YLL**)**:** For each new case, years of life lost equals the number of years between premature death and the standard life expectancy for the individual.

younger onset dementia: Dementia that develops in people aged under 65.

Australia's health 2024: data insights is a collection of 11 in-depth articles on selected health topics, including chronic conditions, communicable diseases, concussions and the health gap between First Nations people and non-Indigenous Australians.

Australia's health 2024 is the 19th biennial health report of the Australian Institute of Health and Welfare. This edition's full product suite comprises:

- *Australia's health 2024: data insights*
- Australia's health: topic summaries
- *Australia's health 2024: in brief.*