



Australian
Commission on
Safety and Quality
in Health Care

Prioritised Clinical Domains for Clinical Quality Registry (CQR) Development

2026

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Executive Summary

Clinical quality registries (CQRs) play an important role in improving the safety and quality of healthcare by systematically collecting, analysing and reporting data on clinical care and patient outcomes. By enabling feedback loops and benchmarking to clinicians, health services and policymakers, registries provide a mechanism to identify unwarranted variation in care and support improvements in clinical practice.

In 2016, the Australian Commission on Safety and Quality in Health Care (the Commission) undertook the first national prioritisation of clinical domains for potential CQR development. That work identified areas where registries were most likely to deliver improvements in the safety and quality of care. Since that time, the registry landscape in Australia has expanded, supported by national policy initiatives including the *National Strategy for Clinical Quality Registries and Virtual Registries 2020–2030* and subsequent investment in registry infrastructure through the Australian Government National Clinical Quality Registry Program. The Australian registry landscape now includes over 140 clinical registries operating nationally or across jurisdictions. Patterns of disease burden, health system expenditure and models of care have also evolved over this time. An updated prioritisation was therefore undertaken to ensure that future national registry planning remains responsive to changes in population needs, health system pressures and emerging priorities over time.

This report presents the findings of the 2026 update to the prioritisation of clinical domains for potential CQR development in Australia, funded by the Australian Government Department of Health, Disability and Ageing. This work is intended to support government planning and priority setting. The prioritisation framework provides an evidence-informed approach to identifying areas for consideration from a population health and whole-of-system perspective. It is intended to support strategic planning by identifying areas where further consideration of registry development may contribute to improvements in the safety and quality of healthcare.

The updated prioritisation builds on the methodology originally developed in the Commission's 2016 report. It has retained the core concepts of threshold assessment and domain-level prioritisation while incorporating updated national data and a more structured comparative scoring framework. Consultation with stakeholders across the CQR sector was also undertaken to test elements of the proposed methodology for prioritisation. Engagement with registry operators, clinicians, researchers and policy stakeholders indicated broad support for the principles underpinning the prioritisation framework and the criteria used to assess potential registry opportunities.

The 2026 prioritisation draws on national data on burden of disease and health system expenditure to identify a list of 75 diseases associated with substantial population health impact or health system cost, including consideration of trends over time, for prioritisation. Suitable conditions were grouped into clinical domains and assessed using a structured framework, resulting in a comparative ranking of 15 clinical domains. This ranking reflects only the 75 identified diseases and does not imply prioritisation of all possible diseases within a prioritised domain.

Clinical domains that ranked highest overall were mental health and substance use disorders, cancer and other neoplasms, musculoskeletal disorders, neurological conditions and cardiovascular diseases. These domains ranked strongly due to a combination of substantial population burden, high or increasing health system expenditure and evidence of clinical engagement supporting registry-based quality improvement. Other domains identified in the prioritised list include infectious diseases, gastrointestinal disorders, respiratory diseases, endocrine disorders, kidney and urinary diseases, hearing and vision disorders, injury, reproductive and maternal conditions, skin disorders and infant and congenital conditions. The diseases included within each domain are shown in Figure 1.

The prioritisation results highlight areas where registry-based monitoring may offer strategic value. In domains with both high disease burden and substantial health system expenditure, improvements in care quality have the potential to affect large patient populations and significant areas of health system spending. At the same time, the analysis highlights domains where burden or costs are increasing rapidly, indicating emerging areas of pressure for the health system.

It should be noted that the prioritised domains should be interpreted as reflecting system-level priorities for planning purposes, rather than a definitive or exhaustive list of areas where CQRs may provide value. Prioritisation at the domain level provides a structured starting point for identifying opportunities for registry development but decisions regarding individual registries must consider additional factors. These include feasibility of data collection, availability of clinical leadership, existing monitoring infrastructure and alignment with national safety and quality priorities.

The 2026 update reinforces that priority areas for CQR development and investment should reflect both the disease and the way care is delivered across the health system. Although the 2026 methodology is primarily disease-driven, this report builds on the 2016 approach by underscoring the important role of registries organised around health interventions and care settings, recognising their relevance across the patient journey.

By identifying common interventions and care settings linked to prioritised clinical areas, findings highlighted how intervention- or setting-based CQR models can strengthen system-wide monitoring of safety, quality, and patient outcomes. This approach recognises the value of registries that align with real-world care pathways and capture outcomes spanning multiple diseases, offering a potential avenue for more comprehensive visibility of the health system.

The findings of the 2026 update are intended as a decision-support tool to inform national planning. The prioritisation approach taken provides a structured, transparent basis for identifying areas where further investment and feasibility assessment may be warranted. The analysis adopts a population level and whole of system perspective to ensure that resources are directed towards areas of greatest potential impact, but it does not fully capture all contexts in which a CQR may be appropriate. In particular, some conditions, interventions or care settings may warrant registry development based on clinical complexity, safety considerations, emerging technologies or policy priorities, even where they are not highly ranked in this analysis. Interpretation of the prioritisation results should therefore recognise that opportunities for registry development are influenced not only by disease burden and health system expenditure but also by broader factors related to care delivery across the health system. Consideration of these broader system factors will remain important when assessing the potential value and feasibility of future registry initiatives.

Figure 1 Prioritised list of clinical domains

Score	Domain	Disease		
Highest				
6.25	Mental health and substance use disorders	<ul style="list-style-type: none">Alcohol use disordersAnxiety disordersAutism spectrum disorders	<ul style="list-style-type: none">Bipolar affective disorderDepressive disordersEating disorders	<ul style="list-style-type: none">Schizophrenia
6	Cancer and other neoplasms	<ul style="list-style-type: none">Acute lymphoblastic leukaemiaAcute myeloid leukaemiaBowel cancerBrain and central nervous system cancer	<ul style="list-style-type: none">Breast cancerChronic lymphocytic leukaemiaChronic myeloid leukaemiaLung cancerNon-Hodgkin lymphoma	<ul style="list-style-type: none">Non-melanoma skin cancerOther lymphohaematopoietic (blood) cancersPancreatic cancerProstate cancer
5.5	Musculoskeletal disorders	<ul style="list-style-type: none">Back pain and problemsDislocationsHip fracture	<ul style="list-style-type: none">Humerus fractureOsteoarthritisRheumatoid arthritis	<ul style="list-style-type: none">Tibia and ankle fracture
	Neurological conditions	<ul style="list-style-type: none">DementiaMultiple sclerosis	<ul style="list-style-type: none">Spinal cord injuryTraumatic brain injury	
5	Cardiovascular diseases	<ul style="list-style-type: none">Aortic aneurysmAtrial fibrillation and flutterCardiomyopathy	<ul style="list-style-type: none">Coronary heart diseaseHeart failureNon-rheumatic valvular disease	<ul style="list-style-type: none">Rheumatic heart disease (including acute rheumatic fever)Stroke
4.5	Infectious diseases	<ul style="list-style-type: none">COVID-19		
4.25	Gastrointestinal disorders	<ul style="list-style-type: none">Chronic liver diseaseGallbladder and bile duct disease	<ul style="list-style-type: none">Gastro Oesophageal Reflux Disease (GORD)	<ul style="list-style-type: none">Inflammatory bowel disease (IBD)
	Respiratory disorders	<ul style="list-style-type: none">Asthma	<ul style="list-style-type: none">COPD	
4	Endocrine disorders	<ul style="list-style-type: none">Gestational diabetesType 1 diabetes mellitus	<ul style="list-style-type: none">Type 2 diabetes mellitus	
3.75	Kidney and urinary diseases	<ul style="list-style-type: none">Chronic kidney diseaseRenal failure		
2.75	Hearing and vision disorders	<ul style="list-style-type: none">Cataract and other lens disordersHearing loss		
2.5	Injury	<ul style="list-style-type: none">Burn injuriesDrowning and submersion injuries	<ul style="list-style-type: none">Internal and crush injuryPoisoning	
2.25	Reproductive and maternal conditions	<ul style="list-style-type: none">Genital prolapseHypertensive disorders of pregnancyMaternal haemorrhage	<ul style="list-style-type: none">Maternal infectionsObstructed labourOther maternal conditions	<ul style="list-style-type: none">Pregnancy and postpartum care
	Skin disorders	<ul style="list-style-type: none">Skin infections (incl. Cellulitis)		
1.75	Infant and congenital conditions	<ul style="list-style-type: none">Birth trauma and asphyxiaBrain malformationsCardiovascular defectsCerebral palsy	<ul style="list-style-type: none">Cleft lip and/or palateGastrointestinal malformationsNeonatal infectionsNeural tube defects	<ul style="list-style-type: none">Pre-term birth and low birth weight complicationsUrogenital malformations
Lowest				

Purpose of the 2026 update

The purpose of this project is to update the national prioritisation of clinical domains to inform strategic planning and guide future investment in CQR development. By identifying clinical domains associated with significant population health burden, health system costs and opportunities for quality improvement, the analysis provides an evidence-informed basis for considering where registries may deliver the greatest value for the health system.

This prioritisation is not intended to replace or remove existing registries. Established registries continue to play an important role in monitoring clinical outcomes and supporting quality improvement within their respective clinical areas. Rather, the updated prioritisation is designed to complement the existing registry landscape by identifying areas where additional registry development may be beneficial.

Background

Clinical quality registries are a specific type of clinical registry focused on routinely collecting and analysing health outcome data, and generating risk-adjusted reports, for the purpose of driving ongoing improvements in safety and quality.¹ CQRs are an essential component of a high-performing health system as they systemically monitor the quality of healthcare by using the collected data to identify benchmarks and variation in health outcomes.^{2,3} Through regular feedback to clinicians, health service organisations, jurisdictional health departments, regulators and policy makers, CQRs provide a mechanism to inform improvements in the safety, appropriateness and effectiveness of health care.⁴

The Commission published the *Prioritised List of Clinical Domains for Clinical Quality Registry Development* in 2016.⁵ That report identified clinical areas where the development of new CQRs could deliver the greatest benefit in improving the safety and quality of care in Australia. Since that time, there has been progress in building national and jurisdictional registry capacity and some registries have matured into effective tools for monitoring and improving clinical care.

At the same time, the broader Australian healthcare landscape has continued to evolve, prompting the need for a reassessment of the criteria used to determine priority clinical domains for CQR development. New and emerging clinical priorities may need to be considered with shifting patterns in the burden of disease across the population. Conditions such as mental health disorders, dementia, and musculoskeletal diseases have grown in prevalence, often with increasing care needs, reflecting broader societal and demographic trends, including an ageing population and increased incidence of chronic disease.^{6,7}

¹ Australian Commission on Safety and Quality in Health Care. Australian Framework for National Clinical Quality Registries 2024. Sydney; ACSQHC, 2024.

² Parker KJ, Hickman LD, Ferguson C. The science of clinical quality registries. *Eur J Cardiovasc Nurs*. 2023 Mar 1;22(2):220-225. doi: 10.1093/eurjcn/zvad008. PMID: 36632040.

³ Australian Commission on Safety and Quality in Health Care. *Australian Framework for National Clinical Quality Registries*. Sydney: ACSQHC; 2024.

⁴ Stey AM, Russell MM, Ko CY, Sacks GD, Dawes AJ, Gibbons MM. Clinical registries and quality measurement in surgery: a systematic review. *Surgery*. 2015 Feb;157(2):381-95. doi: 10.1016/j.surg.2014.08.097. PMID: 25616951.

⁵ <https://www.safetyandquality.gov.au/publications-and-resources/resource-library/prioritised-list-clinical-domains-clinical-quality-registry-development-final-report>

⁶ https://www.aihw.gov.au/getmedia/19dbc591-b1ef-4485-80ce-029ff66d6930/6_9-health-ageing.pdf.aspx

⁷ <https://www.aihw.gov.au/mental-health/overview/prevalence-and-impact-of-mental-illness>

National policy developments have also played a critical role in shaping the need for this update. The introduction of the *National Strategy for Clinical Quality Registries and Virtual Registries 2020-2030* and the release of the *Australian Framework for National Clinical Quality Registries* in 2024 have provided a more structured and coordinated approach for registry-based quality improvement, and to align registry development to broader system goals.^{8,9}

The 2026 update revises the prioritised domain list using a framework that remains consistent with the intent of the 2016 approach while strengthening the measures used to compare domains. Burden of disease and health system expenditure continue to serve as primary comparative indicators to identify domains of high impact and increasing pressure. Stakeholder input is incorporated to ensure the approach remains grounded in clinical reality and implementable at scale.

The prioritised list of clinical domains is a national planning tool to guide where further feasibility work may be most valuable. This is particularly relevant in the context of ongoing advances in medicine and evolving models of care and supports efforts to ensure that future registry development is coordinated, responsive to emerging priorities, and aligned with broader national safety and quality improvement strategies.

Clinical quality registries in Australia

CQRs monitor the quality and outcomes of care for specific diseases, conditions, procedures or health care interventions. CQRs collect standardised information on patient characteristics, treatments and outcomes across multiple health service organisations.^{10,11} CQR data is then analysed and risk-adjusted to enable benchmarking of clinical performance to inform quality improvement.¹²

CQRs can be categorised across three broad areas:

- procedures, devices, or drugs,
- diseases or illness, or
- specific healthcare resource.¹³

Table 1 Categories and examples of clinical quality registries

Category	Scope	Clinical Quality Registry Example
Procedure, device, or drug	Joint replacement	Australian Orthopaedic Association National Joint Replacement Registry (AOANJRR)

⁸ https://www.health.gov.au/sites/default/files/2023-04/a-national-strategy-for-clinical-quality-registries-and-virtual-registries-2020-2030_0.pdf

⁹ Australian Commission on Safety and Quality in Health Care. *Australian Framework for National Clinical Quality Registries*. Sydney: ACSQHC; 2024.

¹⁰ Australian Commission on Safety and Quality in Health Care. *Australian Framework for National Clinical Quality Registries 2024*. Sydney: ACSQHC; 2024

¹¹ Evans SM, Scott IA, Johnson NP, Cameron PA, McNeil JJ. Development of clinical-quality registries in Australia: the way forward. *Medical Journal of Australia*. 2011;194(7):360–363.

¹² Parker KJ, Hickman LD, Ferguson C. The science of clinical quality registries. *Eur J Cardiovasc Nurs*. 2023;22(2):220–225.

¹³ Australian Commission on Safety and Quality in Health Care. *Australian Framework for National Clinical Quality Registries*. Sydney: ACSQHC; 2024

Category	Scope	Clinical Quality Registry Example
	Cardiac procedures and devices	National Cardiac Registry (NCR)
	Breast implants	Australian Breast Device Registry (ABDR)
Disease or illness	Diabetes	Australian Diabetes Clinical Quality Registry (ADCQR)
	Stroke	The Australian Stroke Clinical Registry (AuSCR)
Specific healthcare resource	Trauma	The Australian Trauma Registry
	Intensive care	Australian and New Zealand Intensive Care Society (ANZICS) Centre for Outcomes and Resources Evaluation (CORE)

Over the past two decades, CQRs have become an increasingly important component of Australia's national safety and quality infrastructure. Early registries were often established within specific clinical specialties and led by clinicians seeking to monitor outcomes and improve standards of care. Over time, these initiatives have evolved into a broader national ecosystem of registries covering a wide range of clinical areas including cardiovascular disease, cancer, trauma, orthopaedics and critical care.

Registry activity in Australia has grown substantially over the last ten years, particularly in cancer and cardiovascular care, supported by ongoing investment in CQRs. The Australian Register of Clinical Registries lists more than 140 registries operating nationally and across jurisdictions, many of which incorporate quality improvement functions consistent with the CQR model.¹⁴ More recently, many existing national registries have received support from the Australian Government through initiatives such as the National Clinical Quality Registry Program.¹⁵

CQRs in Australia typically operate under independent governance arrangements and require sustained funding, technical infrastructure and ongoing engagement from clinicians and health service organisations. Registry models vary, with some operating at a national level and others embedded within state and territory systems or managed externally by organisations

¹⁴ Australian Commission on Safety and Quality in Health Care. (n.d.). *Australian Register of Clinical Registries*. Retrieved 8 March, 2026, from <https://www.safetyandquality.gov.au/our-work/indicators-measurement-and-reporting/national-guidance-clinical-quality-registries/australian-register-clinical-registries>

¹⁵ Australian Government Department of Health, Disability and Ageing. National Clinical Quality Registry Program. Canberra: Australian Government; 2026. Available from: <https://www.health.gov.au/our-work/national-clinical-quality-registry-program>. Accessed 8 March 2026

such as clinical colleges, universities and research institutes.¹⁶ As these registries require significant and sustained investment to establish and maintain, it is important that national efforts to support registry development are directed towards clinical areas where the potential for improvements in safety, quality and health system performance is greatest.

Previous national prioritisation (2016)

The development of CQRs in Australia has been guided by a national framework established by the Australian Commission on Safety and Quality in Health Care. In 2014, the Commission released the *Australian Framework for Clinical Quality Registries*, which set out principles for the design, governance and operation of registries intended to support improvements in the safety and quality of health care.¹⁷ The framework recognised CQRs as an important component of national health system infrastructure and provided guidance to support consistent and sustainable registry development across Australia.

Building on this framework, the Commission undertook the first national prioritisation of clinical domains for potential clinical quality registry development in 2016.¹⁸ The purpose of that work was to identify areas of health care where the establishment of registries could deliver the greatest benefit in terms of improving patient outcomes and supporting the safety and quality of care.

The 2016 prioritisation process used national data on burden of disease and health system expenditure as the primary indicators of health system impact. These data sources provided an objective basis for identifying conditions associated with significant population health burden and health care costs. The analysis also incorporated stakeholder input and consideration of clinical practice patterns to identify areas where registry-based monitoring could potentially support improvements in care.

To support the analysis, the 2016 report introduced the concept of *clinical domains* as a way of grouping related diseases and conditions into broader categories for prioritisation. The term “clinical domain” does not have a formal definition within the Australian health system. In the context of the 2016 work, clinical domains were used as a practical construct to reconcile differences between the ways in which diseases are classified across major national datasets, including burden of disease reporting (which is typically condition-based) and health expenditure data (which is often organised according to diagnosis-related groups).

Using this approach, conditions identified through national datasets were grouped into a set of clinical domains that reflected major areas of clinical care. These domains provided the organisational structure for prioritisation and enabled comparisons across different areas of health care while maintaining alignment with available national data sources.

The 2016 analysis resulted in a prioritised list of clinical domains representing areas where CQRs were considered most likely to support improvements in the safety and quality of health care. The report also recognised that prioritisation at the domain level was intended as a strategic planning tool rather than a definitive list of registries to be developed. Consideration of specific diseases or conditions within these domains remains part of registry planning and development for the Australian Government Department of Health, Disability and Ageing.

¹⁶ Australian Commission on Safety and Quality in Health Care.

Australian framework for national clinical quality registries. Sydney: ACSQHC; 2024.

¹⁷ Australian Commission on Safety and Quality in Health Care. *Australian Framework for National Clinical Quality Registries*. Sydney: ACSQHC; 2024.

¹⁸ Australian Commission on Safety and Quality in Health Care 2016, Prioritised list of clinical domains for clinical quality registry development: Final report, ACSQHC, Sydney.

The current project builds on the methodological foundations established in the 2016 report, while updating the analysis to reflect contemporary patterns of disease burden, health system expenditure and the evolving clinical quality registry landscape in Australia.

Changes since 2016

Since the publication of the 2016 prioritisation report, the CQR landscape in Australia has continued to evolve. As part of the update process, a targeted environmental scan was undertaken to review developments in registry activity, health system priorities and emerging evidence relevant to CQR development.

Box 1: Key developments since 2016

The environmental scan identified several developments that have influenced the evolving role of clinical quality registries in Australia:

- Growth in the number and maturity of clinical quality registries across multiple clinical domains
- Advances in digital health systems, data linkage and registry infrastructure
- Increasing prevalence of chronic disease and more complex care pathways
- Strengthened national policy support for registry development

Growth in clinical quality registries

Over the past decade, there has been substantial growth in the number and maturity of CQRs operating in Australia. Earlier reviews of the sector identified a smaller CQR landscape in the mid-2010s with fewer established national registries.¹⁹ The Australian Register of Clinical Registries now lists more than 140 registries covering areas such as cardiovascular disease, cancer, trauma, orthopaedics and critical care.²⁰ Many of these registries have expanded their scope, data coverage and analytical capabilities, supported by national investment programs such as the National Clinical Quality Registry Program and funding through mechanisms including the Medical Research Future Fund.^{21,22}

Several mature registries have demonstrated measurable improvements in clinical practice and patient outcomes. For example, registries in areas such as stroke, hip fracture care, joint replacement and cardiac care have enabled benchmarking of clinical practice, improved adherence to evidence-based guidelines and reduced unwarranted variation in care. These developments have highlighted the increasing role of registries as core infrastructure supporting quality improvement within the Australian health system.

However, there is variation in coverage of registry infrastructure across clinical domains. While some areas have well-established registries with national coverage, other high-burden

¹⁹ Evans SM, Scott IA, Johnson NP, Cameron PA 2011, 'Development of clinical-quality registries in Australia: the way forward', Medical Journal of Australia, vol. 194, no. 7, pp. 360–363

²⁰ Australian Commission on Safety and Quality in Health Care. (n.d.). *Australian Register of Clinical Registries*. Retrieved 8 March, 2026, from <https://www.safetyandquality.gov.au/our-work/indicators-measurement-and-reporting/national-guidance-clinical-quality-registries/australian-register-clinical-registries>

²¹ Australian Government Department of Health, Disability and Ageing 2026, National Clinical Quality Registry Program, Australian Government, Canberra, accessed 8 March 2026, <https://www.health.gov.au/our-work/national-clinical-quality-registry-program>

²² Australian Government Department of Health and Aged Care 2023, Medical Research Future Fund – Clinical Quality Registries grant opportunities, Australian Government, Canberra.

conditions such as chronic kidney disease, chronic obstructive pulmonary disease and some neurological conditions remain underrepresented within Australia's registry infrastructure.

Evolving registry infrastructure

The digital infrastructure supporting CQRs has evolved considerably since 2016. Advances in digital health systems, data linkage capabilities and registry design have expanded the potential role of registries within the health system.

Increasingly, CQRs are being integrated with electronic clinical systems and linked with national datasets, enabling connection with administrative data collections such as mortality databases and other health data sources. These linkages support more comprehensive monitoring of patient outcomes across the continuum of care, from diagnosis and treatment through to longer-term follow-up.^{23,24}

Advances in digital health infrastructure have expanded the capabilities of CQRs, enabling the integration of patient-reported outcome measures, more timely feedback to clinicians and enhanced analytical approaches.^{25,26} These developments are strengthening the role of registries as data infrastructure that can support ongoing quality improvement across the health system.

Demographic and disease trends

Changes in Australia's population health profile since 2016 have also influenced priorities for registry development. Australia's population is ageing, with a growing proportion of older adults experiencing multiple chronic conditions. This demographic shift is associated with increasing prevalence of chronic diseases such as cardiovascular disease, diabetes, dementia and chronic kidney disease.

Many of these conditions are characterised by complex care pathways involving multiple providers and care settings. As a result, there is increasing interest in registries that are capable of monitoring patient outcomes across the continuum of care, including primary care, specialist services and hospital-based treatment.

Several high-burden conditions continue to experience substantial variation in care delivery and outcomes. In these areas, CQRs have the potential to provide important insights into clinical practice patterns, adherence to evidence-based guidelines and opportunities for improving health system performance.²⁷

National policy developments

National policy settings supporting CQR development have also progressed since 2016. In particular, the release of the National Clinical Quality Registry and Virtual Registry Strategy 2020–2030 has provided a coordinated national vision for registry capacity development. The

²³ Ahern S, Evans SM, Bohensky M et al. 2022 'Realising the potential: leveraging clinical quality registries for real-world evidence', Medical Journal of Australia.

²⁴ Secombe P, Millar J, Litton E, Chavan S, Hensman T, Hart GK, Slater A, Herkes R, Huckson S, Pilcher DV. Thirty years of ANZICS CORE: A clinical quality success story. Crit Care Resusc. 2023 May 20;25(1):43-46.

²⁵ Zhou Y, Wall CJ, Stevens J, Fraval A, Lewis PL, McAuliffe MJ, Vertullo CJ, Gill DRJ, Stoney JD, Bastiras D, Corfield S, Harvey B, Lorimer MF, Hill K, Smith PN. Data Resource Profile: The Australian Orthopaedic Association National Joint Replacement Registry (AOANJRR). Int J Epidemiol. 2025 Jun 11;54(4):dyaf078. doi: 10.1093/ije/dyaf078. PMID: 40524466; PMCID: PMC12199916.

²⁶ Secombe P, Millar J, Litton E, Chavan S, Hensman T, Hart GK, Slater A, Herkes R, Huckson S, Pilcher DV. Thirty years of ANZICS CORE: A clinical quality success story. Crit Care Resusc. 2023 May 20;25(1):43-46.

²⁷ Evans SM, Scott IA, Johnson NP, Cameron PA, McNeil JJ. Development of clinical-quality registries in Australia: the way forward. Med J Aust. 2011 Apr 4;194(7):360-3.

strategy emphasises the role of registries as key infrastructure for monitoring the quality and safety of health care, supporting clinical research and informing health policy.²⁸

Other national initiatives, including developments in digital health infrastructure, data linkage capabilities and medical device surveillance systems, are also strengthening the environment for registry development. These changes create new opportunities to integrate registry data with broader health system information systems and to support more comprehensive monitoring of care and outcomes.

Principles guiding prioritisation and investment in CQR development

The prioritisation of clinical domains for potential CQR development was guided by a set of principles designed to ensure that registry investment supports improvements in the safety and quality of health care at a population level.

Box 2: Principles guiding prioritisation of clinical quality registries

- Prioritisation should focus on clinical areas with a high burden of disease and substantial health system impact
- Clinical areas should demonstrate potential for measurable improvements in quality and safety through registry-based monitoring and feedback
- Registry development should be feasible within the Australia health system, including the availability of defined clinical cohorts and measurable outcomes
- Prioritisation should support national coordination and avoid unnecessary duplication of registry activity
- Registry development should align with national safety and quality priorities and support improvements in health system performance.

Principles for prioritising CQR development and investment

In line with the 2024 *Australian Framework for National Clinical Quality Registries (CQR Framework)*, principles for prioritising and investment in CQR development aim to support the aspiration to shift CQRs from research to quality improvement paradigm. This is achieved by maintaining an emphasis on population- and system-level impact feasibility, clinician engagement, data governance, and sustainability.

Focus on safety and quality

Registries in prioritised clinical domains have a safety and quality focus as foundational principles in systematically monitoring the delivery of care, identifying unwarranted variation, and driving improvements in clinical practice.²⁹ The CQR Framework positions safety and

²⁸ Australian Commission on Safety and Quality in Health Care & Australian Government Department of Health 2020, *National Clinical Quality Registry and Virtual Registry Strategy 2020–2030*, ACSQHC, Sydney.

²⁹ Strategic Principle 1 Australian Commission on Safety and Quality in Health Care. *Australian Framework for National Clinical Quality Registries*. Sydney: ACSQHC; 2024.

quality at the centre of registry design and governance, ensuring that CQRs contribute meaningfully to better health outcomes and system-level accountability.

Targets high-cost health areas

Registries should be prioritised in clinical areas that have substantial impact on population health (disease burden) and impose significant financial burden on the health system with known or suspected variation in processes or outcomes that may highlight inappropriate or inefficient use of limited resources.³⁰ These include treatments or procedures that are expensive to deliver and where poor outcomes result in costly downstream care.

Established coordinated care pathway and patient-level data

CQRs should be developed in clinical areas where good outcomes depend on a coordinated sequence of care and operated with sound governance arrangements and delivered by multiple providers and clinical groups.³¹ For example, optimal treatment of stroke or myocardial infarction requires rapid emergency response, accurate diagnosis, timely transfer to specialised facilities, effective hospital triage, skilled clinical management, and prompt rehabilitation. CQRs enable detailed evaluation of each step in the care pathway, supporting continuous quality improvement.³² Investment and prioritisation in CQRs should focus on scalable, future-oriented infrastructure that enhances data management that allows for the collection, storage, and analysis of patient-level data.³³

Practicality of implementation and registry infrastructure

When prioritising new CQRs, the feasibility of implementation is critical. This includes ensuring appropriate data infrastructure, integration with existing clinical workflows, and minimising administrative burden on clinicians. CQR development where there is strong clinician involvement should be prioritised as active engagement is essential for embedding registry processes into routine practices and improves data completeness.³⁴ A registry that is too disconnected from clinical reality risks underuse, undermining its purpose and wasting resources.³⁵

Overview of the prioritisation approach

The prioritisation of clinical domains for potential CQR development was undertaken using a structured and evidence-informed methodology. The approach builds on the framework developed for the 2016 prioritisation while incorporating updated national data sources and contemporary health system considerations. Key methodological enhancements include:

- the use of expanded expenditure data across multiple care settings
- consideration of trends in burden and expenditure over time

³⁰ Australian Commission on Safety and Quality in Health Care. *Australian Framework for National Clinical Quality Registries*. Sydney: ACSQHC; 2024. p.7

³¹ Strategic Principle 3 Australian Commission on Safety and Quality in Health Care. *Australian Framework for National Clinical Quality Registries*. Sydney: ACSQHC; 2024.

³² Evans SM, Scott IA, Johnson NP, Cameron PA, McNeil JJ. Development of clinical-quality registries in Australia: the way forward. *Med J Aust*. 2011 Apr 4;194(7):360-3. doi: 10.5694/j.1326-5377.2011.tb03007.x. PMID: 21470087.

³³ Strategic Principle 4 and 5 Australian Commission on Safety and Quality in Health Care. *Australian Framework for National Clinical Quality Registries*. Sydney: ACSQHC; 2024.

³⁴ Strategic Principles 3, 4 and 5. Australian Commission on Safety and Quality in Health Care. *Australian Framework for National Clinical Quality Registries*. Sydney: ACSQHC; 2024.

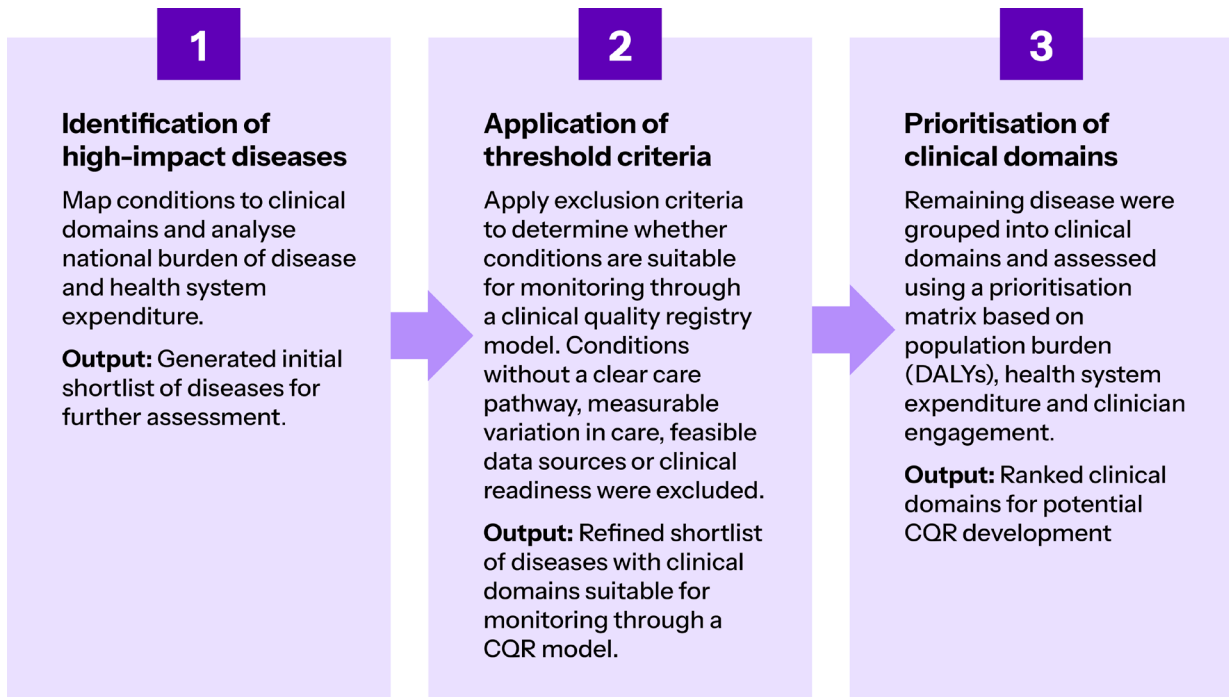
³⁵ Evans SM, Scott IA, Johnson NP, Cameron PA, McNeil JJ. Development of clinical-quality registries in Australia: the way forward. *Med J Aust*. 2011 Apr 4;194(7):360-3. doi: 10.5694/j.1326-5377.2011.tb03007.x. PMID: 21470087.

- broader recognition of intervention and setting-based registry models.

National data on burden of disease and health system expenditure were used to identify clinical areas with substantial population impact. Data was analysed through a series of structured steps designed to identify clinical domains where CQR development may have the greatest potential to support improvements in the safety and quality of care. Practical considerations relevant to registry implementation were also examined as part of the assessment process.

An overview of the prioritisation process is shown in Figure 2.

Figure 2 Overview of prioritisation approach



Step 1: Identification of high-impact diseases

Generating an initial list of diseases

The first step in the prioritisation process involved identifying a set of diseases for further consideration as potential candidates for CQR development. The aim of this step was to identify diseases associated with substantial population health burden or health system expenditure in Australia. By focusing on conditions that contribute significantly to illness, disability, mortality or healthcare spending, the analysis ensures that subsequent prioritisation is directed towards areas where registries may deliver the greatest potential benefit in improving the safety and quality of care.

Expanding on the approach adopted in the 2016 prioritisation, Step 1 drew on two complementary national datasets produced by the Australian Institute of Health and Welfare (AIHW):

- burden of disease estimates from the Australian Burden of Disease Study (ABDS) 2024
- disease-specific health system expenditure estimates from *Health system spending on disease and injury in Australia 2022–23*

These datasets provide two perspectives on disease impact. Burden of disease captures the loss of healthy life associated with illness and premature death, measured using disability-adjusted life years (DALYs).³⁶ Health system expenditure captures the financial resources used to diagnose, treat and manage disease across the health system. Considering both measures helps ensure that prioritisation reflects conditions that have significant implications for both population health and health system sustainability. As the two datasets use slightly different condition classifications, conditions were mapped to a unified list of diseases within the clinical domains used in this report. The full mapping of conditions between the burden of disease and health expenditure datasets is provided in [Appendix A](#).

In addition to current estimates, the 2026 methodology also considered change over time. Trends in burden of disease were examined between 2015 and 2024, while trends in health system expenditure were examined between 2015–16 and 2022–23. The consideration of growth trends allows the analysis to identify conditions where the burden or cost to the health system is increasing, as well as those that already represent a substantial share of national health impact.

Mapping conditions to clinical domains

Once the initial disease list was generated, conditions identified were mapped to clinical domains to enable comparison across related areas of care. To support comparison across related areas of clinical care, diseases identified in the burden of disease and expenditure datasets were grouped into clinical domains. This domain based approach supports strategic planning for registry development by identifying areas where registry infrastructure, data elements or quality measures may be shared across related conditions.

The 2026 methodology used the Australian Burden of Disease Study classification as the primary basis for grouping conditions. Both the burden of disease and health system expenditure datasets broadly align with this framework, which categorises conditions into major disease groups. In most cases, diseases were assigned to domains consistent with their original ABDS grouping.

A small number of conditions were reassigned to alternative domains to better reflect clinical practice and maintain alignment with the domain structure used in the 2016 prioritisation. For example, traumatic brain injury and spinal cord injury were grouped within neurological conditions rather than injury, and selected fractures were grouped within musculoskeletal disorders.

Removal of non-disease-specific conditions

Following domain mapping, non-disease-specific and residual categories were removed from the analysis to focus the shortlist on clearly defined diseases or conditions that are suitable for

³⁶ Australian Institute of Health and Welfare. *Australian Burden of Disease Study 2023: Frequently asked questions*. Canberra: AIHW; 2023.

registry monitoring. Exclusions included categories that do not represent discrete clinical conditions including:

- broad residual categories labelled “Other” within the burden of disease and expenditure datasets
- health system expenditure groupings that represent services rather than diseases (for example counselling services and donor activity)
- categories relating to preventive or risk-factor management rather than specific clinical conditions (for example treatment of hypertension, treatment of obesity and tobacco interventions)
- general health service categories that do not correspond to a specific disease, such as “well person” services.

These exclusions ensured that subsequent analysis focus on clearly identifiable diseases or conditions that could feasibly be monitored through a clinical quality registry.

After removal of these categories, totals for burden of disease and health system expenditure were recalculated to allow the relative contribution of each remaining disease to be assessed accurately.

Identifying high impact diseases

Diseases were then assessed according to their contribution to recalculated burden of disease and health system expenditure. To maintain continuity with the previous national prioritisation, conditions included in the 2016 prioritised list were retained in the analysis. This approach recognises the importance of sustaining investment in CQRs established under the 2016 prioritisation, ensuring these registries can continue to develop and mature over time. The ranking of each CQR domain in the 2026 update reflects its relative priority within this revision, rather than any change in the underlying value of existing registries. Each condition was mapped to their corresponding ABDS 2024 disease definitions to ensure they could be assessed using current burden of disease and health expenditure estimates.

Within each dataset, diseases were ranked according to their contribution to the recalculated total burden of disease or health system expenditure. Conditions contributing to the top 60% of total burden or expenditure were retained in the shortlist for further analysis. This approach allowed the prioritisation to focus on diseases responsible for the majority of population health impact and health system cost in Australia, while maintaining a manageable set of conditions for further assessment. A full list of diseases included in the Step 1 shortlist and the criteria under which they were retained (high burden, high cost, or carried over from the 2016 prioritised list) is provided in [Appendix B](#).

Outcome at Step 1

The final outcome of Step 1 was a shortlist of 82 diseases across the 15 clinical domains. Collectively, these conditions accounted for approximately 4.1 million DALYs and \$89.1 billion in health system expenditure, accounting for 82% and 79% of the re-calculated totals respectively. These diseases progressed to Step 2, where they were assessed against threshold criteria relating to their suitability for monitoring through a clinical quality registry. Detailed burden of disease and health system expenditure estimates for diseases assessed in Step 1 are provided in [Appendix C](#) and [Appendix D](#).

Table 2 Summary of Step 1 shortlisting process

Stages	Burden of disease dataset	Expenditure dataset
Original conditions identified	206	219
Non-specific conditions removed	29	39
Remaining conditions	177	180
Recalculated total	5.0 million DALYs	\$112.9 billion
Shortlisted threshold	Top 60% of recalculated total	Top 60% of recalculated total
Combined Step 1 shortlist		82 diseases

Step 2: Apply threshold criteria for registry suitability

Following the identification of high-impact diseases in Step 1, the second step of the prioritisation process assessed whether these 82 unique conditions were suitable for monitoring through a CQR. While some diseases may contribute substantially to population health burden or health system expenditure, not all conditions are appropriate for registry-based monitoring.

Step 2 therefore applied a set of threshold criteria designed to identify diseases where a CQR could be implemented effectively and where registry data would be capable of supporting improvements in the safety and quality of care.

Consistent with the approach used in the 2016 prioritisation, the following threshold criteria were applied as exclusion parameters. These are the diseases that did not demonstrate the characteristics necessary for successful registry implementation and were therefore removed from further consideration.

The threshold criteria reflect characteristics widely recognised in the literature as necessary for the effective development and operation of CQRs. These include the presence of defined care pathways, the ability to measure variation in care, feasible population capture, robust data infrastructure and engagement of clinical communities supporting registry governance and participation.^{37,38,39,40}

³⁷ Australian Commission on Safety and Quality in Health Care. *Australian Framework for National Clinical Quality Registries*. Sydney: ACSQHC; 2024.

³⁸ Gliklich RE, Leavy MB, Dreyer NA, editors. *Registries for Evaluating Patient Outcomes: A User's Guide*. 4th ed. Rockville, MD: Agency for Healthcare Research and Quality; 2020. <https://doi.org/10.23970/AHRQEPCCREGISTRIES4>

³⁹ Hoque DME et al. Impact of clinical registries on quality of patient care and clinical outcomes: A systematic review. PLoS ONE. 2017.

⁴⁰ Evans SM et al. Development of clinical quality registries in Australia. Medical Journal of Australia. 2011.

Threshold criteria for registry suitability

Table 3 Threshold criteria applied in Step 2

Criterion	Description
2.1 Evidence-based care pathway	<ul style="list-style-type: none"> The condition has an established sequence of care supported by clinical guidelines, consensus statements or recognised models of care, enabling the definition of meaningful quality indicators and treatment outcomes. Without a structured care pathway for treatment, registries are constrained in their ability to generate longitudinal outcome data or produce risk-adjusted reports on the appropriateness and effectiveness of care. Diseases identified in the initial list that do not have an established sequence of care were excluded from further consideration.
2.2 Ability to identify unwarranted variation	<ul style="list-style-type: none"> Registry data should allow variation in clinical practice or patient outcomes to be identified and examined across providers, services or jurisdictions. Diseases were excluded where it was not possible to reliably detect or respond to variation in care. The existence of clinical guidelines or treatment consensus outlining best practice care, together with registry infrastructure or other national data collections, indicates the potential for registries to identify unwarranted variation and support continuous quality improvement.
2.3 The clinical condition is suited to clinical quality registry data collection	<ul style="list-style-type: none"> A CQR must have the potential to capture the relevant clinical population. Capture of data about all or the substantial majority of the population included in a registry domain helps minimise selection bias and ensures registry outputs accurately reflect the quality of care delivered in practice.
2.3.1 The relevant clinical population can be captured	<ul style="list-style-type: none"> A clinical domain may define a subset of a larger clinical population (for example, patients receiving a specific treatment or procedure). However, once the scope of a registry is defined it is necessary to capture the entire population within that focus for the registry to operate effectively.
2.3.2 The clinical condition can be systematically recognised	<ul style="list-style-type: none"> For a registry to be feasible, the clinical condition must be capable of being consistently and systematically recognised. Conditions lacking clear diagnostic thresholds, staging criteria or case definitions may generate unreliable data and compromise registry validity. Diseases, conditions or interventions that cannot be reliably identified, or where it is not possible to capture the relevant clinical population, were not included in further prioritisation. Improvements in diagnostic methods or data collection capability may allow these areas to be considered for registry development in the future.
2.4 Availability of foundational information infrastructure	<ul style="list-style-type: none"> Suitable data sources, clinical datasets or registry infrastructure exist, or could feasibly be developed, to support national monitoring. These foundations include the ability to capture relevant clinical data, define performance indicators and support risk-adjusted comparison across providers and services. Foundational infrastructure may include administrative datasets, clinical data collections, existing registries or other health information systems that support consistent and reliable data capture. These systems must also support the development of meaningful performance indicators and allow appropriate risk adjustment to enable fair comparison of outcomes across providers, services or jurisdictions.

Criterion	Description
2.5 Clinical and organisational readiness	<ul style="list-style-type: none"> The condition is supported by an identifiable clinical community or professional network capable of supporting registry participation, governance and implementation. Engagement of clinicians and health services is essential for the sustainability and effectiveness of a clinical quality registry. The feasibility of registry development is closely linked to the presence of an engaged clinical community with the capacity to support data collection, interpret findings and implement quality improvement activities. Where clinical groups could not be clearly identified, or where no coordinated clinical networks or supporting infrastructure were evident, registry implementation was considered unlikely to be feasible. Conditions involving multidisciplinary models of care were not excluded on this basis alone, provided the relevant clinical groups and care pathways could be clearly identified and coordinated within a registry framework.

Application of the criteria

Diseases were considered to satisfy the threshold criteria where there was evidence of an established clinical framework capable of supporting registry monitoring.

In practice, this was indicated by the presence of:

- clinical guidelines
- consensus statements
- national data collections
- existing clinical quality registries defining best-practice care or
- relevant treatment outcomes.

Conditions included in the 2016 prioritised list had previously been assessed against similar threshold considerations as part of the earlier prioritisation process. To maintain methodological continuity, these conditions were retained in the 2026 update unless they represented broad residual categories or non-specific disease groupings that could not be meaningfully monitored through a registry framework.

Outcome of Step 2

Application of the threshold criteria resulted in the removal of a number of diseases that did not demonstrate the characteristics necessary to support effective registry monitoring. These exclusions generally occurred where conditions lacked clearly defined clinical populations, did not have established evidence-based care pathways, or where existing data infrastructure was insufficient to support meaningful registry development.

In some cases, diseases were excluded because the conditions represented broad or heterogeneous groupings that could not be consistently defined for registry data collection. In other cases, exclusions reflected the absence of established diagnostic definitions or the lack of a clearly identifiable clinical community capable of supporting registry governance and participation.

Following application of the threshold criteria, 75 diseases were retained for further consideration in the prioritisation process. These conditions represented diseases where

registry-based monitoring was considered both feasible and capable of supporting improvements in the safety and quality of care.

Diseases that did not meet the threshold criteria, together with the primary reason for exclusion, are summarised in Table 4.

Table 4 Diseases excluded following application of Step 2 Threshold Criteria

Disease	Threshold criteria not satisfied	Rationale for exclusion
Functional gastrointestinal disorders	2.2, 2.3.2, 2.4	Although clinical guidelines exist, the condition lacks clear diagnostic markers and is often diagnosed by exclusion, creating challenges for consistent case identification and registry data quality. No registry identified.
Lower respiratory infections (including influenza and pneumonia)	2.3.1, 2.4	Conditions represent a broad group of diseases managed across diverse clinical settings, limiting the feasibility of defining and capturing a consistent registry population.
Upper respiratory infections	2.1, 2.3.1, 2.4	Conditions lack a clearly defined treatment pathway and represent heterogeneous clinical presentations that are difficult to capture consistently through registry monitoring.
Urinary tract infections	2.4	Limited existing infrastructure for systematic national data capture across diverse care settings.
Dental caries	2.4	National data infrastructure for consistent monitoring was not established at the time of analysis.
Upper respiratory conditions	2.3.1, 2.4	Broad grouping of heterogeneous conditions unsuitable for defining a registry population.
Soft tissue injuries	2.3.1, 2.4	Conditions represent a heterogeneous group lacking clearly defined populations and care pathways suitable for registry monitoring.

The diseases retained following Step 2 progressed to the final prioritisation stage (Step 3), where the relative priority for potential clinical quality registry development was assessed.

Step 3: Prioritisation of clinical domains

Following Step 2, the remaining diseases were used to inform prioritisation of clinical domains for potential CQR development at the national level.

A total of 75 diseases met the threshold criteria applied in Step 2 and were retained for final prioritisation. These diseases were grouped within their respective clinical domains and assessed using a structured prioritisation matrix designed to identify areas where registry development may deliver the greatest benefit in improving the safety and quality of care.

Table 5 Diseases included in Step 3 prioritisation by clinical domain

Clinical domain	Diseases included in prioritisation
Cancer and other neoplasms	Acute lymphoblastic leukaemia; Acute myeloid leukaemia; Bowel cancer; Brain and central nervous system cancer; Breast cancer; Chronic lymphocytic leukaemia; Chronic myeloid leukaemia; Lung cancer; Non-Hodgkin lymphoma; Non-melanoma skin cancer; Other lympho-haematopoietic cancers; Pancreatic cancer; Prostate cancer
Cardiovascular diseases	Aortic aneurysm; Atrial fibrillation and flutter; Cardiomyopathy; Coronary heart disease; Heart failure; Non-rheumatic valvular disease; Rheumatic heart disease (including acute rheumatic fever); Stroke
Endocrine disorders	Gestational diabetes; Type 1 diabetes mellitus; Type 2 diabetes mellitus
Gastrointestinal disorders	Chronic liver disease; Gallbladder and bile duct disease; Gastro-oesophageal reflux disease; Inflammatory bowel disease
Hearing and vision disorders	Cataract and other lens disorders; Hearing loss
Infant and congenital conditions	Birth trauma and asphyxia; Brain malformations; Cardiovascular defects; Cerebral palsy; Cleft lip and/or palate; Gastrointestinal malformations; Neonatal infections; Neural tube defects; Pre-term birth and low birth weight complications; Urogenital malformations
Infectious diseases	COVID-19
Injury	Burn injuries; Drowning and submersion injuries; Internal and crush injury; Poisoning
Kidney and urinary diseases	Chronic kidney disease; Renal failure
Mental health and substance use disorders	Alcohol use disorders; Anxiety disorders; Autism spectrum disorders; Bipolar affective disorder; Depressive disorders; Eating disorders; Schizophrenia
Musculoskeletal disorders	Back pain and problems; Dislocations; Hip fracture; Humerus fracture; Osteoarthritis; Rheumatoid arthritis; Tibia and ankle fracture
Neurological conditions	Dementia; Multiple sclerosis; Spinal cord injury; Traumatic brain injury
Reproductive and maternal conditions	Genital prolapse; Hypertensive disorders of pregnancy; Maternal haemorrhage; Maternal infections; Obstructed labour; Other maternal conditions; pregnancy and postpartum care
Respiratory diseases	Asthma; Chronic obstructive pulmonary disease (COPD)
Skin disorders	Skin infections (including cellulitis)

Prioritisation criteria

Each clinical domain and their respective diseases were assessed using a multi-criteria prioritisation matrix comprising three core criteria:

- serious consequences associated with poor health
- cost to the health system
- clinician support

The first two criteria were based on quantitative national data and formed the primary basis for scoring. These were ranked on each component and assigned scores using quintile-based cut-offs. This approach enabled comparison across domains while ensuring that both current impact and growth trajectories were reflected in the final prioritisation. Burden of disease and health system cost were treated as the primary criteria and given equal weight. This reflects the importance of considering both the impact of disease on population health and the demand placed on the health system. Considering both measures together helps identify conditions where improvements in care may deliver the greatest benefit for patients and the health system.

Clinician support was used as additional qualitative considerations to support interpretation of the prioritisation results.

Table 6 Prioritisation criteria applied in Step 3

Criterion	Basis for assessment	Scoring range	Notes
3.1 Serious consequences associated with poor health	Burden of disease (DALYs) and growth in burden over time	0–3	Based on: <ul style="list-style-type: none"> • total burden in the most recent year • absolute growth over time • relative contribution to overall growth
3.2 Cost to the health system	Health system expenditure and growth in expenditure over time	0–3	Based on: <ul style="list-style-type: none"> • total expenditure in the most recent year • absolute growth over time • relative contribution to overall growth
3.3 Clinician support	Stakeholder input and evidence of clinical leadership or registry readiness	0–1	Assessed qualitatively from stakeholder survey; strong clinical backing increases likelihood of success; evidence of established registry and clinical leadership group.

The maximum score available through the prioritisation matrix was 7 points.

Outcome of Step 3

Application of the prioritisation criteria involved analysis of the 75 diseases retained following Step 2. Burden of disease and health system expenditure were first examined at the individual

disease level. These results were then aggregated to the clinical domain level to inform prioritisation of broader areas for potential clinical quality registry development.

This approach ensured that prioritisation reflected the combined impact of the diseases within each domain, while maintaining alignment with the domain-based framework used for national CQR planning. Domain-level measures of burden of disease and health system expenditure were therefore derived by collating the results for the included diseases within each clinical domain.

The resulting domain-level estimates formed the basis for scoring against the two primary prioritisation criteria: serious consequences associated with poor health and cost to the health system.

Criteria 1: serious consequences associated with poor health

Burden of disease was assessed using disability-adjusted life years (DALYs), including total burden in 2024, absolute growth in burden between 2015 and 2024, and each domain's contribution to overall growth in burden across the study period. Table 7 presents the aggregated burden of disease estimates for the prioritised CQR domains, in alphabetical order.

Table 7 Burden of disease for prioritised CQR domains

Clinical domain	2015 DALYs	2024 DALYs	2024 DALYs (%)	Absolute growth in DALYs, 2015 to 2024 (%)	Relative growth in DALYs, 2015 to 2024 (%)
Cancer and other neoplasms	546,921	586,522	11.7%	7.2%	4.9%
Cardiovascular diseases	582,384	597,622	11.9%	2.6%	1.9%
Endocrine disorders	121,025	148,266	3.0%	22.5%	3.4%
Gastrointestinal disorders	99,816	121,221	2.4%	21.4%	2.6%
Hearing and vision disorders	78,235	99,692	2.0%	27.4%	2.6%
Infant and congenital conditions	69,273	83,894	1.7%	21.1%	1.8%
Infectious diseases	0	43,950	0.9%	N/A	5.4%
Injury	136,295	144,732	2.9%	6.2%	1.0%
Kidney and urinary diseases	57,664	65,089	1.3%	12.9%	0.9%
Mental health and substance use disorders	558,600	735,939	14.7%	31.7%	21.9%

Clinical domain	2015 DALYs	2024 DALYs	2024 DALYs (%)	Absolute growth in DALYs, 2015 to 2024 (%)	Relative growth in DALYs, 2015 to 2024 (%)
Musculoskeletal disorders	437,030	548,909	11.0%	25.6%	13.8%
Neurological conditions	228,221	320,214	6.4%	40.3%	11.3%
Reproductive and maternal conditions	31,557	38,402	0.8%	21.7%	0.8%
Respiratory diseases	288,726	355,501	7.1%	23.1%	8.2%
Skin disorders	4,823	6,527	0.1%	35.3%	0.2%
All CQR domains	3,240,570	3,896,480	77.9%	20.2%	80.8%
Recalculated totals ⁴¹	4,190,204	5,001,750	100%	19.4%	100%

Criteria 2: cost to the health system

Health system expenditure was assessed using national health expenditure estimates, including total expenditure in 2022–23, absolute growth in costs between 2015–16 and 2022–23, and each domain's contribution to overall expenditure growth over the study period. Table 8 presents the aggregated health system expenditure estimates for the prioritised CQR domains, in alphabetical order.

Table 8 Health system expenditure for prioritised CQR domains

Clinical domain	2015–16 cost	2022–23 cost	2022–23 cost (%)	Absolute growth in cost, 2015–16 to 2022–23 (%)	Relative growth in cost, 2015–16 to 2022–23 (%)
Cancer and other neoplasms	\$8.1 billion	\$11.6 billion	10.3%	42.5%	14.0%
Cardiovascular diseases	\$7.8 billion	\$10.6 billion	9.4%	36.2%	11.4%
Endocrine disorders	\$2.6 billion	\$3.4 billion	3.0%	31.2%	3.3%

⁴¹ Recalculated totals refer to the total cost, expressed in constant prices, after excluding non-disease-specific conditions in Step 1 (that is, only defined diseases included in the analysis).

Clinical domain	2015–16 cost	2022–23 cost	2022–23 cost (%)	Absolute growth in cost, 2015–16 to 2022–23 (%)	Relative growth in cost, 2015–16 to 2022–23 (%)
Gastrointestinal disorders	\$3.7 billion	\$4.6 billion	4.1%	25.9%	3.9%
Hearing and vision disorders	\$1.9 billion	\$2.4 billion	2.1%	23.8%	1.9%
Infant and congenital conditions	\$1.5 billion	\$1.7 billion	1.5%	8.2%	0.5%
Infectious diseases	\$0 billion	\$1.8 billion	1.6%	N/A	7.4%
Injury	\$0.7 billion	\$1.0 billion	0.8%	35.3%	1.0%
Kidney and urinary diseases	\$2.2 billion	\$3.3 billion	2.9%	46.7%	4.2%
Mental health and substance use disorders	\$6.5 billion	\$8.8 billion	7.8%	34.7%	9.1%
Musculoskeletal disorders	\$10.2 billion	\$12.0 billion	10.7%	17.6%	7.3%
Neurological conditions	\$1.6 billion	\$2.2 billion	1.9%	37.2%	2.4%
Reproductive and maternal conditions	\$6.1 billion	\$6.2 billion	5.5%	2.4%	0.6%
Respiratory diseases	\$2.5 billion	\$2.8 billion	2.5%	12.8%	1.3%
Skin disorders	\$1.4 billion	\$1.9 billion	1.7%	36.1%	2.0%
All CQR domains	\$57.0 billion	\$74.3 billion	65.8%	30.5%	70.2%
Recalculated totals ⁴²	\$88.2 billion	\$112.9 billion	100%	28.1%	100%

⁴² Recalculated totals refer to the total cost, expressed in constant prices, after excluding non-disease-specific conditions in Step 1 (that is, only defined diseases included in the analysis).

Criteria 3: clinician support

Clinician support was included as a prioritisation criterion in the 2016 methodology and remains an important enabler of successful CQR implementation. Strong engagement from the clinical workforce supports data completeness, facilitates investigation and interpretation of registry findings, and promotes the use of results to drive improvements in clinical practice.

For these reasons, clinician support was retained as a criterion within the prioritisation framework. While it was not applied as a threshold requirement, it was used as a supporting consideration within the prioritisation matrix to reflect the practical feasibility of registry development and the likelihood of successful implementation. Evidence of an active clinical leadership group (for example, a recognised professional network), or evidence of active registry development within a domain (such as an establishment registry or a formally proposed initiative), was considered a strong indicator of clinical engagement and readiness to support registry development.

Clinician support was assessed qualitatively at the clinical domain level, drawing on stakeholder consultation and evidence of an identifiable clinical community capable of supporting registry participation and governance. Domains demonstrating strong clinical leadership, established or emerging registry activity, or clear prioritisation through the stakeholder survey received higher scores. Scores ranged from 0 to 1 (0, 0.5, 0.75, and 1), with higher scores indicating stronger clinical engagement and readiness to support registry implementation.

Table 9 highlights that clinical support for registry development is well established across most prioritised domains, with many demonstrating both active leadership and existing registry infrastructure. While the list of CQRs is not exhaustive, corresponding clinical domains reflect areas where registry-based monitoring is already embedded within clinical practice and supported by strong professional engagement. Cancer, cardiovascular diseases and musculoskeletal disorders have long-standing national registries that have demonstrated a high level of maturity, sustained investment and the availability of longitudinal data to support benchmarking and quality improvement.

Other domains, such as hearing and vision disorders and skin disorders, demonstrated more limited or emerging evidence of clinical support. In these areas, registry activity is either localised, condition-specific, or not yet established at a national level. For example, care for many skin conditions is highly dispersed, with management occurring across primary care, emergency departments and private specialist services. This results in a large and fragmented provider base, making it more challenging to establish coordinated clinician engagement. As a result, participation in registry-based data collection for these domains may be more variable, which can affect data completeness and the feasibility of implementing a traditional CQR model.

However, the absence of established registry infrastructure does not necessarily indicate a lack of clinical need. Rather, it may signal opportunities for future investment, particularly where there is emerging clinical advocacy or unmet need for improved monitoring of safety and quality of care.

Table 9 Clinical support for prioritised domains

Clinical domain	Evidence of clinical support	Existing CQRs ⁴³ / registries	Score
Cancer and other neoplasms	Established national registry infrastructure and identifiable clinical leadership across multiple tumour streams	ABDR; LaRDR; BCOR; NBCR; PCOR-ANZ; UGICR; VLCR	1
Cardiovascular diseases	Strong national clinical leadership and extensive registry infrastructure for cardiac and stroke care	ACOR; Aus-ROC OHCA Epistry; ANZCPR; AuSCR ANZSCTS Database; NCR; QCOR; VCOR	1
Endocrine disorders	Established national registry with clinical leadership and participation across diabetes care	ADCQR	1
Gastrointestinal disorders	Established national registry activity and clinical leadership in inflammatory bowel disease and transplant care	ANZLITR; (CCCare) Registry	1
Hearing and vision disorders	Emerging clinical advocacy for registry development; several local registries and datasets exist but no established national CQR	ANCHOR; Aussie Ear Bank; Save Sight Registry	0.5
Infant and congenital conditions	Established national registries and clinical networks supporting congenital and neonatal care	ANZ CHD Registry; ANZFR; ANZNN	1
Infectious diseases	Limited suitability for a dedicated CQR; monitoring largely undertaken through administrative and surveillance datasets	CHOPAN registry (COVID-19 related outcomes)	1
Injury	Strong clinical leadership and established trauma and burns registry infrastructure	ANZICS Registry; ANZTR; BRANZ	1
Kidney and urinary diseases	Established national registry with strong clinical leadership and participation	ANZDATA Registry	1
Mental health and substance use disorders	Established registry infrastructure with identifiable clinical leadership in eating disorders	TrEAT Registry; AEPCC CQR; The Lily Registry; TMS-REG; ePBRN	1

⁴³ Full registry names are provided in Appendix E.

Clinical domain	Evidence of clinical support	Existing CQRs ⁴³ / registries	Score
Musculoskeletal disorders	Extensive national registry infrastructure and strong professional leadership in orthopaedics and rheumatology	ANZHFR; ANZFFR; AOANJRR; ARAD	1
Neurological conditions	Established national registries with clinical leadership across dementia and neurological care	ADNeT Registry; MS AHSCT Registry; Australasian Shunt Registry; Australian Spine Registry	1
Reproductive and maternal conditions	Established registries and national initiatives supporting maternity and pelvic floor outcomes monitoring	AMCR; APFPR; Data4ME; ABS-Obstetrics	1
Respiratory diseases	Established registry infrastructure supporting severe asthma monitoring	ASAR	1
Skin disorders	Limited evidence of registry infrastructure covering prioritised conditions	None identified	0

Note: The examples presented in Table 9 are illustrative of an active clinical leadership group and was compiled using publicly available sources, including the Australian Register of Clinical Registries and other identified registry programs. They are not intended to represent a comprehensive inventory of all CQRs or sources of clinical support within each domain. A list of CQR acronyms is provided in [Appendix E](#).

Stakeholder engagement

Stakeholder engagement was undertaken to seek input from the CQR sector on the proposed methodological approach for the 2026 update. This included a targeted stakeholder survey on the principles underpinning prioritisation for CQR investment, with input from organisations involved in CQRs, clinical governance, health system management and clinical research. The Commission's Clinical Quality Registries Advisory Group was also engaged to provide high-level guidance and ensure that the prioritisation approach reflected practical considerations relevant to registry development within the Australian health system.

Stakeholder survey

A stakeholder survey was undertaken to seek input from the CQR sector on aspects of the approach used for the 2026 update, and was distributed to over 470 organisations for feedback.

A total of 169 respondents participated in the survey. Respondents represented a broad range of stakeholder groups across the health system, including clinicians, researchers, policy makers, consumers, industry representatives and healthcare funders. Some respondents held

multiple roles within the CQR landscape. Table 10 summarises the profile of survey respondents.

Table 10 Respondent profile

Stakeholder role	% (N)
Academic / Researcher	39.05 (66)
Healthcare provider (e.g, clinician, nurse, allied health professional)	31.9 (54)
Other	17.75 (30)
Healthcare worker (eg, administrative staff, support staff, health support staff)	13.61 (23)
Policy maker / Government official	8.28 (14)
Consumer / Carer	6.51 (11)
Industry representative (eg, medical technology, pharmaceuticals)	4.14 (7)
Healthcare funder / Insurer (eg, private health insurer, government funder)	1.18 (2)
Total	169

Survey responses provided useful input on the relevance and appropriateness of the proposed criteria. There was broad endorsement of the core principles underpinning the framework, particularly the focus on safety and quality, continuous improvement, transparency and stakeholder/clinician engagement. These principles were consistently rated as highly important by survey respondents, reinforcing their central role in guiding registry development.

There was similarly strong support for the key criteria used in the prioritisation framework. Criteria relating to contribution to quality improvement, scientific and evidence generation, burden of disease and feasibility were all rated highly. These findings indicate clear sector support for a balanced approach to prioritisation that considers both population health impact and practical implementation factors. Key findings from stakeholder responses on prioritisation criteria are summarised in Box 3.

Box 3: Stakeholder views on prioritisation criteria

When asked to rate prioritisation criteria, stakeholders prioritised those linked to improving clinical outcomes, generating evidence and supporting feasible implementation.

- Contribution to quality improvement was the highest rated criterion (4.55 out of 5), followed by scientific and evidence generation (4.26 out of 5) and relevance to stakeholders (4.22 out of 5).
- Burden of disease (4.15 out of 5) and feasibility and system readiness (4.01 out of 5) were also strongly supported, indicating that both population health impact and implementation feasibility are important considerations in prioritisation decisions.
- Ethical considerations (rated 3.87 out of 5) were recognised among stakeholders but seen as more difficult to operationalise within the framework.

Respondents also emphasised the importance of practical considerations relevant to registry development, including clearly defined care pathways, the ability to measure meaningful variation in care or outcomes, the feasibility of data collection and the availability of clinical leadership to support implementation.

While overall support for the prioritisation framework was strong, respondents identified several considerations for future registry development. These included the importance of sustainable funding arrangements for registries and the need to ensure that registry models are suited to the characteristics of different clinical domains.

Targeted consultation

In addition to the stakeholder survey, targeted consultation was undertaken with members of the Commission's CQR Advisory Group to ensure expert input was obtained not only from their individual professional perspectives but also the considered views of organisations members represented. This allowed for multi-level feedback on key elements of the proposed prioritisation approach, ensuring the advice captured both sector expertise and positions of organisations consulted.

The Advisory Group members comprise representatives from clinical registries, Commonwealth agencies including the Australian Institute of Health and Welfare, Australian Digital Health Agency, Independent Health and Aged Care Pricing Authority, and the Therapeutic Goods Administration, as well as state and territory health departments, consumer representatives and the private sector. This broad representation ensured that perspectives from clinical practice, registry operations, health system governance, and medical device regulation were considered in refining the prioritisation criteria and implementation considerations.

These consultations provided an opportunity to test key elements of the methodology with stakeholders who have experience in registry development, data analysis and quality improvement. Feedback indicated overall support for the methodological approach, including the use of burden of disease and health system cost as primary drivers of prioritisation.

Consultation also highlighted several important considerations for the application of the framework. Stakeholders noted that prioritisation at the national clinical domain level provides an indication of areas of potential focus but does not determine whether a registry should be established for a specific disease or procedure. Further engagement with relevant clinical

communities and registry stakeholders is important to assess feasibility, clinical readiness and the potential value of registry-based monitoring.

Stakeholders also highlighted practical constraints affecting registry implementation, including the challenges of achieving national coverage for high-prevalence conditions, the need for sufficient and sustained funding, and the importance of clinician engagement and leadership. These factors were identified as critical enablers of registry feasibility and long-term impact.

A list of the Commission's CQR Advisory Group membership is provided in [Appendix F](#).

Results

Prioritised list of clinical domains

Application of the prioritisation matrix produced a composite score for each clinical domain based on the combined contribution of disease burden, health system cost and implementation considerations. Table 11 presents the prioritisation scores.

The highest ranked domains were mental health and substance use disorders, cancer and other neoplasms, musculoskeletal disorders, neurological conditions, and cardiovascular diseases. These domains ranked strongly due to a combination of substantial burden of disease, high or increasing health system expenditure, and evidence of clinical support for registry-based quality improvement.

The ranking reflects the relative contribution of each domain across the prioritisation criteria applied in this analysis.

Table 11 Final prioritisation scores by clinical domains

Total prioritisation score	Clinical domain	Burden of disease score (0–3)	Health system cost score (0–3)	Clinician support (0–1)
6.25	Mental health and substance use disorders	3.00	2.25	1
6.00	Cancer and other neoplasms	2.00	3.00	1
5.50	Musculoskeletal disorders	2.50	2.00	1
5.50	Neurological conditions	2.75	1.75	1
5.00	Cardiovascular diseases	1.25	2.75	1
4.50	Infectious diseases	1.75	1.75	1
4.25	Gastrointestinal disorders	1.50	1.75	1
4.25	Respiratory diseases	2.25	1.00	1
4.00	Endocrine disorders	1.50	1.50	1

Total prioritisation score	Clinical domain	Burden of disease score (0–3)	Health system cost score (0–3)	Clinician support (0–1)
3.75	Kidney and urinary diseases	0.50	2.25	1
2.75	Hearing and vision disorders	1.50	0.75	0.5
2.50	Injury	0.75	0.75	1
2.25	Reproductive and maternal conditions	0.50	0.75	1
2.25	Skin disorders	1.00	1.25	0
1.75	Infant and congenital conditions	0.75	0.00	1

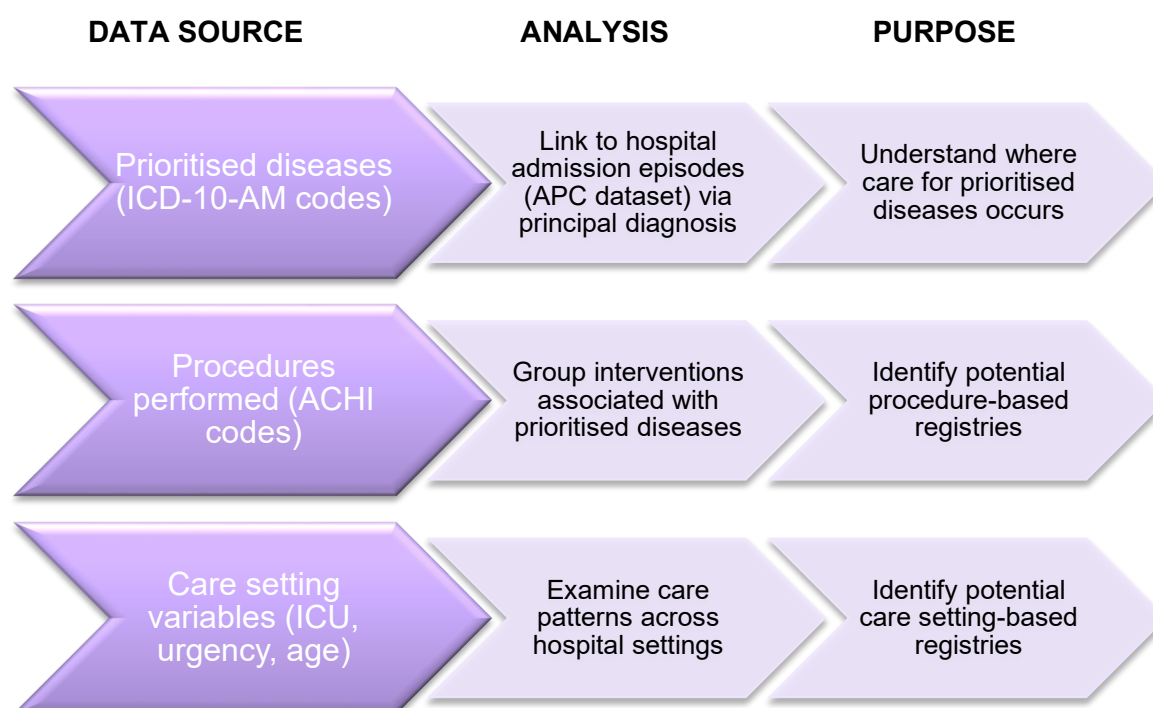
Additional information on the key burden, expenditure and clinical support signals underlying the prioritisation results is provided in [Appendix G](#).

Intervention and care-setting-based registry models

While the prioritisation framework used in this report focuses on disease-level domains, CQRs are not always organised around specific diseases. In practice, many CQRs are structured around interventions, procedures, technologies/devices or healthcare settings. Interventions and healthcare settings also frequently span multiple disease domains. For example, surgical procedures, device implantation or intensive care services may involve patients with a wide range of underlying conditions but share common processes, risks and outcome measures that are relevant to quality improvement. Quality and safety considerations may therefore extend beyond the point of diagnosis or a single procedure and can occur across multiple stages of care.

To explore how prioritised diseases relate to common interventions and care settings, additional analysis was undertaken using national hospital admissions data to map the principal diagnosis for each episode of care to a prioritised disease and clinical domain, and to identify interventions recorded during the same admission using the Australian Classification of Health Interventions (ACHI). In this report and consistent with the ACHI context, surgeries, therapies, dental services, allied health interventions, imaging services and other clinical procedures are considered different types of interventions. The analytical approach used to examine these relationships is illustrated in Figure 3.

Figure 3 Analytical framework used to examine relationships between diseases, interventions and care settings



This mapping provides additional context for understanding how registry development could potentially occur beyond disease-specific registries. In practice, many healthcare services involve multidisciplinary models of care where treatment is delivered across multiple services and care environments. For example, patients may move between emergency care, acute hospital treatment, rehabilitation services and community care as part of the same clinical episode.

Findings from the exploratory analysis

The results identified common patterns in the types of interventions delivered for prioritised diseases during hospital care. In this analysis, a ‘common intervention’ was defined as an intervention recorded in at least 50% of admitted patient separations associated with a prioritised disease in 2023–24.

Across many prioritised diseases, the most frequently recorded interventions were services delivered by allied health professionals. These services were observed across a wide range of conditions including neurological, musculoskeletal and cardiovascular diseases, with allied health services recorded in:

- 87% of stroke-related separations
- 79% of dementia separations
- 93% of spinal cord injury separations.

Anaesthesia and analgesia interventions were also common for diseases requiring surgical treatment in the hospital admitted care setting. For example, anaesthesia and analgesia were recorded in:

- 78% of breast cancer-related separations
- 53% of atrial fibrillation and flutter separations

- 74% of separations associated with gallbladder and bile duct disease.

Other intervention types reflected the clinical characteristics of particular diseases. Breast and lymph nodes related interventions were common in treatment of breast cancer in admitted care. Similarly, pharmacotherapy interventions were recorded in 58% of hospital separations for acute lymphoblastic leukaemia, while pharmacotherapy was also frequently observed for conditions such as inflammatory bowel disease and multiple sclerosis.

These results highlight the multidisciplinary nature of contemporary healthcare. In many cases, treatment involves a combination of medical procedures, pharmacological management and allied health services delivered across multiple stages of care. Detailed results showing prioritised diseases and their associated common interventions are provided in [Appendix H](#).

The exploratory analysis of care settings also demonstrated that several healthcare environments provide care for patients across multiple disease domains. Using admitted patient data, clinical domains that accounted for at least 10% of hospital separations within a care setting for the prioritised diseases were identified for further analysis.

Results showed that ICU admissions occurred across multiple domains, including cancer and other neoplasms, cardiovascular diseases, mental health and substance use disorders, musculoskeletal disorders and reproductive and maternal conditions. Other multi-domain care settings included emergency admissions, geriatric and psychogeriatric care, palliative care and rehabilitation services.

Some care settings were more commonly linked to particular clinical domains. For example, paediatric care was predominantly associated with infant and congenital conditions, while palliative care admissions were most commonly linked to cancer and other neoplasms, followed by cardiovascular diseases. Table 12 summarises the main care settings identified in the analysis.

Table 12 Care settings and common clinical domains

Care setting for CQR diseases	Clinical domain
Emergency admission	Cardiovascular diseases
Emergency admission	Mental and substance use disorders
Emergency admission	Musculoskeletal disorders
Geriatric and psychogeriatric	Cardiovascular diseases
Geriatric and psychogeriatric	Mental and substance use disorders
Geriatric and psychogeriatric	Musculoskeletal disorders
Geriatric and psychogeriatric	Neurological conditions
ICU	Cancer and other neoplasms
ICU	Cardiovascular diseases
ICU	Mental and substance use disorders
ICU	Musculoskeletal disorders

Care setting for CQR diseases	Clinical domain
ICU	Reproductive and maternal conditions
Paediatric	Infant and congenital conditions
Palliative	Cancer and other neoplasms
Palliative	Cardiovascular diseases
Rehabilitation	Cardiovascular diseases
Rehabilitation	Musculoskeletal disorders

The analysis also demonstrated that some healthcare settings provide care for patients across multiple disease domains. Intensive care units, emergency departments, rehabilitation services and palliative care services commonly treat patients with a wide range of underlying conditions. In these contexts, monitoring the safety and quality of care may be more appropriately undertaken at the level of the care setting rather than through disease-specific registries alone. These findings illustrate how intervention-based or setting-based registries may complement disease-focused registries within the national CQR landscape. While disease-based registries remain central to monitoring outcomes for specific conditions, registries focused on procedures, devices or healthcare settings may provide additional insights into the safety and quality of care processes that occur across multiple clinical domains.

Discussion

The final prioritisation generated an ordered ranking of the clinical domains based on their combined criteria scores. The results highlight areas where the combined scale of health impact and system cost suggests the greatest opportunity for improvement through systematic monitoring and benchmarking. Domains that ranked high under the framework were those with consistently high impact across multiple indicators.

Australia's Burden of Disease profile has evolved over the past decade. Some conditions have increased in relative burden due to population ageing, changes in risk factors, and improved survival among people living with chronic disease. In other cases, increases in measured burden may reflect changes in diagnostic practices, improved detection, or greater recognition of previously under-identified conditions rather than a true rise in underlying incidence.

Mental health and substance use disorders ranked highest overall in the 2026 results reflecting substantial population burden and strong growth in burden over the past decade. For example, within the mental health and substance use disorders domain, Autism Spectrum Disorder increased from 31,540 DALYs in 2015 (0.8% of total DALYs) to 102,080 DALYs in 2024 (2.0%) representing an increase of around 223.7% in DALYs over the period. These changes may reflect a genuine increase in population burden but may also be influenced by increased identification and reporting of cases. Factors such as changes in diagnostic criteria, increased awareness and screening, improved access to diagnostic services, and broader societal and policy recognition of neurodevelopmental conditions are likely to have contributed to higher recorded prevalence over time. These patterns highlight the importance of interpreting changes in prioritised domains within the broader context of evolving clinical practice, health service delivery and recognition of health conditions.

A key consideration of this report is that the level of clinician support identified for a clinical domain should not be interpreted as evidence of an established or mature CQR landscape within that domain. Rather, clinician support reflects the presence of identifiable clinical leadership and availability of foundational data infrastructure - in the form of an existing CQR, or a registry with potential to be expanded into a national CQR. This distinction is particularly relevant for mental health and substance use disorders. Although this domain ranked the highest, current CQR infrastructure and coverage remains somewhat limited, with only a small number of national CQRs in place (e.g. Lily and TrEAT). This highlights a mismatch between prioritisation and sector maturity. Unlike more established domains such as cancer, which have had more sustained investment, longer development timelines, and well-established registry networks, the mental health sector is at a comparatively earlier stage of CQR development.

Cancer and other neoplasms, musculoskeletal disorders and cardiovascular diseases also ranked strongly due to their large population impact and significant health system expenditure. In these areas, improvements in care delivery have the potential to influence large patient populations and substantial areas of health system spending.

The positioning of the infectious diseases domain reflects the specific context of the data used in the analysis. In this case, the domain is driven by COVID-19, which contributed substantially to both burden and cost in the 2022-23, influencing the overall ranking of the domain. However, this reflects the temporal impact of the pandemic rather than a sustained pattern of burden across infectious diseases more broadly. As the impact of COVID-19 evolves, the relative positioning of this domain may change in future iterations of the prioritisation.

Some domains ranked lower because their impact was more concentrated in a single indicator rather than across multiple measures. For example, neurological conditions showed substantial growth in disease burden over the past decade, largely driven by dementia. Dementia-related DALYs increased from 181,498 in 2015 to 262,052 in 2024. However, diseases within this domain account for a comparatively small share of total health system expenditure (approximately 2% of total expenditure in 2022–23). Despite this, dementia has been recognised nationally as an area requiring improved monitoring and coordination of care. The more recent establishment of the Australian Dementia Network Registry demonstrates the potential value of registry-based monitoring in this area, supporting benchmarking of diagnostic practices and identification of variation in care across services.

In contrast, kidney and urinary diseases demonstrated rapid growth in health system expenditure, largely driven by chronic kidney disease, where expenditure increased from \$1.9 billion to \$2.9 billion over the same period. This is because the clinical burden of CKD reflects the high cost of long-term management and dialysis services associated with the disease compared to its overall population-level disability or mortality. Evidence from the environmental scan indicates that much of the health system expenditure associated with chronic kidney disease is concentrated in the management of end-stage kidney disease, particularly dialysis and kidney transplantation. Existing registry infrastructure in Australia largely reflects this focus, with established registries such as ANZDATA primarily monitoring patients receiving dialysis or transplant care, while earlier stages of chronic kidney disease remain comparatively under-monitored at a national level.

Contextual considerations across care settings

While the prioritisation framework applied in this report focuses on disease-based clinical domains, CQRs are not always organised around specific diseases. In practice, many CQRs are structured around interventions, procedures, technologies/devices or healthcare settings.

These registry models enable monitoring of safety and quality across a range of conditions where patients receive care within a shared treatment pathway or care environment.

Findings from the exploratory analysis presented earlier in this report highlight that many prioritised diseases involve interventions that occur across multiple clinical domains and healthcare settings. For example, procedures requiring anaesthesia and surgical intervention are common across several domains including cancer, cardiovascular diseases and musculoskeletal disorders. Allied health services also feature prominently across many disease areas, reflecting the multidisciplinary and patient-centred nature of contemporary healthcare delivery. These patterns suggest that monitoring safety and quality often needs to consider the broader patient journey rather than focusing only on a single diagnosis or procedure.

The analysis also highlights the importance of considering healthcare settings when identifying opportunities for registry development. Certain settings, such as intensive care units, emergency departments, geriatric care and rehabilitation services, provide care for patients with a wide range of underlying conditions. In these contexts, registry models organised around the care setting rather than a specific disease may provide a more appropriate mechanism for monitoring safety, quality and consistency of care across diverse patient groups.

Setting-based registries may also offer opportunities to examine transitions of care across the health system which are recognised risk points for patient safety. Capturing patient outcomes and experiences across different stages of the care pathway, including acute care, rehabilitation and community follow-up, may provide valuable insights into system performance and opportunities for improvement. In this context, registry models that incorporate patient-reported outcome measures and patient-reported experience measures may support more comprehensive monitoring of the quality of care delivered across the patient journey.

There are some existing registries that are organised around specific healthcare settings or services rather than individual diseases. Examples include intensive care registries such as the Australian and New Zealand Intensive Care Society Adult Patient Database (ANZICS-APD), trauma registries such as the Victorian State Trauma Registry, and obstetric or maternity registries that monitor pregnancy and birth outcomes across maternity services. These registry models enable monitoring of safety and quality within defined care environments where patients may present with a wide range of underlying diagnoses.

Some conditions are managed across a broader range of healthcare settings, including primary care, emergency departments and community services. In these areas, care may be delivered by a large and dispersed provider base, and treatment pathways may involve a combination of outpatient management, short hospital admissions and community follow-up. These characteristics can make national registry implementation more complex and may influence the degree to which registry infrastructure has historically developed within particular clinical domains.

The clinical domain skin disorders is an example of this pattern. The retained condition within this domain was skin infections, including cellulitis, which accounted for approximately 6,500 DALYs and \$1.9 billion in health system expenditure. Despite this burden, these conditions are commonly managed in primary care and emergency department settings and are typically treated using relatively standardised antimicrobial therapies. As care is distributed across a large and dispersed provider base, these conditions have historically attracted less focus for disease-specific registries compared with areas where care is concentrated within specialist services or procedural settings. This example highlights that the feasibility of registry development is influenced not only by disease burden but also by patterns of care delivery within the health system. In conditions where care is highly distributed across settings and providers, establishing and sustaining a national CQR may be more challenging. In some of

these areas, alternative monitoring approaches such as analysis of routinely collected administrative datasets may provide a more feasible mechanism for monitoring safety, quality and outcomes at a national level.

These findings illustrate that opportunities for registry development may arise not only from disease burden but also from patterns of care delivery within the health system. In some areas, disease-based registries may be most appropriate, while in others registries organised around specific interventions or healthcare settings may provide a more practical approach to monitoring safety, quality and outcomes.

Implications for future CQR development

The prioritisation results highlight several areas where registry-based monitoring may offer particular strategic value. In high burden, high expenditure domains, CQRs have the potential to support improvements in care quality at scale while influencing large areas of health system spending. Through benchmarking and feedback, registries can help identify unwarranted variation in practice, complications, avoidable adverse events and opportunities for more efficient care delivery, contributing to continuous improvement within a learning health system.

While health system expenditure reflects current patterns of resource use, it may not fully capture areas of emerging demand. The findings suggest that growth is itself an important strategic signal. Domains such as mental health and substance use disorders and neurological conditions appear to represent areas of increasing pressure on the health system, even where expenditure profiles differ. In these areas, improved national visibility of care pathways and outcomes may become increasingly important over time.

CQRs may not always be the most appropriate monitoring mechanism for every clinical domain. For example, the infectious diseases ranked moderately based on its combined burden and cost criteria, which was influenced by the impact of COVID-19 during the analysis period. COVID-19 has been extensively monitored through surveillance and administrative data systems, which have provided near real-time insights into disease trends and health system impact. This disease illustrates that alternative data sources may, in some cases, be more appropriate than CQRs, which are better suited to conditions with clearly defined care pathways, measurable outcomes and more concentrated care delivery.

At the same time, lower-ranked clinical domains should be interpreted with caution. Lower ranking does not imply lack of importance, nor does it preclude registry development. Rather, it indicates that the domain did not demonstrate the same combined burden, cost and growth profile as the leading domains within this framework. Some lower-ranked domains may nonetheless contain individual conditions of high strategic importance. For example, within the hearing and vision disorders domain, cataract surgery represents a high-volume procedure associated with substantial health system expenditure and measurable clinical outcomes. The comparatively low burden score partly reflects the fact that cataract is a highly treatable condition, meaning that long-term disability is often avoided despite the need for surgical intervention. While no national CQR currently exists, emerging advocacy for a cataract registry and the presence of local data collections suggest potential for future development.

Consultation feedback also highlighted the important relationship between registry development and the availability of clinical guidelines. Stakeholder feedback on the prioritisation methodology emphasised that while unwarranted variation and established clinical guidelines are important considerations, the absence of well-developed guidelines should not necessarily preclude registry development. In some clinical areas, registries themselves can contribute to building the evidence base needed to inform future clinical guidelines and more consistent models of care. For example, data from the Australian Orthopaedic Association National Joint Replacement Registry (AOANJRR) have been used to

identify poorly performing hip prostheses and variations in surgical practice, leading to changes in prosthesis selection recommendations and contributing to improvements in clinical practice and regulatory decision-making.⁴⁴ Similarly, the Australian Stroke Clinical Registry has generated national benchmarking data on stroke care processes and outcomes, supporting improvements in adherence to evidence-based care and informing national stroke care policy and clinical guidance.⁴⁵ These examples illustrate how registries can function not only as monitoring tools but also as platforms for driving improvements in care and building the evidence base needed to support more consistent, evidence-based care.

Conditions with rapidly increasing burden, gaps in national monitoring infrastructure, or emerging opportunities for quality improvement may warrant further assessment for registry development even where their broader clinical domain ranks low. This limitation is particularly relevant for rare diseases. Because population-level prioritisation is based on aggregate burden and health system expenditure, conditions affecting very small patient populations may rank lower despite being associated with significant clinical complexity, high per-patient costs, or substantial unmet clinical need. Environmental scan findings indicate that many rare disease registries currently operate at small scale or within individual clinical networks, limiting opportunities for national benchmarking and quality improvement. However, in some cases, certain rare conditions may warrant registry development where diagnostic criteria are clearly defined, treatments are high cost, and outcomes may be improved through more consistent models of care. In Australia, rare diseases are recognised within the National Strategic Action Plan for Rare Diseases as an area requiring improved data collection and coordination of care.⁴⁶ Registry development for rare diseases may therefore require tailored assessment approaches that consider disease severity, clinical uncertainty and opportunities for evidence generation within small patient populations.

Prioritisation of clinical domains provides a structured starting point for identifying areas where registry development may deliver the greatest national benefit. However, decisions about individual CQR development should also consider additional contextual factors, including patterns of care delivery, gaps in existing monitoring infrastructure, clinician engagement/leadership and opportunities provide evidence to support safety and quality of care. These results are intended to guide strategic discussion and investment decisions, rather than determining a fixed list of future registries, recognising that CQRs play a critical role in supporting continuous improvement and better patient outcomes across the health system.

Role of Electronic Medical Records (EMRs) in CQR development

Sustainability of CQRs is predicated on the alignment of policy, workforce capability, and enabling digital infrastructure to support long-term success. The *National Strategy for Clinical Quality Registries and Virtual Registries 2020–2030* articulates a vision in which CQR data are ‘integrated into Australia’s health care information systems and systematically drive patient-centred improvements in the quality and value of health care’. Central to achieving this vision is leveraging the increasing adoption of EMRs across health services and systems. By ingesting information seamlessly, this shifts the operational burden of manual data entry by

⁴⁴ Australian Orthopaedic Association National Joint Replacement Registry (AOANJRR). *Annual Report 2023*. Adelaide: AOA; 2023.

⁴⁵ Australian Stroke Clinical Registry. *Annual Report*. Melbourne: Monash University.

⁴⁶ Department of Health. (2020). *National Strategic Action Plan for Rare Diseases*. Australian Government. <https://www.health.gov.au/sites/default/files/documents/2020/03/national-strategic-action-plan-for-rare-diseases.pdf>

clinical staff to having technology and infrastructure support registries pivot from research repositories into real-time tools to support clinical care.

As EMR implementation accelerates, there is both a critical opportunity and requirement to ensure these systems are designed to be fit for purpose from a quality improvement and clinical registry perspective. Operating Principle 3: Data collection from the *Australian Framework for National Clinical Quality Registries 2024* states that CQR data should be sourced ‘directly from clinical information systems where possible’. To support this, EMRs should be configured at the planning, procurement, and implementation stages to enable structured, standardised capture of key clinical data elements within routine workflows. This includes ensuring alignment with nationally agreed data definitions and registry requirements, so that information recorded during care delivery can be directly reused for CQR reporting.

Embedding these capabilities within EMRs would enable automated extraction and population of data at the point of care and across transitions of care, reducing duplication, minimising manual data entry burden, and improving data completeness and quality. It would also support more timely data flows, allowing CQRs to provide closer to real-time feedback to clinicians and services, enabling meaningful benchmarking, reporting, and actionable insights to inform clinical decision-making.

Integration of EMR and CQRs represents one enabler of a learning health system, where data generated through routine care are continuously fed back to drive improvement in safety and quality. Operationalising this loop requires deliberate coordination between digital infrastructure planning and CQR development, ensuring that EMRs are systems of record that can actively support measurement and improvement. Strengthening this alignment will be particularly important in emerging or less mature registry domains, where building efficient and scalable data capture mechanisms from the outset is critical to supporting future CQR expansion.

Considerations for individual CQR development

The 2026 prioritised results identify clinical domains where the combination of population burden, health system expenditure and sector engagement indicates substantial potential for registry-based quality improvement. It considers the greatest potential impact from a population and health system perspective.

Domains that ranked high under this framework represent areas of sustained or increasing system impact. In these areas, systematic measurement and benchmarking may support improvements in safety, consistency of care and efficient use of resources. However, prioritisation at the domain level does not in itself determine whether a CQR should be established for a specific disease, procedure or treatment within that domain. The prioritised list should be interpreted as a comparative planning tool that provides a structured basis for directing further feasibility assessment and strategic planning.

Consultations with the CQR sector highlighted that decisions regarding registry development must ultimately occur at the level of individual registry proposals. While some conditions may rank highly based on burden of disease or health system expenditure, practical considerations such as clinical readiness, feasibility of data collection and stakeholder engagement may influence whether a registry is appropriate or achievable in practice.

Consultations with the CQR sector also highlighted that CQRs represent one of several potential approaches for monitoring healthcare quality and outcomes and may not necessarily

be the most appropriate monitoring mechanism for all conditions. In some circumstances, existing administrative data collections (such as hospital admissions data, MBS claims, PBS prescribing data, emergency department collections or mortality data) may already provide sufficient information to support monitoring and quality improvement activities. For example, administrative datasets can support monitoring of conditions where care pathways are relatively standardised and outcomes are routinely captured through existing datasets, such as prescribing patterns for common chronic conditions like hypertension, COVID-19 or hospital utilisation for asthma or COPD exacerbations. In these circumstances, the marginal benefit of establishing a CQR may be limited relative to the cost and complexity of developing and maintaining a new data collection. Strengthening the analysis or linkage of existing administrative datasets may therefore represent a more efficient approach to monitoring care quality and outcomes than establishing a dedicated CQR.

Stakeholder feedback also highlighted the importance of considering practical implementation factors when assessing potential registry development. These include the availability of structured clinical data, the ability to integrate data collection within existing clinical workflows, and the presence of strong clinical leadership to support registry governance and implementation. Sustainable funding arrangements and national coordination were also identified as important factors influencing the long-term success of registry initiatives.

For these reasons, further discussion with clinical communities, registry experts and policymakers is required before progressing to CQR development within any prioritised domain.

Criteria for assessing the potential value, impact and feasibility of individual CQR proposals

This report also provides considerations for assessing the potential value and feasibility of establishing a CQR for a specific condition within prioritised domains. These considerations draw on stakeholder feedback received through the consultation process, CQR principles, as well as existing guidance on the establishment and operation of CQRs including evidence on registry design, care pathways and quality improvement.^{47,48} They are intended to guide planning for registry development rather than to represent prescriptive criteria.

While these considerations are presented together in Table 13, they reflect different dimensions of registry assessment. Some considerations relate to the fundamental suitability of a condition for monitoring through a clinical quality registry. Other considerations relate to the practical feasibility and strategic value of registry development. While these factors may not represent absolute prerequisites, they can significantly influence the sustainability, effectiveness and policy relevance of a registry.

Table 13 Considerations for potential CQR development

Consideration	Type	Assessment considerations
Clearly defined patient cohort and care pathway	Implementation	CQRs are most effective where patients move through a recognisable sequence of care and where clear treatment endpoints can be defined. Sequential

⁴⁷ Evans SM, Scott IA, Johnson NP, Cameron PA, McNeil JJ. Development of clinical-quality registries in Australia: the way forward. *Medical Journal of Australia*. 2011;194(7):360–363.

⁴⁸ Australian Commission on Safety and Quality in Health Care. *Australian Framework for National Clinical Quality Registries*. Sydney: ACSQHC; 2024.

Consideration	Type	Assessment considerations
		care pathways enable monitoring of adherence to recommended care and allow meaningful comparisons of outcomes across services. Conditions lacking a defined pathway or endpoint may be more difficult to monitor through a CQR model.
Appropriateness of a CQR model	Strategic	Consultation with the CQR sector highlighted the importance of considering whether a clinical quality registry is the most appropriate monitoring mechanism when assessing potential registry development. In some clinical areas, routinely collected administrative datasets or existing surveillance systems may already provide sufficient information to monitor outcomes or service utilisation. If indicators can be derived from existing datasets, strengthening analysis or linkage of existing datasets may represent a more efficient monitoring approach than establishing a dedicated CQR.
Alignment with safety and quality improvement objectives	Strategic	The proposed registry should address a clearly identified safety or quality issue and have the potential to improve clinical practice, patient outcomes or health system performance. CQRs are most effective where they support benchmarking, feedback and continuous quality improvement.
Registry and digital readiness	Implementation feasibility	The feasibility of implementing a CQR is influenced by the availability of structured clinical data and the ability to integrate data collection within existing digital systems and clinical workflows. Conditions where relevant data elements are routinely captured within electronic medical records, clinical information systems or established data standards may enable more efficient registry implementation and reduce reporting burden.
Clinical leadership and stakeholder engagement	Governance	Successful registries typically require strong clinical leadership and engagement from relevant professional groups, health services, policymakers and consumers. Clinical support is often essential to support data collection, interpretation of results and translation of findings into practice.
Ability to measure variation in care and outcomes	Analytical	A CQR is most useful where there is potential to identify variation in clinical practice, treatment pathways or patient outcomes. Registry data should support benchmarking across services and provide insights into opportunities for improvement.
Data availability and feasibility of data collection	Operational	Consider whether relevant clinical and outcome data can be collected reliably and consistently across participating sites. Factors influencing feasibility may include data availability, standardisation of clinical definitions, and the ability to integrate with existing data systems.

Consideration	Type	Assessment considerations
Concentration of care within identifiable services or networks	Implementation feasibility	Registry implementation is generally more feasible where care for a condition is delivered within identifiable services, specialist centres or clinical networks. Concentration of care can support consistent case identification, clinician engagement and benchmarking across comparable services.
Alignment with national strategies, emerging policy priorities, or high-risk technologies	Implementation feasibility / policy consideration	Alignment with national health strategies, regulatory priorities, or emerging technologies may influence the strategic value of developing a CQR in a particular area. Registries have historically played a key role in monitoring the safety and effectiveness of new technologies, high risk devices, and priority policy areas. Where a condition or intervention aligns with national safety and quality priorities, the establishment of a CQR may support policy implementation, surveillance, and quality improvement at a national level.
Longitudinal follow-up and outcome measurement	Analytical	Registries should ideally enable longitudinal follow-up to monitor outcomes over time, track changes in clinical practice and assess long-term safety and effectiveness of treatments or procedures.
Capacity to monitor equity and priority populations	Implementation feasibility / equity consideration	Registries provide an important mechanism for monitoring equity in access to care and outcomes. Conditions where it is feasible to capture relevant demographic and population identifiers, including Aboriginal and Torres Strait Islander status and other markers of vulnerability, may allow registries to identify disparities in care and support targeted quality improvement initiatives. Consideration should therefore be given to whether data elements required to monitor priority populations can be reliably collected within the registry design.
Potential impact on clinical care and health system performance	Impact	A registry should have the potential to generate information that can inform clinical practice, policy decisions and health system improvement. Evidence from existing CQRs demonstrates that systematic monitoring and feedback can support reductions in unwarranted variation in care and improvements in patient outcomes.
Avoidance of duplication with existing registries or national monitoring mechanisms	System efficiency consideration	Consideration should be given to whether existing registries, surveillance systems, or national datasets already capture information relevant to the clinical condition or intervention. Establishing multiple registries addressing similar clinical questions may lead to fragmentation, duplication of effort, and reduced data completeness. Where appropriate, expansion or enhancement of existing registries may represent a more efficient approach than developing new registry infrastructure.

In applying these considerations, it is also important to recognise that prioritisation occurs at a national level and is intended to support coordinated development of registry infrastructure. National oversight remains important to avoid duplication of registries addressing similar clinical areas and to promote interoperability, shared data standards and sustainable governance arrangements across the registry landscape. The long-term sustainability of CQRs is also influenced by broader system-level factors, including resourcing and infrastructure, which sit beyond the scope of condition-level prioritisation but are critical to successful implementation. Detailed design and implementation decisions should occur through further feasibility assessment and consultation with relevant clinical communities and registry stakeholders.

Limitations and Future Directions

Limitations

The prioritisation framework relies on nationally available burden of disease and health expenditure datasets. While these sources provide a consistent and transparent basis for comparison across clinical domains, several limitations should be acknowledged.

First, there are inherent time lags in national datasets. Although the most recent available data was used, changes in clinical practice, emerging technologies and evolving models of care may not yet be reflected in the data. Rapid advancements in therapeutics, medical devices and digital health may alter patterns of disease burden, treatment pathways and health system expenditure between reporting cycles. In some areas, changes in diagnostic frameworks or clinical definitions may also influence apparent disease prevalence.

Second, burden of disease and health expenditure are population-level measures. While appropriate for national prioritisation, these metrics may not fully capture strategic importance in specific contexts. Rare diseases, for example, may have relatively low total burden at a population level but involve high per-patient cost, significant clinical complexity or alignment with national policy priorities. Many rare diseases also lack comprehensive national monitoring infrastructure. In these cases, registries may have an important role in generating evidence to support clinical practice and policy development. Future assessment of registry proposals in these areas may therefore require supplementary criteria that consider factors such as per-patient impact, treatment complexity and strategic policy relevance.

Third, the prioritisation is undertaken at the clinical domain level and does not assess specific procedures, devices, interventions or sub-populations. Some CQRs are structured around procedures or therapeutic technologies rather than individual diseases. Examples include registries monitoring implantable medical devices or surgical procedures. As the prioritisation framework is primarily based on diagnosis-level burden of disease and health system expenditure, some opportunities for procedure- or device-focused registries may not be fully captured through this approach. Feedback from the TGA reiterated that registries are frequently used to monitor the safety and performance of therapeutic goods, particularly implantable medical devices. Such registries may be established in response to product safety signals or regulatory requirements rather than disease burden or healthcare expenditure. As the prioritisation framework in this report is based primarily on diagnosis-level burden of disease and expenditure, opportunities for device or procedure-focused registries may not be fully captured and may need to be considered and supported through other policy, regulatory or safety processes. Opportunities for device-focused registries may therefore arise outside the scope of the prioritisation framework presented in this report.

Fourth, clinician support was incorporated as an indicator of sector engagement. While this measure provides useful insight into implementation readiness, it does not constitute a comprehensive feasibility assessment. Broader considerations relating to governance arrangements, digital infrastructure, data capture capability and long-term sustainability require further evaluation when progressing from domain-level prioritisation to individual registry proposals.

Finally, the prioritised results reflect the best available national data at the time of analysis. As patterns of disease, clinical practice and health system expenditure continue to evolve, periodic review of the prioritised domains will be necessary to ensure that the framework remains responsive to emerging health system pressures and advances in care.

Future directions

The 2026 update strengthens alignment between CQR prioritisation and contemporary patterns of population burden and health system expenditure. Future iterations of the prioritisation framework may build on this foundation in several ways.

Regular review of the prioritised domain list is recommended to ensure responsiveness to changing disease patterns, technological advancement and evolving health system pressures. Consultation feedback highlighted that advances in clinical practice, emerging technologies and changes in models of care can occur rapidly, potentially altering the relative impact of different conditions over relatively short timeframes. Consideration could therefore be given to implementing a more regular revision cycle for the prioritisation framework, supported by updated national datasets and stakeholder input, to maintain relevance over time.

Further methodological refinement may also be considered in future iterations of the prioritisation framework. This could include exploration of additional measures that capture broader economic and societal impacts of disease beyond direct healthcare expenditure. For example, Productivity-Adjusted Life Years (PALYs) estimate the impact of illness on workforce participation and productivity by quantifying years of productive life lost due to morbidity and premature mortality.⁴⁹ PALY estimates were not incorporated in the 2026 analysis because comparable national estimates across all disease groups are not currently available. The prioritisation methodology therefore relied on nationally consistent datasets for burden of disease (DALYs) and health system expenditure. As additional datasets and methodologies become available, future prioritisation work may consider incorporating productivity-based measures to provide a more comprehensive assessment of disease burden.

Advances in digital health infrastructure may also expand future opportunities for registry development. Increasing capacity for automated data extraction from electronic health records, linkage across national administrative datasets, and improved interoperability between digital systems may enhance the feasibility and scalability of registries in clinical areas that were previously difficult to monitor.

Regulatory developments may also influence future registry priorities and direction. Clinical registries already play an important role in supporting post-market surveillance of therapeutic goods, particularly implantable medical devices. The introduction of the Unique Device Identification (UDI) system in Australia in 2025-26 is expected to improve the traceability of medical devices across the health system and support more consistent monitoring of device performance and safety. As the UDI system becomes more widely implemented, there may be opportunities to strengthen links between device identification systems and registry activities.

⁴⁹ Ademi, Z., Liew, D., Zomer, E., & Owen, A. (2019). Productivity-adjusted life-years: a new metric for quantifying disease burden. *PharmacoEconomics*, 37(3), 331–338. <https://doi.org/10.1007/s40273-018-0736-x>

This could support improvement monitoring of device outcomes in real-world settings and assist in the earlier identification of potential safety issues.

Finally, continued national coordination of CQR development will remain important. As registry activity expands, oversight mechanisms should seek to minimise duplication or fragmentation within clinical domains and promote interoperability, shared data standards and sustainable governance arrangements across the national registry ecosystem.

Conclusion

This report presents the 2026 update to the national prioritisation of clinical domains for potential CQR development and investment. The updated framework retains continuity with the 2016 approach while strengthening alignment with contemporary burden of disease and system expenditure data.

Burden of disease and health system expenditure were used as the primary measures in the prioritisation framework, supported by clinician input. This approach provides a clear and consistent basis for comparing clinical domains. The resulting ranked list highlights areas of significant and sustained impact where registry-based monitoring may contribute most to improvements in safety, quality and value.

The prioritisation is intended to inform strategic planning at a national level. It does not prescribe specific registry models nor mandate immediate establishment of new CQRs. Further assessment at the level of individual conditions, procedures or care pathways remains essential to determine feasibility, avoid duplication and ensure alignment with national governance arrangements.

As the health system continues to evolve, periodic review of the prioritised domains will be important to maintain responsiveness to emerging technologies, changing patterns of disease and evolving models of care. Ongoing national coordination will also be required to support coherent, sustainable development of CQR infrastructure across Australia.

The 2026 prioritisation findings provide a structured foundation for future CQR investment decisions and supports continued maturation of quality improvement within the Australian healthcare system. Interpretation of the prioritisation results should recognise that opportunities for registry development are influenced not only by disease burden and cost, but also by the ways in which care is organised and delivered across the Australian healthcare system.

Glossary

Term	Definition
Administrative data	Data routinely collected through health system operations (such as hospital admissions, Medicare claims, PBS prescribing data) that can be used to monitor service use, costs and outcomes. In some cases, these data may provide an alternative to registry-based monitoring.
Australian Burden of Disease Study (ABDS)	A national study conducted by the Australian Institute of Health and Welfare that quantifies the impact of diseases and injuries in Australia using measures such as DALYs.
Australian Classification of Health Interventions (ACHI)	A national classification system used to classify surgical operations, procedures and non-surgical health interventions used in Australian public and private hospitals.
Australian Register of Clinical Registries	A national directory hosted by the Commission of clinical registries (the ARCR) operating in Australia, used to identify existing registry activity across clinical domains..
Burden of disease	The impact of a disease or condition on a population, measured in disability-adjusted life years (DALYs), which combine premature mortality and time lived with illness or disability.
Clinical domain	A grouping of related diseases or conditions used as the unit of analysis for prioritisation in this report/methodology. Clinical domains are used to structure comparisons across areas of healthcare using national data sources.
Clinical quality registry (CQR)	A specific type of clinical registry focused on routinely collecting and analysing health outcome data, and generating risk-adjusted reports, for the purpose of driving ongoing improvements in safety and quality.
Disability-adjusted life years (DALYs)	A comprehensive measure presenting the total burden of disease, equivalent to one lost year of “healthy” life. It combines years of life lost due to premature death and years lived with illness or disability.
Health system expenditure (disease-specific)	Estimates of health system spending attributed to specific diseases and injuries, as reported in national expenditure studies.
Productivity-adjusted life years (PALYs)	A measure that estimates/quantifies the broader societal and economic impact of diseases, specifically focusing on workforce participation and productivity. PALYs capture the impact of chronic conditions on working-age populations over their remaining working lifespan.
Threshold criteria	Minimum criteria applied to determine whether a condition is suitable for inclusion in prioritisation. Conditions not meeting these criteria are excluded from further analysis.
Unwarranted variation	Differences in healthcare practice or outcomes that cannot be explained by patient characteristics or preferences and may indicate opportunities for improvement in care.

Term	Definition
Care setting variables	Variables used to describe the context in which care is delivered (for example the intensive care, emergency care, age group), which may influence analysis and interpretation of data.
The Commission	The Australian Commission on Safety and Quality in Health Care is the national body responsible for leading and coordinating improvements in the safety and quality of health care in Australia.

Appendices

Appendix A. Mapping of conditions between the Burden of Disease and Health Expenditure datasets

Appendix B. Diseases included in the Step 1 shortlist and corresponding selection criteria

Appendix C. Burden of disease estimates for diseases included in Step 1 shortlist

Appendix D. Health system expenditure estimates for diseases included in Step 1 shortlist

Appendix E. Clinical Quality Registry Acronyms

Appendix F. Commission CQR Advisory Group membership as at March 2026

Appendix G. Summary of key burden, cost and clinical support signals by prioritised domain

Appendix H. Prioritised diseases and common interventions

Appendix A. Mapping of conditions between the Burden of Disease and Health Expenditure datasets

Clinical domain	Disease	Condition (Burden of Disease report)	Condition (Health expenditure report)
Blood and metabolic disorders	Cystic Fibrosis	Cystic Fibrosis	Cystic fibrosis
Blood and metabolic disorders	Haemolytic anaemias	Haemolytic anaemias	Haemolytic anaemias
Blood and metabolic disorders	Haemophilia	Haemophilia	Haemophilia
Blood and metabolic disorders	Iron-deficiency anaemia	Iron-deficiency anaemia	Iron-deficiency anaemia
Blood and metabolic disorders	Protein-energy deficiency	Protein-energy deficiency	Protein-energy deficiency
Cancer and other neoplasms	Acute lymphoblastic leukaemia (ALL)	Acute lymphoblastic leukaemia (ALL)	Acute lymphoblastic leukaemia (ALL)
Cancer and other neoplasms	Acute myeloid leukaemia (AML)	Acute myeloid leukaemia (AML)	Acute myeloid leukaemia (AML)
Cancer and other neoplasms	Benign and uncertain brain tumours	Benign and uncertain brain tumours	Benign and uncertain brain tumours
Cancer and other neoplasms	Bladder cancer	Bladder cancer	Bladder cancer
Cancer and other neoplasms	Bowel cancer	Bowel cancer	Bowel cancer
Cancer and other neoplasms	Brain and central nervous system cancer	Brain and central nervous system cancer	Brain and CNS cancer
Cancer and other neoplasms	Breast cancer	Breast cancer	Breast cancer
Cancer and other neoplasms	Cervical cancer	Cervical cancer	Cervical cancer
Cancer and other neoplasms	Chronic lymphocytic leukaemia (CLL)	Chronic lymphocytic leukaemia (CLL)	Chronic lymphocytic leukaemia (CLL)
Cancer and other neoplasms	Chronic myeloid leukaemia (CML)	Chronic myeloid leukaemia (CML)	Chronic myeloid leukaemia (CML)
Cancer and other neoplasms	Ductal carcinoma in situ (breast)	Ductal carcinoma in situ (breast)	Ductal carcinoma in situ (breast)
Cancer and other neoplasms	Gallbladder cancer	Gallbladder cancer	Gallbladder cancer

Clinical domain	Disease	Condition (Burden of Disease report)	Condition (Health expenditure report)
Cancer and other neoplasms	Hodgkin lymphoma	Hodgkin lymphoma	Hodgkin lymphoma
Cancer and other neoplasms	Kidney cancer	Kidney cancer	Kidney cancer
Cancer and other neoplasms	Laryngeal cancer	Laryngeal cancer	Laryngeal cancer
Cancer and other neoplasms	Lip and oral cavity cancer	Lip and oral cavity cancer	Lip and oral cavity cancer
Cancer and other neoplasms	Liver cancer	Liver cancer	Liver cancer
Cancer and other neoplasms	Lung cancer	Lung cancer	Lung cancer
Cancer and other neoplasms	Melanoma of the skin	Melanoma of the skin	Melanoma of the skin
Cancer and other neoplasms	Mesothelioma	Mesothelioma	Mesothelioma
Cancer and other neoplasms	Myeloma	Myeloma	Myeloma
Cancer and other neoplasms	Nasopharyngeal cancer	Nasopharyngeal cancer	Nasopharyngeal cancer
Cancer and other neoplasms	Non-Hodgkin lymphoma	Non-Hodgkin lymphoma	Non-Hodgkin lymphoma
Cancer and other neoplasms	Non-melanoma skin cancer	Non-melanoma skin cancer	Non-melanoma skin cancer
Cancer and other neoplasms	Oesophageal cancer	Oesophageal cancer	Oesophageal cancer
Cancer and other neoplasms	Ovarian cancer	Ovarian cancer	Ovarian cancer
Cancer and other neoplasms	Pancreatic cancer	Pancreatic cancer	Pancreatic cancer
Cancer and other neoplasms	Prostate cancer	Prostate cancer	Prostate cancer
Cancer and other neoplasms	Stomach cancer	Stomach cancer	Stomach cancer
Cancer and other neoplasms	Testicular cancer	Testicular cancer	Testicular cancer

Clinical domain	Disease	Condition (Burden of Disease report)	Condition (Health expenditure report)
Cancer and other neoplasms	Thyroid cancer	Thyroid cancer	Thyroid cancer
Cancer and other neoplasms	Unknown primary	Unknown primary	Unknown primary
Cancer and other neoplasms	Uterine cancer	Uterine cancer	Uterine cancer
Cardiovascular diseases	Aortic aneurysm	Aortic aneurysm	Aortic aneurysm
Cardiovascular diseases	Atrial fibrillation and flutter	Atrial fibrillation and flutter	Atrial fibrillation and flutter
Cardiovascular diseases	Cardiomyopathy	Cardiomyopathy	Cardiomyopathy
Cardiovascular diseases	Coronary heart disease	Coronary heart disease	Coronary heart disease
Cardiovascular diseases	Heart failure		Heart failure
Cardiovascular diseases	Hypertensive heart disease	Hypertensive heart disease	Hypertensive heart disease
Cardiovascular diseases	Inflammatory heart disease	Inflammatory heart disease	Inflammatory heart disease
Cardiovascular diseases	Non-rheumatic valvular disease	Non-rheumatic valvular disease	Non-rheumatic valvular disease
Cardiovascular diseases	Peripheral vascular disease	Peripheral vascular disease	Peripheral vascular disease
Cardiovascular diseases	Rheumatic heart disease (including acute rheumatic fever)	Rheumatic heart disease (including acute rheumatic fever)	Rheumatic heart disease (incl. acute rheumatic fever)
Cardiovascular diseases	Septicemia		Septicemia
Cardiovascular diseases	Stroke	Stroke	Stroke
Endocrine disorders	Gestational diabetes	Gestational diabetes	Gestational diabetes
Endocrine disorders	Type 1 diabetes mellitus	Type 1 diabetes mellitus	Type 1 diabetes
Endocrine disorders	Type 2 diabetes mellitus	Type 2 diabetes mellitus	Type 2 diabetes

Clinical domain	Disease	Condition (Burden of Disease report)	Condition (Health expenditure report)
Gastrointestinal disorders	Abdominal wall hernia	Abdominal wall hernia	Abdominal wall hernia
Gastrointestinal disorders	Appendicitis	Appendicitis	Appendicitis
Gastrointestinal disorders	Chronic liver disease	Chronic liver disease	Chronic liver disease
Gastrointestinal disorders	Diverticulitis	Diverticulitis	Diverticulitis
Gastrointestinal disorders	Functional gastrointestinal disorders (FGID)	Functional gastrointestinal disorders (FGID)	Functional gastrointestinal disorders (FGID)
Gastrointestinal disorders	Gallbladder and bile duct disease	Gallbladder and bile duct disease	Gallbladder and bile duct disease
Gastrointestinal disorders	Gastro Oesophageal Reflux Disease (GORD)	Gastro Oesophageal Reflux Disease (GORD)	Gastro Oesophageal Reflux Disease (GORD)
Gastrointestinal disorders	Gastroduodenal disorders	Gastroduodenal disorders	Gastroduodenal disorders
Gastrointestinal disorders	Inflammatory bowel disease (IBD)	Inflammatory bowel disease (IBD)	Inflammatory bowel disease (IBD)
Gastrointestinal disorders	Intestinal obstruction (without hernia)	Intestinal obstruction (without hernia)	Intestinal obstruction (without hernia)
Gastrointestinal disorders	Pancreatitis	Pancreatitis	Pancreatitis
Gastrointestinal disorders	Vascular disorders of intestine	Vascular disorders of intestine	Vascular disorders of intestine
Hearing and vision disorders	Age-related macular degeneration	Age-related macular degeneration	Age-related macular degeneration
Hearing and vision disorders	Cataract and other lens disorders	Cataract and other lens disorders	Cataract
Hearing and vision disorders	Glaucoma	Glaucoma	Glaucoma
Hearing and vision disorders	Hearing loss	Hearing loss	Hearing loss
Hearing and vision disorders	Refractive errors	Refractive errors	Refractive errors
Infant and congenital conditions	Birth trauma and asphyxia	Birth trauma and asphyxia	Birth trauma and asphyxia

Clinical domain	Disease	Condition (Burden of Disease report)	Condition (Health expenditure report)
Infant and congenital conditions	Brain malformations	Brain malformations	Brain malformations
Infant and congenital conditions	Cardiovascular defects	Cardiovascular defects	Cardiovascular defects
Infant and congenital conditions	Cerebral palsy	Cerebral palsy	Cerebral palsy
Infant and congenital conditions	Cleft lip and/or palate	Cleft lip and/or palate	Cleft lip and/or palate
Infant and congenital conditions	Down syndrome	Down syndrome	Down syndrome
Infant and congenital conditions	Gastrointestinal malformations	Gastrointestinal malformations	Gastrointestinal malformations
Infant and congenital conditions	Neonatal infections	Neonatal infections	Neonatal infections
Infant and congenital conditions	Neural tube defects	Neural tube defects	Neural tube defects
Infant and congenital conditions	Pre-term birth and low birth weight complications	Pre-term birth and low birth weight complications	Pre-term birth and low birth weight complications
Infant and congenital conditions	Sudden infant death syndrome	Sudden infant death syndrome	Sudden infant death syndrome
Infant and congenital conditions	Urogenital malformations	Urogenital malformations	Urogenital malformations
Infectious diseases	Barmah Forest virus	Barmah Forest virus	Barmah Forest virus
Infectious diseases	COVID-19	COVID-19	COVID-19
Infectious diseases	Campylobacteriosis	Campylobacteriosis	Campylobacteriosis
Infectious diseases	Chlamydia	Chlamydia	Chlamydia
Infectious diseases	Dengue	Dengue	Dengue
Infectious diseases	Diphtheria	Diphtheria	Diphtheria
Infectious diseases	Gonorrhoea	Gonorrhoea	Gonorrhoea
Infectious diseases	HIV/AIDS	HIV/AIDS	HIV/AIDS
Infectious diseases	Haemophilus influenzae type-b	Haemophilus influenzae type-b	Haemophilus influenzae type-b
Infectious diseases	Hepatitis A	Hepatitis A	Hepatitis A

Clinical domain	Disease	Condition (Burden of Disease report)	Condition (Health expenditure report)
Infectious diseases	Hepatitis B (acute)	Hepatitis B (acute)	Hepatitis B (acute)
Infectious diseases	Hepatitis C (acute)	Hepatitis C (acute)	Hepatitis C (acute)
Infectious diseases	Herpes-zoster	Herpes-zoster	Herpes-zoster
Infectious diseases	Lower respiratory infections incl influenza and pneumonia	Lower respiratory infections incl influenza and pneumonia	Lower respiratory infections
Infectious diseases	Malaria	Malaria	Malaria
Infectious diseases	Measles	Measles	Measles
Infectious diseases	Meningococcal disease	Meningococcal disease	Meningococcal disease
Infectious diseases	Mumps	Mumps	Mumps
Infectious diseases	Otitis media	Otitis media	Otitis media
Infectious diseases	Pertussis	Pertussis	Pertussis
Infectious diseases	Pneumococcal disease	Pneumococcal disease	Pneumococcal disease
Infectious diseases	Ross River virus	Ross River virus	Ross River virus
Infectious diseases	Rotavirus	Rotavirus	Rotavirus
Infectious diseases	Rubella	Rubella	Rubella
Infectious diseases	Salmonellosis	Salmonellosis	Salmonellosis
Infectious diseases	Syphilis	Syphilis	Syphilis
Infectious diseases	Tetanus	Tetanus	Tetanus
Infectious diseases	Trachoma	Trachoma	Trachoma
Infectious diseases	Tuberculosis	Tuberculosis	Tuberculosis
Infectious diseases	Upper respiratory infections	Upper respiratory infections	Upper respiratory infections
Infectious diseases	Urinary tract infections	Urinary tract infections	Urinary tract infections
Infectious diseases	Varicella	Varicella	Varicella
Injury	Burn injuries	Burn injuries	Burn injuries
Injury	Drowning and submersion injuries	Drowning and submersion injuries	Drowning and submersion injuries
Injury	Internal and crush injury	Internal and crush injury	Internal and crush injury

Clinical domain	Disease	Condition (Burden of Disease report)	Condition (Health expenditure report)
Injury	Poisoning	Poisoning	Poisoning
Kidney and urinary diseases	Chronic kidney disease	Chronic kidney disease	Chronic kidney disease
Kidney and urinary diseases	Enlarged prostate	Enlarged prostate	Enlarged prostate
Kidney and urinary diseases	Institial Nephritis	Institial Nephritis	Interstitial Nephritis
Kidney and urinary diseases	Kidney stones	Kidney stones	Kidney stones
Kidney and urinary diseases	Renal failure		Renal failure
Mental health and substance use disorders	Alcohol use disorders	Alcohol use disorders	Alcohol use disorders
Mental health and substance use disorders	Anxiety disorders	Anxiety disorders	Anxiety disorders
Mental health and substance use disorders	Attention deficit hyperactivity disorder	Attention deficit hyperactivity disorder	Attention deficit hyperactivity disorder
Mental health and substance use disorders	Autism spectrum disorders	Autism spectrum disorders	Autism spectrum disorders
Mental health and substance use disorders	Bipolar affective disorder	Bipolar affective disorder	Bipolar affective disorder
Mental health and substance use disorders	Conduct disorder	Conduct disorder	Conduct disorder
Mental health and substance use disorders	Depressive disorders	Depressive disorders	Depressive disorders
Mental health and substance use disorders	Drug use disorders (excluding alcohol)	Drug use disorders (excluding alcohol)	Drug use disorders (excl. alcohol)
Mental health and substance use disorders	Eating disorders	Eating disorders	Eating disorders

Clinical domain	Disease	Condition (Burden of Disease report)	Condition (Health expenditure report)
Mental health and substance use disorders	Intellectual disability	Intellectual disability	Intellectual disability
Mental health and substance use disorders	Schizophrenia	Schizophrenia	Schizophrenia
Musculoskeletal disorders	Back pain and problems	Back pain and problems	Back pain and problems
Musculoskeletal disorders	Dislocations	Dislocations	Dislocations
Musculoskeletal disorders	Gout	Gout	Gout
Musculoskeletal disorders	Hip fracture	Hip fracture	Hip fracture
Musculoskeletal disorders	Humerus fracture	Humerus fracture	Humerus fracture
Musculoskeletal disorders	Osteoarthritis	Osteoarthritis	Osteoarthritis
Musculoskeletal disorders	Rheumatoid arthritis	Rheumatoid arthritis	Rheumatoid arthritis
Musculoskeletal disorders	Soft tissue injuries	Soft tissue injuries	Soft tissue injuries
Musculoskeletal disorders	Tibia and ankle fracture	Tibia and ankle fracture	Tibia and ankle fracture
Neurological conditions	Dementia	Dementia	Dementia
Neurological conditions	Epilepsy	Epilepsy	Epilepsy
Neurological conditions	Guillain-Barre Syndrome	Guillain-Barre Syndrome	Guillain-Barre Syndrome
Neurological conditions	Migraine	Migraine	Migraine
Neurological conditions	Motor neurone disease	Motor neurone disease	Motor neurone disease
Neurological conditions	Multiple sclerosis	Multiple sclerosis	Multiple sclerosis
Neurological conditions	Parkinson disease	Parkinson disease	Parkinson disease
Neurological conditions	Spinal cord injury	Spinal cord injury	Spinal cord injury
Neurological conditions	Traumatic brain injury	Traumatic brain injury	Traumatic brain injury
Oral disorders	Dental caries	Dental caries	Dental caries

Clinical domain	Disease	Condition (Burden of Disease report)	Condition (Health expenditure report)
Oral disorders	Periodontal disease	Periodontal disease	Periodontal disease
Oral disorders	Severe tooth loss	Severe tooth loss	
Reproductive and maternal conditions	Early pregnancy loss	Early pregnancy loss	Early pregnancy loss
Reproductive and maternal conditions	Endometriosis	Endometriosis	Endometriosis
Reproductive and maternal conditions	Genital prolapse	Genital prolapse	Genital prolapse
Reproductive and maternal conditions	Hypertensive disorders of pregnancy	Hypertensive disorders of pregnancy	Hypertensive disorders of pregnancy
Reproductive and maternal conditions	Infertility	Infertility	Infertility
Reproductive and maternal conditions	Maternal haemorrhage	Maternal haemorrhage	Maternal haemorrhage
Reproductive and maternal conditions	Maternal infections	Maternal infections	Maternal infections
Reproductive and maternal conditions	Obstructed labour	Obstructed labour	Obstructed labour
Reproductive and maternal conditions	Other maternal conditions	Other maternal conditions	Other maternal conditions
Reproductive and maternal conditions	Polycystic ovarian syndrome	Polycystic ovarian syndrome	Polycystic ovarian syndrome
Reproductive and maternal conditions	Pregnancy and postpartum care		Pregnancy and postpartum care
Reproductive and maternal conditions	Uterine fibroids	Uterine fibroids	Uterine fibroids
Respiratory diseases	Asbestosis	Asbestosis	Asbestosis
Respiratory diseases	Asthma	Asthma	Asthma
Respiratory diseases	COPD	COPD	COPD
Respiratory diseases	Interstitial lung disease	Interstitial lung disease	Interstitial lung disease
Respiratory diseases	Sarcoidosis	Sarcoidosis	Sarcoidosis
Respiratory diseases	Silicosis	Silicosis	Silicosis
Respiratory diseases	Upper respiratory conditions	Upper respiratory conditions	Upper respiratory conditions

Clinical domain	Disease	Condition (Burden of Disease report)	Condition (Health expenditure report)
Skin disorders	Acne	Acne	Acne
Skin disorders	Dermatitis and eczema	Dermatitis and eczema	Dermatitis and eczema
Skin disorders	Psoriasis	Psoriasis	Psoriasis
Skin disorders	Scabies	Scabies	Scabies
Skin disorders	Skin infections(incl. Cellulitis)	Skin infections(incl. Cellulitis)	Skin infections (incl. cellulitis)
Skin disorders	Ulcers	Ulcers	Ulcers

Appendix B. Diseases included in the Step 1 shortlist and corresponding selection criteria

Clinical domain	Disease	CQR 2016 report	Top 60% burden	Top 60% expenditure
Cancer and other neoplasms	Acute lymphoblastic leukaemia (ALL)	Yes		
Cancer and other neoplasms	Acute myeloid leukaemia (AML)	Yes		
Cancer and other neoplasms	Bowel cancer	Yes	Yes	Yes
Cancer and other neoplasms	Brain and central nervous system cancer	Yes		
Cancer and other neoplasms	Breast cancer	Yes	Yes	Yes
Cancer and other neoplasms	Chronic lymphocytic leukaemia (CLL)	Yes		
Cancer and other neoplasms	Chronic myeloid leukaemia (CML)	Yes		
Cancer and other neoplasms	Lung cancer	Yes	Yes	
Cancer and other neoplasms	Non-Hodgkin lymphoma	Yes		
Cancer and other neoplasms	Non-melanoma skin cancer			Yes

Clinical domain	Disease	CQR 2016 report	Top 60% burden	Top 60% expenditure
Cancer and other neoplasms	Other lymphohaematopoietic (blood) cancers	Yes		
Cancer and other neoplasms	Pancreatic cancer		Yes	
Cancer and other neoplasms	Prostate cancer	Yes		Yes
Cardiovascular diseases	Aortic aneurysm	Yes		
Cardiovascular diseases	Atrial fibrillation and flutter	Yes	Yes	Yes
Cardiovascular diseases	Cardiomyopathy	Yes		
Cardiovascular diseases	Coronary heart disease	Yes	Yes	Yes
Cardiovascular diseases	Heart failure	Yes		
Cardiovascular diseases	Non-rheumatic valvular disease	Yes		
Cardiovascular diseases	Rheumatic heart disease (including acute rheumatic fever)	Yes		
Cardiovascular diseases	Stroke	Yes	Yes	Yes
Endocrine disorders	Gestational diabetes	Yes		
Endocrine disorders	Type 1 diabetes mellitus	Yes		
Endocrine disorders	Type 2 diabetes mellitus	Yes	Yes	Yes
Gastrointestinal disorders	Chronic liver disease		Yes	
Gastrointestinal disorders	Functional gastrointestinal disorders (FGID)			Yes
Gastrointestinal disorders	Gallbladder and bile duct disease	Yes		Yes
Gastrointestinal disorders	Gastro Oesophageal Reflux Disease (GORD)			Yes
Gastrointestinal disorders	Inflammatory bowel disease (IBD)			Yes
Hearing and vision disorders	Cataract and other lens disorders			Yes

Clinical domain	Disease	CQR 2016 report	Top 60% burden	Top 60% expenditure
Hearing and vision disorders	Hearing loss		Yes	
Infant and congenital conditions	Birth trauma and asphyxia	Yes		
Infant and congenital conditions	Brain malformations	Yes		
Infant and congenital conditions	Cardiovascular defects	Yes		
Infant and congenital conditions	Cerebral palsy	Yes		
Infant and congenital conditions	Cleft lip and/or palate	Yes		
Infant and congenital conditions	Gastrointestinal malformations	Yes		
Infant and congenital conditions	Neonatal infections	Yes		
Infant and congenital conditions	Neural tube defects	Yes		
Infant and congenital conditions	Pre-term birth and low birth weight complications	Yes		
Infant and congenital conditions	Urogenital malformations	Yes		
Infectious diseases	COVID-19			Yes
Infectious diseases	Lower respiratory infections incl influenza and pneumonia			Yes
Infectious diseases	Upper respiratory infections			Yes
Infectious diseases	Urinary tract infections			Yes
Injury	Burn injuries	Yes		
Injury	Drowning and submersion injuries	Yes		
Injury	Internal and crush injury	Yes		
Injury	Poisoning	Yes	Yes	
Kidney and urinary diseases	Chronic kidney disease	Yes		Yes

Clinical domain	Disease	CQR 2016 report	Top 60% burden	Top 60% expenditure
Kidney and urinary diseases	Renal failure	Yes		
Mental health and substance use disorders	Alcohol use disorders		Yes	
Mental health and substance use disorders	Anxiety disorders	Yes	Yes	Yes
Mental health and substance use disorders	Autism spectrum disorders		Yes	
Mental health and substance use disorders	Bipolar affective disorder	Yes		
Mental health and substance use disorders	Depressive disorders	Yes	Yes	Yes
Mental health and substance use disorders	Eating disorders	Yes		
Mental health and substance use disorders	Schizophrenia	Yes		Yes
Musculoskeletal disorders	Back pain and problems	Yes	Yes	Yes
Musculoskeletal disorders	Dislocations	Yes		
Musculoskeletal disorders	Hip fracture	Yes		
Musculoskeletal disorders	Humerus fracture	Yes		
Musculoskeletal disorders	Osteoarthritis	Yes	Yes	Yes
Musculoskeletal disorders	Rheumatoid arthritis	Yes	Yes	
Musculoskeletal disorders	Soft tissue injuries			Yes
Musculoskeletal disorders	Tibia and ankle fracture	Yes		
Neurological conditions	Dementia	Yes	Yes	
Neurological conditions	Multiple sclerosis	Yes		
Neurological conditions	Spinal cord injury	Yes		
Neurological conditions	Traumatic brain injury	Yes		
Oral disorders	Dental caries			Yes
Reproductive and maternal conditions	Genital prolapse	Yes		

Clinical domain	Disease	CQR 2016 report	Top 60% burden	Top 60% expenditure
Reproductive and maternal conditions	Hypertensive disorders of pregnancy	Yes		
Reproductive and maternal conditions	Maternal haemorrhage	Yes		
Reproductive and maternal conditions	Maternal infections	Yes		
Reproductive and maternal conditions	Obstructed labour	Yes		
Reproductive and maternal conditions	Other maternal conditions	Yes		
Reproductive and maternal conditions	Pregnancy and postpartum care			Yes
Respiratory diseases	Asthma		Yes	
Respiratory diseases	COPD		Yes	Yes
Respiratory diseases	Upper respiratory conditions			Yes
Skin disorders	Skin infections(incl. Cellulitis)			Yes

Appendix C. Burden of disease estimates for diseases included in Step 1 shortlist

Clinical domain	Disease	2015 DALYs (%)	2024 DALYs (%)
Cancer and other neoplasms	Acute lymphoblastic leukaemia (ALL)	4,531 (0.1%)	3,543 (0.1%)
Cancer and other neoplasms	Acute myeloid leukaemia (AML)	18,256 (0.4%)	23,301 (0.5%)
Cancer and other neoplasms	Bowel cancer	100,360 (2.4%)	97,903 (2.0%)
Cancer and other neoplasms	Brain and central nervous system cancer	38,577 (0.9%)	42,682 (0.9%)
Cancer and other neoplasms	Breast cancer	70,886 (1.7%)	73,309 (1.5%)
Cancer and other neoplasms	Chronic lymphocytic leukaemia (CLL)	4,627 (0.1%)	4,649 (0.1%)

Clinical domain	Disease	2015 DALYs (%)	2024 DALYs (%)
Cancer and other neoplasms	Chronic myeloid leukaemia (CML)	1,463 (0.0%)	1,801 (0.0%)
Cancer and other neoplasms	Lung cancer	159,329 (3.8%)	158,445 (3.2%)
Cancer and other neoplasms	Non-Hodgkin lymphoma	26,521 (0.6%)	30,077 (0.6%)
Cancer and other neoplasms	Non-melanoma skin cancer	12,652 (0.3%)	14,579 (0.3%)
Cancer and other neoplasms	Other lymphohaematopoietic (blood) cancers	10,209 (0.2%)	12,562 (0.3%)
Cancer and other neoplasms	Pancreatic cancer	48,990 (1.2%)	65,453 (1.3%)
Cancer and other neoplasms	Prostate cancer	50,520 (1.2%)	58,218 (1.2%)
Cardiovascular diseases	Aortic aneurysm	13,661 (0.3%)	15,714 (0.3%)
Cardiovascular diseases	Atrial fibrillation and flutter	51,359 (1.2%)	70,799 (1.4%)
Cardiovascular diseases	Cardiomyopathy	26,706 (0.6%)	27,630 (0.6%)
Cardiovascular diseases	Coronary heart disease	328,873 (7.8%)	317,105 (6.3%)
Cardiovascular diseases	Non-rheumatic valvular disease	31,129 (0.7%)	35,450 (0.7%)
Cardiovascular diseases	Rheumatic heart disease (including acute rheumatic fever)	6,577 (0.2%)	5,783 (0.1%)
Cardiovascular diseases	Stroke	124,079 (3.0%)	125,141 (2.5%)
Endocrine disorders	Gestational diabetes	545 (0.0%)	879 (0.0%)
Endocrine disorders	Type 1 diabetes mellitus	14,575 (0.3%)	19,795 (0.4%)
Endocrine disorders	Type 2 diabetes mellitus	105,905 (2.5%)	127,592 (2.6%)
Gastrointestinal disorders	Chronic liver disease	59,447 (1.4%)	72,149 (1.4%)
Gastrointestinal disorders	Functional gastrointestinal disorders (FGID)	20,129 (0.5%)	22,969 (0.5%)

Clinical domain	Disease	2015 DALYs (%)	2024 DALYs (%)
Gastrointestinal disorders	Gallbladder and bile duct disease	5,454 (0.1%)	7,977 (0.2%)
Gastrointestinal disorders	Gastro Oesophageal Reflux Disease (GORD)	12,214 (0.3%)	14,221 (0.3%)
Gastrointestinal disorders	Inflammatory bowel disease (IBD)	22,701 (0.5%)	26,874 (0.5%)
Hearing and vision disorders	Cataract and other lens disorders	3,832 (0.1%)	5,321 (0.1%)
Hearing and vision disorders	Hearing loss	74,403 (1.8%)	94,371 (1.9%)
Infant and congenital conditions	Birth trauma and asphyxia	14,359 (0.3%)	17,225 (0.3%)
Infant and congenital conditions	Brain malformations	5,442 (0.1%)	5,669 (0.1%)
Infant and congenital conditions	Cardiovascular defects	11,203 (0.3%)	12,800 (0.3%)
Infant and congenital conditions	Cerebral palsy	6,213 (0.1%)	7,915 (0.2%)
Infant and congenital conditions	Cleft lip and/or palate	316 (0.0%)	583 (0.0%)
Infant and congenital conditions	Gastrointestinal malformations	2,071 (0.0%)	2,327 (0.0%)
Infant and congenital conditions	Neonatal infections	1,959 (0.0%)	2,896 (0.1%)
Infant and congenital conditions	Neural tube defects	2,465 (0.1%)	3,446 (0.1%)
Infant and congenital conditions	Pre-term birth and low birth weight complications	23,455 (0.6%)	29,108 (0.6%)
Infant and congenital conditions	Urogenital malformations	1,790 (0.0%)	1,925 (0.0%)
Infectious diseases	COVID-19		43,950 (0.9%)
Infectious diseases	Lower respiratory infections incl influenza and pneumonia	41,782 (1.0%)	46,968 (0.9%)
Infectious diseases	Upper respiratory infections	2,957 (0.1%)	3,345 (0.1%)
Infectious diseases	Urinary tract infections	9,563 (0.2%)	13,580 (0.3%)
Injury	Burn injuries	7,257 (0.2%)	7,734 (0.2%)

Clinical domain	Disease	2015 DALYs (%)	2024 DALYs (%)
Injury	Drowning and submersion injuries	14,657 (0.3%)	15,005 (0.3%)
Injury	Internal and crush injury	18,397 (0.4%)	19,356 (0.4%)
Injury	Poisoning	95,984 (2.3%)	102,637 (2.1%)
Kidney and urinary diseases	Chronic kidney disease	57,664 (1.4%)	65,089 (1.3%)
Mental health and substance use disorders	Alcohol use disorders	68,126 (1.6%)	76,329 (1.5%)
Mental health and substance use disorders	Anxiety disorders	179,242 (4.3%)	224,765 (4.5%)
Mental health and substance use disorders	Autism spectrum disorders	31,540 (0.8%)	102,080 (2.0%)
Mental health and substance use disorders	Bipolar affective disorder	46,158 (1.1%)	55,644 (1.1%)
Mental health and substance use disorders	Depressive disorders	150,867 (3.6%)	181,530 (3.6%)
Mental health and substance use disorders	Eating disorders	47,766 (1.1%)	56,101 (1.1%)
Mental health and substance use disorders	Schizophrenia	34,901 (0.8%)	39,490 (0.8%)
Musculoskeletal disorders	Back pain and problems	196,291 (4.7%)	246,913 (4.9%)
Musculoskeletal disorders	Dislocations	1,425 (0.0%)	1,545 (0.0%)
Musculoskeletal disorders	Hip fracture	15,707 (0.4%)	20,390 (0.4%)
Musculoskeletal disorders	Humerus fracture	1,430 (0.0%)	1,529 (0.0%)
Musculoskeletal disorders	Osteoarthritis	115,804 (2.8%)	145,485 (2.9%)
Musculoskeletal disorders	Rheumatoid arthritis	95,140 (2.3%)	117,214 (2.3%)

Clinical domain	Disease	2015 DALYs (%)	2024 DALYs (%)
Musculoskeletal disorders	Soft tissue injuries	1,038 (0.0%)	1,364 (0.0%)
Musculoskeletal disorders	Tibia and ankle fracture	11,233 (0.3%)	15,833 (0.3%)
Neurological conditions	Dementia	181,498 (4.3%)	262,052 (5.2%)
Neurological conditions	Multiple sclerosis	12,841 (0.3%)	16,125 (0.3%)
Neurological conditions	Spinal cord injury	2,359 (0.1%)	2,163 (0.0%)
Neurological conditions	Traumatic brain injury	31,523 (0.8%)	39,874 (0.8%)
Oral disorders	Dental caries	45,810 (1.1%)	53,893 (1.1%)
Reproductive and maternal conditions	Genital prolapse	30,143 (0.7%)	36,640 (0.7%)
Reproductive and maternal conditions	Hypertensive disorders of pregnancy	290 (0.0%)	421 (0.0%)
Reproductive and maternal conditions	Maternal haemorrhage	208 (0.0%)	344 (0.0%)
Reproductive and maternal conditions	Maternal infections	155 (0.0%)	71 (0.0%)
Reproductive and maternal conditions	Obstructed labour	213 (0.0%)	308 (0.0%)
Reproductive and maternal conditions	Other maternal conditions	548 (0.0%)	618 (0.0%)
Respiratory diseases	Asthma	120,420 (2.9%)	143,782 (2.9%)
Respiratory diseases	COPD	168,306 (4.0%)	211,719 (4.2%)
Respiratory diseases	Upper respiratory conditions	18,879 (0.5%)	20,770 (0.4%)
Skin disorders	Skin infections(incl. Cellulitis)	4,823 (0.1%)	6,527 (0.1%)

Appendix D. Health system expenditure estimates for diseases included in Step 1 shortlist

Clinical domain	Disease	2015-16 Cost (%)	2022-23 Cost (%)
Cancer and other neoplasms	Acute lymphoblastic leukaemia (ALL)	\$0.2 billion (0.2%)	\$0.2 billion (0.2%)

Clinical domain	Disease	2015-16 Cost (%)	2022-23 Cost (%)
Cancer and other neoplasms	Acute myeloid leukaemia (AML)	\$0.3 billion (0.4%)	\$0.3 billion (0.3%)
Cancer and other neoplasms	Bowel cancer	\$1.2 billion (1.4%)	\$1.7 billion (1.5%)
Cancer and other neoplasms	Brain and central nervous system cancer	\$0.3 billion (0.3%)	\$0.3 billion (0.3%)
Cancer and other neoplasms	Breast cancer	\$1.3 billion (1.4%)	\$1.8 billion (1.6%)
Cancer and other neoplasms	Chronic lymphocytic leukaemia (CLL)	\$0.1 billion (0.1%)	\$0.2 billion (0.2%)
Cancer and other neoplasms	Chronic myeloid leukaemia (CML)	\$0.1 billion (0.2%)	\$0.1 billion (0.1%)
Cancer and other neoplasms	Lung cancer	\$0.8 billion (0.9%)	\$1.2 billion (1.1%)
Cancer and other neoplasms	Non-Hodgkin lymphoma	\$0.5 billion (0.6%)	\$0.8 billion (0.7%)
Cancer and other neoplasms	Non-melanoma skin cancer	\$1.3 billion (1.5%)	\$1.8 billion (1.6%)
Cancer and other neoplasms	Other lymphohaematopoietic (blood) cancers	\$0.4 billion (0.5%)	\$0.6 billion (0.5%)
Cancer and other neoplasms	Pancreatic cancer	\$0.2 billion (0.3%)	\$0.4 billion (0.3%)
Cancer and other neoplasms	Prostate cancer	\$1.5 billion (1.7%)	\$2.1 billion (1.9%)
Cardiovascular diseases	Aortic aneurysm	\$0.2 billion (0.2%)	\$0.3 billion (0.3%)
Cardiovascular diseases	Atrial fibrillation and flutter	\$1.4 billion (1.5%)	\$2.0 billion (1.7%)
Cardiovascular diseases	Cardiomyopathy	\$0.3 billion (0.3%)	\$0.3 billion (0.3%)
Cardiovascular diseases	Coronary heart disease	\$3.3 billion (3.8%)	\$3.8 billion (3.4%)
Cardiovascular diseases	Heart failure	\$0.9 billion (1.1%)	\$1.2 billion (1.1%)
Cardiovascular diseases	Non-rheumatic valvular disease	\$0.5 billion (0.5%)	\$0.8 billion (0.7%)
Cardiovascular diseases	Rheumatic heart disease (including acute rheumatic fever)	\$0.1 billion (0.1%)	\$0.2 billion (0.2%)

Clinical domain	Disease	2015-16 Cost (%)	2022-23 Cost (%)
Cardiovascular diseases	Stroke	\$1.1 billion (1.3%)	\$2.0 billion (1.7%)
Endocrine disorders	Gestational diabetes	\$0.1 billion (0.1%)	\$0.1 billion (0.1%)
Endocrine disorders	Type 1 diabetes mellitus	\$0.5 billion (0.5%)	\$0.4 billion (0.4%)
Endocrine disorders	Type 2 diabetes mellitus	\$2.1 billion (2.4%)	\$2.9 billion (2.6%)
Gastrointestinal disorders	Chronic liver disease	\$0.4 billion (0.4%)	\$0.5 billion (0.5%)
Gastrointestinal disorders	Functional gastrointestinal disorders (FGID)	\$1.3 billion (1.5%)	\$1.8 billion (1.6%)
Gastrointestinal disorders	Gallbladder and bile duct disease	\$1.1 billion (1.2%)	\$1.4 billion (1.3%)
Gastrointestinal disorders	Gastro Oesophageal Reflux Disease (GORD)	\$1.4 billion (1.6%)	\$1.4 billion (1.2%)
Gastrointestinal disorders	Inflammatory bowel disease (IBD)	\$0.9 billion (1.0%)	\$1.3 billion (1.1%)
Hearing and vision disorders	Cataract and other lens disorders	\$1.6 billion (1.8%)	\$1.9 billion (1.7%)
Hearing and vision disorders	Hearing loss	\$0.4 billion (0.4%)	\$0.5 billion (0.4%)
Infant and congenital conditions	Birth trauma and asphyxia	\$0.1 billion (0.1%)	\$0.1 billion (0.1%)
Infant and congenital conditions	Brain malformations	\$0.0 billion (0.0%)	\$0.0 billion (0.0%)
Infant and congenital conditions	Cardiovascular defects	\$0.2 billion (0.2%)	\$0.4 billion (0.4%)
Infant and congenital conditions	Cerebral palsy	\$0.0 billion (0.1%)	\$0.1 billion (0.1%)
Infant and congenital conditions	Cleft lip and/or palate	\$0.0 billion (0.0%)	\$0.0 billion (0.0%)
Infant and congenital conditions	Gastrointestinal malformations	\$0.1 billion (0.1%)	\$0.1 billion (0.1%)
Infant and congenital conditions	Neonatal infections	\$0.1 billion (0.1%)	\$0.1 billion (0.1%)
Infant and congenital conditions	Neural tube defects	\$0.0 billion (0.0%)	\$0.0 billion (0.0%)

Clinical domain	Disease	2015-16 Cost (%)	2022-23 Cost (%)
Infant and congenital conditions	Pre-term birth and low birth weight complications	\$1.0 billion (1.1%)	\$0.7 billion (0.6%)
Infant and congenital conditions	Urogenital malformations	\$0.1 billion (0.1%)	\$0.2 billion (0.1%)
Infectious diseases	COVID-19		\$1.8 billion (1.6%)
Infectious diseases	Lower respiratory infections incl influenza and pneumonia	\$2.7 billion (3.0%)	\$3.2 billion (2.9%)
Infectious diseases	Upper respiratory infections	\$1.3 billion (1.5%)	\$1.3 billion (1.1%)
Infectious diseases	Urinary tract infections	\$1.3 billion (1.5%)	\$1.9 billion (1.7%)
Injury	Burn injuries	\$0.2 billion (0.2%)	\$0.2 billion (0.2%)
Injury	Drowning and submersion injuries	\$0.0 billion (0.0%)	\$0.0 billion (0.0%)
Injury	Internal and crush injury	\$0.2 billion (0.2%)	\$0.3 billion (0.2%)
Injury	Poisoning	\$0.3 billion (0.4%)	\$0.5 billion (0.4%)
Kidney and urinary diseases	Chronic kidney disease	\$1.9 billion (2.2%)	\$2.9 billion (2.5%)
Kidney and urinary diseases	Renal failure	\$0.3 billion (0.4%)	\$0.4 billion (0.3%)
Mental health and substance use disorders	Alcohol use disorders	\$0.6 billion (0.6%)	\$0.9 billion (0.8%)
Mental health and substance use disorders	Anxiety disorders	\$1.8 billion (2.1%)	\$2.4 billion (2.1%)
Mental health and substance use disorders	Autism spectrum disorders	\$0.1 billion (0.2%)	\$0.2 billion (0.2%)
Mental health and substance use disorders	Bipolar affective disorder	\$0.5 billion (0.6%)	\$0.6 billion (0.6%)
Mental health and substance use disorders	Depressive disorders	\$2.2 billion (2.5%)	\$2.5 billion (2.2%)
Mental health and substance use disorders	Eating disorders	\$0.1 billion (0.1%)	\$0.3 billion (0.3%)
Mental health and substance use disorders	Schizophrenia	\$1.2 billion (1.3%)	\$1.9 billion (1.7%)
Musculoskeletal disorders	Back pain and problems	\$3.2 billion (3.7%)	\$3.9 billion (3.5%)

Clinical domain	Disease	2015-16 Cost (%)	2022-23 Cost (%)
Musculoskeletal disorders	Dislocations	\$0.3 billion (0.3%)	\$0.3 billion (0.3%)
Musculoskeletal disorders	Hip fracture	\$0.7 billion (0.7%)	\$0.9 billion (0.8%)
Musculoskeletal disorders	Humerus fracture	\$0.2 billion (0.2%)	\$0.3 billion (0.3%)
Musculoskeletal disorders	Osteoarthritis	\$4.2 billion (4.8%)	\$4.9 billion (4.3%)
Musculoskeletal disorders	Rheumatoid arthritis	\$1.2 billion (1.4%)	\$1.0 billion (0.9%)
Musculoskeletal disorders	Soft tissue injuries	\$1.4 billion (1.6%)	\$1.5 billion (1.4%)
Musculoskeletal disorders	Tibia and ankle fracture	\$0.4 billion (0.5%)	\$0.6 billion (0.6%)
Neurological conditions	Dementia	\$0.6 billion (0.7%)	\$0.8 billion (0.8%)
Neurological conditions	Multiple sclerosis	\$0.5 billion (0.6%)	\$0.6 billion (0.6%)
Neurological conditions	Spinal cord injury	\$0.1 billion (0.1%)	\$0.1 billion (0.1%)
Neurological conditions	Traumatic brain injury	\$0.4 billion (0.4%)	\$0.5 billion (0.5%)
Oral disorders	Dental caries	\$2.8 billion (3.1%)	\$3.3 billion (2.9%)
Reproductive and maternal conditions	Genital prolapse	\$0.2 billion (0.3%)	\$0.3 billion (0.2%)
Reproductive and maternal conditions	Hypertensive disorders of pregnancy	\$0.1 billion (0.2%)	\$0.2 billion (0.2%)
Reproductive and maternal conditions	Maternal haemorrhage	\$0.2 billion (0.2%)	\$0.3 billion (0.3%)
Reproductive and maternal conditions	Maternal infections	\$0.0 billion (0.1%)	\$0.1 billion (0.0%)
Reproductive and maternal conditions	Obstructed labour	\$0.1 billion (0.1%)	\$0.2 billion (0.2%)
Reproductive and maternal conditions	Other maternal conditions	\$0.5 billion (0.6%)	\$0.5 billion (0.5%)
Reproductive and maternal conditions	Pregnancy and postpartum care	\$4.8 billion (5.4%)	\$4.7 billion (4.1%)
Respiratory diseases	Asthma	\$1.0 billion (1.1%)	\$1.2 billion (1.1%)
Respiratory diseases	COPD	\$1.5 billion (1.7%)	\$1.7 billion (1.5%)
Respiratory diseases	Upper respiratory conditions	\$1.2 billion (1.4%)	\$1.6 billion (1.4%)
Skin disorders	Skin infections(incl. Cellulitis)	\$1.4 billion (1.6%)	\$1.9 billion (1.7%)

Appendix E. Clinical Quality Registry Acronyms

Acronym	Registry name
ABDR	Australian Brain Tumour Registry
ABS-Obstetrics	Anaesthetic Benchmarking System – Obstetrics
ACOR	Australasian Cardiac Outcomes Registry
ADCQR	Australian Diabetes Clinical Quality Registry
ADNeT Registry	Australian Dementia Network Clinical Quality Registry
AEPCQ CQR	Australian Early Psychosis Clinical Quality Registry
AIPPAP	Australian Interventional Pharmacotherapy and Psychedelic-Assisted Psychotherapy Research Registry
AMCR	Australian Mastitis Clinical Registry
ANCHOR	Australian National Child Hearing Health Outcomes Registry
ANZ CHD Registry	Australia and New Zealand Congenital Heart Disease Registry
ANZFR	Australia and New Zealand Fontan Registry
ANZNN	Australia and New Zealand Neonatal Network
ANZCPR	Australia and New Zealand Cardiac Procedures Registry
ANZDATA Registry	Australia and New Zealand Dialysis and Transplant Registry
ANZFFR	Australia and New Zealand Femoral Fracture Registry
ANZHFR	Australian and New Zealand Hip Fracture Registry
ANZICS Registry	Australian and New Zealand Intensive Care Society Centre for Outcome and Resource Evaluation (ANZICS CORE) Registry
ANZLITR	Australia and New Zealand Liver Transplant Registry
ANZSCTS Database	Australia and New Zealand Society of Cardiac and Thoracic Surgeons Database
ANZTR	Australia New Zealand Trauma Registry
AOANJRR	Australian Orthopaedic Association National Joint Replacement Registry
APFPR	Australasian Pelvic Floor Procedure Registry

Acronym	Registry name
ARAD	Australian Rheumatology Association Database
ASAR	Australasian Severe Asthma Registry
Aus-ROC OHCA Epistry	Australian Resuscitation Outcomes Consortium Out-of-Hospital Cardiac Arrest Epistry
Australasian Shunt Registry	Australasian Shunt Registry
Australian Spine Registry	Australian Spine Registry
AuSCR	Australian Stroke Clinical Registry
Aussie Ear Bank	Aussie Ear Bank Registry
BCOR	Breast Cancer Outcomes Registry
BRANZ	Burns Registry of Australia and New Zealand
CCCare Registry	Crohn's Colitis Care Registry
CHOPAN Registry	Coronavirus Health Outcomes in Pregnancy and Newborns Registry
Data4ME	Data for Maternity Excellence Registry
ePBRN	Electronic practice based research network
LaRDR	Lymphoma and Related Diseases Registry
MS AHSCT Registry	Multiple Sclerosis Autologous Haematopoietic Stem Cell Transplant Registry
NBCR	National Breast Cancer Registry
NCR	National Cardiac Registry
PCOR-ANZ	Prostate Cancer Outcomes Registry – Australia and New Zealand
QCOR	Queensland Cardiac Outcomes Registry
Save Sight Registry	Save Sight Keratoconus Registry and Ophthalmic Outcomes Registry
TMS-REG	Transcranial Magnetic Stimulation and Brain Stimulation Research Registry
TrEAT Registry	Australia and New Zealand Clinical Quality Registry for the Treatment of Eating Disorders
UGICR	Upper Gastrointestinal Cancer Registry
VCOR	Victorian Cardiac Outcomes Registry

Acronym	Registry name
VLCR	Victorian Lung Cancer Registry

Appendix F. Commission CQR Advisory Group membership as at March 2026

Member name	Role title and organisation	Committee contribution	Jurisdiction
Distinguished Professor Sandy Middleton	Director, Nursing Research Institute, St Vincent's Health Network Sydney, St Vincent's Hospital Melbourne and Australian Catholic University	Chair	National
Ms Bernice Cropper	Head, Health Systems Group, Australian Institute of Health and Welfare (AIHW)	AIHW representative	National
Ms Chereta Daylight	Director, Policy Development, Independent Health and Aged Care Pricing Authority (IHACPA)	IHACPA representative	National
Mr Chris Boyd Skinner	Assistant Director Clinical Governance, Clinical Governance and Assurance Branch, Policy, Programs and Engagement Division, Australian Digital Health Agency	Australian Digital Health Agency representative	National
Dr David Gill	Assistant Deputy, Australian Orthopaedic Association National Joint Replacement Registry (AOANJRR)	CQR representative	National
Professor David Pilcher	Chairman, Australian and New Zealand Intensive Care Society (ANZICS) Centre for Outcome and Resource Evaluation (CORE)	CQR representative	National
Ms Di O'Kane	Director, Patient Safety and Quality Improvement Service, Clinical Excellence Division, Queensland Health	Jurisdictional representative	Queensland
Dr Elizabeth Webber	Department of Health, Tasmania	Jurisdictional representative	Tasmania

Member name	Role title and organisation	Committee contribution	Jurisdiction
Ms Fiona Wake	Executive Director, Clinical Excellence and Patient Safety, Commissioning and System Improvement, Northern Territory Health	Jurisdictional representative	Northern Territory
Dr Heather Buchan	Senior Medical Advisor, the Commission	Commission representative	National
Ms Helen Mees	Consumer advocate	Consumer representative	Western Australia
Dr Isuru Ranasinghe	Senior Cardiologist, Department of Cardiology, The Prince Charles Hospital, Brisbane Associate Professor in Cardiology, Northside Clinical Unit, Faculty of Medicine, The University of Queensland	CQR representative	Queensland
Professor John Beltrame AM	Chair, CADOSA Registry; Professor of Medicine - Michell Chair, Adelaide Medical School	CQR representative Clinician representative	South Australia
Dr Jui Tham	Medical Officer, Strategy and Development, Australian Health Service Alliance	Private health insurance sector representative	National
Ms Linda Brown	Director, Translational Research, Clinical Trials, Strategic Projects and Response, Clinical and Professional Leadership Unit, Safer Care Victoria	Jurisdictional representative	Victoria
Ms Maureen Woodward	Consumer advocate	Consumer representative	Queensland
Ms Melissa Tinsley	Associate Director, IDEA (Integrated Digital Enablement Accelerator), Agency for Clinical Innovation	Jurisdictional representative	New South Wales

Member name	Role title and organisation	Committee contribution	Jurisdiction
Ms Nicola Ware	CEO, Ramsay Hospital Research Foundation; Head of Research, Innovation and Integrated Care, Ramsay Health Care	Private hospital sector representative	National
Dr Nisha Antony	Senior Medical Advisor, Healthcare Quality Intelligence Unit, Clinical Excellence Division, Department of Health, Western Australia	Jurisdictional representative	Western Australia
Professor Stephen McDonald	Executive Officer, Australia and New Zealand Dialysis and Transplantation (ANZDATA) Registry Director, Adelaide Centre for Clinical Epidemiology, University of Adelaide and Senior Staff Nephrologist, Royal Adelaide Hospital	CQR representative Clinician representative	National
Professor Susannah Ahern	Chair, Australian Breast Device and Australasian Pelvic Floor Procedure Registry (APFPR) Head, Clinical Outcomes Reporting and Research, Monash University	CQR representative	Victoria
Ms Terrie O'Brien	Director, Clinical Quality Registries Section, Health Modelling Partnerships and Evaluation Branch, Australian Government Department of Health, Disability and Ageing	Australian Government Department of Health, Disability and Ageing representative	National
Ms Tina Hardin	Executive Director, Clinical Informatics, Commission on Excellence and Innovation in Health, SA Health	Jurisdictional representative	South Australia
Ms Tracey Duffy	First Assistant Secretary, Medical Devices and Product Quality Division, Therapeutic Goods Administration	Therapeutic Goods Administration representative	National

Appendix G. Summary of key burden, cost and clinical support signals by prioritised domain

Rank	Clinical Domain	Total score	Key signals
1	Mental health and substance use disorders	6.25	<p>Score breakdown: Burden 3.00 Cost 2.25 Clinical support 1.00</p> <p>Diseases: Alcohol use disorders, anxiety disorders, autism spectrum disorders, bipolar affective disorder, depressive disorders, eating disorders, schizophrenia</p> <p>Burden: 735,939 DALYs (14.7%) Growth (2015–2024): 31.7% Relative growth: 21.9%</p> <p>Cost: \$8.8 billion (7.8%) Growth (2015–16 to 2022–23): 34.7% Relative growth: 9.1%</p> <p>Clinical support: Registry infrastructure is limited but present in selected areas, including the TrEAT Registry and AEPCC CQR; stakeholder feedback indicated strong clinical interest.</p>
2	Cancer and other neoplasms	6	<p>Score breakdown: Burden 2.00 Cost 3.00 Clinical support 1.00</p> <p>Diseases: Acute lymphoblastic leukaemia, acute myeloid leukaemia, bowel cancer, brain and central nervous system cancer, breast cancer, chronic lymphocytic leukaemia, chronic myeloid leukaemia, lung cancer, non-Hodgkin lymphoma, non-melanoma skin cancer, other lymphohaematopoietic (blood) cancers, pancreatic cancer, prostate cancer</p> <p>Burden: 586,522 DALYs (11.7%) Growth (2015–2024): 7.2% Relative growth: 4.9%</p> <p>Cost: \$11.6 billion (10.3%) Growth (2015–16 to 2022–23): 42.5% Relative growth: 14.0%</p> <p>Clinical support: Multiple established registries and leadership groups, including BCOR, NBCR, PCOR-ANZ, VLCR and LaRDR.</p>
3	Musculoskeletal disorders	5.5	<p>Score breakdown: Burden 2.50 Cost 2.00 Clinical support 1.00</p> <p>Diseases: Back pain and problems, dislocations, hip fracture, humerus fracture, osteoarthritis, rheumatoid arthritis, tibia and ankle fracture</p> <p>Burden: 548,909 DALYs (11.0%) Growth (2015–2024): 25.6% Relative growth: 13.8%</p> <p>Cost: \$12.0 billion (10.7%) Growth (2015–16 to 2022–23): 17.6% Relative growth: 7.3%</p> <p>Clinical support: Established registries and leadership groups including AOANJRR, ANZHFR, ANZFFR and ARAD.</p>
4	Neurological conditions	5.5	<p>Score breakdown: Burden 2.75 Cost 1.75 Clinical support 1.00</p> <p>Diseases: Dementia, multiple sclerosis, spinal cord injury, traumatic brain injury</p> <p>Burden: 320,214 DALYs (6.4%) Growth (2015–2024): 40.3% Relative growth: 11.3%</p> <p>Cost: \$2.2 billion (1.9%) Growth (2015–16 to 2022–23): 37.2% Relative growth: 2.4%</p> <p>Clinical support: Established or emerging registries include ADNeT, the MS AHSCT Registry, Australasian Shunt Registry and Australian Spine Registry.</p>
5	Cardiovascular diseases	5	<p>Score breakdown: Burden 1.25 Cost 2.75 Clinical support 1.00</p> <p>Diseases: Aortic aneurysm, atrial fibrillation and flutter, cardiomyopathy, coronary heart disease, heart failure, non-rheumatic valvular disease, rheumatic heart disease (including acute rheumatic fever), stroke</p> <p>Burden: 597,622 DALYs (11.9%) Growth (2015–2024): 2.6% Relative growth: 1.9%</p> <p>Cost: \$10.6 billion (9.4%) Growth (2015–16 to 2022–23): 36.2% Relative growth: 11.4%</p> <p>Clinical support: Multiple established registries and leadership groups, including ACOR, National Cardiac Registry, AuSCR, VCOR and QCOR.</p>

Rank	Clinical Domain	Total score	Key signals
6	Infectious diseases	4.5	<p>Score breakdown: Burden 1.75 Cost 1.75 Clinical support 1.00</p> <p>Disease: COVID-19</p> <p>Burden: 43,950 DALYs (0.9%) Growth (2015–2024): NA Relative growth: 5.4%</p> <p>Cost: \$1.8 billion (1.6%) Growth (2015–16 to 2022–23): NA Relative growth: 7.4%</p> <p>Clinical support: Limited disease-specific CQR infrastructure; COVID-19 was the only condition retained and is largely capable of being monitored through surveillance and administrative data systems.</p>
7	Gastrointestinal disorders	4.25	<p>Score breakdown: Burden 1.50 Cost 1.75 Clinical support 1.00</p> <p>Diseases: Chronic liver disease, gallbladder and bile duct disease, gastro-oesophageal reflux disease, inflammatory bowel disease</p> <p>Burden: 121,221 DALYs (2.4%) Growth (2015–2024): 21.4% Relative growth: 2.6%</p> <p>Cost: \$4.6 billion (4.1%) Growth (2015–16 to 2022–23): 25.9% Relative growth: 3.9%</p> <p>Clinical support: Existing registry infrastructure including ANZLITR and CCCare, with evidence of clinical support.</p>
8	Respiratory diseases	4.25	<p>Score breakdown: Burden 2.25 Cost 1.00 Clinical support 1.00</p> <p>Diseases: Asthma, chronic obstructive pulmonary disease (COPD)</p> <p>Burden: 355,501 DALYs (7.1%) Growth (2015–2024): 23.1% Relative growth: 8.2%</p> <p>Cost: \$2.8 billion (2.5%) Growth (2015–16 to 2022–23): 12.8% Relative growth: 1.3%</p> <p>Clinical support: Existing registry infrastructure through the Australasian Severe Asthma Registry and evidence of an identifiable clinical community.</p>
9	Endocrine disorders	4	<p>Score breakdown: Burden 1.50 Cost 1.50 Clinical support 1.00</p> <p>Diseases: Gestational diabetes, type 1 diabetes mellitus, type 2 diabetes mellitus</p> <p>Burden: 148,266 DALYs (3.0%) Growth (2015–2024): 22.5% Relative growth: 3.4%</p> <p>Cost: \$3.4 billion (3.0%) Growth (2015–16 to 2022–23): 31.2% Relative growth: 3.3%</p> <p>Clinical support: Established national CQR and identifiable clinical leadership through the Australian Diabetes Clinical Quality Registry.</p>
10	Kidney and urinary diseases	3.75	<p>Score breakdown: Burden 0.50 Cost 2.25 Clinical support 1.00</p> <p>Diseases: Chronic kidney disease, renal failure</p> <p>Burden: 65,089 DALYs (1.3%) Growth (2015–2024): 12.9% Relative growth: 0.9%</p> <p>Cost: \$3.3 billion (2.9%) Growth (2015–16 to 2022–23): 46.7% Relative growth: 4.2%</p> <p>Clinical support: Established national registry infrastructure through ANZDATA and an identifiable clinical leadership group.</p>
11	Hearing and vision disorders	2.75	<p>Score breakdown: Burden 1.50 Cost 0.75 Clinical support 0.50</p> <p>Diseases: Cataract and other lens disorders, hearing loss</p> <p>Burden: 99,692 DALYs (2.0%) Growth (2015–2024): 27.4% Relative growth: 2.6%</p> <p>Cost: \$2.4 billion (2.1%) Growth (2015–16 to 2022–23): 23.8% Relative growth: 1.9%</p> <p>Clinical support: No established national CQRs and not among the top two stakeholder-ranked domains, but there is emerging advocacy for a cataract registry and some local registries/data collections with potential for expansion.</p>

Rank	Clinical Domain	Total score	Key signals
12	Injury	2.5	<p>Score breakdown: Burden 0.75 Cost 0.75 Clinical support 1.00</p> <p>Diseases: Burn injuries, drowning and submersion injuries, internal and crush injury, poisoning</p> <p>Burden: 144,732 DALYs (2.9%) Growth (2015–2024): 6.2% Relative growth: 1.0%</p> <p>Cost: \$1.0 billion (0.8%) Growth (2015–16 to 2022–23): 35.3% Relative growth: 1.0%</p> <p>Clinical support: Established registries and leadership groups, including ANZTR, BRANZ and ANZICS-related infrastructure.</p>
13	Reproductive and maternal conditions	2.25	<p>Score breakdown: Burden 0.50 Cost 0.75 Clinical support 1.00</p> <p>Diseases: Genital prolapse, hypertensive disorders of pregnancy, maternal haemorrhage, maternal infections, obstructed labour, other maternal conditions, pregnancy and postpartum care</p> <p>Burden: 38,402 DALYs (0.8%) Growth (2015–2024): 21.7% Relative growth: 0.8%</p> <p>Cost: \$6.2 billion (5.5%) Growth (2015–16 to 2022–23): 2.4% Relative growth: 0.6%</p> <p>Clinical support: Existing registry infrastructure includes AMCR, APFPR and maternity-related benchmarking activity.</p>
14	Skin disorders	2.25	<p>Score breakdown: Burden 1.00 Cost 1.25 Clinical support 0.00</p> <p>Diseases: Skin infections (including cellulitis)</p> <p>Burden: 6,527 DALYs (0.1%) Growth (2015–2024): 35.3% Relative growth: 0.2%</p> <p>Cost: \$1.9 billion (1.7%) Growth (2015–16 to 2022–23): 36.1% Relative growth: 2.0%</p> <p>Clinical support: No established national CQR and limited evidence of clinical support for registry development in the retained disease area.</p>
15	Infant and congenital conditions	1.75	<p>Score breakdown: Burden 0.75 Cost 0.00 Clinical support 1.00</p> <p>Diseases: Birth trauma and asphyxia, brain malformations, cardiovascular defects, cerebral palsy, cleft lip and/or palate, gastrointestinal malformations, neonatal infections, neural tube defects, pre-term birth and low birth weight complications, urogenital malformations</p> <p>Burden: 83,894 DALYs (1.7%) Growth (2015–2024): 21.1% Relative growth: 1.8%</p> <p>Cost: \$1.7 billion (1.5%) Growth (2015–16 to 2022–23): 8.2% Relative growth: 0.5%</p> <p>Clinical support: Existing registries including ANZ CHD Registry, ANZFR and ANZNN, with evidence of an identifiable clinical community.</p>

Appendix H. Prioritised diseases and common interventions

Domain	Disease	Intervention type (ACHI)	Percentage within each disease
Cancer and other neoplasms	Acute lymphoblastic leukaemia (ALL)	Pharmacotherapy interventions	55%
Cancer and other neoplasms	Acute myeloid leukaemia (AML)	Therapeutic interventions	63%
Cancer and other neoplasms	Bowel cancer	Anaesthesia and analgesia	62%
Cancer and other neoplasms	Bowel cancer	Generalised allied health professions	55%
Cancer and other neoplasms	Brain and central nervous system cancer	Generalised allied health professions	80%
Cancer and other neoplasms	Breast cancer	Anaesthesia and analgesia	78%
Cancer and other neoplasms	Breast cancer	Breast	76%
Cancer and other neoplasms	Breast cancer	Lymph nodes	64%
Cancer and other neoplasms	Chronic lymphocytic leukaemia (CLL)	Therapeutic interventions	74%
Cancer and other neoplasms	Chronic myeloid leukaemia (CML)	Bone marrow	51%
Cancer and other neoplasms	Lung cancer	Generalised allied health professions	61%
Cancer and other neoplasms	Non-melanoma skin cancer	Skin and subcutaneous tissue	95%
Cancer and other neoplasms	Non-melanoma skin cancer	Anaesthesia and analgesia	63%
Cancer and other neoplasms	Other lymphohaematopoietic (blood) cancers	Therapeutic interventions	71%
Cancer and other neoplasms	Pancreatic cancer	Generalised allied health professions	60%
Cancer and other neoplasms	Prostate cancer	Anaesthesia and analgesia	92%

Domain	Disease	Intervention type (ACHI)	Percentage within each disease
Cancer and other neoplasms	Prostate cancer	Prostate and seminal vesicle	88%
Cardiovascular diseases	Aortic aneurysm	Generalised allied health professions	69%
Cardiovascular diseases	Aortic aneurysm	Anaesthesia and analgesia	62%
Cardiovascular diseases	Atrial fibrillation and flutter	Anaesthesia and analgesia	53%
Cardiovascular diseases	Coronary heart disease	Coronary arteries	68%
Cardiovascular diseases	Coronary heart disease	Anaesthesia and analgesia	52%
Cardiovascular diseases	Heart failure	Generalised allied health professions	72%
Cardiovascular diseases	Non-rheumatic valvular disease	Anaesthesia and analgesia	65%
Cardiovascular diseases	Non-rheumatic valvular disease	Generalised allied health professions	56%
Cardiovascular diseases	Rheumatic heart disease (including acute rheumatic fever)	Anaesthesia and analgesia	62%
Cardiovascular diseases	Rheumatic heart disease (including acute rheumatic fever)	Generalised allied health professions	58%
Cardiovascular diseases	Stroke	Generalised allied health professions	87%
Endocrine disorders	Type 1 diabetes mellitus	Generalised allied health professions	67%
Endocrine disorders	Type 2 diabetes mellitus	Generalised allied health professions	64%
Gastrointestinal disorders	Gallbladder and bile duct disease	Anaesthesia and analgesia	74%
Gastrointestinal disorders	Gallbladder and bile duct disease	Gallbladder and biliary tract	73%
Gastrointestinal disorders	Gastro Oesophageal Reflux Disease (GORD)	Anaesthesia and analgesia	91%

Domain	Disease	Intervention type (ACHI)	Percentage within each disease
Gastrointestinal disorders	Gastro Oesophageal Reflux Disease (GORD)	Other and multiple sites of the digestive system	85%
Gastrointestinal disorders	Inflammatory bowel disease (IBD)	Pharmacotherapy interventions	57%
Hearing and vision disorders	Cataract and other lens disorders	Anterior segment - lens	99%
Hearing and vision disorders	Cataract and other lens disorders	Anaesthesia and analgesia	97%
Hearing and vision disorders	Hearing loss	Anaesthesia and analgesia	55%
Infant and congenital conditions	Brain malformations	Anaesthesia and analgesia	54%
Infant and congenital conditions	Cardiovascular defects	Anaesthesia and analgesia	72%
Infant and congenital conditions	Cerebral palsy	Anaesthesia and analgesia	58%
Infant and congenital conditions	Cleft lip and/or palate	Anaesthesia and analgesia	76%
Infant and congenital conditions	Cleft lip and/or palate	Plastic procedures on soft tissue	68%
Infant and congenital conditions	Gastrointestinal malformations	Anaesthesia and analgesia	78%
Infant and congenital conditions	Neonatal infections	Pharmacotherapy interventions	56%
Infant and congenital conditions	Neural tube defects	Anaesthesia and analgesia	72%
Infant and congenital conditions	Pre-term birth and low birth weight complications	Pharmacotherapy interventions	56%
Infant and congenital conditions	Urogenital malformations	Anaesthesia and analgesia	82%
Infectious diseases	COVID-19	Generalised allied health professions	52%
Injury	Burn injuries	Skin and subcutaneous tissue	54%
Injury	Burn injuries	Generalised allied health professions	50%

Domain	Disease	Intervention type (ACHI)	Percentage within each disease
Injury	Internal and crush injury	Generalised allied health professions	78%
Kidney and urinary diseases	Renal failure	Generalised allied health professions	64%
Mental and substance use disorders	Alcohol use disorders	Therapeutic interventions	53%
Mental and substance use disorders	Anxiety disorders	Therapeutic interventions	60%
Mental and substance use disorders	Bipolar affective disorder	Therapeutic interventions	53%
Mental and substance use disorders	Depressive disorders	Therapeutic interventions	68%
Mental and substance use disorders	Eating disorders	Generalised allied health professions	60%
Mental and substance use disorders	Schizophrenia	Generalised allied health professions	56%
Musculoskeletal disorders	Back pain and problems	Anaesthesia and analgesia	52%
Musculoskeletal disorders	Dislocations	Anaesthesia and analgesia	58%
Musculoskeletal disorders	Dislocations	Generalised allied health professions	51%
Musculoskeletal disorders	Hip fracture	Generalised allied health professions	93%
Musculoskeletal disorders	Humerus fracture	Generalised allied health professions	69%
Musculoskeletal disorders	Osteoarthritis	Generalised allied health professions	94%
Musculoskeletal disorders	Rheumatoid arthritis	Pharmacotherapy interventions	64%
Musculoskeletal disorders	Tibia and ankle fracture	Generalised allied health professions	83%
Musculoskeletal disorders	Tibia and ankle fracture	Anaesthesia and analgesia	54%
Neurological conditions	Dementia	Generalised allied health professions	79%

Domain	Disease	Intervention type (ACHI)	Percentage within each disease
Neurological conditions	Multiple sclerosis	Pharmacotherapy interventions	91%
Neurological conditions	Spinal cord injury	Generalised allied health professions	93%
Neurological conditions	Traumatic brain injury	Generalised allied health professions	63%
Reproductive and maternal conditions	Genital prolapse	Anaesthesia and analgesia	91%
Reproductive and maternal conditions	Genital prolapse	Vagina	71%
Reproductive and maternal conditions	Genital prolapse	Bladder	50%
Reproductive and maternal conditions	Other maternal conditions	Delivery procedures	66%
Respiratory diseases	COPD	Generalised allied health professions	68%



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