Development of clinical-quality registries in Australia: the way forward

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ABSTRACT

- Australia is developing a national performance framework aimed at measuring health outcomes across the health system.
- Clinical registries provide a clinically credible means of monitoring health care processes and outcomes, yet only five Australian registries currently have national coverage.
- At a national level, clinical registry development should be prioritised to target conditions or procedures that are suspected of being associated with large variations in processes or outcomes of care and that impact significantly on health care costs and patient morbidity.
- Registries should also aim to capture information across care interfaces and to monitor the medium and long-term safety and effectiveness of specific devices, procedures and drugs.

MJA 2011; 194: 360–363

The final report of the National Health and Hospitals Reform Commission, released in 2009, recommended that, in promoting better quality care, "we have systems in place to provide comparative clinical performance data back to health services and hospitals, clinical units and clinicians."[1]

Also in 2009, the Australian Institute of Health and Welfare (AIHW) released a report proposing 55 quality indicators for national reporting on safety and quality (Box).[2] However, of the 31 hospital and specialised health service-specific indicators, only two indicators (22 and 25) are currently being reported nationally.[3] Most cannot be measured in an epidemiologically sound manner (ie, reproducibly and accurately) within the available routinely collected data sources without extensive development of both the indicator and the systems to collect it.[2] Most importantly, the AIHW indicators omit key outcome measures for hospital activities associated with high cost, such as cardiac surgery, trauma care and intensive care, where poor quality care can impose a significant ongoing burden on the community.

Given these deficiencies, attention has turned towards developing clinical registries from which robust quality indicators can be derived.[4] In this article, we outline the rationale for developing registries, and a framework to ensure they are strategically developed to provide the best return on investment.

Rationale for developing clinical registries

Clinical-quality registries collect a defined minimum dataset from people who undergo a particular procedure, are diagnosed with a disease, or use a health care resource.[5] Quality indicators derived from registries and adjusted for differences in casemix are used to benchmark and improve performance across institutions. This information is, in general, credible to clinicians and effective at driving quality improvement.

More than 70 clinical registries have been developed in Sweden. The Swedish stroke registry has identified variations in care,[6] characteristics of clinical units providing the best service[7] and attributes of patients most likely to benefit from such care.[8] Longer-term information has included quality of life and factors influencing capacity to return to work;[9] and — through linkage with a prescribing database — adherence to medication such as statins 2 years after commencing treatment.[10] Quality indicators routinely collected within the registry are reported back to hospitals; they allow comparisons at regional and hospital level and have driven development, evaluation and improvement of stroke services.[11]

In Australia, high-quality registries that collect outcome data from eligible populations are fewer. Only five national registries, encompassing joint replacement, renal dialysis and various forms of organ transplantation (kidney, bone marrow, liver and cardiothoracic organs), have national coverage. One of these, the Australia and New Zealand Dialysis and Transplant Registry (ANZDATA), collects data on patients receiving renal transplants or renal dialysis. It provides risk-adjusted outcomes to contributing organisations that can be compared within Australia and internationally. They can also be used to determine compliance with best practice guidelines[12] and to identify problems with access and equity in the delivery of renal services.[13]

While other high-quality Australian registries exist, many lack high levels of coverage.[14] For example, the Australian and New Zealand Intensive Care Society Adult Patient Database, which benchmarks performance, enables resource planning, monitors clinical practice and is a valuable research resource in identifying risk factors for poor outcomes,[15,16] does not collect data from 30% of eligible intensive care units in Australia.

Prioritising registry development in Australia

Increasing the number of nationwide clinical registries will provide an enlarged inventory of valid, reliable and clinically credible measures of quality that can be compared among different institutions within Australia and internationally. As with initiatives in other developed countries, this can be achieved by expanding several existing registries to become national in scope and by developing new registries in key areas where they currently do not exist. This calls for a framework for prioritising registry development that ensures they are developed in areas of greatest need.

High-cost areas of medicine

The most pressing areas for registry development are high-cost areas of medicine with known or suspected variation in processes or outcomes that may indicate inappropriate care or inefficient use of limited resources. In the case of renal transplantation, for example, failed grafts typically lead to patients returning to high-cost dialysis associated with major reductions in quality of life. Registry data collected continuously from transplantation units provide a strong incentive for institutions to maximise performance on the basis of peer comparisons, which has contributed to the observed increase in rates of renal allograft survival.[17]

National quality indicators proposed by the Australian Institute of Health and Welfare in 2009 and current capacity to collect data[2]

Indicator	Category*
Primary care and community health services	
1 Enhanced primary care services in general practice	A
2 General practices with a register and recall system for patients with chronic disease	B
3 People with moderate to severe asthma who have a written asthma action plan	B
4 Management of hypertension in general practice	B
5 Management of arthritis and musculoskeletal conditions	D
6 Mental health care plans in general practice	A
7 Annual cycle of care for people with diabetes mellitus	A
8 Cervical cancer screening rates	A
9 Immunisation rates for vaccines in the national schedule	A
10 Eye testing for target groups	B
11 Quality of community pharmacy services	D
12 Developmental health checks in children	B
13 People receiving a medication review	B
Hospitals	
14 Assessment for risk of venous thromboembolism in hospitals	C
15 Pain assessment in the emergency department	C
16 Reperfusion for acute myocardial infarction in hospitals	B
17 Stroke patients treated in a stroke unit	B
18 Complications of transfusion	C
19 Health care-associated infections acquired in hospital	B
20 *Staphylococcus aureus* (including methicillin-resistant *S. aureus*) bacteraemia in hospitals	B
21 Adverse drug events in hospitals	B
22 Intentional self-harm in hospitals	B
23 Malnutrition in hospitals and residential aged care facilities	B
24 Pressure ulcers in hospitals and residential aged care facilities	B
25 Falls resulting in patient harm in hospitals and residential aged care facilities	B
26 Complications of anaesthesia†	A
27 Accidental puncture/laceration in hospitals†	A
28 Obstetric trauma — third and fourth degree tears	A
29 Birth trauma — injury to neonate†	A
30 Postoperative haemorrhage†	A
31 Postoperative venous thromboembolism†	A
32 Unplanned return to operating theatre	B
33 Unplanned readmission to an intensive care unit	B
34 Hospital standardised mortality ratio	A
35 Death in low mortality diagnosis-related groups	B
36 Independent peer review of surgical deaths	C
37 Discharge medication management for acute myocardial infarction	C
38 Timely transmission of discharge summaries	D
Specialised health services	
39 Mental health admitted patients having seclusion	B
40 Postdischarge community care for mental health patients	A
41 Quality of palliative care	D
42 Functional gain achieved in rehabilitation	B
43 Multidisciplinary care plans in subacute care	D
(5) Management of arthritis and musculoskeletal conditions	D
Residential aged care	
44 Oral health in residential aged care	C
(13) People receiving a medication review	B
(23) Malnutrition in hospitals and residential aged care facilities	B
(24) Pressure ulcers in hospitals and residential aged care facilities	B
(25) Falls resulting in patient harm in hospitals and residential aged care facilities	B
Multiple service categories	
45 Unplanned hospital readmissions	B
46 Inappropriate co-prescribing of medicines	D
47 Selected potentially preventable hospitalisations	A
48 End-stage kidney disease in people with diabetes	A
49 Lower-extremity amputation in people with diabetes	A
50 Cancer survival	A
51 Failure to diagnose	D
52 Potentially avoidable deaths	A
All service categories	
53 Patient experience	D
54 Presence of appropriate incident monitoring arrangements	C
55 Accreditation of health care services	A

* A = indicators can currently be collected and reported nationally. Future data development may be proposed to enhance the collection and/or reporting of some indicators, but is not an immediate priority. B = indicators require data development, such as refinement of data items in data collections or linkage with other data collections, to address gaps in data availability. C = a suitable data source is not currently available, has yet to be identified, and/or substantial development is required to operationalise the indicator. D = concept proposed for further development. Areas that are considered of importance but where a suitable indicator has yet to be identified and/or developed, and where there are a number of potential means of measurement depending on the indicator specification agreed upon. Not currently reportable — indicator and/or data development required. † Australian patient safety indicators, developed through modification of indicators developed by the US Agency for Healthcare Research and Quality. ◆

Establishing registries in other clinical areas, such as cardiac procedures involving angioplasty and stenting, may realise similar benefits.[18] Despite rapid growth in the number and cost of these procedures, and in the number of studies showing variations according to factors such as operator skill and annual volumes of procedures,[19] outcomes are not routinely monitored across Australia. Suboptimal outcomes may result in repeated hospitalisations for recurrent angina and heart failure, and consequent greater cost and reduced quality of life.

Sequenced care

Registries should also focus on areas of medicine where achievement of good outcomes depends on a well performed sequence of care from different providers. For example, achieving the best outcomes in the management of myocardial infarction and stroke requires rapid attendance by emergency services, speedy diagnosis by paramedics and expedited transport to hospitals that have appropriate investigative and interventional care facilities. After the patient's arrival at hospital, efficient triage, high levels of technical skill, excellent acute care and effective rehabilitation are needed for optimal outcomes. If any step is seriously deficient then outcomes may be poor despite excellence in other parts of the chain.

Registries can gather data for evaluating performance of each component of the sequence of care. The Victorian State Trauma Registry monitors the care of severely injured patients from the time of the injury and ascertains outcomes 2 years after the event. Analyses of trauma registry data showed better outcomes after the introduction of a new trauma management policy in Victoria stipulating that cases of severe trauma be transported directly to major trauma centres and bypass local hospitals, provided the transport time to the major trauma centre was 30 minutes or less.[20] The registry also subsequently showed continuing improvement in each of the components of care, and resultant further improvement in overall trauma outcomes.[21]

Devices, procedures and drugs

Another high priority area for registries is medium to long-term monitoring of specific devices, procedures and drugs where an imperative exists to establish medium-term to long-term safety. Devices may malfunction, break and cause injury because of misuse or design flaws. Unlike new drugs, devices are commonly incorporated into medical practice without systematic pre-marketing evaluation of their clinical safety.[22] Subsequent to marketing, reliance is usually placed on voluntary reporting to identify unanticipated safety concerns, whereas ongoing, systematic surveillance would provide a greater level of consumer protection.

The Australian National Joint Replacement Registry monitors outcomes such as revision surgery and prosthesis removal following hip, knee, spinal disc, shoulder, elbow, wrist and ankle surgery. This registry has changed clinical practice through analysis of and feedback on the performance of different types of joint prosthesis.[23] A recent federal government review of health technology in Australia has recommended that registries for high-risk implantable devices or procedures be established to assist with post-marketing surveillance of safety and efficacy.[24] If accepted by the current Cabinet, it would require manufacturers to establish registries or other forms of systematic data collection as a condition of licence approval.

Areas requiring modest resources

For practical reasons, a program of registry development should also focus initially on areas of practice where the logistic challenges of establishing or expanding registries are relatively straightforward and the resources required are expected to be modest and commensurate with the potential benefits. In particular, priority should be given to procedures or diseases that are easily identified, are managed at a limited number of centres, and attract wide consensus on appropriate process and outcome measures that can be measured relatively easily. 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. For example, fibromyalgia, irritable bowel syndrome or some mental health disorders pose challenges due to inconsistencies in diagnostic definitions and measures of illness severity.

The primary purpose of some registries is to monitor compliance with evidence-based clinical practice guidelines. In the United States, the ACTION Registry-GWTG (Acute Coronary Treatment and Intervention Outcomes Network Registry — Get with the Guidelines), related to care of acute coronary syndromes,[25] and the OPTIMIZE-HF Registry (Organized Program to Initiate Life-saving Treatment in Hospitalized Patients with Heart Failure), related to care of acute heart failure,[26] collect and benchmark process indicators. For both registries, this process has been positively associated with increased use of evidence-based therapy, more efficient patient care, and reduced length of stay.[25,26] More work is required to assess whether these indicators are best collected by ongoing registries, targeted audits or defined cohort studies.[27]

Challenges in registry development

Registries prioritised for development or expansion must be underpinned by robust governance structures and mechanisms to ensure transparency to stakeholders in terms of managerial decision making and oversight, data collection and analysis methodologies, and systems for reporting and disseminating results.[28] This, in turn, requires consideration of a framework that ensures data are used responsibly to drive quality improvement and to analyse and address variation in clinical approach.[5] Those reporting adverse outcomes that may be uncommon or rare need to use techniques of data display that will best motivate quality improvement, such as exponentially weighted moving average charts.[29] More research into refining these methods is needed.

In future, it is likely that a broad range of medical conditions will be monitored using registries that collect data inexpensively from electronic medical records and administrative datasets. To reduce the burden and cost of registry data collection, registry science will need to evolve in ensuring that required data items are reliably captured within, and easily extracted from, these routinely collected electronic datasets.

Conclusion

Like most developed countries, Australia has few registries capable of benchmarking outcomes nationally. Given the increasing attention to quality in the health agenda both here and overseas, policymakers will be in need of a clinical registry prioritisation strategy which ensures that registry development targets three areas — conditions or procedures associated with large variations

in processes or outcomes of care, which have a significant impact on overall health care costs and patient morbidity; areas where transition of care across health services influences optimal outcomes; and medium-term to long-term safety of new clinical interventions. Clinical registries can play an increasingly important role as a stimulus for quality improvement by providing high-quality data and analyses that are respected by clinicians.

Acknowledgements

Sue Evans is supported by a National Health and Medical Research Council Public Health Fellowship (519580).

Competing interests

None identified.

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Provenance: *Not commissioned; externally peer reviewed.*

(Received 5 Sep 2010, accepted 22 Dec 2010) ❑