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ON SAFETY AND QUALITY IN HEALTH CARE

Prioritised list of clinical domains for clinical quality registry development

Final report

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Contents

Executive summary

This is the report of a project undertaken by the Australian Commission on Safety and Quality in Health Care (the Commission) to implement and document a process, applying the prioritisation criteria and other elements (prioritisation criteria) in the *Framework for Australian clinical quality registries**, to create a prioritised list of clinical domains for potential development of national clinical quality registries.

The *Framework for Australian clinical quality registries*, including the prioritisation criteria, was endorsed by the Australian Health Ministers' Advisory Council in September 2014. The prioritisation criteria address both clinical relevance and feasibility.

Clinical quality registries are a specific type of clinical registry. They collect longitudinal health outcome data for an eligible population and generate risk-adjusted reports on appropriateness and effectiveness of health care. The information is used to inform quality improvement. Therefore, deep engagement of all the clinicians who deliver care to the defined patient group is critical to the success of clinical quality registries. This usually requires established organisational and/or professional linkages between the relevant clinicians.

The project terms of reference required the identification of 10 to 20 clinical domains for potential national development. An initial analysis using data from the National Hospital Cost Data Collection was conducted to identify a manageable list of diseases, conditions and interventions for further analysis. The NHCDC includes mainly hospital-based cost data. Because of concerns about its adequacy for the purpose of short-listing, the approach was supplemented with an analysis of Australian Institute of Health and Welfare Burden of Disease data†, and a survey of clinical, consumer and jurisdictional stakeholders. The objective was to identify diseases, conditions and interventions that are high cost for health service provision, represent a high BOD in the general population and/or are considered a priority for system improvement by Governments and all stakeholders.

A short-list of clinical domains was developed by grouping the diseases, conditions and interventions that were assessed as suitable for potential registry development. Short-listed diseases and interventions were assessed against a threshold criteria of: evidence-based sequence of care; the ability to identify and address variation from the evidence-based sequence of care; suitability of the domain to a clinical quality registry data collection and suitability of the clinical domain to meet the information requirements of a national registry.

The final priority list of clinical domains as set out in Figure 1 is not exhaustive. While the prioritised clinical domains could be considered by funding bodies, funders should also consider the key components of the threshold criteria, and consistency with the *Framework for Australian clinical quality registries* to independently assess the suitability of supporting registries in other clinical domains.

The ranking of the final priority list of clinical domains should be viewed as preliminary, as the comprehensive data required to objectively analyse the relative performance of all short-listed clinical domains against all prioritisation criteria was not available. For example, it was difficult to find comprehensive data to assess the priority of diseases, conditions and interventions that had significant components of care in the community.

The approach used combined the available data with collective judgement of experts, an approach that is often used where evidence or data is limited. Ultimately, it is likely that a prioritisation process of this nature will continue to rely significantly on informed but subjective assessment of the potential benefits of development by clinicians, administrators and other stakeholders.

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* Australian Commission on Safety and Quality in Health Care, Framework for Australian clinical quality registries. Sydney. ACSQHC, March 2014.

† AIHW 2016. Australian Burden of Disease Study: Impact and causes of illness and death in Australia 2011. Australian Burden of Disease Study series no. 3. BOD 4. Canberra: AIHW.

Figure 1: Prioritised list of clinical domains*

SCORE	DOMAINS	SUMMARY
HIGHEST 3	**Ischaemic heart disease**	Serious consequences of poor quality care, very high burden of disease and cost to the health system. Strong clinical support registries in this domain. Current national registries and potential to expand into non-surgical interventions in the future.
	Musculo-skeletal disorders	Serious consequences of poor quality care, very high cost and high burden of disease. A number of national registries in hip and knee procedures. Potential to expand to registries for non-surgical interventions in the future.
2.75	**Major trauma**	Serious consequences of poor quality care, very high burden of disease and high cost to the system. Established leadership group and national registry with incomplete capture as well as jurisdictional registries.
	Adult critical care	Serious consequences of poor quality care, very high cost to the health system and estimated high burden of disease. Very strong clinical support and leadership. National registry with close to complete coverage.
	High burden cancers	Serious consequences of poor quality care, very high cost and high burden of disease. Current national population based registers and a number of jurisdictional cancer specific registries. National registry for prostate cancer.
2.5	**Stroke**	Serious consequences of poor quality care, high burden of disease and moderately high cost to the system. Strong leadership and a national registry.
	Renal disease	Serious consequences of poor quality care, very high cost and moderately high burden of disease. Established leadership group for dialysis and transplantation and expand to registries in this domain.
2.25	**Neonatal critical care**	Serious consequences of poor quality care, high burden of disease and moderately high cost. Existing leadership group and national registry with substantial capture.
	Mental health	Serious consequences of poor quality care, very high burden of disease and very high cost. Clinical advocacy for registries but no identified leadership group or current registries. Initial registries may focus on sub-groups of patients where the entire population can be captured.
1.75	**Maternity**	Serious consequences of poor quality care, moderate burden of disease and high cost. Current data collections by jurisdictions and through administrative data are substantial which could be drawn on to develop clinical quality registries.
1.25	**Dementia**	Serious consequences of poor quality care, high burden of disease and moderate acute care costs. No current registries. Clinical advocacy for registry development in this area. Scoping study on potential to develop registry in this domain is underway.
1 LOWEST	**Major burns**	Serious consequences of poor quality care, moderate burden of disease and moderate cost. Established leadership group and national registry with incomplete patient capture.
	Diabetes	Serious consequences of poor quality care, high burden of disease and moderate cost. Clinical advocacy for the development of clinical quality registries.

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* Table with larger text provided at Attachment 7.

Background

Clinical quality registries

Clinical registries gather information about patients' diagnoses and/or interventions. Clinical quality registries are a sub-set of this larger group. Clinical quality registries are organisations that systematically monitor the quality (appropriateness and effectiveness) of health care, within specific clinical domains, by routinely collecting, analysing and reporting health-related information.*

The information collected from clinical quality registries is used to identify benchmarks, significant outcome variance, and inform improvements in healthcare quality (see Figure 2). The defining feature of clinical quality registries is the provision of feedback to clinicians on their clinical outcomes.

The purpose of clinical quality registries in the Australian context is:

- To inform improvements in the quality of health care by routinely collecting, analysing and reporting on information about the care provided to patients and how well that care is being provided
- To provide a mechanism to feedback specific information to clinicians and providers about
  - the appropriateness of health care (whether the care delivered to patients is based on the best available evidence)
  - the effectiveness of health care (measured by the degree to which the care benefits the patient).†

This information is used to inform improvements in the healthcare system.

Further, the aims of clinical quality registries are:

- To collect longitudinal health outcome data for the entire eligible population of the clinical domain
- To generate risk-adjusted reports on the appropriateness and effectiveness of health care.

If a clinical quality registry is to support continuous quality improvement, it must provide benchmarked data to the clinicians who care for the patients in the registry population and sustain engagement of those clinicians in analysing and responding to their performance data. Within the data governance framework, reports may also be provided to jurisdictions, healthcare providers, funders, clinical colleges and researchers, to identify significant variance and to benchmark nationally and internationally. Capture of data relating to an entire patient population usually requires deep engagement of the multidisciplinary group of clinicians who care for that patient population. If a population of clinicians is large, professionally diverse and does not have strong organisational governance arrangements (e.g. via professional associations or employing organisations) it is not usually possible to establish an effective clinical quality registry. Other quality improvement methodologies such as audit may be useful in such circumstances.

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* Australian Commission on Safety and Quality in Health Care, **Framework for Australian clinical quality registries**. Sydney. ACSQHC, March 2014.

† Australian Commission on Safety and Quality in Health Care. **What are clinical quality registries?** Accessed on 9 September 2016.

Figure 2: Improvement cycle for clinical quality registries

The *Framework for Australian clinical quality registries* and prioritisation criteria

The Commission released the *Framework for Australian clinical quality registries* in September 2014 after endorsement by the Australian Health Ministers' Advisory Council. The *Framework for Australian clinical quality registries* specifies national arrangements under which peak clinical groups and healthcare organisations can partner with governments to monitor and report on the appropriateness and effectiveness of health care* through clinical quality registries. The *Framework for Australian clinical quality registries* comprises the following five key elements:

1. Strategic principles
2. National health information arrangements
3. National infrastructure model
4. Principles, guidelines and standards
5. Prioritisation criteria.†

Clinical quality registry prioritisation criteria are listed in Table 1. More information about the *Framework for Australian clinical quality registries* elements is included at Attachment 1. A detailed description of the application of each prioritisation criterion is provided later in this report.

Categorisation of the prioritisation criteria

The *Framework for Australian clinical quality registries*' prioritisation criteria generally fall into two groups:

1. Some criteria are necessary for the successful functioning of a clinical quality registry – these were designated **threshold criteria**. These criteria were assessed with the overarching principle that the core purpose of a clinical quality registry is to improve safety and quality of care by routinely collecting, analysing and feeding back health-related information
2. Others were identified as more appropriate to use to rank the priority of clinical domains – these were designated **prioritisation criteria**. A summary of the application of the criteria as either threshold or prioritisation is provided at Table 1.

To avoid limiting the prioritisation process to domains where registries were already established, the threshold criteria were interpreted as the potential to meet the requirements. For example prioritisation Criterion 2.4 'The information requirements for a successful clinical quality registry are in place' is interpreted as 'The information requirements for a successful clinical quality registry are in place or **can be established**'. Some criteria were not suitable for assessing potential registry domains (for example, the existence of governance arrangements or resources) and were therefore not applied.

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* Australian Commission on Safety and Quality in Health Care. Corporate Plan. 2015–2019. Page 10.

† Australian Commission on Safety and Quality in Health Care, Framework for Australian clinical quality registries. Sydney. ACSQHC, March 2014.

Table 1: Categorisation of the prioritisation criteria

Criteria	Type	Assessment of the criteria
1.1 There are serious consequences for the patient associated with poor quality care for the clinical condition or with poor quality of the device or procedure	Prioritisation	▪ Areas of medicine where there are serious consequences for the patient if poor quality care is delivered should be prioritised for registry development as these have the greatest impacts on patient morbidity, mortality and quality of life. Sub-optimal outcomes may also result in repeat hospitalisations and increased use of healthcare resources. ▪ This criterion was used to rank domains in terms of priority.
1.2 An evidence-based, well executed sequence of care improves patient outcomes for the clinical condition	Threshold	▪ The core purpose of clinical quality registries is to identify and address unwarranted variation from defined sequences of care. Where no evidence-based sequence of care has been defined, registries will be unable to collect longitudinal health outcome data for the eligible patient population and generate risk-adjusted reports on the appropriateness and effectiveness of health care. In some cases, the sequence of care for a clinical condition is articulated in clinical practice guidelines. Other clinical conditions may not have clinical practice guidelines that describe the appropriate sequence of care; however a well-executed sequence of care has been shown to influence patient outcomes. ▪ The importance of this criterion to the utility of a clinical quality registry was confirmed by a number of workshop participants. Where no evidence of a well-executed sequence of care was found in the literature or the existence of a functional clinical quality registry (national or international) shortlisted domains were excluded from further prioritisation. Domains that do not meet this criterion may benefit from research, epidemiological or other types of registries to improve understanding of the incidence and illness trajectory of clinical conditions and develop an evidence-based sequence of care.
1.3 Unwarranted variation from this sequence of care can be identified and addressed	Threshold	▪ Some clinical conditions may have a well-defined sequence of care, but unwanted variation from this sequence of care can be difficult to identify and/or address. This can occur where a condition has a long illness trajectory; variation in presentation; patient preference affecting treatment decisions or a lack of uniformity in outcomes. Similarly, where the sequence of care for a condition involves multiple service providers across multiple settings and over a long duration, addressing unwanted variations from the sequence of care is difficult. ▪ The importance of this criterion to the utility of a clinical quality registry was confirmed by a number of workshop participants. Where shortlisted diseases, conditions and interventions were identified as unable to meet this criterion they were not considered further in the prioritisation process.

Criteria	Type	Assessment of the criteria
1.4 The condition, device or procedure of interest is associated with a high cost to the health system	Prioritisation	▪ In order to ensure care is both high quality and efficient, providers must identify and promote treatment that yields better, more cost-effective care. Conditions associated with a high cost to the health system are a priority for registry development because these registries provide a potential information source for identifying and responding to inappropriate care or inefficient use of limited resources. ▪ All domains have some cost to the health system and this criterion was therefore assessed to rank the domains in terms of priority.
2.1 The clinical condition is suited to clinical quality registry data collection: 2.1.1 The relevant clinical population can be captured 2.1.2 The clinical condition or event is able to be systematically recognised	Threshold	▪ In order to be feasible, a clinical quality registry needs to have the potential to capture the relevant clinical population. Capture of data about all or the substantial majority of the population of patients included in a registry domain avoids selection bias and ensures registry outputs validly reflect quality of care. A clinical domain may define a sub-set of a larger clinical population (for example, all patients with a specified condition who are treated as inpatients), but once a registry's focus is defined it is necessary to capture the entire population within that focus for a clinical quality registry to operate effectively. ▪ For a registry to be feasible the clinical condition needs to be systematically recognised. Monitoring diseases that cannot be systematically recognised at a defined point in their clinical history may generate misleading data as a result of subjective definitions of conditions or diseases and ill-defined staging criteria for disease. ▪ Diseases, conditions and interventions that were not systematically recognised or where it was not possible at this time to capture the relevant clinical population were not included in further prioritisation. Improvements in diagnostics and in data collection capabilities may lead to these diseases, conditions and interventions becoming suitable for clinical quality registry development in the future.

Criteria	Type	Assessment of the criteria
2.2 There is clinician support for the clinical quality registry (or the proposed clinical quality registry)	Prioritisation	▪ Clinician support for the registry (or proposed registry) is essential for clinician participation in data collection and for engaging clinicians in quality improvement activities that result from data collection. Where clinicians have a sense of ownership of the registry, their supply of information, investigation of the results of data analysis and application of findings is likely to be greater. ▪ It has been assumed that a committed and skilled clinical leadership group could be identified and/or developed for all clinical quality registries where there is sufficient need. This criterion was therefore not considered a threshold criterion but was used later in the prioritisation process.
2.3 The governance requirements for a successful clinical quality registry are in place	Not applied	▪ Registry governance must include systems and processes to protect and share data, address outliers or unexplained variance, and have a mechanism to ensure that quality of care issues are effectively addressed and escalated appropriately. The *Framework for Australian clinical quality registries* requires formal governance structures to oversee resource application, provide focus, optimise output and ensure effectiveness and accountability. ▪ A number of participants highlighted the contribution of good governance to the success of clinical quality registries, and noted that the Commission is addressing governance requirements in its overall registry policy work ▪ This criterion was not applied to the prioritisation process as it has been assumed that best practice policies and procedures could be implemented in all circumstances if there was clinical support for the registry. Evidence of these arrangements should be included in any assessment of the appropriateness of proposed clinical quality registries.

Criteria	Type	Assessment of the criteria
2.4 The information requirements for a successful clinical quality registry are in place (or can be established): 2.4.1 An entire population with a chronic condition or disease, or who have undergone an acute event, can be captured 2.4.2 There is a suitable data source 2.4.3 Clinically meaningful performance indicators can be defined 2.4.4 There is potential for reliable risk adjustment	Threshold	▪ As noted under Criterion 2.1, if it is not possible to identify and capture data from the relevant clinical population, a clinical quality registry will not achieve its objectives, because of inevitable selection bias ▪ Complete collection of data is necessary for indicators to be adjusted for differences in casemix and so they can be used reliably to benchmark and improve performance across institutions. Collection of these data relies on clinician input and engagement of the group of clinicians that cares for the relevant patient cohort is necessary. Prioritisation Criteria 2.4.1 and 2.4.2 (similar to 2.1.1) are unlikely to be met if all the relevant clinicians are not bound together professionally and/or organisationally. ▪ Clinicians who manage patients with the relevant condition or event generally need to be strongly organised within a clinical college or society and/or work within committed, participating healthcare organisations to meet these prioritisation criteria. If relevant clinical groups are large and dispersed and do not have strong and pervasive professional and/or organisational linkages, the requisite widespread commitment to complete data capture is not usually achievable. ▪ Application of these prioritisation criteria led to the exclusion of a number of potential clinical domains, particularly those in which there is a large, geographically- and organisationally-dispersed non-hospital population of patients and/or clinicians ▪ Improvements in data collection capabilities or professional and organisational links may lead to these domains becoming suitable for clinical quality registry development in the future.
2.5 There are sufficient resources available for the sustainable operation of the clinical quality registry	Not applied	▪ A key element in determining the feasibility of developing a new registry or maintaining current registries relates to funding. While the availability of sufficient resources is essential for ongoing clinical quality registry operations, it was assumed that this prioritisation criterion can be addressed for all potential clinical domains, if a decision was made to prioritise them. Therefore, this criterion was not considered in the prioritisation process.

The project

The project aimed to implement and document a process, applying the prioritisation criteria and other elements in the *Framework for Australian clinical quality registries*, to create a prioritised list of clinical domains for potential development of national clinical quality registries.

Clayton Utz was engaged for the initial prioritisation of the list. This process involved identifying diseases, conditions and interventions that have a high burden on the Australian healthcare system, through an indicative cost analysis using data from the NHCDC. An environment scan of the identified high cost diseases, conditions and interventions was conducted to confirm the existence of evidence-based clinical guideline(s) and assess the diseases, conditions and interventions against the prioritisation criteria provided in the *Framework for Australian clinical quality registries*.

Four consultation workshops were held for this project. Workshop participants included stakeholders with backgrounds in health care provision, health care management, consumer advocacy, government, registry science, professional leadership and peak body representation. Participants were provided with a discussion document prior to the workshops, which described the background to the project, an initial non-prioritised list and issues for consideration.

Following the workshops, the project was expanded to include supplementation of the initial short-list of diseases, conditions and interventions identified through the NHCDC analysis with:

- An analysis of AIHW BOD data*
- An online survey of a targeted group of clinical, government and consumer stakeholders to determine their priorities for clinical quality registry development.

Once the short-list of diseases, conditions and interventions was identified, threshold criteria were applied to remove areas that were not suitable for clinical quality registry development. The Commission, with clinical input, conducted an analysis to group the remaining diseases, conditions and interventions into appropriate clinical domains. The remaining prioritisation criteria were then applied to rank the domains and develop the final prioritised list.

The prioritisation process

A flow chart of the prioritisation process is presented in Figure 3 and is followed by a detailed description of the key steps in the prioritisation process. Key steps undertaken were:

1. Shortlisting to identify a manageable list of diseases, conditions and interventions based on cost to the health system, BOD and stakeholder priority
2. Application of the threshold criteria to remove diseases, conditions and interventions that are not suitable for registry development
3. Grouping of diseases, conditions and interventions into clinical domains
4. Prioritisation of clinical domains against the remaining prioritisation criteria.

The process combines the available data with collective judgement of experts to develop a statement regarding the priorities for clinical quality registry development. Similar approaches are often used where evidence or data is limited, for example RAND/UCLA appropriateness method† and other Delphi based approaches.

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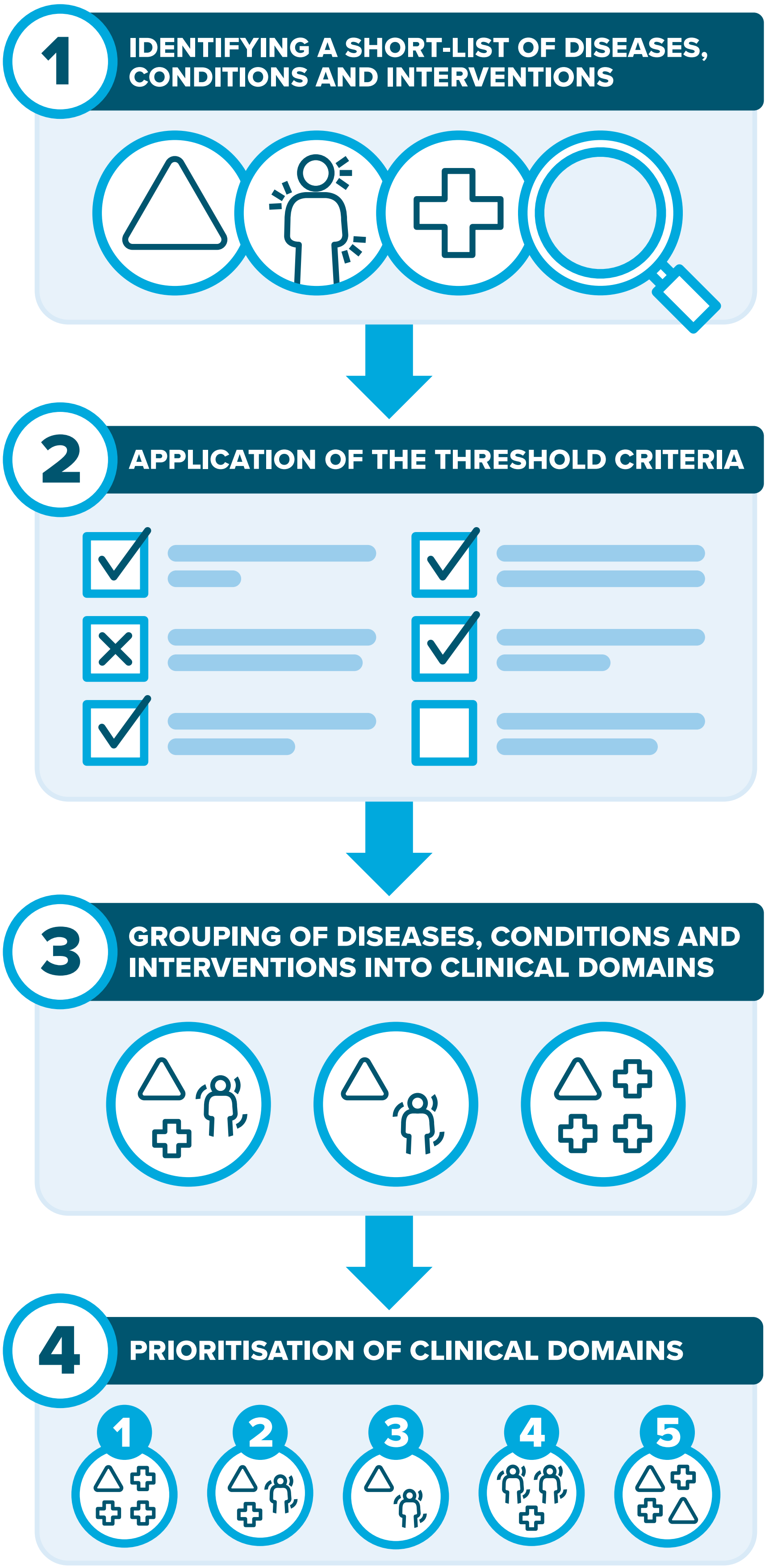
* AIHW 2016. Australian Burden of Disease Study: Impact and causes of illness and death in Australia 2011. Australian Burden of Disease Study series no. 3. BOD 4. Canberra: AIHW.

† Fitch K, Bernstein SJ, Aguilar MD, Burnand B, LaCalle JR, Lázaro P, van het Loo M, McDonnell J, Vader JP, Kahan JP. RAND/UCLA Appropriateness Method User's Manual.

Figure 3: Prioritisation process



1 IDENTIFYING A SHORT-LIST OF DISEASES, CONDITIONS AND INTERVENTIONS

Identify a manageable list for further analysis based on:

- Burden of disease (44 identified)
- Cost to the health system (36 identified)
- Survey of key stakeholders (21 identified).

2 APPLICATION OF THE THRESHOLD CRITERIA

Short-listed diseases, conditions and interventions assessed against the threshold criteria of:

- Evidence-based sequence of care (Criterion 1.2)
- Ability to identify and address variation from the sequence of care (Criterion 1.3)
- Suitability of the domain to clinical quality registry data collection (Criterion 2.1)
- Ability to meet the information requirements for a successful registry (Criterion 1.2).

3 GROUPING OF DISEASES, CONDITIONS AND INTERVENTIONS INTO CLINICAL DOMAINS

The remaining short-listed diseases, conditions and interventions were systemically grouped into clinical domains.

4 PRIORITISATION OF CLINICAL DOMAINS

These groups were assessed against the prioritisation criteria of:

- Serious consequences for the patient (Criterion 1.1)
- High cost to the health system (Criterion 1.4)
- Clinician support (Criterion 2.2).

1. Identifying a short-list of diseases, conditions and interventions

Cost analysis

The first step in developing a manageable list of diseases, conditions and interventions for further consideration was to conduct an indicative cost analysis using data from the NHCDC to identify diseases, conditions or interventions that have a high burden on the Australian healthcare system.

Rationale

The NHCDC was established to collate information in order to determine cost weights and relativities among (mainly) acute hospital products. These elements were then used as inputs into cost and funding models in both the public and private sectors and as a tool to compare cost efficiency. The NHCDC is now described as 'the best available national source of benchmark costs'.* However, it has limitations as follows:

- Not all hospitals are represented nor are all separations captured, although this is improving. Currently, around 92% of admitted acute public hospital activity and 60% of overnight private hospital separations are captured in the NHCDC
- Private hospital costs do not include the cost of Medicare-rebated interventions for medical services, pathology and imaging
- It has a focus on acute inpatient costs and has limited data on, for example, the costs of
  - care provided in any community setting, including pre-admission and referral costs intrinsic to an acute intervention
  - community-based care for people with serious chronic conditions
  - post-discharge care directly relevant to an acute inpatient intervention such as rehabilitation costs, which can be substantial.

There was, overall, acknowledgement by workshop participants that cost burden is an important criterion for identifying priority clinical domains for potential national investment and development. However, some workshop participants questioned the use of the NHCDC as a 'short-listing' tool, for the following reasons:

- The NHCDC categorises conditions by DRG and does not capture potentially relevant non-DRG-based clinical domains
- The NHCDC does not capture conditions that result in a high cost of care in the community, but are not associated with high hospital-based care costs
- Various examples were provided of clinical domains relevant to diseases or conditions that affect a small proportion of the Australian population and therefore are responsible for a correspondingly small proportion of overall health system costs, but for which a clinical quality registry may lead to significant quality benefits for individual patients.

A number of workshop participants also made suggestions about how a cost analysis as a principal tool for short-listing could be enhanced, including suggestions that:

- The additional cost of poor quality care is a more relevant metric than the total cost of care, for prioritisation purposes
- Rather than establishing an initial prioritised list of clinical domains based on acute hospital costs (i.e. the NHCDC) alone, the initial prioritisation process should systematically incorporate total costs (hospital and community) for all potential domains
- Various data sets could be interrogated to develop a more complete picture of system-wide costs, including the Medicare and Pharmaceutical Benefit Scheme collections, jurisdictional collections and health insurer collections
- Disease or condition-based costs could be determined from specific reviews of the literature for each potential domain.

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* Independent Hospital Pricing Authority. Strategic review of the national hospital cost data collection. Sydney. IHPA 2013.

The limitations of the NHCDC data analysis as an initial short-listing tool are recognised. However, none of the potential data sets identified by workshop participants offers a useful tool for an initial short-listing process. While there are numerous sources of domain-specific cost data, the available data collections use diverse and often unique clinical categorisation systems. There is no comprehensive national collection of health system costs (total costs, and additional costs associated with poor quality care) or a variety of separate collections that are both accessible and categorised in a way that would enable aggregation and/or comparison of cost data across collections. It is therefore not possible to develop, *de novo*, a short-list of clinical domains based on a comprehensive analysis of costs incurred in all healthcare settings in Australia.

The concern expressed by some workshop participants about the tendency for an initial analysis based solely on the NHCDC to exclude clinical domains in which patients are primarily treated in community settings is valid. However, many of the clinical domains that primarily involve community-based care are unlikely to meet other essential conditions for a successful clinical quality registry.* Specifically, if the clinicians who care for patients in a defined clinical domain are not strongly organised within a clinical college, society or association and/or do not work within committed, participating health care organisations, the relevant patient cohort is unlikely to be captured and both data capture and clinician engagement criteria are unlikely to be met. This is likely to be the case with many, but not all, conditions for which people receive the majority of their care in the community. Other types of data collection are likely to be better suited to driving quality improvement in many conditions for which care is primarily community-based. An exception applies when highly specialised care is provided by small cohorts of professionally-linked clinicians in community settings, if both the patient population and clinician group can be clearly identified and engaged.

Method

Public and private sector data from Round 17 of the NHCDC (2012/13) were extracted and summed to provide an ordered list of high cost Australian refined DRGs – where each DRG represents a class of patients with similar clinical conditions requiring similar hospital services. A cut-off of $0.1 billion was used, leading to 44 DRGs and DRG groupings being considered.

The initial scan and analysis of the NHCDC identified individual and adjacent high cost DRGs. Some DRGs are broad and encompass more than one clinical population but do not represent high cost DRGs. Other clinical populations are represented in more than one or adjacent DRGs. The latter situation is true for the cancer, which usually have a specific medical or surgical DRG but rarely both, so that an estimate of the costs does not encompass the entirety of the cost of the condition.

The costs attributable to the critical care groups were estimated based upon the critical care component costs of all neonatal separations for the neonatal critical care domain and critical care costs for all other separations for the adult critical care domain.

In the first instance, trauma included only codes for multi-trauma diagnoses (DRG W). Subsequently, a wider perspective of trauma including less severe injuries (selected codes from DRGs I and X) was advanced and an adjusted cost determination for trauma was made.

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* 2.1.1 – The relevant clinical population can be captured.
2.3 – The governance requirements for a successful clinical quality registry are in place.
2.4.1 – An entire population with a chronic condition or disease, or who have undergone an acute event, can be captured.
2.4.2 – There is a suitable data source.

Results

The initial analysis of the NHCDC yielded the list of high cost groups identified in Table 2.

Table 2: High cost clinical diseases, conditions and interventions

Diagnoses related group	Description	NHCDC 2012/13 costs	Total separations 2012/13	Per separation
All NHCDC critical care costs except P01Z-P67ABCD	Critical care (excluding neonatal)	$2.40 billion	> 150,000 estimated	$16,000
I04AB, I32ABC	Knee replacement, revision	$1.2 billion	45,390	$26,438
I03AB, I31AB	Hip replacement, revision	$1.1 billion	38,838	$28,323
O60ABC	Vaginal delivery	$1.1 billion	202,656	$5,428
O01ABC	Caesarean delivery	$1.0 billion	102,007	$9,803
I06Z, I09AB	Spinal fusion	$0.65 billion	14,872	$43,706
L61Z	Haemodialysis	$0.64 billion	1.17 million	$547
E62ABC	Respiratory infection / inflammatory	$0.59 billion	80,176	$7,359
U61AB	Schizophrenia disorder	$0.59 billion	26,692	$22,104
G46ABC, G47ABC	Gastroscopy	$0.53 billion	239,709	$2,211
G02AB	Major small and large bowel procedure	$0.51 billion	22,981	$22,192
F41AB, F42ABC	Circulatory disorder +/– acute myocardial infarction (with invasive procedure)	$0.50 billion	89,817	$5,567
F12AB, F17AB, F18AB	Pacemaker related	$0.45 billion	18,860	$26,430
R63Z	Chemotherapy	$0.43 billion	347,290	$1,238
P01Z – P67ABCD	Critical care costs only for neonatal admits	$0.43 billion	Not reported	Not reported
U63AB	Major affective disorder	$0.43 billion	22,977	$18,714
F03AB, F04AB	Cardiac valve procedure	$0.41 billion	8,543	$47,993
E65AB	COAD (COPD)	$0.40 billion	58,263	$6,865
F01AB, F02Z	AICD related	$0.40 billion	5,977	$66,923
I08AB	Other hip and femur procedures	$0.39 billion	22,528	$17,312
B69AB, B70ABCD	TIA, stroke	$0.39 billion	47,046	$8,290
F05AB, F06AB	Coronary bypass	$0.37 billion	10,365	$35,697
F62AB	Heart failure	$0.37 billion	46,036	$8,037
B02ABC	Cranial procedures	$0.36 billion	17,673	$20,370

Diagnoses related group	Description	NHCDC 2012/13 costs	Total separations 2012/13	Per separation
G10AB	Hernia procedures	$0.36 billion	70,923	$5,076
I13AB	Humerus, other lower limb procedures	$0.36 billion	35,087	$10,260
H08AB	Laparoscopic cholecystectomy	$0.36 billion	49,426	$7,284
F72AB, F74Z	Unstable angina, chest pain	$0.36 billion	138,845	$2,593
R60AB, R61ABC	Lymphoma, acute and non-acute leukaemia	$0.36 billion	42,218	$8,527
J64AB	Cellulitis	$0.34 billion	64,558	$5,267
G70AB	Other digestive system disorders	$0.33 billion	94,006	$3,510
L63AB	Kidney and urinary tract infection	$0.32 billion	59,643	$5,365
G48ABC	Colonoscopy	$0.31 billion	182,528	$1,698
J06AB, J07AB, J14Z, J62AB	Breast condition procedure, reconstruction, breast malignancy	$0.31 billion	60,654	$5,111
C16Z	Lens procedures	$0.28 billion	104,993	$2,667
G01AB	Rectal resection	$0.26 billion	9,728	$26,727
G07AB	Appendicectomy	$0.24 billion	34,812	$6,894
F08AB	Major vascular procedure	$0.21 billion	7,158	$29,338
I05AB	Other joint replacement	$0.14 billion	5,297	$26,430
M01AB	Prostate cancer – major male pelvic procedure, surgical only	$0.13 billion	7,974	$16,303
W01Z-W61AB	Multiple or significant trauma	$0.13 billion	4,752	$27,357
L71AB	Respiratory cancer – medical only	$0.11 billion	14,847	$7,409
Y01Z, Y02AB, Y03Z, Y60Z, Y61Z, Y62AB	Major burns	$0.11 billion	8,034	$12,447
B66AB	Nervous system malignancy – medical only	$0.07 billion	7,526	$9,301

Burden of disease analysis

To identify conditions that have a high impact on population health and wellbeing but do not necessarily generate high hospital-based costs, the NHCDC-derived short-list was supplemented with an analysis of population BOD data.

Rationale

Workshop participants raised the following methodological issues relevant to the use of BOD data as a short-listing tool:

- The extent to which the burden of poor quality care directly correlates with the BOD is unknown, for example
  - a clinical domain associated with very high existing standards of care may exhibit little potential for quality improvement, even if it is associated with a high BOD; and
  - a clinical domain associated with a lower BOD may also be associated with significant variation in care, and therefore significant improvement potential
- Analysing BOD at a population level does not identify conditions in which small numbers of individuals incur significant adverse health outcomes (either directly, as a consequence of the disease or condition, or if evidence-based care is not provided)
- Some potential clinical domains that appear well suited to clinical quality registry development (e.g. patients treated in intensive care units) are not captured through the methodology currently applied by the AIHW to quantifying BOD in Australia.

Nevertheless, if there is similar quality improvement potential across a number of clinical domains, the diagnosis and procedures associated with the greatest BOD are likely to yield the greatest population benefit if that potential for improvement can be captured. The project scope was therefore amended to incorporate a BOD analysis in the short-listing phase.

Method

We analysed the 2016 AIHW estimates of the BOD in Australia, which are based on data collected in 2011. The data are presented as a measure of total BOD expressed as DALYs. This measure combines estimates of fatal burden (years of life lost (YLL) due to premature death) and non-fatal burden (years lived with disability (YLD)) to identify the total years of life lost from disease and injury for specific diseases and disorders (Table 3).

Table 3: Burden of disease in Australia 2011 top 20 DALY (AIHW 2016)*†

Condition	YLD 2011 (rank)	YLL 2011 (rank)	Total DALYs 2011	Percentage of total DALYs 2011 (rank)
Coronary heart disease	70,946 (10)	275,704 (1)	346,651	7.7% (1)
Other musculoskeletal	173,106 (1)	10,841 (>20)	183,947	4.1% (2)
Back pain and problems	162,393 (2)	1,395 (>20)	163,788	3.6% (3)
COPD	84,985 (7)	75,361 (7)	160,346	3.6% (4)
Lung cancer	3,685 (>20)	151,205 (2)	154,890	3.4% (5)
Dementia	70,658 (11)	80,650 (6)	151,308	3.4% (6)
Anxiety disorders	140,936 (3)	35 (>20)	140,971	3.1% (7)
Stroke	16,782 (>20)	119,989 (3)	136,771	3.0% (8)
Depressive disorders	127,034 (4)	625 (>20)	127,659	2.8% (9)
Suicide and self-inflicted injuries	1,550 (>20)	111,920 (4)	113,470	2.5% (10)
Asthma	100,017 (5)	7,296 (>20)	107,313	2.4% (11)
Diabetes	47,543 (14)	54,110 (9)	101,653	2.3% (12)
Bowel cancer	6,598 (>20)	85,824 (5)	92,422	2.1% (13)
Osteoarthritis	85,088 (6)	718 (>20)	85,806	1.9% (14)
Rheumatoid arthritis	81,036 (8)	2,453 (>20)	83,489	1.9% (15)
Upper respiratory conditions	75,151 (9)	523 (>20)	75,674	1.7% (16)
Breast cancer	7,307 (>20)	63,368 (8)	70,675	1.6% (17)
Hearing loss	66,506 (12)	0	66,506	1.5% (18)
Alcohol use disorders	58,211 (13)	7,831 (>20)	66,042	1.5% (19)
Falls	34,982 (20)	24,134 (>20)	59,116	1.3% (20)

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* AIHW 2016. Australian Burden of Disease Study: Impact and causes of illness and death in Australia 2011. Australian Burden of Disease Study series no. 3. BOD 4. Canberra: AIHW.

† Ibid, reproduced from Table 3.3 of report.

Stakeholder survey

To identify any gaps in the short-listing process based on NHCDC and BOD data sets, a survey was conducted inviting key organisations to nominate domains that they considered clinically important. The organisations that were contacted were:

- Consumer organisations (n=3)
- Professional organisations (n=61)
- All Australian state and territory departments of health (n=8)
- The Australian Government Department of Health and Ageing.

A list of organisations invited to participate in the survey and those that responded is at Attachment 2. Thirty-two organisations (44% of those invited) responded. Because not all clinical organisations and professional associations that were invited to participate responded, some clinical domains where development of a clinical quality registry is a priority may not be represented. Nevertheless, the survey yielded useful information. Survey respondents were asked to identify their top three priorities for clinical quality registry development. Many of the respondents identified clinical domains aligned with those already captured by the NHCDC and BOD analyses; however, a small number of new clinical domains emerged from this process. Not all respondents identified three priorities.

Priority 1

- Pancreatectomy/oesophagectomy
- Cardiac procedures and devices
- Mesh in gynaecological surgery
- Colorectal cancer
- Major burns
- Cancer
- Cancer surgery
- Surgical mortality
- Obstructive sleep apnoea
- Dementia
- Spinal surgery outcomes
- Fractures
- Diabetes
- Transition care
- Breast Cancer Surgery
- Breast Implants
- Disease-specific cancer registries
- Ear disease in Aboriginal and Torres Strait Islander people
- Mental Health – psychosis and schizophrenia, major affective disorders
- CSF shunt.

Priority 2

- Spinal surgery
- Dialysis, transplantation, organ donation
- Maternity
- Breast surgery
- Non-invasive ventilation
- Surgery for joint pain (knee, shoulder, back)
- Stroke
- Insomnia
- Pancreatic adenocarcinoma
- Osteoporotic hip fractures
- Immunisation coverage
- High cost interventional/surgical procedures/devices
- Rhinology, otology, head and neck surgery, specifically outcomes for tonsil, grommet and nasal septum surgery.

Priority 3

- Cancer treatment
- Joint replacement
- Renal
- Gastro-oesophageal surgery
- Insomnia
- Antibiotic resistant bacterial infections
- Depression
- Non-invasive ventilation
- Pregnancy outcomes
- Critical care
- Outcomes for general rhinology, otology and head and neck surgery.

2. Application of the threshold criteria

In order to identify diseases, conditions and interventions that were not suitable for development, the threshold criteria were applied. These threshold prioritisation criteria describe characteristics that were considered necessary for successful functioning of a clinical quality registry (using the *Framework for Australian clinical quality registries* criteria as a guide). A full list of prioritisation criteria, together with the rationale for their application as threshold criteria, is listed in Table 1. Diseases, conditions and interventions that did not meet these threshold criteria were not included in further prioritisation. The method of assessment of the threshold criteria is provided in Table 4.

Attachment 3 provides information about diseases, conditions and interventions that did not meet one or more threshold prioritisation criterion.

Table 4: Assessment of compliance with threshold prioritisation criteria

Prioritisation criteria		Assessment
1.2	**An evidence-based, well executed sequence of care**	Whether there is an existing effective clinical quality registry and/or existing evidence-based guidelines and/or literature defining an established sequence of care – see detail in Attachment 4
1.3	**Unwarranted variation can be identified and addressed**	A qualitative assessment of whether clinical processes and unwarranted variation from the sequence of care can be defined, identified and addressed through a clinical quality registry
2.1.1	**Relevant clinical population can be captured**	Whether there are: ▪ Existing established administrative or clinical datasets defining the population group ▪ One or more identifiable clinical groups that care for the relevant patients and can be engaged in a clinical quality registry via professional or organisational links, for data submission purposes ▪ Any identifiable barriers to registry engagement by patients
2.1.2	**Relevant clinical condition or event can be systematically recognised**	Whether the clinical domain identifies certain and definable diagnoses, conditions or events sufficiently
2.4.1	**Entire population can be captured**	Whether there are: ▪ Existing established administrative or clinical datasets defining the population group ▪ One or more identifiable clinical groups that care for the relevant patients and can be engaged in a clinical quality registry via professional or organisational links, for data submission purposes ▪ Any identifiable barriers to registry engagement by patients
2.4.2	**Suitable data source**	Whether: ▪ Data can be collected through established administrative or clinical datasets ▪ Patients are sufficiently concentrated in the care of one or more identifiable clinical groups that can be engaged in and submit data to a clinical quality registry ▪ There are any barriers to data collection and submission
2.4.3	**Clinically meaningful performance indicators**	Whether there is existing effective clinical quality registry and/or literature that identifies relevant performance indicators
2.4.4	**Potential for reliable risk adjustment**	Whether there is an existing effective clinical quality registry and/or literature that confirms potential to risk adjust

3. Grouping of diseases, conditions and interventions into clinical domains

NHCDC data are DRG-based, BOD data are condition-based and stakeholder priorities were described in varying terms. A process was therefore undertaken to identify clinical domains that were pragmatically suitable and clinically meaningful for further prioritisation.

'Domain' is not a defined term in the Australian healthcare system. Existing Australian clinical quality registries have developed organically in response to multiple drivers. These include clinician and/or consumer interest, practical, and funding considerations. Successful clinical registries in Australia all reflect identifiable patient populations characterised by one or more of the following:

- Single DRGs
- Groups of DRGs
- Commonly-recognised diseases
- Aggregates of commonly-recognised diseases
- Single interventions that are not DRG-specific
- Aggregates of interventions that are not DRG-specific
- The provision of care in defined healthcare settings.

Commonly, registries reflect a similar sequence of care provided to a specific patient population group by an identifiable group of clinicians and/or in an identifiable clinical setting.

Workshop participants emphasised the need to ensure that a proliferation of registries does not lead to multiple collections of data relating to the same cohort of patients. This was a key consideration in aggregating and recategorising various diverse clinical diseases, conditions and interventions into potential domains.

An approach was therefore adopted that grouped similar diseases, conditions and interventions to provide a structure of domains under which multiple registries may exist. Under these domains, there may be various device, procedure and clinical registries, which could be developed depending on clinical need and support.

Focusing on these groupings, rather than specific interventions or procedures, allows for increased understanding of the appropriateness of interventions and provides opportunities to improve care across the continuum. It encourages communication between registries under each domain to avoid the burden of data collection and allows for the continuation of a bottom-up approach that has historically dominated registry development.

This approach also provides a structure for national registries in Australia that is flexible to changes in the healthcare system. For example, changing clinical coordination, such as healthcare homes and care coordinators may allow registries to be developed in areas where there were previously dispersed groups of treating clinicians. Improved data collections such as electronic health records may also provide opportunities for registries that were previously not possible.

The application of threshold criteria and pragmatic grouping of conditions resulted in a short-list of clinical domains (Table 5).

Table 5: Consolidated short-list

Clinical domain	NHCDC potential priority	Burden of disease potential priority	Stakeholder-identified potential priority
Ischaemic heart disease	▪ AICD related ▪ Cardiac valve procedure ▪ Pacemaker related ▪ Circulatory disorder +/– acute myocardial infarction (with invasive procedure) ▪ Coronary bypass ▪ Unstable angina, chest pain	Coronary heart disease	▪ Cardiac procedures and devices ▪ High cost interventional/surgical procedures/devices
Musculoskeletal disorders	▪ Knee replacement, revision ▪ Hip replacement, revision ▪ Other hip and femur procedures ▪ Other joint replacement ▪ Humerus, other lower limb procedures	▪ Osteoarthritis ▪ Rheumatoid Arthritis ▪ Other musculoskeletal	▪ Fragility fractures ▪ Osteoporotic hip fractures ▪ Surgery for joint pain (knee, shoulder, back) ▪ Joint replacement
	Spinal fusion	Back pain and problems	Spinal surgery outcomes
Major trauma	Multiple or significant trauma	N/A	N/A
Adult critical care	Critical care (excluding neonatal)	N/A	Critical care
High burden cancers	Lymphoma, acute and non-acute leukaemia	N/A	N/A
	Prostate cancer – major male pelvic procedure, surgical only	N/A	N/A
	Major small and large bowel procedure	N/A	N/A
	Rectal resection	Bowel cancer	Colorectal cancer
	Respiratory cancer – medical only	Lung cancer	N/A
	Breast condition procedure, reconstruction, breast malignancy	Breast cancer	▪ Breast cancer surgery ▪ Breast implants ▪ Breast surgery
Stroke	TIA, stroke	Stroke	Stroke
Renal disease	Haemodialysis	N/A	▪ Dialysis, transplantation and organ donation ▪ Renal
Neonatal critical care	Critical care costs only for neonatal admits	N/A	N/A

Clinical domain	NHCDC potential priority	Burden of disease potential priority	Stakeholder-identified potential priority
Mental health	▪ Schizophrenia disorder ▪ Major affective disorder	▪ Depressive disorders ▪ Suicide and self-inflicted injuries ▪ Anxiety disorders	▪ Mental health – psychosis and schizophrenia, major affective disorders ▪ Depression
Maternity	▪ Vaginal delivery ▪ Caesarean delivery	N/A	▪ Maternity ▪ Pregnancy outcomes
Dementia	N/A	Dementia	Dementia
Major burns	Burns	N/A	Burns
Diabetes	N/A	Diabetes	Diabetes

These domains are described in broad terms only. Further detailed consultation with relevant clinicians would be required to define the specific scope (inclusions and exclusions) of registries that are suitable for development. In relation to specific clinical domains, considerations would include, for example:

- Maternity – It would be sensible to build on existing data collections already held in all jurisdictions. A significant amount of care is community-based and would be difficult to capture in a registry – the scope of data collection would need to be defined and is likely to be primarily hospital-based but would include hospital-based collection of data about some aspects of ante-natal and post-natal care
- Mental health – A significant amount of care is community-based, however most patients experiencing major affective and psychotic disorders are likely to be under the care of a psychiatrist and therefore a registry that includes both hospital- and community-based data collection is likely to be feasible
- Major burns – This clinical domain is likely to be defined by the location of care, consistent with the existing Burns Registry of Australia and New Zealand.*

4. Prioritisation of clinical domains

The final list of domains was assessed against the remaining (non-threshold) prioritisation criteria:

- Criterion 1.1: There are serious consequences for the patient associated with poor quality care for the clinical condition or with poor quality of the device or procedure
- Criterion 1.3: The condition, device or procedure of interest is associated with a high cost to the health system
- Criterion 2.2: There is clinician support for the clinical quality registry (or the proposed clinical quality registry).

Assessment against prioritisation Criterion 1.1: Serious consequences associated with poor quality care

There are numerous sources of information about the impact of poor quality care in individual clinical domains. The project scanned the literature and identified the main consequences of poor quality care for each of the clinical domains. All short-listed potential clinical domains were assessed as associated with serious clinical risk.

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* Cleland et. al. The Burns Registry of Australia and New Zealand: progressing the evidence base for burn care. Med J Aust 2016; 204 (5): 195.

Because no specific data sources were identified that could reasonably be applied to systematically analyse and rank the impact of poor quality care across all short-listed potential clinical domains, BOD data was used to provide an estimate of the consequences to patients. If there is similar quality improvement potential across a number of clinical domains, the diagnosis and procedures associated with the greatest BOD are likely to yield the greatest population benefit if that potential for improvement can be captured. The BOD associated with clinical domains where registries were considered feasible was assessed using estimates from AIHW 2011 data* and data provided directly by the AIHW.†

There are significant methodological challenges in assigning an accurate numeric rating to the BOD associated with each short-listed clinical domain, including:

- BOD analysis is based on clinical diagnoses and does not capture the burden of location-based care such as care provided in intensive care units
- BOD data is presented in broad categories that do not necessarily directly relate to the relevant clinical domain being assessed, for example, osteo- and rheumatoid arthritis BOD relates to many more people than those who require a major joint procedure.

Because of the methodological limitations, four broad categories, rather than a highly granular categorisation, were adopted for the rating of relative BOD associated with the short-listed clinical domains. Estimates of the BOD for each domain are provided in Table 6.

Table 6: Burden of disease in Australia 2011 for short-listed domains

Clinical domain	Total DALYs 2011	Estimated percentage of total DALYs 2011
Ischaemic heart disease	499,468	11.10%
Musculoskeletal disorders	532,002	11.84%
Major trauma	280,984	6.25%
Adult critical care	Not suitable for burden of disease analysis	Not suitable for burden of disease analysis
High burden cancers	471,422	10.49%
Stroke	136,771	3.04%
Renal disease	56,236	1.25%
Neonatal critical care	102,773	2.27%
Mental health	341,271	7.55%
Maternity	23,083	0.51%
Dementia	151,308	3.4%
Diabetes	101,860	2.3%
Major burns	7,768	0.17%

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* Australian Institute of Health and Welfare 2016. Australian Burden of Disease Study: Impact and causes of illness and death in Australia 2011. Australian Burden of Disease Study series no. 3. BOD 4. Canberra: AIHW.

† Australian Institute of Health and Welfare 2016. Unpublished burden of disease data.

More detail of the conditions used by the BOD data within each domain is provided in Attachment 5.

Using the results of this analysis, the domains were given a score using proportion of the total BOD data in accordance with the system described in Table 7.

Table 7: Scoring for burden of disease

Percentage of total burden of disease	Score
>3%	1
2% – 3%	0.75
1% – 2%	0.5
0.75% – 1%	0.25
<0.75%	0

Assessment against prioritisation Criterion 1.4 – High cost to the health care system

As noted earlier, the NHCDC collection has limitations for use in analysing costs to the healthcare system, as it does not provide a completely accurate picture of the total costs of care associated with various clinical domains. However, the NHCDC does help to establish broad rankings of potential clinical domains based on hospital costs.

Estimates of the cost of each domain is provided in Table 8.

Table 8: Cost analysis for short-listed domains

Clinical domain	NHCDC 2012/13 total costs	Percentage of total cost from NHCDC
Ischaemic heart disease	$2.68 billion	7.94%
Musculoskeletal disorders	$4.33 billion	12.83%
Major trauma	$0.83 billion	2.46%
Adult critical care	$2.40 billion	7.11%
High burden cancers	$2.52 billion	7.47%
Stroke	$0.39 billion	1.16%
Renal disease	$2.19 billion	6.49%
Neonatal critical care	$0.43 billion	1.27%
Mental health	$1.6 billion	4.74%
Maternity	$2.1 billion	6.22%
Dementia	$0.0953 billion	0.28%
Major burns	$0.11 billion	0.33%
Diabetes	$0.193 billion	0.56%

More detail of the DRGs applied to each clinical domain is provided in Attachment 6.

Clinical domains were ranked using proportion of the total NHCDC costs in accordance with the scoring system described in Table 9.

Table 9: Scoring for cost

Percentage of total costs	Score
>3%	1
2% – 3%	0.75
1% – 2%	0.5
0.75% – 1%	0.25
<0.75%	0

The category boundaries were chosen to represent broad grouping of the cost to the health system. More gradual scoring was not used due to the limitations of the data discussed earlier. However, as with the BOD analyses, the approach is subject to considerable methodological challenges and is intended to be indicative only.

Assessment against prioritisation Criterion 2.2 – Clinician support

Workshop participants agreed that without strong clinician support, attempts to develop clinical quality registries are generally unsuccessful.

Organisational linkages that facilitate clinician engagement are required to identify relevant patients, ensure data are submitted to the registry and initiate quality improvements based on registry analyses.

The level of clinician leadership is considered to be a key success factor for clinical quality registries. However, some participants questioned whether a deficiency in clinician support should limit the potential development of a clinical quality registry in circumstances where there is otherwise significant potential to improve clinical quality.

The level of clinician support in relation to each potential clinical domain was qualitatively assessed by two senior Commission staff independently, with differences resolved by agreement, in accordance with the scoring system set out in Table 10.

Table 10: Scoring for clinical support

Level of clinical support	Score
Established national clinical quality registry leadership group across the potential clinical domain or national clinical quality registry	1
Existing state clinical registry/audit or existing national clinical registry/audit with limited participation and/or without the characteristics of a clinical quality registry	0.75
Clinician advocacy for a registry in the potential clinical domain, registry under development, leadership group in limited jurisdictions or an existing audit or limited existing registry	0.5
Limited stakeholder engagement in development of clinical quality registries	0.25
No known existing registry resources or no known explicit clinician support for a clinical quality registry	0

Table 11: Clinical support for short-listed domains

Clinical domain	Evidence of clinical support	Current clinical quality registries	Score
Ischaemic heart disease	Established leadership group (ACOR)	▪ ACOR – Cardiac Devices Registry ▪ Cardiac Procedures Registry ▪ National Cardiac Surgery Database	1
Musculoskeletal disorders	▪ Established leadership group (Spine Society of Australia, Australian Spine Registry) ▪ Australian Orthopaedic Association National Joint Replacement Registry is a device surveillance registry ▪ ANZHFR launched September 2016 ▪ Clinician support for an osteoporotic hip fracture clinical quality registry expressed through stakeholder survey	▪ Australian Orthopaedic Association ▪ National Joint Replacement Registry	1
Major trauma	▪ Established leadership group (AusTQIP) ▪ Existing state clinical quality registry with incomplete patient capture	▪ AusTQIP ▪ NT Trauma ▪ Victorian State Trauma System	1
Adult critical care	Established leadership group – ANZICS CORE includes Adult Patient Database	ANZICS CORE registries	1
High burden cancers	Key agencies support the development of clinical quality registries. National registry for prostate cancer. Established leadership groups in some jurisdictions and for some specific cancer types.	▪ Australian Association of Cancer Registries Existing audit – Binational Colorectal Cancer Audit ▪ ABDR / Breast Surgeons of Australia and New Zealand Quality Audit ▪ PCOR-ANZ ▪ Cutaneous Lymphoma Registry under development ▪ Victorian Lung Cancer Registry	0.75
Stroke	Established leadership group – Australian Stroke Clinical Registry	▪ Australian Stroke Clinical Registry ▪ Australian Thrombolysis Registry	1
Renal disease	Established leadership group (ANZDATA)	ANZDATA	1
Neonatal critical care	▪ Established leadership group – ANZICS CORE includes Paediatric Intensive Care Registry ▪ Existing national registry with substantial patient capture	ANZICS CORE registries	1
Mental health	Clinician advocacy – identified as a high priority in stakeholder survey	No existing registry	0.25

Clinical domain	Evidence of clinical support	Current clinical quality registries	Score
Maternity	Existing jurisdiction-based data collections, no national clinical quality registries	▪ Australian Maternity Obstetric Surveillance System ▪ Maternity Care Indicators data collection	0.75
Dementia	Dementia collaborative research centres is conducting a scoping project for the National Dementia Register in Australia	No current registry	0.25
Major burns	Established leadership group and existing national registry with incomplete patient capture (Burns Registry of Australia and New Zealand)	Burns Registry of Australia and New Zealand	1
Diabetes	Clinician advocacy – identified as a high priority in stakeholder survey	▪ ANDA is a research audit that is conducted annually ▪ No current registry	0.25

Final list of priority clinical domains

The results of the prioritisation process are consolidated in Table 12. The scope of some prioritised clinical domains is readily identifiable by virtue of the location in which care is provided (e.g. critical care) others, such as maternity, have a potentially broad scope and will need further specification. Definition of specific inclusion/exclusion criteria for some of the prioritised clinical domains will require further detailed consultation with relevant clinical groups and may change over time. Due to the methodological challenges described in this report, the identified clinical domains and their relative priority for development should be regarded as indicative only.

Development of clinical registries in all the clinical domains listed in Table 13 could generate significant benefit for the relevant patient group. Some domains may benefit from multiple registries. However as these registries develop it is important that information and improvements are shared within the domain.

The priority and scope of the registries within each domain should be determined through further consultation with the relevant clinical groups. In some cases specific sub-populations, such as dementia patients receiving care in memory clinics or specific procedures, may be prioritised for development under these domains due to limitations in ability to collect data on the entire patient cohort. As capacity to collect data and coordination of care improves, registries may be expanded to other aspects of care where improvements can be made.

It would be appropriate to conduct a targeted expression of interest process to assess potential registries under these domains. This would allow for a more fulsome and contemporary assessment against each of the prioritisation criteria as well as the *Operating principles for clinical quality registries* endorsed by Health Ministers in November 2010 described in the *Framework for Australian clinical quality registries*.

The prevalence of poor outcomes associated with specific procedures such as use of mesh in gynaecological surgery and AMD treated with new anti-vascular endothelial growth factor drugs are of significant concern. These have not been considered in the prioritisation of clinical domains as they were considered post-market surveillance. Assessment of the suitability and priority of registries such as these should be considered separately to this work and as specific issues associated with care are identified.

The domains identified in this report provide a focus for registry development in the future based on the burden to the health system and potential for harm to patients. There may be other specific areas where a registry could provide significant improvement in care and cost savings. For example, *The First Australian Atlas of Healthcare Variation** identifies conditions in which there is variation in service provision that may correlate with poor quality care. While the atlas does not identify variation in safety or effectiveness and focuses on a limited number of healthcare interventions, further investigation of the cause of variation may identify areas where registries are an appropriate mechanism for quality improvement. Variation in care and potential for patient harm may also be identified through other mechanisms and should be considered individually and as required.

The domains identified represent the current priorities for registry development. As the registry landscape in Australia develops, data availability improves, and clinical practice changes, there is potential for priority domains to be expanded and for these priorities to change.

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* Australian Commission on Safety and Quality in Health Care and National Health Performance Authority. **The First Australian Atlas of Healthcare Variation.** Sydney: ACSQHC, 2015.

Table 12: Consolidated summary of prioritisation of potential domains

Clinical domain	Short-listed by	Criteria	Prioritisation category	Outcome
Ischaemic heart disease	▪ Cost ▪ Burden of disease ▪ Stakeholder priority	1.1 Serious consequences to the patient	Evidence – Total DALYs 2011	499,468
			Evidence – Percentage of total DALYs 2011	11.10%
			Score	**1**
		1.3 High cost to health system	Evidence – NHCDC hospital cost	$2.68 billion
			Evidence – Percentage of total cost from NCCH	7.94%
			Score	**1**
		2.2 Clinician support	Evidence – Leadership group	Established leadership group (ACOR)
			Evidence – Current clinical quality registries	▪ ACOR – Cardiac Devices Registry ▪ Cardiac Procedures Registry ▪ National Cardiac Surgery Database
			Score	**1**
			Total score	**3**

Clinical domain	Short-listed by	Criteria	Prioritisation category	Outcome
Musculoskeletal disorders	▪ **Cost** ▪ **Burden of disease** ▪ **Stakeholder priority**	1.1 **Serious consequences to the patient**	Evidence – Total DALYs 2011	532,002
			Evidence – Percentage of total DALYs 2011	11.84%
			Score	**1**
		1.3 **High cost to health system**	Evidence – NHCDC hospital cost	$4.33 billion
			Evidence – Percentage of total cost from NCCH	12.83%
			Score	**1**
		2.2 Clinician support	Evidence – Leadership group	▪ Established leadership group (Spine Society of Australia, Australian Spine Registry) ▪ Australian Orthopaedic Association National Joint Replacement Registry is a device surveillance registry ▪ ANZHFR launched September 2016 ▪ Clinician support for an osteoporotic hip fracture clinical quality registry expressed through stakeholder survey
			Evidence – Current clinical quality registries	Australian Orthopaedic Association. National Joint Replacement Registry collects comprehensive data for all knee replacements
			Score	**1**
			Total score	**3**

Clinical domain	Short-listed by	Criteria	Prioritisation category	Outcome
Major trauma	▪ Cost	**1.1 Serious consequences to the patient**	Evidence – Total DALYs 2011	280,984
			Evidence – Percentage of total DALYs 2011	6.25%
			Score	**1**
		1.3 High cost to health system	Evidence – NHCDC hospital cost	$0.83 billion
			Evidence – Percentage of total cost from NCCH	2.46%
			Score	**0.75**
		2.2 Clinician support	Evidence – Leadership group	▪ Established leadership group (AusTQIP) ▪ Existing state clinical quality registry with incomplete patient capture
			Evidence – Current clinical quality registries	▪ AusTQIP ▪ NT Trauma ▪ Victorian State Trauma System
			Score	**1**
			Total score	**2.75**

Clinical domain	Short-listed by	Criteria	Prioritisation category	Outcome
Adult critical care	▪ Cost ▪ Stakeholder priority	1.1 Serious consequences to the patient	Evidence – Total DALYs 2011	X
			Evidence – Percentage of total DALYs 2011	X
			Score	**0.75***
		1.3 High cost to health system	Evidence – NHCDC hospital cost	$2.4 billion
			Evidence – Percentage of total cost from NCCH	7.11%
			Score	**1**
		2.2 Clinician support	Evidence – Leadership group	Established leadership group – ANZICS CORE includes Adult Patient Database
			Evidence – Current clinical quality registries	ANZICS CORE registries
			Score	**1**
			Total score	**2.75**

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* Difficult to assess as contains a number of conditions. Estimated at 2–3%.

Clinical domain	Short-listed by	Criteria	Prioritisation category	Outcome
High burden cancers	▪ Cost ▪ Burden of disease ▪ Stakeholder priority	1.1 Serious consequences to the patient	Evidence – Total DALYs 2011	471,422
			Evidence – Percentage of total DALYs 2011	10.49%
			Score	1
		1.3 High cost to health system	Evidence – NHCDC hospital cost	$2.52 billion
			Evidence – Percentage of total cost from NCCH	7.47%
			Score	1
		2.2 Clinician support	Evidence – Leadership group	▪ Key agencies support the development of clinical quality registries ▪ National registry for prostate cancer ▪ Established leadership groups in some jurisdictions and for some specific cancer types
			Evidence – Current clinical quality registries	▪ Australian Association of Cancer Registries Existing audit – Binational Colorectal Cancer Audit ▪ ABDR ▪ Breast Surgeons of Australia and New Zealand Quality Audit ▪ PCOR-ANZ ▪ Cutaneous Lymphoma Registry under development ▪ Victorian Lung Cancer Registry
			Score	0.75
			Total score	**2.75**

Clinical domain	Short-listed by	Criteria	Prioritisation category	Outcome
Stroke	▪ Cost ▪ Burden of disease ▪ Stakeholder priority	**1.1 Serious consequences to the patient**	Evidence – Total DALYs 2011	136,771
			Evidence – Percentage of total DALYs 2011	3.00%
			Score	**1**
		1.3 High cost to health system	Evidence – NHCDC hospital cost	$0.39 billion
			Evidence – Percentage of total cost from NCCH	1.16%
			Score	**0.5**
		2.2 Clinician support	Evidence – Leadership group	Established leadership group (Australian Stroke Clinical Registry)
			Evidence – Current clinical quality registries	▪ Australian Stroke Clinical Registry ▪ Australian Thrombolysis Registry
			Score	**1**
			Total score	**2.5**

Clinical domain	Short-listed by	Criteria	Prioritisation category	Outcome
Renal disease	▪ Cost ▪ Stakeholder priority	**1.1 Serious consequences to the patient**	Evidence – Total DALYs 2011	56,236
			Evidence – Percentage of total DALYs 2011	1.25%
			Score	**0.5**
		1.3 High cost to health system	Evidence – NHCDC hospital cost	$2.19 billion
			Evidence – Percentage of total cost from NCCH	6.49%
			Score	**1**
		2.2 Clinician support	Evidence – Leadership group	Established leadership group (ANZDATA)
			Evidence – Current clinical quality registries	ANZDATA
			Score	**1**
			Total score	**2.5**

Clinical domain	Short-listed by	Criteria	Prioritisation category	Outcome
Neonatal critical care	▪ Cost	1.1 Serious consequences to the patient	Evidence – Total DALYs 2011	102,773
			Evidence – Percentage of total DALYs 2011	2.27%
			Score	**0.75**
		1.3 High cost to health system	Evidence – NHCDC hospital cost	$0.43 billion
			Evidence – Percentage of total cost from NCCH	1.27%
			Score	**0.5**
		2.2 Clinician support	Evidence – Leadership group	Established leadership group – ANZICS CORE includes Paediatric Intensive Care Registry (existing national registry with substantial patient capture)
			Evidence – Current clinical quality registries	ANZICS CORE registries
			Score	**1**
			Total score	**2.25**

Clinical domain	Short-listed by	Criteria	Prioritisation category	Outcome
Mental health	▪ Cost ▪ Burden of disease ▪ Stakeholder priority	**1.1 Serious consequences to the patient**	Evidence – Total DALYs 2011	341,271
			Evidence – Percentage of total DALYs 2011	7.55%
			Score	**1**
		1.3 High cost to health system	Evidence – NHCDC hospital cost	$1.6 billion
			Evidence – Percentage of total cost from NCCH	4.74%
			Score	**1**
		2.2 Clinician support	Evidence – Leadership group	Clinician advocacy – identified as a high priority in stakeholder survey
			Evidence – Current clinical quality registries	No existing registry
			Score	**0.25**
			Total score	**2.25**

Clinical domain	Short-listed by	Criteria	Prioritisation category	Outcome
Maternity	▪ Cost ▪ Stakeholder priority	**1.1 Serious consequences to the patient**	Evidence – Total DALYs 2011	23,083
			Evidence – Percentage of total DALYs 2011	0.51%
			Score	**0**
		1.3 High cost to health system	Evidence – NHCDC hospital cost	$2.1 billion
			Evidence – Percentage of total cost from NCCH	6.22%
			Score	**1**
		2.2 Clinician support	Evidence – Leadership group	Existing jurisdiction-based data collections, no national clinical quality registries
			Evidence – Current clinical quality registries	▪ Australian Maternity Obstetric Surveillance System ▪ Maternity Care Indicators data collection
			Score	**0.75**
			Total score	**1.75**

Final list of priority clinical domains

Clinical domain	Short-listed by	Criteria	Prioritisation category	Outcome
Dementia	▪ Burden of disease ▪ Stakeholder priority	1.1 Serious consequences to the patient	Evidence – Total DALYs 2011	151,308
			Evidence – Percentage of total DALYs 2011	3.40%
			Score	**1**
		1.3 High cost to health system	Evidence – NHCDC hospital cost	$0.0953 billion*
			Evidence – Percentage of total cost from NCCH	0.28%
			Score	**0**
		2.2 Clinician support	Evidence – Leadership group	Dementia collaborative research centres is conducting a scoping project for the National Dementia Register in Australia
			Evidence – Current clinical quality registries	No current registry
			Score	**0.25**
			Total score	**1.25**

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* Estimate to be viewed with caution – high non-acute costs for this condition.

Clinical domain	Short-listed by	Criteria	Prioritisation category	Outcome
Major burns	▪ Cost ▪ Stakeholder priority	1.1 Serious consequences to the patient	Evidence – Total DALYs 2011	7,768
			Evidence – Percentage of total DALYs 2011	0.17%
			Score	**0**
		1.3 High cost to health system	Evidence – NHCDC hospital cost	$0.11 billion
			Evidence – Percentage of total cost from NCCH	0.33%
			Score	**0**
		2.2 Clinician support	Evidence – Leadership group	Established leadership group and existing national registry with incomplete patient capture (Burns Registry of Australia and New Zealand)
			Evidence – Current clinical quality registries	Burns Registry of Australia and New Zealand
			Score	**1**
			Total score	**1**

Final list of priority clinical domains

Clinical domain	Short-listed by	Criteria	Prioritisation category	Outcome
Diabetes	▪ Cost ▪ Burden of disease ▪ Stakeholder priority	1.1 Serious consequences to the patient	Evidence – Total DALYs 2011	101,653
			Evidence – % of total DALYs 2011	2.30%
			Score	**0.75**
		1.3 High cost to health system	Evidence – NHCDC hospital cost	$0.19 billion*
			Evidence – % of total cost from NCCH	0.56%
			Score	**0**
		2.2 Clinician support	Evidence – Leadership group	Clinician advocacy – identified as a high priority in stakeholder survey
			Evidence – Current clinical quality registries	▪ ANDA is a research audit that is conducted annually ▪ No current registry
			Score	**0.25**
			Total score	**1**

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* AIHW 2016. Australian Burden of Disease Study: Impact and causes of illness and death in Australia 2011. Australian Burden of Disease Study series no. 3. BOD 4. Canberra: AIHW.

Attachments

Attachment 1: Elements of the *Framework for Australian clinical quality registries*

The *Framework for Australian clinical quality registries* comprises five key elements, summarised in points 1 to 5 below:

1. Strategic principles

Strategic principles for clinical quality registries were endorsed by Health Ministers in 2010. The Strategic principles provide a national approach to development of clinical quality registries, and are detailed in Section 2 of the *Framework for Australian clinical quality registries*.

2. National health information arrangements

National health information arrangements for best practice governance and custodianship of clinical quality registry data were developed by a working group of the NHIPPC. Those arrangements were endorsed by NHIPPC (15 November 2012) and by the Commission Board (29 November 2012). The elements of National health information arrangements are detailed in Section 3 of the *Framework for Australian clinical quality registries* and summarised below.

National health information arrangements for clinical quality registries:

- Specify data custodianship requirements that are incumbent on organisations and staff participating in activity under national arrangements
- Recognise existing health information arrangements incorporated in existing legislation, regulation and policies
- Will be documented for specific domains in schedules in the National Health Information Agreement.

National health information arrangements for clinical quality registries provide assurance to all participating stakeholders, including jurisdictions, health services, private hospital groups, clinicians and patients, that requirements regarding registry data custodianship, security and reporting are specified in official arrangements.

3. National infrastructure model

The literature suggests significant cost avoidance associated with improved patient outcomes where clinical quality registries operate and report under national arrangements. Efficiencies are realised by developing a single national clinical quality registry per clinical domain, rather than separate databases in multiple hospitals and jurisdictions.

The Commission has developed a national infrastructure model for the efficient design, build, development, operation and security of clinical quality registries under national arrangements. The infrastructure model was developed in collaboration with jurisdictions, the NEHTA and registry experts. The national model features a small number of expert registry centres (or clusters), with each centre operating multiple clinical quality registries in partnership with jurisdictions, healthcare providers, funders and peak clinical organisations. Interoperability with existing clinical information systems is optimised through the model, providing efficiencies in data collection. Security of data is assured through the application of robust access and reporting controls. Further detail on the elements and benefits of the national infrastructure model is provided in Section 4 of the *Framework for Australian clinical quality registries*.

4. Principles, guidelines and standards

The Commission and registry experts have developed principles, guidelines and standards for best-practice design, build, development, operation and security of clinical quality registries.

The *Operating principles for clinical quality registries* (*Framework for Australian clinical quality registries*, Section 5.1), endorsed by Health Ministers in November 2010, specify best clinical quality registry practice.

Technical guidelines and standards (*Framework for Australian clinical quality registries*, Section 5.2) have been prepared to inform standardised development of national registry infrastructure, and promote best practice registry design, development, operation and security. They include a requirements specification, infrastructure and technical standards, a logical architecture and design and a security compliance guideline.

The security compliance guideline is based on the National eHealth Security and Access framework. It provides clear guidance to those operating clinical quality registries, and can be used to assure stakeholders that registry data is managed securely.

5. Prioritisation criteria

The Commission has developed prioritisation criteria for clinical quality registries (*Framework for Australian clinical quality registries*, Section 6). The prioritisation criteria support the strategic principles for a national approach to the development of clinical quality registries.

Prioritisation criteria are grouped according to two principal considerations for prioritisation; clinical need and the feasibility of establishing the clinical quality registry for a given domain.*

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* Australian Commission on Safety and Quality in Health Care, **Framework for Australian clinical quality registries**. Sydney. ACSQHC, March 2014.

Attachment 2: Summary of stakeholder survey respondents and invitees

Organisations that responded to the stakeholder survey

- Australian Capital Territory Health
- Australian Professional Society on Alcohol and other Drugs
- Australasian College of Dermatology
- Australasian Sleep Association
- Australian and New Zealand Bone and Mineral Society
- Australian and New Zealand Burns Association
- Australian Association for Adolescent Health
- Australian College of Nursing
- Australian Society of Plastic Surgeons
- Breast Surgeons of Australia and New Zealand
- Colorectal Surgical Society of Australia and New Zealand
- Consumer (not specified)
- Department of Health and Human Services Tasmania
- Endocrine Society of Australia
- Epworth Health Care
- Monash University
- Neurosurgical Society of Australasia
- New South Wales Agency for Clinical Innovation
- Northern Territory Health
- Queensland Department of Health
- Queensland Medical Laboratory
- Royal Australian and New Zealand College of Obstetrics and Gynaecology
- Royal Australasian College of Surgeons
- Royal Australian and New Zealand College of Psychiatrists
- Royal College of Pathologists of Australasia
- South Australia Health
- South Australian Prostate Cancer Clinical Outcome Collaborative
- Sonic Healthcare
- South Australian Health and Medical Research Institute
- The Australian Society of Otolaryngology Head and Neck Surgery
- University of South Australia
- Western Australian Department of Health.

Organisations that were invited to participate

Consumer organisations

- Consumer Health Forum of Australia
- Chronic Illness Alliance
- Australian Institute for Patient and Family Centred Care.

Professional organisations

- Australasian College for Emergency Medicine
- Australasian College of Rural and Remote Medicine
- Australasian College of Dermatologists
- Australasian Professional Society on Alcohol and Other Drugs
- Australasian Sleep Association
- Australian Society of Cataract and Refractive Surgeons
- Australasian Society for Infectious Diseases
- Australasian Trauma Society
- Australian and New Zealand Association of Neurologists
- Australian and New Zealand Association of Paediatric Surgeons
- Australian and New Zealand Bone and Mineral Society
- Australian and New Zealand Burns Association
- Australian and New Zealand Child Neurology Society
- Australian and New Zealand College of Anaesthetists
- Australian and New Zealand Society for Geriatric Medicine
- Australian and New Zealand Society for Vascular Surgery
- Australian and New Zealand Society of Cardiac and Thoracic Surgeons
- Australian and New Zealand Society of Nephrology
- Australian College of Midwives
- Australian College of Nursing
- Australian Diabetes Society
- Australian Orthopaedic Association
- Australian Paediatric Orthopaedic Society
- Australian Paediatric Society
- Australian Private Hospitals Association
- Australian Rheumatology Association

- Australasian Society of Clinical Immunology and Allergy
- Australian Society of Orthopaedic Surgeons
- Australian Society of Otolaryngology Head and Neck Surgery
- Australian Society of Plastic Surgeons
- Breast Surgeons of Australia and New Zealand
- Cancer Council Australia
- Cardiac Society of Australia and New Zealand
- College for Intensive Care Medicine of Australia and New Zealand
- Colorectal Surgical Society of Australia and New Zealand
- Cosmetic Physicians College of Australasia
- Endocrine Society of Australia
- Gastroenterological Society of Australia
- Haematology Society of Australia and New Zealand
- Human Genetics Society of Australasia
- Internal Medicine Society of Australia and New Zealand
- Medical Oncology Group of Australia
- Neurosurgical Society of Australia and New Zealand
- Obesity Surgery Society of Australia and New Zealand
- Royal Australasian College of Dental Surgeons
- Royal Australasian College of Medical Administrators
- Royal Australasian College of Physicians
- Royal Australasian College of Surgeons
- Royal Australian and New Zealand College of Obstetricians and Gynaecologists
- Royal Australian and New Zealand College of Ophthalmologists
- Royal Australian and New Zealand College of Psychiatrists
- Royal Australian and New Zealand College of Radiologists
- Royal Australian College of General Practitioners
- Royal College of Pathologists of Australasia
- Spine Society of Australia
- Stroke Society of Australasia
- The Australian Association for Adolescent Health
- The Urological Society of Australia and New Zealand
- Thoracic Society of Australia and New Zealand
- Transplantation Society of Australia and New Zealand
- Clinical Oncological Society of Australia.

Jurisdictions

- All Australian State and Territory Departments of Health
- Australian Government Department of Health and Ageing.

Attachment 3: Analysis of potential conditions, diseases and interventions identified through short-listing

Table A3.1: Rationale for inclusion in short-list

Description	Short-listed by	Whether included or not and rationale
Critical care (excluding neonatal)	Cost	Included, considered under adult critical care
Knee replacement, revision	Cost	Included, considered under musculoskeletal disorders
Hip replacement, revision	Cost	Included, considered under musculoskeletal disorders
Vaginal delivery	Cost	Included, considered under maternity
Caesarean delivery	Cost	Included, considered under maternity
Spinal fusion	Cost	Included, considered under musculoskeletal disorders
Haemodialysis	Cost	Included, considered under renal disease
Respiratory infection / inflammatory	Cost	Not considered further, threshold criteria not met: ▪ Criteria 1.2 / 1.3 DRG is heterogeneous for casemix, whereas guidelines are disease specific and variation from the sequence of care is difficult to address ▪ Criteria 2.1.1 / 2.4.1 / 2.4.2. Relevant clinical population unable to be captured and information requirements unlikely to be met as diverse and dispersed group of treating clinicians and organisations ▪ While respiratory infection/inflammation is a common complaint and contributes to the cost of the health system it is not well suited to clinical quality registry development. Patients are treated by large numbers of general practitioners, general physicians, respiratory physicians and geriatricians in community and hospital settings. Collection of the entire population would not be possible and there is no readily identifiable sequence of care covering all conditions. ▪ An Australian Bronchiectasis Registry* has been developed however this is a research registry rather than a clinical quality registry. The main aims of this registry are to identify and collect health information from patients with non-Cystic Fibrosis (non-CF) Bronchiectasis for doctors to research the causes and to improve treatments.
Schizophrenia disorder	Cost	Included, considered under mental health

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* lungfoundation.com.au/health-professionals/bronchiectasis-registry.

Description	Short-listed by	Whether included or not and rationale
Gastroscopy	Cost	Not considered further, threshold criteria not met: ▪ Criteria 2.1.1 / 2.4.1 / 2.4.2. Relevant clinical population unable to be captured and information requirements unlikely to be met as diverse and dispersed group of treating clinicians and organisations. ▪ Gastroscopies are performed by general practitioners, general physicians, gastroenterologists and surgeons. These disperse professional links would limit the ability to collect data from the entire population. There is also no coherent professional group to feed outcomes from the registry back to in order to improve care. Other methods of quality improvement may be more appropriate such as audit. ▪ The Australia and New Zealand Gastro Oesophageal Surgery Association Audit collects clinical and pathological data of patients undergoing resection for upper gastrointestinal cancer and gastrointestinal stromal tumour.
Major small and large bowel procedure	Cost	Included, considered under high burden cancers
Circulatory disorder +/– acute myocardial infarction (with invasive procedure)	Cost	Included, considered under ischaemic heart disease
Pacemaker related	Cost	Included, considered under ischaemic heart disease
Chemotherapy	Cost	Included, considered under high burden cancers
Critical care costs only for neonatal admits	Cost	Included, considered under neonatal critical care
Major affective disorder	Cost	Included, considered under mental health
Cardiac valve procedure	Cost	Included, considered under ischaemic heart disease

Description	Short-listed by	Whether included or not and rationale
COAD (COPD)	▪ Cost ▪ Burden of disease	Not considered further, threshold criteria not met: ▪ Criteria 2.1.1 / 2.4.1 / 2.4.2. Relevant clinical population unable to be captured and information requirements unlikely to be met as diverse and dispersed group of treating clinicians and organisations. ▪ While COAD/COPD is a common complaint it is not well suited to registry development. Patients are treated by large numbers of general practitioners, general physicians, respiratory physicians and geriatricians in community and hospital settings. These disperse professional links, along with the long disease trajectory, limit the ability to collect data from the entire population and use a registry to make improvements in care. There is currently no coherent professional group to feed outcomes from the registry back to in order to improve care. ▪ No registry found.
AICD related	Cost	Included, considered under ischaemic heart disease
Other hip and femur procedures	Cost	Included, considered under musculoskeletal disorders
TIA, stroke	Cost	Included, considered under stroke
Coronary bypass	Cost	Included, considered under ischaemic heart disease
Heart failure	Cost	Included, considered under ischaemic heart disease
Cranial procedures	Cost	Not considered further, threshold criteria not met: ▪ Criteria 1.2 / 1.3. DRG is heterogeneous for casemix, whereas guidelines are disease specific. No Australian guideline. ▪ The DRG is too diverse to meaningfully be grouped under a single domain. It covers procedures for trauma, malignancy, bleeding, hydrocephalus and other intra-cranial abnormalities. There is no evidence-based sequence of care to cover these diverse conditions, and therefore meaningful performance indicators cannot be developed. ▪ Some cranial procedures would be considered under cancer and trauma domains.
Hernia procedures	Cost	Not considered further, threshold criteria not met: ▪ Criteria 1.2 / 1.3. DRG is heterogeneous for casemix. No Australian guideline. ▪ The DRG is too diverse to be meaningful in a clinical quality registry context. There is no evidence-based sequence of care to cover these diverse conditions, and therefore meaningful performance indicators cannot be developed. ▪ International registries on hernia focus on specific types of hernia, for example the Swedish Hernia Register is a clinical quality registry that contains data on all groin hernia repairs performed in patients aged 15 years or older.*

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* Swedish Hernia Register.

Description	Short-listed by	Whether included or not and rationale
Humerus, other lower limb procedures	Cost	Included, considered under musculoskeletal disorders
Laparoscopic cholecystectomy	Cost	Not considered further, threshold criteria not met: ▪ Criteria 1.2 / 1.3. Changing sequence of care. Unwarranted variation from the sequence of care not evident. ▪ Laparoscopic cholecystectomy is a common procedure for treatment of pancreatitis and gallstones. There is no evidence of variation from the sequence of care for this procedure. There are changing sequences of care for the treatment of gallstones and pancreatitis including the increased use of this procedure. ▪ Sweden has a National Quality Registry for Gallstone Surgery and Endoscopic Retrograde Cholangiopancreatography* and further development of registries in this area could be considered in the future.
Unstable angina, chest pain	Cost	Not considered further, threshold criteria not met: ▪ Criteria 2.1.1 / 2.4.1 / 2.4.2. Relevant clinical population unable to be captured and information requirements unlikely to be met as diverse and dispersed group of treating clinicians and organisations. ▪ Unstable angina is a common complaint. Patients are treated by large numbers of general practitioners, general physicians, geriatricians and cardiologists in community and hospital settings. These disperse professional links would limit the ability to collect data from the entire population. There is also no coherent professional group to feed outcomes from the registry back to in order to improve care. This condition may be included in ischaemic heart disease in the future. ▪ No registry found.
Lymphoma, acute and non-acute leukaemia	Cost	Included, considered under high burden cancers
Cellulitis	Cost	▪ Not considered further, threshold criteria not met: ▪ Criteria 2.1.1 / 2.4.1 / 2.4.2. Relevant clinical population unable to be captured and information requirements unlikely to be met as diverse and dispersed group of treating clinicians and organisations. ▪ Cellulitis is a common complaint. Patients are treated by large numbers of general practitioners, general physicians, general surgeons, geriatricians and infectious diseases specialists in community and hospital settings. These disperse professional links would limit the ability to collect data from the entire population. There is also no coherent professional group to feed outcomes from the registry back to in order to improve care. ▪ No registry found.

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* National Quality Registry for Gallstone Surgery and Endoscopic Retrograde Cholangiopancreatography.

Description	Short-listed by	Whether included or not and rationale
Other digestive system disorders	Cost	Not considered further, threshold criteria not met: ▪ Criteria 1.2 / 1.3 / 2.1.1 / 2.4.1 / 2.4.2. DRG is heterogeneous for casemix, whereas guidelines are disease specific. No Australian guideline. Information requirements unlikely to be met as diverse and dispersed group of treating clinicians and organisations. ▪ The DRG is too diverse to be meaningful in a clinical quality registry context. Patients are treated by large numbers of general practitioners, gastroenterologists, general physicians and surgeons in community and hospital settings. There is no evidence-based sequence of care to cover these diverse conditions, and therefore meaningful performance indicators cannot be developed.
Kidney and urinary tract infection	Cost	Not considered further, threshold criteria not met: ▪ Criteria 2.1.1 / 2.4.1 / 2.4.2. Relevant clinical population unable to be captured and information requirements unlikely to be met as diverse and dispersed group of treating clinicians and organisations. ▪ Kidney and urinary tract infection is a common complaint. Patients are treated by large numbers of general practitioners, general physicians, geriatricians, renal physicians and infectious diseases specialists in community and hospital settings. These disperse professional links would limit the ability to collect data from the entire population. There is also no coherent professional group to feed outcomes from the registry back to in order to improve care. ▪ No registry found.
Colonoscopy	Cost	Not considered further, threshold criteria not met: ▪ Criteria 2.1.1 / 2.4.1 / 2.4.2. Relevant clinical population unable to be captured and information requirements unlikely to be met as diverse and dispersed group of treating clinicians and organisations. ▪ Colonoscopies are performed by general practitioners, general physicians, gastroenterologists, general surgeons and colorectal surgeons. These disperse professional links would limit the ability to collect data from the entire population. There is also no coherent professional group to feed outcomes from the registry back to in order to improve care. Quality, including appropriateness, of colonoscopy is being addressed through other projects. ▪ The appropriate and safe use of colonoscopies would be considered under disease specific registries such as bowel cancer.
Breast condition procedure, reconstruction, breast malignancy	Cost	Included, considered under high burden cancers
Lens procedures	Cost	Not considered further, threshold criteria not met: ▪ Criterion 1.3. Unwarranted variation from the sequence of care not evident. ▪ Lens procedures are common procedures with a high cost to the health system. There is no evidence of variation from the sequence of care for this procedure or harm to patients. Where new procedures are developed there may be a need to undertake post-market surveillance.

Description	Short-listed by	Whether included or not and rationale
Rectal resection	Cost	Included, considered under colorectal cancer
Appendicectomy	Cost	Not considered further, threshold criteria not met: ▪ Criterion 1.2. Changing sequence of care ▪ Recent changes in the treatment of appendicitis, such as the use of antibiotics prior to invasive interventions, have led to a changing sequence of care.
Major vascular procedure	Cost	Not considered further, threshold criteria not met: ▪ While treatment of peripheral vascular disease has a high cost to the health system it is an outcome of multiple disease processes, including smoking and diabetes. The casemix of patients vary and a large proportion is likely to have a number of comorbidities making development of indicators and risk adjustment difficult. A sub-population of patients who receive major vascular procedures may be considered under registries within the diabetes domain.
Other joint replacement	Cost	Included, considered under musculoskeletal disorders
Prostate cancer – major male pelvic procedure, surgical only	Cost	Included, considered under high burden cancers
Multiple or significant trauma	Cost	Included, considered under major trauma
Respiratory cancer – medical only	Cost	Included, considered under high burden cancers
Major burns	Cost	Included, considered under major burns
Nervous system malignancy – medical only	Cost	Included, considered under high burden cancers and hydrocephalus
Coronary heart disease	Burden of disease	Included, considered under ischaemic heart disease
Other musculoskeletal	Burden of disease	Included, considered under musculoskeletal disorders
Back pain and problems	Burden of disease	Included, considered under musculoskeletal disorders
COPD	Burden of disease	Included, considered above
Lung cancer	Burden of disease	Included, considered under high burden cancers
Dementia	Burden of disease	Included, considered under dementia

Description	Short-listed by	Whether included or not and rationale
Anxiety disorders	Burden of disease	Included, considered under mental health
Stroke	Burden of disease	Included, considered under stroke
Depressive disorders	Burden of disease	Included, considered under mental health
Suicide and self-inflicted injuries	Burden of disease	Not considered further, threshold criteria not met: ▪ Criteria 2.1.1 / 2.4.1 / 2.4.2. Relevant clinical population unable to be captured and information requirements unable to be met as diverse and dispersed group of treating clinicians and organisations. ▪ Patients are treated by large numbers of general practitioners, psychiatrists, psychologists and emergency physicians in community and hospital settings. These disperse professional links would limit the ability to collect data from the entire population. There is also no coherent professional group to feed outcomes from the registry back to in order to improve care. Additionally suicide cases are subject to Coronial inquiry and a registry may be difficult to operate effectively in that context. Aspects of suicide as self-harm would be considered in registries for major psychiatric disorders.
Asthma	Burden of disease	Not considered further, threshold criteria not met: ▪ Criteria 2.1.1 / 2.4.1 / 2.4.2. Relevant clinical population unable to be captured and information requirements unlikely to be met as diverse and dispersed group of treating clinicians and organisations. ▪ Asthma is a common complaint. Patients are treated by large numbers of general practitioners, general physicians and respiratory physicians in community and hospital settings. These disperse professional links would limit the ability to collect data from the entire population. There is also no coherent professional group to feed outcomes from the registry back to in order to improve care. ▪ No registry found.
Diabetes	Burden of disease	Included, considered under diabetes
Bowel cancer	Burden of disease	Included, considered under high burden cancers
Osteoarthritis and Rheumatoid arthritis	Burden of disease	Included, considered under musculoskeletal disorders
Upper respiratory conditions	Burden of disease	Not considered further, threshold criteria not met: ▪ Criteria 2.1.1 / 2.4.1 / 2.4.2. Relevant clinical population unable to be captured and information requirements unlikely to be met as diverse and dispersed group of treating clinicians and organisations. ▪ Upper respiratory conditions are common complaints. Patients are treated by large numbers of general practitioners, general physicians and respiratory physicians in community and hospital settings. These disperse professional links would limit the ability to collect data from the entire population. There is also no coherent professional group to feed outcomes from the registry back to in order to improve care.

Description	Short-listed by	Whether included or not and rationale
Breast cancer	Burden of disease	Included, considered under high burden cancers
Hearing loss	Burden of disease	Not considered further, threshold criteria not met: ▪ Criteria 2.1.1 / 2.4.1 / 2.4.2. Relevant clinical population unable to be captured and information requirements unable to be met as diverse and dispersed group of treating clinicians and organisations. ▪ Hearing loss is a common complaint. Patients are treated by large numbers of health professionals including audiologists and ear, nose and throat surgeons, mainly in community settings. These disperse professional links would limit the ability to collect data from the entire population. There is also no coherent professional group to feed outcomes from the registry back to in order to improve care. ▪ No registry found.
Alcohol use disorders	Burden of disease	Not considered further, threshold criteria not met: ▪ Criterion 1.2. Sequence of care is variable ▪ Criteria 2.1.1 / 2.4.1 / 2.4.2 / 2.3. Relevant clinical population unable to be captured and governance and information requirements unlikely to be met as diverse and dispersed group of treating clinicians and organisations. ▪ Alcohol use disorder is a common complaint and has a major impact on burden of disease in Australia; however, it is not well suited to clinical quality registry data collection. Patients are treated by large numbers of general practitioners, general physicians, drug and alcohol physicians, counsellors and allied health professionals in community and hospital settings. These disperse professional links would limit the ability to collect data from the entire population. There is also no coherent professional group to feed outcomes from the registry back to in order to improve care. While there are guidelines for the treatment of alcohol problems, within these, there are multiple options for treatment and patient choice has a large impact on the sequence of care. This variation in the sequence of care limits the ability for a registry to collect longitudinal data and generate risk-adjusted reports on the appropriateness and effectiveness of care. ▪ No registry found.
Falls	Burden of disease	Not considered further, threshold criteria not met: ▪ Criteria 2.1.1 / 2.1.2 / 2.4.1 / 2.4.2. The clinical condition or event is unable to be systematically recognised. Relevant clinical population unable to be captured and information requirements unlikely to be met as diverse and dispersed group of treating clinicians and organisations. ▪ Falls occur commonly in hospital and community settings in the older patient cohort. The causes and harms from falls are diverse and treatment varies. Patients who are harmed by falls are treated by large numbers of general practitioners, general physicians, geriatricians, general surgeons, orthopaedic surgeons and other healthcare professionals. The harm from falls, such as hip fracture, would be considered under major orthopaedic procedures and some patients who received harm from falls would be considered under a trauma registry. Some falls would be considered under the trauma domain. ▪ No registry found specifically for falls.

Description	Short-listed by	Whether included or not and rationale
Pancreatectomy/ oesophagectomy	▪ Stakeholder priority 1 ▪ Stakeholder priority 2 ▪ Stakeholder priority 3	Not considered further, threshold criteria not met: ▪ Criterion 2.4.3. Clinically meaningful performance indicators cannot be defined. ▪ The rationale for this proposed clinical quality registry is that of high complexity surgery being undertaken at low volumes in health services settings where there is insufficient procedural volume to achieve quality. It is a well-documented problem that is amenable to a public policy approach to improve service concentration, rather than an effort to demonstrate poor quality through a clinical quality registry. Some of these procedures would be considered under high burden cancers.
Ischaemic heart disease	Stakeholder priority 1	Included, considered under ischaemic heart disease
Mesh in gynaecological surgery	Stakeholder priority 1	Not considered further, threshold criteria not met: ▪ Criteria 1.2 / 1.3. Sequence of care not clearly defined. ▪ While use of mesh in gynaecological surgery has been raised as a concern, it may be more suitable for a post-market surveillance or epidemiological registry with a goal of determining the risks and benefits of the intervention.
Colorectal cancer	Stakeholder priority 1	Included, considered under high burden cancer
Major burns	Stakeholder priority 1	Included, considered under major burns
Cancer	Stakeholder priority 1	Included, considered under high burden cancers
Cancer surgery	Stakeholder priority 1	Included, considered under high burden cancers
Surgical mortality	Stakeholder priority 1	Not considered further, threshold criteria not met: ▪ Criterion 2.4.1. Does not include an entire population with a chronic condition or disease or who have undergone a common acute event (intervention). ▪ The Australian Audit of Surgical Mortality is an audit rather than a registry. It is understood to be highly effective, however it does not meet the requirements of a clinical quality registry as it offers one-off case review and improvement opportunities rather than continuous benchmarking of performance in relation to care in a specific setting or for a specific clinical condition. Some specific surgical procedures and diagnoses have been assessed individually.

Description	Short-listed by	Whether included or not and rationale
Obstructive sleep apnoea	Stakeholder priority 1	Not considered further, threshold criteria not met: - Criteria 2.1.1 / 2.4.1 / 2.4.2. Relevant clinical population unable to be captured and information requirements unable to be met as diverse and dispersed group of treating clinicians and organisations. - Obstructive sleep apnoea is a common complaint. Patients are treated by large numbers of general practitioners, general physicians, geriatricians and respiratory physicians in community and hospital settings. The professional or organisational links that would enable a functional clinical quality registry (particularly for registry outcomes to be acted on) are not evident. - No registry found.
Dementia	Stakeholder priority 1	Included, considered under dementia
Spinal surgery outcomes	- Stakeholder priority 1 - Stakeholder priority 2	Included, considered under musculoskeletal disorders
Fractures	Stakeholder priority 1	Not considered further, threshold criteria not met: - Criteria 2.1.1 / 2.4.1 / 2.4.2. Relevant clinical population unable to be captured and information requirements unable to be met as diverse and dispersed group of treating clinicians and organisations. - This proposed clinical domain is too diverse to be meaningful in a clinical quality registry context. It includes a number of different sequences of care. Patients are cared for by a range of general practitioners, general surgeons, emergency physicians and orthopaedic surgeons. The professional or organisational links that would enable a functional clinical quality registry (particularly for registry outcomes to be acted on) are not evident. Some fractures would be considered under musculoskeletal disorders.
Diabetes	Stakeholder priority 1	Included, considered under diabetes
Transition care	Stakeholder priority 1	Not considered further, threshold criteria not met: - Criteria 2.1.1 / 2.1.2 / 2.4.1 / 2.4.2. Relevant clinical population unable to be captured and information requirements unable to be met as the clinical condition or event is not always recognisable and there is a diverse and dispersed group of treating clinicians and organisations. - Transition of adolescents with chronic health conditions from paediatric to adult hospitals is a common requirement that, reportedly, is often not done well. Barriers include lack of protocols and lack of resources. There are large numbers of receiving hospitals and clinicians of different disciplines and specialties engaged in the transition process. The event is poorly defined and may not be uniformly recognisable.
Breast Cancer Surgery	Stakeholder priority 1	Included, considered under high burden cancers
Breast Implants	Stakeholder priority 1	Included, considered under high burden cancers

Description	Short-listed by	Whether included or not and rationale
Breast surgery	Stakeholder priority 2	Included, considered under high burden cancers
Disease-specific cancer registries	Stakeholder priority 1	Included, considered under high burden cancers
Indigenous ear disease	Stakeholder priority 1	Not considered further, threshold criteria not met: ▪ Criteria 2.1.1 / 2.4.1 / 2.4.2. Relevant clinical population unable to be captured and information requirements unable to be met as diverse and dispersed group of treating clinicians and organisations. ▪ Indigenous ear disease is a common complaint. Patients are treated by large numbers of general practitioners, paediatricians, public health specialists and other clinicians, mainly in community settings. These disperse professional links would limit the ability to collect data from the entire population. There is also no coherent professional group to feed outcomes from the registry back to in order to improve care. ▪ No registry found.
Mental Health – psychosis and schizophrenia, major affective disorders	Stakeholder priority 1	Included, considered under mental health
CSF shunt	Stakeholder priority 1	Not considered further, threshold criteria not met: ▪ Criteria 2.1.1 / 2.1.2 / 2.2 / 2.4.1. The information requirements required are difficult to establish. ▪ CSF shunts are used to treat a number of different conditions in a variety of clinical populations including trauma, malignancy, bleeding, hydrocephalus and other intra-cranial abnormalities. The casemix of patients vary and a large proportion is likely to have a number of comorbidities making development or indicators and risk adjustment difficult. Use of shunts may be considered under registries within the high burden cancer domain.
Dialysis, transplantation, organ donation	Stakeholder priority 2	Included, considered under renal disease
Maternity	Stakeholder priority 2	Included, considered under maternity
Non-invasive ventilation	▪ Stakeholder priority 2 ▪ Stakeholder priority 3	Not considered further, threshold criteria not met: ▪ Criteria 2.1.1 / 2.4.1 / 2.4.2. Relevant clinical population unable to be captured and information requirements unable to be met as diverse and dispersed group of treating clinicians and organisations. ▪ Patients are treated by large numbers of general practitioners, general physicians, geriatricians and respiratory physicians in community and hospital settings. These disperse professional links would limit the ability to collect data from the entire population. There is also no coherent professional group to feed outcomes from the registry back to in order to improve care. ▪ No registry found.

Description	Short-listed by	Whether included or not and rationale
Surgery for joint pain (knee, shoulder, back)	Stakeholder priority 2	Included, considered under musculoskeletal disorders
Stroke	Stakeholder priority 2	Included, considered under stroke
Insomnia	▪ Stakeholder priority 2 ▪ Stakeholder priority 3	Not considered further, threshold criteria not met: ▪ Criteria 2.1.1 / 2.4.1 / 2.4.2 Relevant clinical population unable to be captured and information requirements unable to be met as diverse and dispersed group of treating clinicians and organisations. ▪ Insomnia is a common complaint. Patients are treated by large numbers of general practitioners, general physicians, respiratory physicians and other sleep specialists, mainly in community settings. These disperse professional links would limit the ability to collect data from the entire population. There is also no coherent professional group to feed outcomes from the registry back to in order to improve care. ▪ No registry found.
Osteoporotic hip fractures	Stakeholder priority 2	Included, considered under musculoskeletal disorders
Immunisation coverage	Stakeholder priority 2	Not considered further, threshold criteria not met: ▪ Criteria 1.1 / 1.2 / 1.3 / 1.4. Clinical relevance is not established. ▪ Immunisation is a simple procedure and there are few risks associated with a routine service. The purpose of a registry would not be to monitor and improve coverage, rather than the quality of the service per se. While that is an important public health goal, an immunisation registry is an epidemiological, rather than a clinical quality registry.
High cost interventional/ surgical procedures/ devices	Stakeholder priority 2	Included, considered under ischaemic heart disease
Rhinology, otology, head and neck surgery, specifically outcomes for tonsil, grommet and nasal septum surgery	▪ Stakeholder priority 2 ▪ Stakeholder priority 3	Not considered further, threshold criteria not met: ▪ Criteria 2.1.1 / 2.4.1 / 2.4.2. The proposed clinical domain is too broad to be meaningful. ▪ This proposed clinical domain is too diverse to be meaningful in a clinical quality registry context. It includes a number of different sequences of care. ▪ No registry found.
Cancer treatment	Stakeholder priority 3	Included, considered under high burden cancers
Joint replacement	Stakeholder priority 3	Included, considered under musculoskeletal disorders
Renal	Stakeholder priority 3	Included, considered under renal disease

Description	Short-listed by	Whether included or not and rationale
Antibiotic resistant bacterial infections	Stakeholder priority 3	Included, considered above
Depression	Stakeholder priority 3	Included, considered under mental health
Pregnancy outcomes	Stakeholder priority 3	Included, considered under maternity
Critical care	Stakeholder priority 3	Included, considered under adult critical care

A clinical domain of ‘AMD treated with new anti-vascular endothelial growth factor drugs’ was also proposed during consultation for this project but is not included in the short-list as it did not emerge from the stakeholder survey.

The population cost (reportedly $12 billion per year in Australia), the prevalence of AMD-related blindness (up to 40,000 new cases each year in Australia) and the availability of new, effective drugs were proposed as the rationale for an AMD clinical quality registry.

A clinical registry has already been established for AMD, the purpose of which is to:

- Track the risks and benefits of the new treatments for macular disease in the general population in Australia to determine how to use these treatments as safely and cost-effectively as possible
- Determine the most appropriate method of treatment for macular disease.

The proposed clinical domain of AMD has been excluded from further consideration because there is no evidence-based, well executed sequence of care that improves patient outcomes for the particular condition (Criterion 1.2). In fact, development of evidence-based clinical management guidelines is one of the anticipated outcomes of the registry. The registry is clearly a valuable and important endeavour, but it does not meet the development criteria for a clinical quality registry. Its purpose appears to be research and/or post-market drug surveillance.

Attachment 4: Analysis of evidence-based sequences of care and/or existing registries

Table A4.1: Evidence analysis

Diagnoses related group	Description	Guidelines and registries
A06AB	Tracheostomy with ventilation >95 hours with / without catastrophic complications	▪ DRG is intervention based, not diagnosis based, so very heterogeneous casemix ▪ Guideline: Not specific to DRG ▪ Australia has the ANZICS CORE registries (adult patient database, paediatric intensive care registry, critical care resources registry and Central Line Associated Blood Stream Infection registry). Note: Not all sites that ventilate patients contribute to the registries.
I04AB, I32ABC	Knee replacement, revision	▪ Guideline: Systematic review – Mak, J. C. S., Fransen, M., Jennings, M., March, L., Mittal, R. and Harris, I. A. (2014), Evidence-based review for patients undergoing elective hip and knee replacement. ANZ Journal of Surgery, 84: 17–24. ▪ Registry: Australian Orthopaedic Association. National Joint Replacement Registry collects comprehensive data for all knee replacements.
I03AB, I31AB	Hip replacement, revision	▪ Guideline: Systematic review – Mak, J. C. S., Fransen, M., Jennings, M., March, L., Mittal, R. and Harris, I. A. (2014), Evidence-based review for patients undergoing elective hip and knee replacement. ANZ Journal of Surgery, 84: 17–24. ▪ Registry: Australian Orthopaedic Association. National Joint Replacement Registry collects comprehensive data for all hip replacements.
O60ABC	Vaginal delivery	▪ Guideline: State Health Department guidelines for example – NSW Health. (2010). PD2010_045, Maternity–Towards Normal Birth in NSW. ▪ No Australian registry, however, national maternal data collection for all pregnancies through National Perinatal Data Collection.
O01ABC	Caesarean delivery	▪ Guideline: State Health Department guidelines, for example, NSW Health. (2014). Supporting women in the first birth after caesarean section. NICE (2011). Caesarean section, (CG132). ▪ No Australian registry, however, national maternal data collection for all pregnancies through National Perinatal Data Collection.
I06Z, I09AB	Spinal fusion	▪ No Australian guideline: Systematic review of seventeen aspects of lumbar spinal fusion management. Groff MW et al. J Neurosurg Spine. 2014 Jul; 21(1):1–139. ▪ Registry: Newly established as the Australian Spine Registry. Data does not appear to be available at this stage. ▪ Multiple spine registries exist internationally, including in Sweden, Europe, Canada, US and the UK. The British Spine Registry was set up by the British Association of Spinal Surgeons to monitor the outcomes of spinal procedures, collecting data to better understand procedures, techniques and a patient's experience and quality of life.

Diagnoses related group	Description	Guidelines and registries
L61Z	Haemodialysis	▪ Guideline: Kidney Health Australia – CARI guidelines ▪ Registry: ANZDATA collects comprehensive data.
U61AB	Schizophrenia disorder	▪ Guideline: No Australian guideline. NICE (2014) Psychosis and Schizophrenia in Adults – prevention and management (CG178). ▪ No Australian schizophrenia registry ▪ Internationally, the Management of Schizophrenia in Clinical Practice registry is a US disease-based schizophrenia registry. Other countries with schizophrenia registries include Malaysia, Latin America, the Netherlands, Denmark, Sweden.
G46ABC, G47ABC	Gastroscopy	▪ No Australian or international guideline ▪ No Australian registry ▪ In the US, the GIQuIC has an endoscopic quality registry of upper gastrointestinal endoscopy and related quality measures. GIQuIC is a quality benchmarking registry co-sponsored by the American College of Gastroenterology and the American Society for Gastrointestinal Endoscopy, to provide reliable and relevant measures of endoscopic quality. The UK Radiofrequency Ablation (RFA) registry captures data on RFA for Barrett's oesophagus from participating centres. Also registries in Malaysia and Sweden.
G02AB	Major small and large bowel procedure	▪ No Australian guideline ▪ Australian registries include the hereditary cancer registry, Australasian Colorectal Cancer Family Registry and Australasian Association of Cancer Registries ▪ Registries that collect data internationally include the Intestinal Transplant Registry and Short Bowel Syndrome Registry. Other countries have inflammatory bowel disease registries (US, UK).
F41AB, F42ABC	Circulatory disorder +/– acute myocardial infarction (with invasive procedure)	▪ Guideline: 2016 ACS guidelines being developed. Also 2011 addendum to the National Heart Foundation of Australia/Cardiac Society of Australia and New Zealand guidelines for the management of acute coronary syndromes (ACS) 2006. ▪ ACOR is a cardiac procedures registry to document and measure outcomes for patients undergoing cardiovascular procedures in Australia and New Zealand with the aim of improving cardiovascular outcomes for patients. Data are collected on a range of procedures including, coronary artery bypass grafting and valve surgery, Percutaneous coronary intervention, implantable cardioverter defibrillator and cardiac resynchronisation therapy device insertion. Not all sites that perform these procedures contribute to the registry. ▪ Australia also has an Australian and New Zealand Society for Vascular Surgery Australasian Vascular Audit, Australian Genetic Heart Disease Registry and Australian Cardiac Procedures Registry ▪ The US, UK and Europe operate clinical quality registries in cardiovascular disease. Sweden has the most extensive group of registries internationally. In the cardiovascular domain they have the following registries: heart failure, coronary angiography and angioplasty, heart surgery, cardiac intensive care, out-of-hospital cardiac arrest, congenital heart disease, adult congenital heart disease, secondary prevention in cardiac intensive care, catheter ablation and atrial fibrillation and anticoagulation.

Diagnoses related group	Description	Guidelines and registries
F12AB, F17AB, F18AB	Pacemaker related	▪ No Australian guideline. International guideline about device selection: Gillis AM, et al. HRS/ACCF expert consensus statement on pacemaker device and mode selection. Heart Rhythm. 2012 Aug;9(8):1344–65. ▪ ACOR is a cardiac procedures registry to document and measure outcomes for patients undergoing cardiovascular procedures in Australia and New Zealand with the aim of improving cardiovascular outcomes for patients. Data are collected on a range of procedures including implantable cardioverter defibrillator and cardiac resynchronisation therapy device insertion. Not all sites tha perform these procedures contribute to the registry. ▪ The US, UK and Europe operate clinical quality registries that include pacemakers.
P01Z – P67ABCD	Critical care costs only for neonatal admits	▪ No Australian guideline ▪ In Australia the national data collection for all births is maintained by the National Perinatal Statistics Unit in the National Perinatal Data Collection.
U63AB	Major affective disorder	▪ Guideline: Australian Society for bipolar and depressive disorders. **A consensus statement for safety monitoring guidelines of treatments for major depressive disorder** 2011. Provides guidance about monitoring treatment effects not treatment itself. NICE (2014) Bipolar Disorder – Assessment and Management (CG 184). ▪ No Australian registry ▪ The Danish Psychiatric Disorders Registry is most comprehensive registry and is used as a basis for assessing effectiveness of different therapy options and monitoring patient outcomes. Also, there are psychiatric registries in some US States and in South-East Asia (Malaysia).
F03AB, F04AB	Cardiac valve procedure	▪ No Australian guideline. International guideline: 2014 AHA/ACC guideline for the management of patients with valvular heart disease: a report of the American College of Cardiology/American Heart Association Task Force on Practice Guidelines. ▪ ACOR is a cardiac procedures registry to document and measure outcomes for patients undergoing cardiovascular procedures in Australia and New Zealand with the aim of improving cardiovascular outcomes for patients. Data are collected on a range of procedures including valve surgery. Not all sites that perform these procedures contribute to the registry. ▪ The US, UK and Europe operate clinical quality registries that include valvular procedures.
F01AB, F02Z	AICD related	▪ No Australian guideline. NICE (2014) Implantable defibrillators and cardiac resynchronisation therapy for arrhythmias and heart failure (TAG314) is guidance about patient and device selection, not a clinical pathway. ▪ ACOR is a cardiac procedures registry to document and measure outcomes for patients undergoing cardiovascular procedures in Australia and New Zealand with the aim of improving cardiovascular outcomes for patients. Data are collected on a range of procedures including AICDs. Not all sites that perform these procedures contribute to the registry. ▪ The US, UK and Europe operate clinical quality registries that include AICDs.

Diagnoses related group	Description	Guidelines and registries
I08AB	Other hip and femur procedures	▪ ANZHFR **Australian and New Zealand Guideline for Hip Fracture Care – Improving Outcomes in Hip Fracture Management of Adults** (2014) ▪ No comprehensive registries identified nationally or internationally for surgeries other than joint replacement (with the exception of spinal registries which collect surgical data on all spinal surgeries).
B69AB, B70ABCD	TIA, stroke	▪ The Australian Guideline: Stroke Foundation – Clinical guidelines. National Service Improvement Framework for Stroke 2010. ▪ The Australian Stroke Clinical Registry is a collaborative national effort to monitor, promote and improve the quality of acute stroke management. The registry collects data from participating hospitals across Australia. ▪ Multiple stroke registries exist internationally, including in the US, UK, multiple European sites, Malaysia and India.
F05AB, F06AB	Coronary bypass	▪ Guideline: 2016 ACS guidelines being developed. Also **2011 addendum to the National Heart Foundation of Australia/Cardiac Society of Australia and New Zealand guidelines for the management of acute coronary syndromes (ACS) 2006**. ▪ ACOR is a cardiac procedures registry to document and measure outcomes for patients undergoing cardiovascular procedures in Australia and New Zealand with the aim of improving cardiovascular outcomes for patients. Data are collected on coronary artery bypass grafting. Not all sites that perform these procedures contribute to the registry. ▪ The US, UK and Europe operate clinical quality registries that capture coronary bypass data.
H08AB	Laparoscopic cholecystectomy	▪ No Australian guideline. International guideline: NICE (2014) Gallstone disease: diagnosis and initial management (CG 188). ▪ No Australian registry ▪ There is a Norwegian National Cholecystectomy Registry. Some jurisdictions in the US have cholecystectomy registries. There is a US National Laparoscopic Surgery Registry, which some laparoscopic surgeons enter data into.
R60AB, R61ABC	Lymphoma, acute and non-acute leukaemia	▪ Comprehensive national data collection through Australasian Association of Cancer Registries. Australia also has the Australian Bone Marrow Donor Registry and Australasian Bone Marrow Transplant Recipient Registry and Australasian Leukaemia and Lymphoma Group Registry and Tissue Bank. There is also a Tasmanian Lymphoma and Leukaemia Registry. ▪ Lymphoma-specific registries internationally include the Swedish Lymphoma Registry, Danish Lymphoma Registry, American Burkitt Lymphoma Registry, German Central Cutaneous Lymphoma Registry and European Blood and Marrow Transplant Lymphoma Registry.

Diagnoses related group	Description	Guidelines and registries
G48ABC	Colonoscopy	▪ No Australian guideline. There are international guidelines with respect to surveillance colonoscopy and the use of colonoscopy in management of specific conditions. ▪ Australia has a bowel cancer screening registry which collects colonoscopy-related data on the sub-group of patients who participate in the National Bowel Cancer Screening Program ▪ The US GIQuIC collects data from physicians from hospitals, universities, ambulatory surgery centres and office-based endoscopy units nationwide on quality indicators for colonoscopy.
J06AB, J07AB, J14Z, J62AB	Breast condition procedure, reconstruction, breast malignancy	▪ No Australian guideline ▪ The ABDR tracks quality and outcomes associated with breast device surgery in participating centres nationally. The Australian Society of Plastic Surgeons operated an Australian Breast Implant Registry which was superseded by the ABDR. ▪ There are international and European breast implant registries. There is a Danish Registry for Plastic Surgery of the Breast and there are breast implant registries in the UK and other Scandinavian countries. The US also has a nipple-sparing mastectomy registry.
C16Z	Lens procedures	▪ No Australian guideline. International guideline: Cataract in the adult eye. 1996 Sep (revised 2011 Sep). NGC:008993 American Academy of Ophthalmology – Medical Specialty Society. ▪ There is no Australia-wide lens registry. The Australian Corneal Graft Registry is an Australia-wide register of human corneal transplants. ▪ The American Academy of Ophthalmology IRIS® Registry (Intelligent Research in Sight) is a comprehensive US eye disease clinical registry. Active engagement with the IRIS Registry enables ophthalmologists to meet accreditation requirements. The Paediatric Cataract Surgery Outcomes Registry collects data in paediatric patients in the US. The European Registry of Quality Outcomes for Cataract and Refractive Surgery (EUREQUO), the UK Royal College of Ophthalmologists' National Ophthalmology Database and the Malaysian Cataract Registry are also comprehensive eye registries.
G01AB	Rectal resection	▪ No Australian guideline. International guideline: NICE (2014) Colorectal cancer: diagnosis and management (CG131). ▪ No Australian registry. Rectal and anal cancer data are within the Australasian Association of Cancer Registries and various Australian bowel cancer registries (described above) ▪ Europe has the European Stapled Transanal Rectal Resection Registry. There is a Swedish Colorectal Cancer Registry, a Spanish National Registry of Anastomotic Leakage and Norwegian Rectal Cancer Registry.
G07AB	Appendicectomy	▪ No Australian guideline. No Australian registry. ▪ The Swedish Inpatient Registry contains detailed appendicectomy data.

Diagnoses related group	Description	Guidelines and registries
F08AB	Major vascular procedure	▪ Guidelines: Australian and New Zealand Comprehensive Guidelines on Leg Ulcer Management. International guidelines from the US include Management of Diabetic Foot, Atherosclerotic Occlusive Disease of the Lower Extremities, Management of Venous Leg Ulcers, Early Thrombus Removal Strategies for Acute DVT, Management of Extracranial Carotid Disease and from Europe include Critical Limb Ischaemia and Diabetic Foot, Management of Abdominal Aortic Aneurysms, Chronic Venous Disease. ▪ Registry: National Vascular Audit.
I05AB	Other joint replacement	▪ No Australian guideline. International guideline: NICE (2010) Shoulder resurfacing arthroplasty (IPG 354). A North American systematic review, American Academy of Orthopaedic Surgeons clinical practice guideline on the treatment of glenohumeral joint osteoarthritis. 2009 Dec 4 (reaffirmed 2014). NGC:007581 American Academy of Orthopaedic Surgeons – Medical Specialty Society, was unable to provide definitive recommendations with respect to arthroplasty. ▪ Australian Orthopaedic Association National Joint Replacement Registry collects comprehensive data on all joint replacement surgery. Other joint procedures not collected. ▪ No comprehensive registries identified nationally or internationally for surgeries other than joint replacement.
M01AB	Prostate cancer – major male pelvic procedure, surgical only	▪ Guidelines: Cancer Council Australia Clinical Practice Guidelines: PSA testing and early management of test-detected prostate cancer (2016). Clinical Practice Guidelines for the management of locally advanced and metastatic prostate cancer (2010). ▪ There is an Australian And New Zealand Prostate Cancer Outcomes Registry that collects information on the type of prostatectomy procedures performed. Information about prostate cancer is also collected by the Australasian Association of Cancer Registries. ▪ The US has the American Urological Association Quality Registry that includes prostate surgery data.
L71AB	Respiratory cancer – medical only	▪ Comprehensive national data collection through Australasian Association of Cancer Registries. Victoria has a lung cancer registry.
Y01Z, Y02AB, Y03Z, Y60Z, Y61Z	Burns	▪ Registry: Burns Registry of Australia and New Zealand ▪ Guidelines: Multiple jurisdictional, e.g. Clinical Practice Guidelines. Burn patient management (NSW Agency for Clinical Innovation). Clinical Practice Guidelines: Burns/ management of burn wounds (RCH Melbourne).
N/A	Mesh in gynaecological surgery	▪ Guidelines: RANZCOG guidelines for propylene vaginal mesh implants for vaginal prolapse (produced by the executive of the Urogynaecological Society of Australasia, 2013) ▪ No Australian registry: Internationally, there is an Austrian urogynecology vaginal mesh registry.

Diagnoses related group	Description	Guidelines and registries
N/A	Dialysis, transplantation, organ donation	▪ Guideline: Kidney Health Australia – Caring for Australasians with Renal Impairment guidelines – chronic kidney disease, dialysis, transplantation ▪ Registry: ANZDATA collects comprehensive data.
N/A	CSF shunt	▪ Registry: Pilot Australasian Shunt Registry based a Children's Hospital Westmead. Neurosurgical Society of Australasia proposes broader development of a registry. Multiple international registries, e.g. UK shunt registry. ▪ Guidelines: Multiple jurisdictional, e.g. Insertion or revision of ventriculoperitoneal shunt. WA Health.

Attachment 5: Burden of disease data for short-listed clinical domains

Table A5.1: Ischaemic heart disease

Conditions used in burden of disease	Total DALYs 2011	As percentage of total DALYs 2011
Coronary heart disease	346,651	7.71%
Aortic aneurysm	15,472	0.34%
Atrial fibrillation and flutter	37,526	0.83%
Cardiomyopathy	23,105	0.51%
Non-rheumatic valvular disease	27,531	0.61%
Rheumatic heart disease	11,539	0.26%
Other cardiovascular diseases	37,644	0.84%
Total ischaemic heart disease	**499,468**	**11.10%**

Table A5.2: Musculoskeletal disorders

Conditions used in burden of disease	Total DALYs 2011	As percentage of total DALYs 2011
Back pain and problems	163,788	3.64%
Spinal cord injuries	7,432	0.17%
Other musculoskeletal, osteoarthritis and rheumatoid arthritis	353,242	7.86%
Other musculoskeletal	183,947	4.09%
Osteoarthritis	85,806	1.91%
Rheumatoid arthritis	83,489	1.86%
Hip fracture	6,977	0.16%
Humerus fracture	142	0.00%
Tibia and ankle fracture	421	0.01%
Total musculoskeletal disorders	**532,002**	**11.84%**

Table A5.3: Major trauma

Conditions used in burden of disease	Total DALYs 2011	As percentage of total DALYs 2011
All other external causes of injury	6,874	0.15%
Drowning	10,723	0.24%
Falls	59,116	1.32%
Fire, burns and scalds	7,768	0.17%
Homicide and violence	26,057	0.58%
Other land transport injuries	13,275	0.30%
Other road traffic injuries	12,916	0.29%
Other unintentional injuries	30,671	0.68%
Poisoning	51,406	1.14%
Road traffic injuries – motor vehicle occupants	49,501	1.10%
Road traffic injuries – motorcyclists	12,677	0.28%
Total major trauma	**280,984**	**6.25%**

Table A5.4: Adult critical care

Conditions used in burden of disease	Total DALYs 2011	As percentage of total DALYs 2011
Not suitable for burden of disease analysis	–	–
Total adult critical care	**–**	**–**

Table A5.5: High burden cancers

Conditions used in burden of disease	Total DALYs 2011	As percentage of total DALYs 2011
Bowel cancer	92,422	2.06%
Gallbladder and bile duct disease	5,110	0.11%
Leukaemia	30,629	0.68%
Non-Hodgkin's lymphoma	25,456	0.57%
Other lymphohaematopoietic (blood) cancers	7,346	0.16%
Breast cancer	70,675	1.57%
Lung cancer	154,890	3.45%
Brain and central nervous system cancer	35,662	0.79%
Prostate cancer	49,232	1.10%
Total high burden cancers	**471,422**	**10.49%**

Table A5.6: Stroke

Conditions used in burden of disease	Total DALYs 2011	As percentage of total DALYs 2011
Stroke	136,771	3.04%
Total stroke	**136,771**	**3.04%**

Table A5.7: Renal disease

Conditions used in burden of disease	Total DALYs 2011	As percentage of total DALYs 2011
Chronic kidney disease	42,574	0.95%
Other kidney and urinary diseases	13,662	0.30%
Total renal disease	**56,236**	**1.25%**

Table A5.8: Neonatal critical care

Conditions used in burden of disease	Total DALYs 2011	As percentage of total DALYs 2011
Birth trauma and asphyxia	18,984	0.42%
Brain malformations	5,217	0.12%
Cardiovascular defects	12,250	0.27%
Cerebral palsy	9,192	0.20%
Cleft lip and/or palate	305	0.01%
Gastrointestinal malformations	3,364	0.07%
Neonatal infections	2,464	0.05%
Neural tube defects	3,001	0.07%
Other congenital conditions	10,238	0.23%
Other disorders of infancy	10,532	0.23%
Pre-term birth and low birth weight complications	25,230	0.56%
Urogenital malformations	1,996	0.04%
Total neonatal critical care	**102,773**	**2.27%**

Table A5.9: Mental health

Conditions used in burden of disease	Total DALYs 2011	As percentage of total DALYs 2011
Depressive disorders	127,659	2.84%
Bipolar affective disorder	38,310	0.85%
Schizophrenia	34,331	0.76%
Anxiety disorders	140,971	3.1%
Total mental health	**341,271**	**7.55%**

Table A5.10: Maternity

Conditions used in burden of disease	Total DALYs 2011	As percentage of total DALYs 2011
Hypertensive disorders of pregnancy	344	0.01%
Maternal haemorrhage	415	0.01%
Maternal infections	93	0.00%
Obstructed labour	199	0.00%
Genital prolapse	18,263	0.41%
Other reproductive conditions	3,140	0.07%
Other maternal conditions	629	0.01%
Total maternity	**23,083**	**0.51%**

Table A5.11: Dementia

Conditions used in burden of disease	Total DALYs 2011	As percentage of total DALYs 2011
Dementia	151,308	3.4%
Total dementia	**151,308**	**3.4%**

Table A5.12: Major burns

Conditions used in burden of disease	Total DALYs 2011	As percentage of total DALYs 2011
Fire, burns and scalds	7,768	0.17%
Total major burns	**7,768**	**0.17%**

Table A5.13: Diabetes

Conditions used in burden of disease	Total DALYs 2011	As percentage of total DALYs 2011
Diabetes	101,653	2.3%
Gestational diabetes	207	0.00%
Total diabetes	**101,860**	**2.3%**

Attachment 6: Cost data for short-listed potential clinical domains

Table A6.1: Ischaemic heart disease

DRG	Description	NHCDC 2012/13 costs
F41AB, F42ABC	Circulatory disorder +/– acute myocardial infarction (with invasive procedure)	$0.50 billion
F12AB, F17AB, F18AB	Pacemaker-related	$0.45 billion
F03AB, F04AB	Cardiac valve procedure	$0.41 billion
F01AB, F02Z	AICD related	$0.40 billion
F05AB, F06AB	Coronary bypass	$0.37 billion
F62ABC	Heart failure	$0.37 billion
F68AB	Congenital heart disease	$0.003 billion
F76AB	Arrhythmia, cardiac arrest and conduction disorders	$0.18 billion
Total ischaemic heart disease		**$2.68 billion**

Table A6.2: Musculoskeletal disorders

DRG	Description	NHCDC 2012/13 costs
I04AB, I32ABC	Knee replacement, revision	$1.2 billion
I03AB, I31AB	Hip replacement, revision	$1.1 billion
I08AB, I78AB	Other hip and femur procedures, fractured neck of femur	$0.41 billion
I05AB	Other joint replacement	$0.14 billion
B68AB	Multiple sclerosis and cerebellar ataxia	$0.193 billion
I09AB	Spinal fusion	$0.20 billion
I68AB	Non-surgical spinal disorders	$0.365 billion
A11AB	Insertion of implantable spinal infusion device	$0.003 billion
B03AB	Spinal procedures	$0.053 billion
I06Z	Spinal fusion for deformity	$0.019 billion
I06Z, I09AB	Spinal fusion	$0.65 billion
Total musculoskeletal disorders		**$4.33 billion**

Table A6.3: Major trauma

DRG	Description	NHCDC 2012/13 costs
W01Z-W61AB, I74Z, I75AB, X02A-X60AB	Multi-trauma and injuries	$0.83 billion
Total major trauma		**$0.83 billion**

Table A6.4: Adult critical care

DRG	Description	NHCDC 2012/13 costs
All DRGs ex P01Z-P67ABCD	All critical care costs except neonatal admits	$2.40 billion
Total adult critical care		**$2.40 billion**

Table A6.5: High burden cancers

DRG	Description	NHCDC 2012/13 costs
G02AB	Major small and large bowel procedure	$0.51 billion
G01AB	Rectal resection	$0.26 billion
G60AB (73%)	Digestive malignancy	$0.07 billion
J06AB, J07AB, J14Z, J62AB	Breast condition procedure, reconstruction, breast malignancy	$0.31 billion
R01AB, R03AB, R60AB, R61ABC	Lymphoma, acute and non-acute leukaemia	$0.48 billion
E01AB, E71AB	Respiratory cancer	$0.29 billion
M01AB, M60AB	Prostate cancer	$0.17 billion
R63Z	Chemotherapy	$0.43 billion
Total high burden cancers		**$2.52 billion**

Table A6.6: Stroke

DRG	Description	NHCDC 2012/13 costs
B69AB, B70ABCD	TIA, stroke	$0.39 billion
Total stroke		**$0.39 billion**

Table A6.7: Renal disease

DRG	Description	NHCDC 2012/13 costs
L61Z	Haemodialysis	$0.64 billion
L60ABC	Chronic kidney disease	$0.16 billion
L62AB, L63AB	Kidney and urinary tract neoplasms and infections	$1.24 billion
L64Z	Urinary stones and obstruction	$0.07 billion
L68Z	Peritoneal dialysis	$0.005 billion
L67AB	Other kidney and urinary tract disorders	$0.077 billion
Total renal disease		**$2.19 billion**

Table A6.8: Neonatal critical care

DRG	Description	NHCDC 2012/13 costs
P01Z – P67ABCD	Critical care costs only for neonatal admits	$0.43 billion
Total neonatal critical care		**$0.43 billion**

Table A6.9: Mental health

DRG	Description	NHCDC 2012/13 costs
U61AB	Schizophrenia disorder	$0.59 billion
U63AB	Major affective disorder	$0.43 billion
U40Z	Mental health treatment with electroconvulsive therapy, sameday	$0.011 billion
U60Z	Mental health treatment without electroconvulsive therapy, sameday	$0.017 billion
U62AB	Paranoia and acute psychiatric disorders	$0.081 billion
U64Z	Other affective and somatoform disorders	$0.093 billion
U65Z	Anxiety disorders	$0.042 billion
U66Z	Eating and obsessive-compulsive disorders	$0.065 billion
U67Z	Personality disorders and acute reactions	$0.16 billion
U68Z	Childhood mental disorders	$0.012 billion
Total mental health		**$1.6 billion**

Table A6.10: Maternity

DRG	Description	NHCDC 2012/13 costs
O60ABC	Vaginal delivery	$1.1 billion
O01ABC	Caesarean delivery	$1.0 billion
Total maternity		**$2.1 billion**

Table A6.11: Dementia

DRG	Description	NHCDC 2012/13 costs
B63Z	Dementia and other chronic disturbances of cerebral function	$0.095 billion
Total dementia		**$0.095 billion**

Table A6.12: Major burns

DRG	Description	NHCDC 2012/13 costs
Y01Z, Y02AB, Y03Z, Y60Z, Y61Z, Y62AB	Burns	$0.11 billion
Total major burns		**$0.11 billion**

Table A6.13: Diabetes

DRG	Description	NHCDC 2012/13 costs
K60ABC, X63AB	Diabetes with and without complications and diabetes sameday	$0.193 billion
Total diabetes		**$0.193 billion**

Attachment 7: Text content for Figure 1

Score (high to low)	Domains	Summary
3	Ischaemic heart disease	Serious consequences of poor quality care, very high burden of disease and cost to the health system. Strong clinical support registries in this domain. Current national registries and potential to expand into non-surgical interventions in the future.
3	Musculoskeletal disorders	Serious consequences of poor quality care, very high cost and high burden domain. A number of national registries in hip and knee procedures. Potential to expand to registries for non-surgical interventions in the future.
2.75	Trauma	Serious consequences of poor quality care, very high burden of disease and high cost to the system. Established leadership group and national registry with incomplete capture as well as jurisdictional registries.
2.75	Adult critical care	Serious consequences of poor quality care, very high cost to the health system and estimated high burden of disease. Very strong clinical support and leadership. National registry with close to complete coverage.
2.75	High burden cancers	Serious consequences of poor quality care, very high cost and high burden of disease. Current national population based registers and a number of jurisdictional cancer specific registries. National registry for prostate cancer.
2.5	Stroke	Serious consequences of poor quality care, high burden of disease and moderately high cost to the system. Strong leadership and a national registry.
2.5	Renal disease	Serious consequences of poor quality care, very high cost and moderately high burden of disease. Established leadership group for dialysis and transplantation and expand to registries in this domain.
2.25	Neonatal critical care	Serious consequences of poor quality care, high burden of disease and moderately high cost. Existing leadership group and national registry with substantial capture.
2.25	Mental health	Serious consequences of poor quality care, very high burden of disease and very high cost. Clinical advocacy for registries but no identified leadership group or current registries. Initial registries may focus on sub-groups of patients where the entire population can be captured.
1.75	Maternity	Serious consequences of poor quality care, moderate burden of disease and high cost. Current data collections by jurisdictions and through administrative data are substantial which could be drawn on to develop clinical quality registries.
1.25	Dementia	Serious consequences of poor quality care, high burden of disease and moderate acute care costs. No current registries. Clinical advocacy for registry development in this area. Scoping study on potential to develop registry in this domain is underway.
1	Major burns	Serious consequences of poor quality care, moderate burden of disease and moderate cost. Established leadership group and national registry with incomplete patient capture.
1	Diabetes	Serious consequences of poor quality care, high burden of disease and moderate cost. Clinical advocacy for the development of clinical quality registries.

Acronyms and abbreviations

ABDR: Australian Breast Device Registry

ACOR: Australasian Cardiac Outcomes Registry

ACS: Acute coronary syndromes

AICD: Automated implantable cardioverter-defibrillator

AIHW: Australian Institute of Health and Welfare

AMD: Age-related macular degeneration

ANDA: Australian National Diabetes Audit

ANZDATA: Australian and New Zealand Dialysis and Transplant Registry

ANZHFR: Australian & New Zealand Hip Fracture Registry

ANZICS: Australian and New Zealand Intensive Care Society

AusTQIP: Australian Trauma Quality Improvement Program

BOD: Burden of disease

COAD: Chronic obstructive airways disease

COPD: Chronic obstructive pulmonary disease

CSF: Cerebrospinal fluid

DALYs: Disability-adjusted life years

DRG: Diagnosis related groups

DVT: Deep vein thrombosis

GIQuIC: Gastrointestinal Quality Improvement Consortium

NCCH: National Centre for Classification in Health

NEHTA: National E-Health Transition Authority

NHCDC: National Hospital Cost Data Collection

NHIPPC: National Health Information and Performance Principal Committee

N/A: Not applicable

PCOR-ANZ: Prostate Cancer Outcomes Registry – Australia and New Zealand

PREMs: Patient reported experience measures

PROMs: Patient reported outcome measures

RANZGOG: Royal Australian and New Zealand College of Obstetricians and Gynaecologists

The Commission: Australian Commission on Safety and Quality in Health Care

TIA: Transient ischaemic attack

YLD: Years lived with disability

YLL: Years of life lost

Glossary

Administrative data: This refers to information that is collected, processed, and stored in automated information systems. Administrative data include enrolment or eligibility information, claims information, and managed care encounters.

Burden of disease (BOD): The quantified impact of a disease or injury on a population using the DALYs measure.

Clinical guidelines: Systematically developed statements to inform practitioner and patient decisions on appropriate health care for specific clinical circumstances.

Clinical quality registry: Organisation that monitor the quality (appropriateness and effectiveness) of health care, within specific clinical domains, by routinely collecting, analysing and reporting health-related information, for a self-improving health system

Clinician: a healthcare provider, trained as a health professional, including registered and non-registered practitioners. Clinicians may provide care within a health service organisation as an employee, a contractor or a credentialed healthcare provider, or under other working arrangements. They include nurses, midwives, medical practitioners, allied health practitioners, technicians, scientists and other clinicians who provide health care, and students who provide health care under supervision.

Consumer: A person who has used, or may potentially use, health services, or is a carer for a patient using health services. A healthcare consumer may also act as a consumer representative to provide a consumer perspective, contribute consumer experiences, advocate for the interests of current and potential health service users, and take part in decision-making processes.

Disability-adjusted life years (DALYs): A measure of healthy life lost, either through premature death or living with disability due to illness or injury. Often used synonymously with health loss.

Governance: The set of relationships and responsibilities established by a health service organisation between its executive, workforce and stakeholders (including patients and consumers). Governance incorporates the processes, customs, policy directives, laws and conventions affecting the way an organisation is directed, administered or controlled. Governance arrangements provide the structure for setting the corporate objectives (social, fiscal, legal, human resources) of the organisation and the means to achieve the objectives. They also specify the mechanisms for monitoring performance. Effective governance provides a clear statement of individual accountabilities within the organisation to help align the roles, interests and actions of different participants in the organisation to achieve the organisation's objectives.

Leadership: Having a vision of what can be achieved, and then communicating this to others and evolving strategies for realising the vision. Leaders motivate people, and can negotiate for resources and other support to achieve goals.

Patient: A person who is receiving care in a health service organisation.

Quality improvement: The combined efforts of the workforce and others – including consumers, patients and their families, researchers, planners and educators – to make changes that will lead to better patient outcomes (health), better system performance (care) and better professional development. Quality improvement activities may be undertaken in sequence, intermittently or continually.

Years lived with disability (YLD): The number of years of what could have been a healthy life that were instead spent in states of less than full health. YLD represent non-fatal burden.

Years of life lost (YLL): The number of years of life lost due to premature death, defined as dying before the ideal life span. YLL represent fatal burden.

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