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Health and Welfare

Exploring the definition of chronic conditions for collective monitoring in Australia

2021

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Australian Institute of Health and Welfare
Canberra

CVD 91

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Context of this working paper

- **Self-reported survey data from 2017–18 reveals that 1 in 2 (47%) Australians had at least 1 of 10 selected common chronic conditions. Around 20% had 2 or more of the selected chronic conditions (AIHW 2020b).**
- **Chronic conditions were responsible for three-quarters of the total non-fatal burden of disease in Australia in 2015 (AIHW 2019b).**
- **Chronic conditions accounted for nearly 9 in 10 deaths in Australia in 2018 (AIHW 2020b)**

As ongoing causes of illness, disability and death, chronic conditions, and their prevention and management, are the focus of significant research and policy interest in Australia.

The statistical statements above are based on three different collective definitions of chronic conditions and they vary in terms of the conditions they encompass. These, and other variations of the definition of chronic conditions, are applied differently across Australian policy, health planning and research contexts, including at the Australian Institute of Health and Welfare (AIHW). Semantics are important because variation leads to confusion regarding the included conditions and inconsistent monitoring and reporting of health statistics. This in turn may affect policy, planning and resource allocation (Hajat & Stein 2018; Hvidberg 2016; Bernell & Howard 2016). Additional information on the variation in reporting is included in Appendix A.

In 2017, Australian Health Ministers endorsed the *National Strategic Framework for Chronic Conditions* (the Framework). This provides high-level guidance for an effective and coordinated national response to chronic conditions strategies, policies and programs. The Framework details a broad definition for the term 'chronic conditions', including

- those that have complex and multiple causes
- affect an individual alone or as comorbidities,
- a gradual onset,
- occur across the life cycle,
- compromise quality of life and create limitations and disability,
- are long-term, persistent, and lead to a gradual deterioration of health, and,
- while usually not immediately life threatening, are the most common and leading cause of premature mortality (Australian Health Ministers' Advisory Council 2017).

The AIHW has a long history, starting in 1996, of monitoring and reporting on chronic conditions, risk factors and health outcomes among the Australian population (AIHW 2002). In 2016, the National Centre for Monitoring Chronic Conditions (NCMCC) was established at the AIHW to provide a more streamlined, integrated and prioritised approach for reporting on chronic conditions.

The AIHW has identified an ongoing need to review, refine and assess how chronic conditions should be monitored generally and what is measurable across the spectrum of risk factors, incidence/prevalence, health care (primary health care and hospitalisation), comorbidities, functional limitation/disability, burden of disease, mortality and expenditure. The first step in this process is to determine which conditions should be monitored, and in what context. This working paper summarises an approach by the AIHW NCMCC to define and select chronic conditions for collective monitoring in Australia with greater transparency. The aim of this approach is to improve consistency and provide guiding principles for the definition of chronic conditions for collective monitoring and thereby improving national statistics for health policy, planning and research.

This approach is supported by national and international evidence and, with the assistance of worked case study examples, may form a useful reference for other organisations in making similar decisions regarding the collective analysis and reporting of chronic conditions.

What is monitoring?

Monitoring is the process of keeping a regular and close watch over important aspects of the public's health and health services through various measurements, and then regularly reporting on the situation, so that the health system and society more generally can plan and respond accordingly (AIHW 2020a).

This term is distinct from surveillance, implying more urgent watching and reporting required for infectious diseases, and from other secondary uses of health data, such as for measurement of safety and quality of patient care, assessing health system performance, cost analysis or research.

Monitoring can:

- include the measurement of risk factors, incidence, prevalence, hospitalisation, comorbidities, burden of disease, mortality, patient experience and journeys, and expenditure
- focus on trends over time
- examine the socioeconomic, geographical and environmental differentials (Kindig and Stoddart 2003; Huynh 2014)
- report on health system responses
- provide evidence for evaluation of health policy and interventions (Fairchild et al. 2017).

Chronic condition monitoring, therefore, broadly measures burden due to chronic conditions in the population, allows healthcare costs to be estimated, and can be used to assess the effectiveness of prevention or intervention efforts at a population level.

What is collective monitoring?

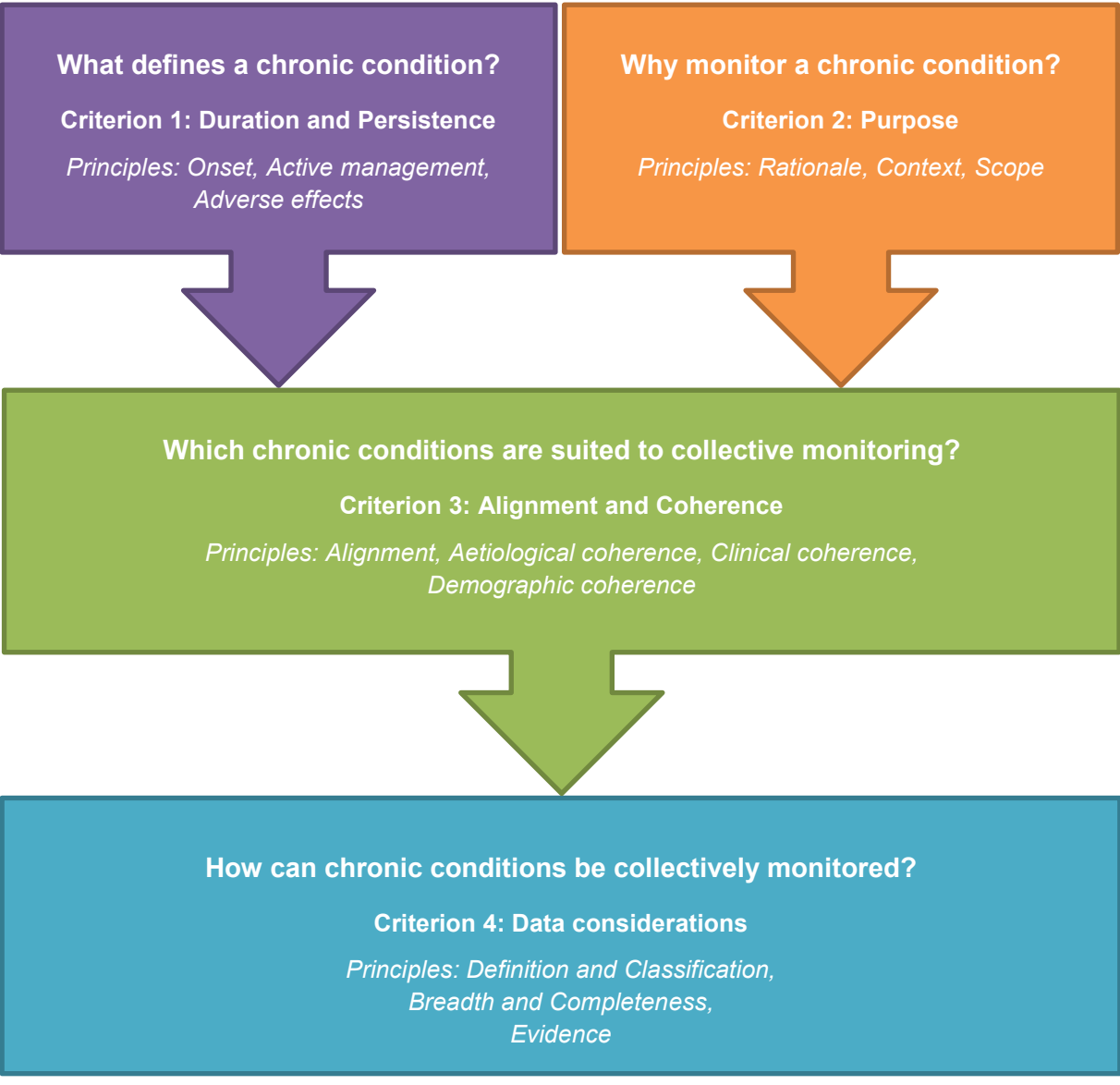
Collective monitoring looks at all chronic diseases together, rather than reporting with a disease-specific approach. This is an important perspective, as many people have more than one chronic condition, and the most common chronic conditions share many risk factors. Importantly, this approach is more people-focused.

Criteria and guiding principles for collective chronic conditions monitoring

The approach developed by the NCMCC starts with four key questions on the selection of chronic conditions for collective monitoring in Australia (Figure 1). Under each question criteria and principles have been identified for consideration. Note that these are not prescriptive.

Criteria 1 and 2 are independent considerations that define the breadth of chronic conditions and the scope of monitoring. That context defined, criteria 3 and 4 assist in forming a conceptual list and then refining it to a practical list of chronic conditions for collective monitoring.

Figure 1: Key questions, criteria and guiding principles on the selection of chronic conditions for collective monitoring in Australia



Criterion 1: Duration and persistence

What defines a chronic condition? The foundational step in determining which conditions to include in collective monitoring is to define chronic conditions, as distinct from other health conditions, for instance communicable diseases, acute diseases (including the trauma phase of injuries) and maternal conditions.

Defining chronic conditions is complex as the term covers a number of broad health and disease and management concepts. At the simplest level, chronic conditions are characterised by their long-lasting and persistent effects.

The threshold timeframe used to define a health condition as chronic varies substantially across agencies and countries, and range from 3–12 months. For example:

- The Global Burden of Disease Study defines chronic prevalence as the prevalence of chronic sequelae with a duration 3 months or longer.
- Eligibility for Medicare Benefit Scheme-funded mechanisms for coordinating care for people with chronic conditions (the Chronic Disease Management Plan or Team Care Arrangement) require a General Practitioner to determine that the condition 'has been (or is likely to be) present for 6 months or more'.
- The Australian Bureau of Statistics use a 6-month threshold for long-term conditions in the National Health and Social Surveys.
- The US Centre for Disease Control class chronic diseases as those that last 1 year or longer.

The first criterion for selecting chronic conditions therefore relates to **duration and persistence**, including consideration of:

- the time over which a condition develops
- the time over which the condition is actively managed and adverse effects persist
- disease concepts and disease progression.

Criterion 1: Duration and persistence

This is broadly defined as a combination of the time over which the condition develops (onset), is actively managed and adverse effects (sequelae) persist. Duration and persistence also takes into account disease concepts (diseases as risk factors, biomedical markers and disease states) and disease progression (latency, progression, recovery or survival).

There is no agreed threshold for duration, with definitions covering 3, 6 and 12 months. For broad monitoring purposes, any condition that develops, is managed and persists over a period of at least 3 months could be considered in scope. Questions and principles to consider in applying this criterion are:

- *Principle 1a: Nature of onset* – is it an event (stroke, heart attack, infection, injury), episodic (recurrent) or gradual development/decline?
- *Principle 1b: Persistence of active management* – is active management short term (over days or weeks), episodic and recurrent, or long-term (> 3 months)?
- *Principle 1c: Persistence of adverse effects* – are adverse effects, including symptoms, impairment, pain, or complications short term (days or weeks) or persistent (including episodic and recurrent) over the longer-term (>3 months)?

This criterion, and its principles, is not definitive or static. The group of conditions will depend on understanding of disease concepts (including diseases as risk factors, biomedical markers and disease states), causality, progression, treatment and management and the expression of those in the Australian population and clinical context.

Chronic conditions include:

- the commonly reported cardiovascular diseases, cancers, chronic respiratory conditions, chronic musculoskeletal conditions, metabolic diseases and mental health conditions
- infectious diseases that persist in the long term (sometimes for life), such as chronic hepatitis B, human immunodeficiency virus (HIV) and, more recently, COVID-19
- congenital (including genetic or chromosomal disorders) disorders, such as spina bifida, cystic fibrosis and Down syndrome
- other conditions, and disorders or disability stemming from injury such as limb amputation or traumatic brain injury.

Consideration of disease concepts and disease progression may mean the inclusion of some conditions commonly excluded from monitoring and the exclusion of some phases of a conditions (such disease-free survival for cancer or corrected eyesight).

Criterion 2: Purpose

Why monitor a chronic condition? The second criterion for selecting chronic conditions is **the purpose**. This purpose broadly provides the rationale, context and scope of the monitoring activity, with consideration of reporting outcomes, the policy, research and data environment and the breadth of population and disease reporting.

Criterion 2: Purpose

Purpose provides the rationale, context and scope of the monitoring activity, as a framework against which to select chronic conditions. Principles to consider in exploring the purpose of the monitoring activity are:

- *Principle 2a: Rationale* – is the monitoring activity aimed at prevention, exploring disparities, or developing an evidence base for health system planning?
- *Principle 2b: Context* – is there a policy or program initiative or directive, a body of emerging or ongoing research, or a reporting (indicator) framework underpinning the monitoring activity?
- *Principle 2c: Scope* – is the monitoring activity population-based or system-level or condition-specific?

The purpose provides the scene-setting statement for undertaking a monitoring activity. It describes the intended outcomes or outputs and takes into account:

- the nature of chronic condition causality and progression
- the burden, incidence, or prevalence, of the condition
- the impact of treatment and management on the individual, population and health system, over an extended period.

Policy drivers are an important contextual factor for the work of the NCMCC, and while policy may be based on evidence generated by monitoring activities, there are other contributing factors that determine the work of the NCMCC. These include:

- Actions from committees and inquiries. For example, there are a range of proposed recommendations from the 2020 Royal Commission into Aged Care Quality and Safety that have direct implications for aged care reporting within the AIHW and these will have implications for reporting of dementia (Commonwealth, Royal Commission into Aged Care Quality and Safety, 2020). Similarly, a 2017 Senate Select Committee Inquiry Report on Funding for Research into Cancers with Low Survival Rates has led to greater attention to rare cancers (Senate Select Committee, Parliament of Australia 2017).
- Global differentials. For example, the age-sex standardised rate for asthma hospital admission is substantially higher in Australia compared with the OECD average (OECD 2019), making it the focus of ongoing monitoring activities.
- Public opinion, advocacy and media attention. For example, the 2015 change.org petition that led to increased public and policy focus on endometriosis in 2018; the 2019–20 bushfires that highlighted the health impacts of poor air quality.

Other contextual drivers of a monitoring activity include research and emerging evidence, the emergence of new diseases (e.g. COVID-19) or an existing framework of indicators and reporting requirements.

The scope of a monitoring activity can be summarised as comprehensive, population- or system-level, or condition-specific. Comprehensive (holistic) monitoring activities have the broadest scope, considering comparisons between overarching disease conceptual groups for the observation of epidemiologic trends over time, between regions and population groups. A population- or system-level monitoring activity may have a comparatively narrower scope related to prevention, management, outcomes, differentials and disparities. However, the available data, and the breadth and depth of analysis and reporting will be considerably more than for a comprehensive monitoring activity. Condition-specific monitoring could be narrower still, focused on targeted analyses aimed at enhancing the evidence base for population, system and comprehensive monitoring. Alternatively, for conditions with well-established monitoring programs and robust available data, the scope of analyses and reporting could be similar to that of a population- or system-level monitoring activity.

Criterion 3: Alignment and coherence

Which chronic conditions are suited to collective monitoring? Not all conditions conceptually defined as chronic, according to criterion 1, will be in scope or fit-for-purpose as defined by criterion 2. In addition, ongoing national-level monitoring through routine data collection and reporting is costly, resource-intensive and requires complex systems (WHO 2005a) and at a practical level, monitoring activities need to be prioritised to make best use of available resources.

The third criterion in selecting chronic conditions for collective monitoring is **alignment and coherence**. For a given monitoring activity, chronic conditions selected for monitoring should, where possible:

- align with the rationale, scope and context
- present as a coherent group of conditions, based on similarity of aetiology, clinical management and demographic context.

This criterion is reflected in the The Framework, which recognises that there are groups of chronic conditions that share determinants and risk factors, have related prevention and management principles and approaches, and affect the same populations.

Criterion 3: Alignment and coherence

For a given monitoring activity, the selection of chronic conditions should align with the purpose of the activity, and, where possible, present as a coherent group. In some circumstances all chronic conditions will be in scope, where for others it will be a smaller (or singular) group of conditions. Questions and principles to consider in exploring the purpose of the monitoring activity are:

- *Principle 3a: Alignment* – does the selected condition support the rationale, context and scope of the monitoring activity?
- *Principle 3b: Aetiological coherence* – do the selected conditions have similar causal pathways, or affected body systems?
- *Principle 3c: Clinical coherence* – do the selected conditions have similar prevention or management approaches?
- *Principle 3d: Demographic coherence* – are the selected conditions of relevance for the population, region, or period of interest?

The selection of chronic conditions according to the principles of alignment and aetiological, clinical and demographic coherence take into account the practical aspects of chronic condition monitoring. That is, the monitoring activity has a purpose and expected statistical or reporting outputs. Factors considered in determining coherence will also be purpose-dependent. For example:

- A monitoring activity to report on the burden of chronic conditions in children would focus on demographic coherence (Principle 3d), and would reasonably exclude age-related conditions such as dementia or chronic obstructive pulmonary disease.
- A monitoring activity focussing on public health prevention programs would take into account causal pathways (Principle 3b), prevention approaches (Principle 3c) and relevant population and regional considerations (Principle 3d).

Criterion 4: Data considerations

How can chronic conditions be collectively monitored? While selection of chronic conditions for collective monitoring should not be driven by data availability, similar to the application of principles of alignment and coherence, it is pragmatic to consider. Can conditions, which are considered in-scope for a monitoring activity, be consistently and accurately measured, and reported in a timely manner?

There are numerous gaps in the existing Australian health information system that influence the availability of data for chronic condition monitoring. For example, there are:

- limited national primary health care data
- limited clinical disease registers linked to administrative data to examine pathways in care, in particular the associations between diagnosis, health service use and health outcomes, and in patient-reported experience (PREMs) and outcomes (PROMs)
- limited data on timeliness of interventions and the appropriateness of care, or health across the life-course
- no regular national collection of biomedical risk factor data.

Criterion 4 in refining chronic conditions for collective monitoring therefore relates to **data considerations** and the availability of quality data for robust monitoring. These considerations will be specific to the purpose of the monitoring activity, as will assessments of the relative importance, value and threshold for data quality. These assessments may consider:

- the consistency and comparability of definitions and accuracy of capture of chronic conditions within and between data sources (for example, clinician confirmed disease registers, clinical coded episodes of care, or self-reported health status)
- the breadth, completeness and representativeness of the available data (for example, cross-sectional or longitudinal surveys, administrative data, disease registers) to capture relevant aspects of the rationale (Principle 2a) and context (Principle 2b) of the monitoring activity.
- the burden of the condition in the population. Typically, conditions with higher burden in the population are well captured across data sources, which allows robust estimates to be produced.

From another perspective, data can also be used to support decision-making about conditions for collective monitoring. For example, factor analysis could be used to demonstrate clustering of conditions in a population group of interest, as a means of refining the conditions under study.

Criterion 4: Data considerations

The availability of comparable, accurate and timely data is an important consideration in finalising the list of conditions that can (or should) be included in statistical reporting outputs of a monitoring activity. The following principles and questions provide a guide to further refining the chronic conditions selected for collective monitoring:

- *Principle 4a:* Definition and classification – is there consistent and comparable capture of the selected conditions in data sets used for the monitoring activity?
- *Principle 4b:* Breadth and completeness – are there sufficient data available for all the selected conditions across the spectrum of the disease continuum, population, health system, and over time, as relevant for the monitoring activity?

In considering these principles on the selection of included chronic conditions, it is also important to note that this assessment should be regularly revisited in the context of the rapidly changing data landscape. Increasing access to data linkage opportunities at a national level, the development of new data collections and other activities underway to fill existing information gaps means that new and enhanced data for chronic condition monitoring is emerging. Additional information about existing and future data sources for collective chronic condition monitoring is included in Appendix B.

Application of the criteria and principles

While the focus of this working paper is the selection of conditions for collective monitoring of chronic disease under the NCMCC, there are other potential uses for the guiding principles. For example, for the development of public health indicators, to guide survey development, for the purpose of informing policy, and to allow for more consistent terminology across the health sector. The criteria and guiding principles are not prescriptive—they are highly contextual and need to be considered in relationship to each other.

Worked examples of the practical application of the criteria and principles to selecting chronic conditions for collective monitoring, from existing AIHW monitoring activities, are provided below.

Example 1: The epidemiologic transition

AIHW reported on the global burden of chronic conditions in *Australia's health 2018* (AIHW 2018). This demonstrated the change in the proportional contribution to the global burden of disease of chronic conditions (non-communicable disease) compared with acute (communicable), injury and maternal and neonatal conditions, over time from 1991 to 2006 (**Criterion 2: Purpose**).

The grouping of conditions was classified according to the Global Burden of Disease (GBD) definition of 'non-communicable' (**Criterion 1: Duration and Persistence**). The benefits of that grouping are that it has inter-country coherence and relevance over time (from 1991) (**Criterion 3: Alignment and Coherence**).

The 'global' nature of the monitoring activity (**Criterion 2: Purpose**), and the single data source, meant that further refinement (**Criterion 4: Data considerations**) was not required. The GBD 'non-communicable diseases' grouping includes some conditions that do not meet the threshold for duration and excludes others that do (such as HIV/AIDS). In the current Australian context, HIV/AIDS is a manageable long-term condition, however over the period of study and in other health system contexts (with varying access to anti-retrovirals) it is considered an acute infectious disease.

Example 2: Collective reporting of chronic conditions among Australia's children

The 2019 report *Australia's children* included collective measures of chronic conditions among children, in recognition that conditions requiring management over the long-term can have a substantial impact on a child's physical, social and emotional development, schooling attendance and education outcomes (AIHW 2019c) (**Criterion 2: Purpose**).

Two different groups of chronic conditions were reported, according to definitions of 'long-term' or 'persistence' (**Criterion 1: Duration and Persistence**) in sources with measures relevant to children (**Criterion 3: Alignment and Coherence**; **Criterion 4: Data considerations**). These measures show that:

- Around 4 in 10 children (aged 0–14) had at least one long-term condition lasting 6 months or more, according to the ABS National Health Survey 2017–18 (ABS 2019). The included conditions covered 16 broad body system and disease groups: diseases of the blood, circulatory system, digestive system, ear, eye, genitourinary system, musculoskeletal system, nervous system, respiratory system and skin; infectious and parasitic diseases; congenital malformations, deformations and chromosomal abnormalities; endocrine, nutritional and metabolic disorders; mental and behavioural conditions; neoplasms; and, symptoms, signs and other non-specified conditions.
- Around 6 in 10 children (aged 0–15) had at least one of 19 persistent paediatric conditions at any point in time, according to the Longitudinal Study of Australian Children (Liu et al 2018). The included conditions were: overweight, obesity, injury, anxiety/depression, frequent headaches, abdominal pain, autism spectrum disorder, attention-deficit hyperactivity disorder, eczema, sleep problems, day-wetting, soiling, constipation, recurrent tonsillitis.

The variation in included conditions and the difference in the collective statistics demonstrate the importance of transparency and clarity of definition, purpose and data source in collective monitoring activities.

Example 3: Heart, stroke and vascular disease monitoring

Since 1996, the AIHW has included heart, stroke and vascular diseases (commonly referred to as cardiovascular diseases, or CVD) in its core monitoring, as these are common (prevalent) and high burden conditions in the Australian population and many, but not all, are preventable and have readily available treatment and management options (**Criterion 2: Purpose**).

CVD is a collective term for a range of conditions affecting the circulatory system, for example coronary heart disease, stroke and heart failure. These conditions are well defined in common sources of data for chronic condition monitoring, such as the National Health Survey, National Hospital Morbidity Database and National Mortality Database. Based on these data sources, CVD:

- affected an estimated 6% of Australians aged 18 years and over in 2017–18
- contributed to an estimated 11% of hospitalisations in 2017–18
- was the underlying cause in 26% of all deaths in 2018 (AIHW 2020c).

However, while congenital heart disease, acute rheumatic fever and rheumatic heart disease meet the overarching definition of CVD (**Criterion 1: Duration and Persistence**), they are often reported separately due to their aetiological differences when compared with other chronic CVD subtypes (**Criterion 3: Alignment and coherence**).

Implications: The varying burden of chronic conditions

When measuring chronic conditions collectively, the inclusion (or exclusion) of specific conditions has the potential to substantially change the perceived impact, cost or intervention outcomes associated with that group of conditions. To illustrate this point, we undertook a sensitivity analysis to examine the result of including or excluding specific conditions from a commonly used collective definition of chronic conditions in recent AIHW publications: the 'eight selected chronic conditions' (see example in Appendix A). These conditions are: arthritis, asthma, cancer, back pain and problems, cardiovascular disease (CVD), chronic obstructive pulmonary disease (COPD), diabetes, mental and behavioural conditions (note that this includes dementia).

Three data sources were used for this analysis: AIHW National Hospital Morbidity Database 2017–18 (hospitalisations), AIHW National Mortality Database 2017 (deaths), and published results from the Australian Burden of Disease Study 2015 (burden of disease).

The eight chronic conditions accounted for:

- 38% of hospitalisations in 2017–18 (principal or additional diagnosis)
- 86% of deaths in 2017 (underlying or associated cause of death)
- 61% of the total burden of disease (Figure 2A).

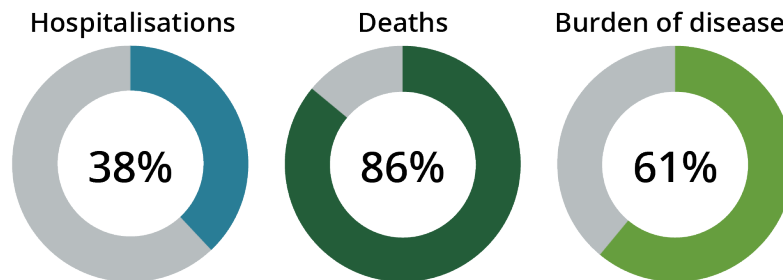
Chronic kidney disease (CKD) is associated with high health service costs. If this condition is included there is little change in burden (62%) or proportion of deaths (88% of deaths). However, there is a substantial increase in the proportion of hospitalisations with at least one chronic condition (from 38% to 51%, Figure 2B). This is largely due to hospitalisations for regular dialysis. When considering hospitalisation costs due to chronic conditions, the inclusion of CKD would substantially drive up estimates. Note also that CKD is often under-reported as a cause of death, and there is likely to be substantial overlap with other chronic conditions, so the 88% may be higher (AIHW 2014).

Osteoporosis is another chronic condition (also reported as a risk factor) of policy relevance with respect to the ageing Australian population (Osteoporosis National Action Plan Working Group 2016). The National Health Survey 2017–18 showed that 3.8% of the population have osteoporosis, with the prevalence higher among women than men (6.2% and 1.5%). However, when osteoporosis is included in the analysis, along with the baseline 8 conditions and CKD, there is no change in the proportion of hospitalisations, deaths or disease burden due to chronic conditions (Figure 2C).

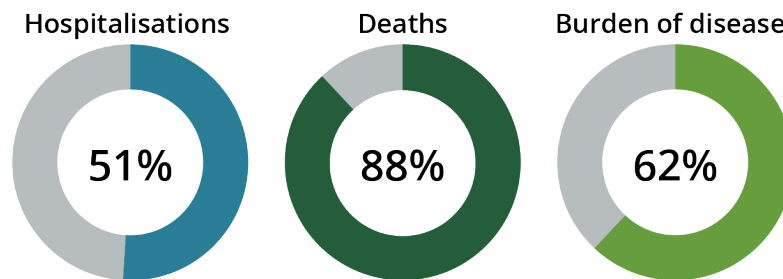
The Public Health Agency of Canada developed a Canadian Chronic Disease Indicator (CCDI) Framework (2019), which includes a collective chronic conditions indicator. This indicator includes the percentage of the population that reports having a major chronic disease, including heart disease, stroke, cancer, asthma, COPD, diabetes, arthritis, Alzheimer's (including dementia), mood disorders, and anxiety disorders. If this narrower definition is applied to the available data sources, the proportion of hospitalisations (29%), deaths (76%) and burden (51%) due to chronic conditions are lower when compared to the previous Australian examples (Figure 2D).

Figure 2: Proportion of hospitalisations in 2017–18, deaths in 2018 and burden of disease in 2015 due to selected chronic conditions, Australia

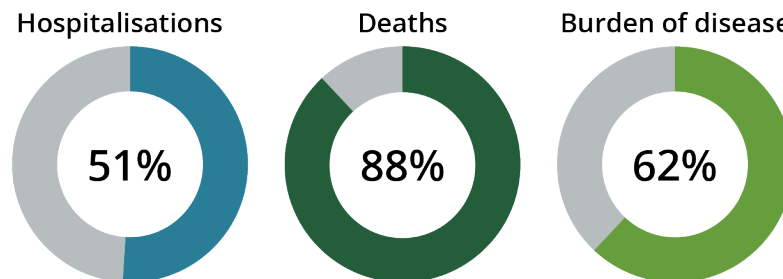
A. 8 conditions (baseline): arthritis, asthma, cancer, back pain and problems, COPD, CVD, diabetes, and mental health conditions



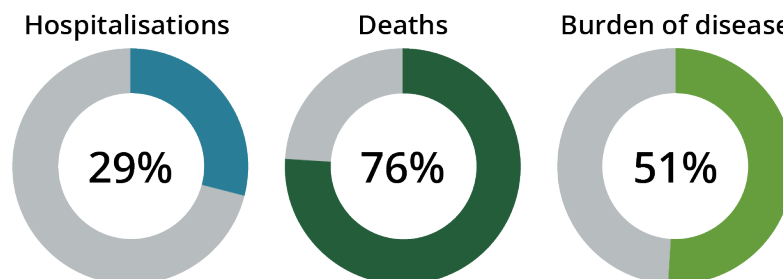
B. 9 conditions: arthritis, asthma, cancer, back pain and problems, COPD, CVD, diabetes, mental health conditions, and CKD



C. 10 conditions: arthritis, asthma, cancer, back pain and problems, COPD, CVD, diabetes, mental health conditions, CKD, and osteoporosis



D. 10 conditions: arthritis, asthma, cancer (ever had), COPD, heart disease, stroke, diabetes, Alzheimer's disease or other dementia, mood disorders and anxiety disorders



Recommendations for the NCMCC

Acknowledging the complexity of chronic conditions, there is increased attention on collective reporting of chronic conditions as part of the monitoring work of the NCMCC and across the AIHW. This work provides an important perspective, as many people have more than one chronic condition, and many chronic conditions share common risk factors.

This working paper summarises an approach by the NCMCC to define and select chronic conditions for collective monitoring in Australia. This paper does not aim to be prescriptive or set a definitive 'list' of chronic conditions for use by AIHW, but aims to highlight an ongoing need to review, refine and reassess how chronic conditions should be selected for collective monitoring. It proposes a more structured and transparent approach, using criteria and principles, to identify and select chronic conditions for the purpose of collective monitoring activities within the NCMCC work and future work plans.

This working paper may be a useful reference to help guide other organisations in making similar decisions regarding analysis and reporting.

Future directions for collective monitoring within scope of the NCMCC work include:

- expanding work on multimorbidities using linked administrative datasets
- longitudinal analysis to examine disease progression (both in terms of the number of chronic conditions and the severity of disease),
- examining health service use and patient pathways, and
- addressing the gaps in disease specific work (for example, prevention, disability and quality of life).

Appendix A: Supporting documentation

This section describes the process undertaken by the AIHW to develop the criterion and the principles for collective monitoring of chronic conditions. It includes:

- the consultation process
- international practices in chronic conditions monitoring
- Australian policy perspectives
- variation in AIHW chronic conditions reporting.

Appendix B describes the important role of data in chronic condition monitoring and of the difference definitions can make to statistical analysis.

Consultation process

Based on a review of existing literature, frameworks, and international examples, AIHW considered a number of characteristics or principles that could be used to assess conditions for inclusion in collective population monitoring. These principles included:

- Disease burden
- Duration and progression
- Complexity
- Functional limitation
- Prevention
- Policy relevance and economic benefit, and
- Data considerations

A consultation paper was developed and circulated, following initial review and comment from the Department of Health in mid-2019. Volunteer reviewers were sought from AIHW disease-specific and the Burden of Disease Expert Advisory Group members. Comments were also received from the Australian Bureau of Statistics and the Western Australia Department of Health. The consultation paper was also discussed at the AIHW Chronic Conditions Advisory Group meeting in November 2019.

Based on feedback through the consultation process AIHW redeveloped the principles into four overarching criteria, each with their own guiding principles, as listed in the paper. These include:

1. define chronic conditions
2. determine the scope of monitoring
3. select chronic conditions for collective monitoring
4. refine the list of included conditions based on available data.

International practices in chronic conditions monitoring

Chronic conditions are the focus of ongoing national and global monitoring and reporting initiatives. There is great variation in the conditions selected for collective monitoring across

countries and organisations. While some conditions, such as CVD, cancer, chronic respiratory disease and diabetes, are consistently included in chronic condition lists, other conditions such as mental health disorders, HIV/AIDS and dementia, are included in some definitions of chronic conditions but not others.

Reasons for this variation includes:

- definitional differences, such as non-communicable disease versus chronic disease versus chronic conditions (reflecting criterion 1)
- the aims of the organisation or project, such surveillance or high level prevention efforts (reflecting criterion 2 and criterion 3)
- the available data (reflecting criterion 4).

One of the key definitional differences is in the use of the terms 'non-communicable disease' (NCD) and 'chronic disease' (or condition). These are often used interchangeably, but are not synonymous. NCDs refer to conditions that are not transmitted from person to person, where chronic diseases refer to those of a long-term or persistent duration. HIV/AIDS is an example of a chronic infectious disease, and sudden infant death syndrome is an example of a non-chronic NCD.

International examples of definitional differences in the choice of conditions for chronic condition (or NCD) monitoring, as well as the context for reporting and available data are given below.

Global initiatives

A number of global initiatives, to which Australia is a member, focus on chronic non-communicable diseases.

The Global Alliance for Chronic Diseases (GACD) supports international and interdisciplinary collaborations in research. The GACD fund programs on what they consider are the five main types of NCDs (CVD, diabetes, certain cancers, lung diseases and mental health).

Similarly, the NCD Alliance is a non-government organisation, based in Switzerland that was founded in 2009. Via a global network, it leads initiatives and programmes to develop civil society capacity to deliver progress on NCD prevention and control. Their focus is cancer, CVD, chronic respiratory diseases and diabetes, due to their contribution to death and disability worldwide, and mental health and neurological disorders (dementia).

The World Health Organization

The World Health Organization (WHO) provides global leadership in the surveillance, prevention and control of NCDs. In 2000, in recognition of the four most prominent NCDs the WHO implemented a *Global Strategy for the Prevention and Control of NCDs* (WHO, 2000). The strategy linked the four most prominent NCDs, which included CVD, cancer, chronic respiratory disease and diabetes, to common preventable risk factors. In 2005, the WHO report *Preventing Chronic Diseases: A Vital Investment* outlined the important features chronic diseases share:

1. The chronic disease epidemics take decades to become fully established - they have their origins at young ages
2. Given their long duration, there are many opportunities for prevention
3. They require a long-term and systematic approach to treatment
4. Health services must integrate the response to these diseases with the response to acute, infectious diseases (WHO 2005b).

The main conditions discussed in this report were CVD (mainly heart disease and stroke), cancer, chronic respiratory diseases and diabetes. The current *Global Action Plan for the Prevention and Control of NCDs, 2013–2020*, provides a selection of policy options and related goals towards achieving a set of nine voluntary targets relating to NCDs. Target 1 is the attain a 25% reduction in premature mortality from CVD, cancer, diabetes, or chronic respiratory conditions (WHO 2013).

In October 2017, at a global conference on NCDs, WHO established an *Independent Global High-level Commission on NCDs*, which concluded in October 2019. The commission aims to support ongoing political efforts to accelerate action on cardiovascular disease, cancers, diabetes and respiratory disease, as well as reducing suffering from mental health issues and the impacts of violence and injuries (WHO 2017). In September 2018, the Third UN High-level Meeting on NCDs was held. Members agreed that efforts to prevent and treat NCDs should include policy, legislative and regulatory measures to protect people from tobacco use, poor diets and the harmful alcohol consumption. Further, they committed to a set of WHO recommended policies including education and awareness campaigns and treating hypertension and diabetes (WHO 2018a). In December 2019, the Commission published their second report *It's time to walk the talk* (WHO 2019). The report aims to build on the recommendations of the *Time to Deliver* report released by the Commission in 2018 and offers eight potential solutions to aid WHO in promoting and monitoring NCDs, globally (WHO 2018c). The recommendations made to WHO include supporting countries to create health enabling environments, encouraging investment into the prevention and control of NCDs and mental health conditions and advising countries to make NCDs essential components of Universal Health Coverage through policies and interventions.

Interestingly, WHO refer to mental and neurological disorders (such as depression, dementia, autism, epilepsy and schizophrenia) as separate to NCDs, and as conditions that can be experienced in isolation but which share many common underlying determinants, have similar consequences, and frequently co-occur (WHO 2018b). The omission of mental health disorders from WHO reporting and strategies on NCDs has been criticised (Pryor, Da Silva & Melchior 2017).

United Nations (UN) General Assembly and the Sustainable Development Goals

At a broader level, the United Nation's Sustainable Development Goals are aimed at achieving a better and more sustainable future for all. They include a specific goal to ensure healthy lives and promote well-being for all ages, by reducing premature mortality from non-communicable diseases by one-third by 2030 (UN 2017), measured via premature deaths (before 70 years of age) owing to cardiovascular disease, cancer, chronic respiratory disease or diabetes and the suicide mortality rate.

Global Burden of Disease Study (Institute of Health Metrics and Evaluation)

In 2016, the Institute of Health Metrics and Evaluation added chronic and acute concepts to their Global Burden of Disease Study Results Tool for 2015 estimates at the disease level (IHME 2017). Specifically, this included: acute incidence, acute prevalence, and chronic prevalence. Chronic prevalence was defined as the prevalence of chronic sequelae with a duration three months or longer. Of note, non-communicable diseases are included at the top level of the Global Burden of Disease hierarchy. The NCDs included in the second tier are: cardiovascular diseases, neoplasms, musculoskeletal disorders, mental and substance use disorders, diabetes and kidney diseases, chronic respiratory diseases, neurological disorders, digestive and sense diseases, skin and subcutaneous diseases and other non-communicable diseases (GBD 2019 Disease and Injury Incidence and Prevalence Collaborators 2020). In 2019, 64% of disability adjusted life years (DALY) were attributed to non-communicable disease, and two of the three leading causes of DALY globally (ischemic

heart disease, and stroke, comprising 12.8% of all DALY) were classed as non-communicable (IHME, 2019).

European Union (EU): toward a strategic framework for the prevention of NCDs

Building on the WHO Global Action plan, and drawing from other key international and European commitments on NCDs, the European Public Health Alliance, the European Chronic Disease Alliance and the NCD Alliance jointly developed a proposal for an EU strategic framework for the prevention of NCDs (EPA 2019). The proposal outlines principles, priority areas and associated actions as a framework that the European Union could use to respond to the challenge of NCDs in their region. The priority areas are to:

- Create health-enabling environments, encouraging physical activity and healthy food choices.
- Implement the WHO 'best buys' (WHO 2017b). A list of policy options to combat NCDs in relation to smoking, harmful use of alcohol, unhealthy diet, low physical activity, cardiovascular disease, diabetes and chronic respiratory disease.
- Address the commercial determinants of health, to reduce the effect of products and choices that are detrimental to health.
- Tackle health inequalities caused by socioeconomic disparity, poverty and social exclusion.
- Adopt a rights-based approach, focused on upholding fundamental rights to health, adequate living standards, food and a clean environment.
- Pursue an integrated approach to mental health, on parity with physical health.

Other country reporting

There are differences between the chronic diseases routinely monitored between different countries, which reflects differences in disease burden profiles, population characteristics, and key policy issues.

United States

The Centers for Medicare and Medicaid Services use Medicare data to regularly report on 21 conditions at a state and national level. Those beneficiaries with a claim indicating that they received a service or treatment for a relevant condition are considered to have a chronic disease. Conditions include a wide range of communicable (e.g. HIV/AIDS and hepatitis), non-communicable diseases (e.g. Alzheimer's and related dementia and stroke), conditions (e.g. autism spectrum disorder), and risk factors (hypertension and hyperlipidaemia).

The Centers for Disease Control and Prevention (CDC) National Center for Chronic Disease Prevention and Health Promotion reports on 124 chronic disease indicators (CDI). THE CDC considers a condition chronic if it lasts for 1 year or more and requires ongoing medical attention and/or results in functional impairment. The 124 indicators were agreed via consensus of subject-matter experts to ensure that the CDI were responsive to the expanded scope and priorities of chronic disease prevention programs in state health departments. This body of work provides an example of state based health surveillance indicators, developed through consensus, which are consistent at national, state and local public health areas.

United Kingdom

The National Health Service Outcomes Framework is a set of indicators that measure performance in the health and care system at a national-level. The Framework includes five domains. Domain 1 relates to 'Preventing people from dying prematurely'. This includes indicators for premature death due to CVD, respiratory disease, liver disease, cancer, and among people with serious mental illness. Domain 2 has the aim of 'Enhancing quality of life for people with long-term health conditions'. This includes those living with dementia and mental illness. In addition, there is a specific indicator related to the quality of life of those living with multiple long-term conditions.

Europe

In 2012, the Netherlands National Institute for Public Health and the Environment (RIVM) presented a report to the Council of the European Union collating comparable information at the European level on the incidence, prevalence, risk factors and outcomes of chronic diseases. The report focused on the following conditions:

- cardiovascular disease (as a group of diseases that involve the heart or blood vessels): ischemic heart disease and stroke
- cancer
- diabetes
- respiratory diseases (as a group of diseases of throat and lungs): chronic obstructive pulmonary disease (COPD), asthma, allergic rhinitis
- mental disorders: depression
- neurodegenerative disorders (diseases characterised by progressive nervous system dysfunction): dementia, Parkinson's disease and multiple sclerosis

The European Core Health Indicators (ECHI) indicator on self-reported chronic morbidity provides information on the prevalence of chronic illness. This includes any long-standing chronic illness or health problem. The data on self-reported chronic morbidity are available for all EU countries and Iceland, Norway, Switzerland and Croatia.

The Norwegian Institute of Public Health specifically report chronic diseases such as asthma and allergy, cancer, cardiovascular disease, dementia, diabetes and osteoporosis and fractures. Dental and mental health statistics are reported separately to other chronic diseases.

Canada

The Public Health Agency of Canada (PHAC) supports a World Health Organization (WHO) Collaborating Centre on Chronic Non-communicable Disease Policy by providing the data, analysis, web tools and technical advice that support policies, programs and public health interventions for chronic disease prevention. PHAC funds the Canadian Primary Care Sentinel Surveillance Network (CPCSSN) that is a national chronic disease surveillance system based on electronic health record data. It captures information on hypertension, osteoarthritis, diabetes, chronic obstructive pulmonary disease, depression, and three neurologic conditions (dementia, epilepsy and Parkinson's disease) from primary care providers using detailed case definitions (Garies et al. 2017). Of note, each diagnosis requires an explicit clinical diagnosis, rather than biomedical measurements alone.

PHAC also developed a Chronic Disease Indicator Framework to allow for consistent and reliable information gathering on chronic diseases. Interestingly, they report a collective chronic conditions indicator, which is the percentage of the population that reports having a

major chronic disease, which is inclusive of cardiovascular diseases, cancer, chronic respiratory diseases, diabetes and mental illness.

The Canadian Institute for Health Information (CIHI) website and products do not provide any overarching definition of chronic conditions, however they are referred to in a generic way. For example, a study on chronic disease management in primary health care: a demonstration of electronic medical record data for Quality and Health System Monitoring identified seven chronic diseases in collaboration with primary health care clinicians using validated algorithms including: asthma, chronic obstructive pulmonary disease, coronary artery disease, depression, diabetes, hypertension and or osteoarthritis (CIHI 2014).

New Zealand

Increasing the effort on prevention, early intervention, rehabilitation and wellbeing for people with long-term conditions, as well as addressing common risk factors is an area for action under the New Zealand Health Strategy (Minister of Health 2016a). The focus for New Zealand is to address the challenges arising from the changing patterns of disease, the rise of conditions that are related to unhealthy lifestyles (both acute and long-term) and of conditions that are long term (whether preventable or not).

In the document *National Expectations for the Prevention and Management of Long-Term Health Conditions* the authors provide that long-term health conditions, or non-communicable diseases, are defined as: any ongoing, long term or recurring condition that can have a significant impact on people's lives. Example long-term conditions include: cancers, cardiovascular diseases, chronic kidney disease, chronic pain, chronic respiratory conditions, dementia, diabetes, enduring mental health conditions and addiction, musculoskeletal conditions (Ministry of Health 2016b).

Australian policy perspectives

The National Strategic Framework for Chronic Conditions

The National Strategic Framework for Chronic Conditions (the Framework) was publicly released in May 2017. The Framework provides guidance for the development and implementation of policies, strategies, actions and services to address chronic conditions and improve health outcomes and is the overarching policy document for chronic conditions that sets the direction and outcomes to achieve the vision that 'all Australians live healthier lives through effective prevention and management of chronic conditions'. The term 'chronic conditions' is used in the Framework to replace terms such as chronic disease, non-communicable diseases and long-term conditions.

The Framework details a broad definition for the term 'chronic conditions', encompassing many different long-term and complex health conditions across the spectrum of illness. As an overarching definition, the Framework provides that chronic conditions:

- have complex and multiple causes;
- may affect individuals either alone or as comorbidities;
- usually have a gradual onset, although they can have sudden onset and acute stages;
- occur across the life cycle, although they become more prevalent with older age;
- can compromise quality of life and create limitations and disability;
- are long-term and persistent, and often lead to a gradual deterioration of health and loss of independence; and

- while not usually immediately life threatening, are the most common and leading cause of premature mortality (Australian Health Ministers' Advisory Council 2017).

Within the context of this definition, the Framework provides guidance to 'enhance current disease-specific policies and develop new and innovative approaches to address chronic conditions'.

The Australian Health Ministers' Advisory Council (AHMAC) agreed to the development of a nationally agreed reporting mechanism (the Reporting Framework), led by the Commonwealth Department of Health, to complement the Framework. The aim of the Reporting Framework is to allow progress against the Objectives of the Framework to be monitored. In addition to The National Strategic Framework for Chronic Conditions, a number of current and past policies are relevant to the monitoring of chronic conditions. They include the Australian Health Performance Framework, the Aboriginal and Torres Strait Islander Health Performance Framework and The National Health Reform Agreement.

National Health Reform Agreement

To improve coordination of care for people with chronic conditions the Australian Government has implemented a range of approaches including access to care plans and assessments through the Medicare Benefits Schedule for the planning and management of chronic conditions; and similarly, subsidies through the Pharmaceutical Benefits Scheme for a range of medicines used in the treatment of chronic conditions.

In 2011, the Council of Australian Governments (COAG) agreed to major structural reforms to the organisation, funding and delivery of health care, and new financial and governance arrangements for Australian public hospital services. In 2017, an addendum was agreed to the *National Health Reform Agreement: Revised Public Hospital Arrangements*, which included sections on 'Coordinated care for patients with chronic and complex disease', and Health Care Homes implementation. The amendment included an agreement to develop bilateral jurisdiction-specific activities based on common principles, including the requirement to be evidence-based. Activities funded under this agreement should target patients that have multiple chronic and complex conditions and can most benefit from enhanced coordinated care. The addendum also detailed how these bilateral activities will complement the introduction of the Health Care Homes model in primary health care. This initiative is where patients are enrolled to a specific general practice or Aboriginal Community Controlled Health Service to coordinate a patient's care and to facilitate services by a care team, which can include a range of health professionals (for example, the general practitioners (GP), specialists, allied health professionals, practice nurses) (Department of Health 2017b).

The 2020–25 National Health Reform Agreement (NHRA) was announced in May 2020 and took effect on 1 July 2020. The NHRA is between the Australian Government and all state and territory governments. It provides that the Australian Government will contribute around \$133.6 billion between 1 July 2020 and 30 June 2025 for state and territory public hospital services. The NHRA seeks to provide improved coordinated care in the community and to ensure the future sustainability of the Australian Health System. The NHRA introduced 6 health reforms. These are:

- empowering people through health literacy – person-centred health information and support will empower people to manage their own health well and engage effectively with health services
- prevention and wellbeing – to reduce the burden of long-term chronic conditions and improve people's quality of life
- paying for value and outcomes – enabling new and flexible ways for governments to pay for health services

- joint planning and funding at a local level – improving the way health services are planned and delivered at the local level
- enhanced health data – integrating data to support better health outcomes and save lives
- nationally cohesive health technology assessment – improving health technology decisions will deliver safe, effective and affordable care (Department of Health 2020).

Past national policies and initiatives related to chronic conditions

It is important to note the changes in national policies and initiatives related to chronic conditions to understand how the definition has changed over time. The policies and programs outlined below are by no means exhaustive, but have been included to demonstrate change in the definition over time.

The Framework supersedes the National Chronic Disease Strategy 2005 and associated National Service Improvement Frameworks. The National Chronic Disease Strategy was endorsed in 2005 as the principal framework to direct the way policies for chronic disease prevention and care were developed (NHPAC 2006). The Strategy focused on five disease groups, including asthma; cancer; diabetes; heart, stroke and vascular disease; and osteoarthritis, rheumatoid arthritis and osteoporosis.

In the same period, a Blueprint for nation-wide surveillance of chronic disease and associated determinants was also endorsed in November 2005 (NPHP 2006). The Blueprint documented the framework for surveillance of preventable chronic diseases and their determinants in Australia. Interestingly, at that stage, ongoing surveillance was recommended with a nation-wide approach to aspects of chronic disease management.

A range of programs and strategies were released over the last 15 years to reduce and control the burden of chronic conditions. As an example, the National Preventative Health Taskforce was established in 2008 to develop a National Preventative Health Strategy (NPHS) referred to as Australia: the Healthiest Country by 2020. The strategy focused on obesity, tobacco and alcohol, key risk factors for chronic disease, and set targets for prevention.

The Council of Australian Governments (COAG) signed the National Partnership Agreement on Preventive Health (NPAPH) in 2008, which formed an agreement to reform Australia's efforts in preventing the lifestyle risks that cause chronic disease and set a number of complementary targets. Furthermore, to promote a consistent approach to prevention of chronic conditions, the creation of a national health prevention body was recommended by the National Health and Hospital Reforms Commission in 2009, and in 2010 the Australian National Preventive Health Agency (ANPHA) was established (and subsequently ceased operations).

The Australian Health Performance Framework

The Australian Health Performance Framework (AHPF) was endorsed by AHMAC in September 2017. The primary objective of the AHPF is to improve health outcomes for all Australians and ensure the sustainability of the Australian health system. The AHPF seeks to provide 'a single, enduring and flexible vehicle to support system-wide reporting on Australia's health and health care performance, to support the assessment and evaluation of value and sustainability, and to inform the identification of priorities for improvement and development'. With relevance to chronic conditions, the AHPF includes a number of measures relating to chronic disease risk factors, potentially avoidable deaths, and reporting for specific chronic conditions (e.g. incidence of end-stage kidney disease, prevalence of diabetes).

The Aboriginal and Torres Strait Islander Health Performance Framework

The Aboriginal and Torres Strait Islander Health Performance Framework was released in 2006, under the auspices of AHMAC. The framework aims to monitor progress in Indigenous health outcomes, health system performance and determinants of health. Further, it aims to support coordinated efforts to address the complex and interrelated factors that contribute to health outcomes (Department of Health 2017a).

Reporting against the Aboriginal and Torres Strait Islander Health Performance Framework is now in its sixth edition and includes 68 performance measures across three tiers. Tier 1 relates to health conditions and includes data for a range of chronic conditions including respiratory disease, circulatory disease, rheumatic heart disease, cancer, diabetes, kidney disease, oral health and HIV/AIDS. Tier 2 relates to determinants of health and includes health behaviours and person related factors (e.g. tobacco use, risky alcohol consumption, and overweight and obesity), and tier 3 relates to health system performance. This tier includes a specific measure of care planning for chronic disease.

Of interest, the most recent report finds that chronic diseases account for two thirds of the health gap between Indigenous and non-Indigenous Australians, based on AIHW burden of disease estimates. The conditions included in this figure are mental health and substance use disorders, injuries (including suicides), cardiovascular diseases, cancer, respiratory diseases, and musculoskeletal conditions.

Australia's Health Tracker and the Australian Health Policy Collaboration

The aim of the Australian Health Policy Collaboration (AHPC), based at Victoria University, is to inform and influence public policy and its practice with the aim of improving the health of Australians, in particular those from socio-economically disadvantaged communities. In 2015, the AHPC released a proposed set of national targets and indicators to assist in tracking progress on action on reducing chronic disease and reviewed the suitability of the WHO 25x25 approach (McNamara et al. 2015; Tolhurst 2015). This work involved seven working groups that reviewed target indicators in Australia including mortality, morbidity and high-risk populations; alcohol; physical inactivity; salt; tobacco; obesity and diabetes; and, mental health. Unlike the WHO approach, mental health was recognised as a significant area of chronic disease, and thus was included in the seven topics.

Variation in AIHW chronic conditions reporting

The definition on the AIHW website refers to the common features of chronic conditions, including:

- complex causality, with multiple factors leading to their onset
- a long development period, for which there may be no symptoms
- a prolonged course of illness, perhaps leading to other health complications
- associated functional impairment or disability (AIHW 2017a).

Despite this, the term chronic conditions is not used consistently across current AIHW products. While this is, in part, due to individual reporting requirements and data availability, the lack of consistency can be confusing and misleading for readers. Two examples are outlined below.

Example 1: The ‘eight chronic conditions’

The AIHW has primarily published data on chronic conditions for eight key diseases and disease groups, including arthritis, asthma, back problems, cancer, Chronic Obstructive Pulmonary Disease (COPD), cardiovascular disease (CVD), diabetes, and mental health conditions.

The eight conditions were originally selected, based on self-reported data from the Australian Bureau of Statistics (ABS) 2014–15 National Health Survey (NHS), because they are common, pose significant health problems, and action can be taken to prevent their occurrence. Since then, these eight diseases and disease groups have been commonly used to represent all chronic conditions in AIHW products. However, this provides only a limited picture of the ways in which chronic conditions affect the health system and Australia’s health collectively.

More recently, the AIHW and ABS have expanded this definition to include 10 chronic conditions. The additional conditions include chronic kidney disease and osteoporosis (AIHW 2020b, ABS 2018).

Example 2: Australian Burden of Disease Study 2011

Within the products and publications based on the results from the Australian Burden of Disease Study (ABDS) 2011, chronic conditions were referred to in various combinations. The use of different lists of chronic conditions, in this case, within the same project, highlights the critical issue with consistency, where published statistics are not strictly comparable, and most readers will not discern that there is a methodological difference.

In the *Australian Burden of Disease Study: impact and causes of illness and death in Australia 2011—summary report* (AIHW 2016a), the top five disease groups were estimated to account for 66% of total burden and this was published under the heading ‘chronic disease and injury dominate’, which implies that these five disease groups were considered chronic conditions. The disease groups included were cancer, cardiovascular diseases, mental and substance use disorders, musculoskeletal conditions and injuries. Note that this same approach was repeated in the summary report of the Australian Burden of Disease Study 2015 (AIHW 2019a). In *Australia’s Health 2016* (AIHW 2016b), a slightly different analysis was undertaken using the ABDS database to report that the contribution of chronic conditions was 61% of total burden. This analysis was aligned with the 8 chronic conditions discussed above in Example 1. A different definition, which resulted in a substantially broader range of conditions, was developed for reporting in the *Australian Burden of Disease Study: impact and causes of illness and death in Aboriginal and Torres Strait Islander people 2011*. In this report, it was estimated that chronic conditions caused 64% of the total disease burden among Indigenous Australians in 2011.

Appendix B: Data sources for collective chronic condition monitoring

Data considerations are the fourth criteria in determining a list of chronic conditions for collective monitoring. To reduce the impact of methodological differences (such as self-report versus a diagnosis from a medical practitioner), collective monitoring should ideally make use of a single data source. Further, chronic conditions should be listed at a consistent level for comparability, this means comparison should be made as individual conditions or as disease groups (all-inclusive of the individual conditions), but not a mix of the two. For example, comparison could be made between asthma and osteoarthritis, but not between asthma and musculoskeletal conditions.

There are a number of data sources that provide information on the prevalence of chronic conditions, and their associated risk factors, in the population. These include registry, survey and administrative data. The following provides examples of these. It is not an exhaustive list.

Survey data

National Health Surveys, ABS

The 2017–18 National Health Survey was designed to allow for estimation of the prevalence of long-term health conditions and risk factors in Australia and by state and territories. The self-report survey included a broad range of conditions that have lasted, or were expected to last, six months or more. Of note, as the survey includes self-report data only, the prevalence is likely to be underestimated for some conditions. For example, the 2011–12 NHS, which included a biomedical component, identified that 1 in 5 people living with diabetes were unaware they had the condition.

National Health surveys have been completed in 1989–90, 1995, 2001, 2004–05, 2007–08, 2011–12, 2014–15 and 2017–18.

General Social Survey, ABS

The most recent survey was completed in 2019. The survey collected information social circumstances and outcomes. One component of this was long-term health conditions. A long term health conditions was defined as a 'current disease or disorder that has been diagnosed by a doctor, nurse or other health professional and has lasted, or is likely to last, for six months or more'.

2021 Census of Population and Housing, ABS

The next national census will be held in August 2021. This census will include a new question about long-term health conditions. Conditions include: arthritis, asthma, cancer (including remission), dementia (including Alzheimer's), diabetes (excluding gestational), heart disease (including heart attack or angina), kidney disease, lung condition (including COPD or emphysema), mental health condition (including depression or anxiety), stroke, and any other long term health condition(s).

It is intended that these data will inform health policy, inform service planning at the local level, target programs and resources for prevention and treatment, and monitor change under the National Health Reform Agreement and other reporting frameworks and initiatives. These data will allow for estimates to be derived at more granular geographies and sub-populations when compared to existing National Health Surveys (ABS 2020)

Coordination of Health Care Study, ABS & AIHW

The Coordination of Health Care Study examined coordination and continuity of care among people aged 45 years and over who had visited a GP between November 2014 and November 2015. The survey collected information on long-term health conditions, which were defined as those that has lasted, or is expected to last, 6 months or more. This included diabetes, heart disease, high blood pressure or hypertension, effects of a stroke, cancer, asthma, chronic lung disease, osteoporosis, arthritis, mental health condition, Alzheimer's disease or dementia, and moderate or severe pain, or other. These diseases and/or symptoms were selected based on prevalence, with the intention of disaggregating results at the Primary Health Network area level.

Administrative data

Increasing access to administrative datasets, and in particular linked datasets, provide a growing opportunity to monitor chronic conditions, and their associated service use, in the population. Advantages of administrative data include a high degree of population coverage (or potential for), timeliness, and the potential for longitudinal analysis.

Existing AIHW datasets that provide insight into the burden of chronic disease in the population include the National Hospital Morbidity Database and National Mortality Database. Further, the Medicare Benefits Schedule (MBS) dataset includes specific chronic disease management items that provide a measure of service use. However, it is important to highlight that these datasets do not allow prevalence to be estimated.

The National Integrated Health Services Information Analysis Asset (NIHSI AA) is a linked analysis resource, which combines data from multiple AIHW-held data collections. NIHSI AA contains de-identified data on admitted patient care services (in all public and, where available, private hospitals), emergency department services and outpatient services in public hospitals for all participating states and territories. It also includes national data for the same period from the MBS, Pharmaceutical Benefits Scheme and Repatriation Schedule of Pharmaceutical Benefits as well as Residential Aged Care data and National Deaths Index data. NIHSI AA provides an opportunity to improve estimates of the frequency of specific chronic conditions within the Australian population, and to develop a national system for the surveillance of those conditions.

While Australia currently lacks primary health care data that can be used for national surveillance, international examples exist. As outlined previously, the Canadian Primary Care Sentinel Surveillance Network, which is based on electronic health record data, captures information on hypertension, osteoarthritis, diabetes, chronic obstructive pulmonary disease, depression, and three neurologic conditions (Alzheimer's and related dementias, epilepsy and Parkinson's disease) from primary care providers using detailed case definitions (Williamson et al. 2014).

My Health Record (MHR) is an Australian digital health record system, which allows for the sharing of health information between healthcare providers. This may be a future data source for monitoring chronic conditions. In 2018 the AIHW was appointed to manage and release datasets for the MHR. This dataset contains a rich source of health information, including records written by doctors, diagnostic imaging, referral documents and personal health notes. While individuals are able to opt out of MHR, which means data is not captured for the whole population, MHR may provide an opportunity to improve estimates of chronic condition prevalence, our understanding of the management of conditions, and better understand patient pathways through the health care system.

National Hospital Morbidity Database, AIHW

The National Hospital Morbidity Database (NHMD) is a compilation of episode-level records from admitted patient morbidity data collection systems in Australian hospitals.

The data supplied are based on the National Minimum Data Set (NMDS) for Admitted patient care and include demographic, administrative and length of stay data, as well as data on the diagnoses of the patients, the procedures they underwent in hospital and external causes of injury and poisoning.

The purpose of the NMDS for Admitted patient care is to collect information about care provided to admitted patients in Australian hospitals. The scope of the NMDS is episodes of care for admitted patients in all public and private acute and psychiatric hospitals, free-standing day hospital facilities, and alcohol and drug treatment centres in Australia. Hospitals operated by the Australian Defence Force, corrections authorities and in Australia's off-shore territories are not in scope but some are included.

An admitted patient is a patient who undergoes a hospital's formal admission process to receive treatment and/or care. Statistics on admitted patients are compiled when an admitted patient completes an episode of admitted patient care and 'separates' from the hospital. Separation is the term used to refer to the episode of admitted patient care, which can be a total hospital stay (from admission to discharge, transfer or death) or a portion of a hospital stay beginning or ending in a change of type of care (for example, from acute to rehabilitation care). 'Separation' also means the process by which an admitted patient completes an episode of care by being discharged, dying, transferring to another hospital or changing type of care.

For the analysis in Table B1-B4, the data set includes records for admitted patient separations between 1 July 2016 and 30 June 2017. The following care types were excluded when undertaking the analysis: 7.3 (newborn—unqualified days only), 9 (organ procurement—posthumous) and 10 (hospital boarder).

Table B1 lists ICD-10-AM codes for common chronic conditions.

Table B1: ICD-10-AM coding (9th edition, ACCD 2014)

Condition	Codes
Arthritis	M05, M06, M08, M09, M13-M19
Asthma	J45, J46
Back pain and problems	M40-M43, M45-M51, M53, M54, M99
Osteoporosis	M80-M82
Cancer	C00-C99, D45, D46, D47.1 D47.3 D47.4 D47.5
Cardiovascular disease	I00-I99
Diabetes	E10, E11, E13, E14
Chronic obstructive pulmonary disease (COPD)	J40-J44
Mental health conditions	F00-F99
Mood and anxiety disorder	F30-F39, F40-F48
Alzheimer's and other dementia	F00, F01, F02, F03
Chronic Kidney disease	E10.2, E11.2, E13.2, E14.2, I12, I13, I15.0, I15.1, T82.4, T86.1, Q60-Q63, N00-N08, N11, N12, N14-N16, N18, N19, N25-N28, N39.1, N39.2, Z49.0, Z49.1, Z49.2, Z49.0

In July 2015, a list of 29 supplementary codes for chronic conditions (U78-U88) and a new Australian Coding Standard (0003) were implemented in the *International Statistical Classification of Diseases and Related Health Problems, Tenth Revision, Australian Modification (ICD-10-AM) 9th edition* and *Australian Coding Standards (ACS)*. These codes were introduced as clinically important chronic conditions that would not normally be coded in hospitalisations as a principal or additional diagnosis (under the current ACS) (ACCD 2014). The supplementary codes are not used in the allocation of diagnosis related groups. For 2015–16, about 4.8 million supplementary codes were reported, with the most common being for hypertension, depression, ischaemic heart disease and arthritis and osteoarthritis (AIHW 2017c).

The list is interesting as it includes conditions that have not historically been included for routine collection, for example neurological conditions such as Parkinson's disease and Dementia (including in Alzheimer's disease); and congenital and chromosomal abnormalities such as Spina bifida and Down's syndrome. Note that these codes have not been used in the analysis in this report (the section titled Implications: the varying burden of chronic conditions). See Table B2 below for the detailed list of conditions included.

Table B2: Extract from ICD-10-AM supplementary codes for chronic conditions

Condition	Codes
Endocrine, nutritional and metabolic diseases	U78
Obesity	U78.1
Cystic fibrosis	U78.2
Mental and behavioural disorders	U79
Dementia (including in Alzheimer's disease)	U79.1
Schizophrenia	U79.2
Depression	U79.3
Disorder of intellectual development	U79.4
Developmental delay	
Intellectual: development disorder; disability	
Mental retardation	
Diseases of the nervous system	U80
Parkinson's disease	U80.1
Multiple sclerosis	U80.2
Epilepsy	U80.3
Cerebral palsy	U80.4
Tetraplegia, paraplegia, diplegia, monoplegia and hemiplegia due to any cause	U80.5
Quadriplegia	
Diseases of the circulatory system	U82
Ischaemic heart disease	U82.1
Coronary artery disease	
Chronic heart failure	U82.2
Chronic congestive heart: disease; failure	
Hypertension	U82.3
Diseases of the respiratory system	U83
Emphysema, without mention of chronic obstructive pulmonary disease	U83.1
Chronic obstructive pulmonary disease	U83.2
Asthma, without mention of chronic obstructive pulmonary disease	U83.3
Bronchiectasis, without mention of cystic fibrosis	U83.4
Chronic respiratory failure	U83.5
Diseases of the digestive system	U84
Crohn's disease	U84.1
Ulcerative colitis	U84.2
Chronic liver failure	U84.3
Disorders of the musculoskeletal system and connective tissue	U86
Rheumatoid arthritis	U86.1
Arthritis and osteoarthritis	U86.2
Systemic lupus erythematosus	U86.3
Osteoporosis	U86.4

(continued)

Table B2: (continued) Extract from ICD-10-AM supplementary codes for chronic conditions

Condition	Codes
Diseases of the genitourinary system	U87
Chronic kidney disease, stage 3–5	U87.1
Chronic kidney: failure (stage 3–5); injury	
Congenital malformations, deformities and chromosomal abnormalities	U88
Spina bifida	U88.1
Down's syndrome	U88.2
Trisomy 21	

National Mortality Database, AIHW

Information of causes of deaths nationally is sourced from the Registries of Births, Deaths and Marriages in each state and territory, and the National Coroners Information System (managed by the Victorian Department of Justice), and coded by the Australian Bureau of Statistics (ABS). These data are maintained by the Australian Institute of Health and Welfare (AIHW) in the National Mortality Database (NMD).

The data quality statements underpinning the AIHW NMD can be found in the following Australian Bureau of Statistics (ABS) publications:

- [ABS quality declaration summary for Deaths, Australia \(ABS cat. no. 3302.0\)](#)
- [ABS quality declaration summary for Causes of death, Australia \(ABS cat. no. 3303.0\)](#)

For more information on the AIHW National Mortality Database see [Deaths data at AIHW](#).

Table B3: ICD-10 Coding

Condition	Codes
Arthritis	M05, M06, M08, M09, M13-M19
Asthma	J45, J46
Back pain and problems	M40-M43, M45-M51, M53, M54, M99
Osteoporosis	M80-M82
Cancer	C00-C99, D45, D46, D47.1 D47.3 D47.4 D47.5
Cardiovascular disease	I00-I99
Diabetes	E10, E11, E13, E14
Chronic obstructive pulmonary disease (COPD)	J40-J44
Mental health conditions	F00-F99
Mood and anxiety disorder	F30-F39, F40-F48
Alzheimer's and other dementia	F00, F01, F02, F03
Chronic Kidney disease	E10.2, E11.2, E13.2, E14.2, I12, I13, I15.0, I15.1, T82.4, T86.1, Q60-Q63, N00-N08, N11, N12, N14-N16, N18, N19, N25-N28, N39.1, N39.2

Other sources

Australian Burden of Disease Study, AIHW

The Australian Burden of Disease Study undertaken by the AIHW provides information on the burden of disease for the Australian population. The study builds on the AIHW's previous

burden of disease studies and disease monitoring work and provides Australian-specific estimates for 216 diseases and injuries, grouped into 17 disease groups, for 2003, 2011 and 2015. It also provides estimates of how much of the burden can be attributed to 38 different risk factor exposures.

The summary measure of burden of disease analysis is the DALY. One DALY is one year of 'healthy life' lost due to illness and/or death. The more DALY associated with a disease or injury, the greater the burden. DALY are estimated for every occurrence of every disease and then added together for the whole population, to indicate the total disease burden. The DALY is produced by combining the non-fatal and fatal burden together. People generally experience more burden as they age.

Information on the health impacts and distribution of different diseases, injuries and risk factors is important for monitoring population health and providing an evidence base to inform health policy and service planning. Burden of disease information can also be used to measure the health impact of interventions, and to highlight which diseases or risk factors to focus on when investigating the cost-effectiveness of programs and interventions.

More information on the Australian Burden of Disease Study can be found on the AIHW website, <https://www.aihw.gov.au/reports-data/health-conditions-disability-deaths/burden-of-disease/overview>

Longitudinal studies

Longitudinal studies, which provide data for the same individuals at multiple time points, provide an opportunity to gain insight on the antecedents of chronic conditions, better understand health care use and the patient experience, improve understanding of comorbidities, and examine quality of life. Surveys may provide more detailed insight into an individual's experience, decision making and quality of life when compared with administrative data sources. In addition, many longitudinal studies are linked to administrative databases, which may improve their utility in monitoring chronic conditions and associated factors.

There are a large number of longitudinal studies in Australia with varying size, sample representativeness and usefulness in monitoring. For example, Growing Up in Australia: Longitudinal Study of Australian Children began in 2003 includes data from 10,000 families and children from across Australia. The study examines a broad range of research topics, and survey data is supplemented with administrative data. Sources include Medicare, Centrelink and the Murdoch Children's Research Institute's Child Health CheckPoint. Footprints in Time – The Longitudinal Study of Indigenous Children, which began in 2008, includes around 1,200 families. The study aims to examine a wide range of topics relating to children, their family and their community. This includes children's physical and mental health, diet, height and weight, and parent's health, social and emotional wellbeing. As these studies follow participants from early childhood, they provide an opportunity to examine risk factors for disease and the impact of early intervention on subsequent health outcomes.

45 and Up Study is a large longitudinal study of people living in New South Wales who are 45 years and over. The study includes over 250,000 people, which represents around 10 percent of the people in this age group in the state. While the study only includes participants from NSW, the size of the cohort, and linkages with multiple administrative databases, provide an opportunity to improve understanding of chronic conditions, multimorbidity and pathways through the health care system.

The Household, Income and Labour Dynamics in Australia Survey is large, nationally representative household based survey. The survey focuses on social and economic information but specific survey waves have included questions relating to 'serious illness conditions', including chronic conditions. This, in addition to information relating to risk factors, employment and general health and wellbeing, could contribute to chronic disease monitoring (AIHW 2019a).

The Australian Longitudinal Study of Women's Health seeks to examine health and wellbeing of Australian women across the life course. The study includes data from over 57,000 women and includes linkage to a number of administrative health datasets. A recent report highlights the use of this data source for examining chronic conditions. The publication, titled *The impact of multiple chronic conditions: Findings from the Australian Longitudinal Study on Women's Health* (Dobson et al 2020), examined the development of multimorbidity, which was defined as the development of two or more chronic conditions. The report focussed on eight groups of common conditions including musculoskeletal conditions, mental health conditions, coronary heart disease, respiratory disease, cancers, diabetes, dementia and stroke.

National registry data and clinical databases

There are a number of clinical registries that capture specific chronic conditions in Australia. Examples include:

- Australian Mesothelioma Registry
- Australian and New Zealand Dialysis and Transplant Registry
- Australian Cystic Fibrosis Data Registry
- Rheumatic heart disease/Acute rheumatic fever registries (state/territory)
- Australian Spinal Cord Injury Register.
- Australian National Diabetes Audit
- National Cardiac Registry.

While these data sources provide good population coverage for the condition of interest, they are unlikely to contribute substantially to collective monitoring.

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- Burden of Disease Expert Advisory Group
- Chronic Conditions Advisory Group
- Cardiovascular Disease Expert Advisory Group
- Diabetes Expert Advisory Group
- Chronic Kidney Disease Expert Advisory Group
- National Arthritis and Musculoskeletal Conditions Monitoring Advisory Group
- National Asthma and other Chronic Respiratory Conditions Monitoring Advisory Group.

Abbreviations

ABDS	Australian Burden of Disease Study
ABS	Australian Bureau of Statistics
AHMAC	Australian Health Ministers' Advisory Council
AHPC	Australian Health Policy Collaboration
AHPF	Australian Health Performance Framework
AIHW	Australian Institute of Health and Welfare
CCDI	Canadian Chronic Disease Indicators
CKD	chronic kidney disease
COPD	chronic obstructive pulmonary disease
CVD	cardiovascular disease
DALY	disability adjusted life year
GACD	Global Alliance for Chronic Diseases
GBD	Global Burden of Disease
GP	general practitioner
HIV	human immunodeficiency virus
MBS	Medicare Benefits Schedule
MHR	My Health Record
NCD	non-communicable disease
NCMCC	National Centre for Monitoring Chronic Conditions
NHMD	National Hospital Morbidity Database
NHS	National Health Survey
NMD	National Mortality Database
NMDS	National Minimum Data Set
OECD	Organisation for Economic Co-operation and Development
PHAC	Public Health Agency of Canada
WHO	World Health Organization

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Glossary

Additional diagnosis: The diagnosis of a condition or recording of a complaint—either coexisting with the principal diagnosis or arising during the episode of admitted patient care (hospitalisation), episode of residential care or attendance at a health care establishment—that requires the provision of care. Multiple diagnoses may be recorded.

Chronic conditions: A term describing a health condition that is persistent and long lasting.

Associated cause(s) of death: A cause(s) listed on the Medical Certificate of Cause of Death, other than the underlying cause of death. They include the immediate cause, any intervening causes, and conditions that contributed to the death but were not related to the disease or condition causing death. See also cause(s) of death.

Burden of disease: The quantifiable impact of a disease, injury or risk factor on a population, using the disability-adjusted life year (DALY) measure.

Data linkage: The bringing together (linking) of information from two or more different data sources that are believed to relate to the same entity (for example, the same individual or the same institution). This linkage can yield more information about the entity and, in certain cases, provide a time sequence—helping to ‘tell a story’, show ‘pathways’ and perhaps unravel cause and effect. The term is used synonymously with ‘record linkage’ and ‘data integration’.

monitoring (of health): A process of keeping a regular and close watch over important aspects of the public’s health and health services through various measurements, and then regularly reporting on the situation, so that the health system and society more generally can plan and respond accordingly. The term is often used interchangeably with surveillance, although surveillance may imply more urgent watching and reporting, such as the surveillance of infectious diseases and their epidemics. Monitoring can also be applied to individuals, such as hospital care where a person’s condition is closely assessed over time.

Morbidity: The ill health of an individual and levels of ill health in a population or group.

Mortality: Number or rate of deaths in a population during a given time period.

My Health Record: An online platform for storing a person’s health information, including their Medicare claims history, hospital discharge information, diagnostic imaging reports, and details of allergies and medications.

Principal diagnosis: The diagnosis established after study to be chiefly responsible for occasioning an episode of patient care (hospitalisation), an episode of residential care or an attendance at the health care establishment. Diagnoses are recorded using the relevant edition of the International statistical classification of diseases and related health problems, 10th revision, Australian modification (ICD-10-AM).

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

Related publications

The following AIHW publications relating to chronic conditions also be of interest:

- Australian Institute of Health and Welfare 2020. Experiences in health care for people with chronic conditions: exploring the data on how GPs and other specialists communicate with their patients. Cat. no. CHC 05. Canberra: AIHW. Viewed 14 December 2020. <https://www.aihw.gov.au/reports/health-care-quality-performance/experiences-in-health-care-for-people-with-chronic>
- Australian Institute of Health and Welfare 2020. Chronic conditions and multimorbidity. Canberra: AIHW. <https://www.aihw.gov.au/reports/australias-health/chronic-conditions-and-multimorbidity>



Chronic conditions are the focus of significant research and policy interest in Australia. There is an ongoing need to review, refine and reassess how chronic conditions should be monitored. This paper summarises an approach by the AIHW National Centre for Monitoring Chronic Conditions to define and select chronic conditions for collective monitoring in Australia.

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