

Clinical-quality registries: their role in quality improvement

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Registries can provide sound data needed by clinicians and organisations to improve patient safety and quality of care

In June 2009, the National Health and Hospitals Reform Commission released its report proposing an agenda to transform the Australian health system.¹ A critical element of this agenda is improved monitoring of service delivery and outcomes of care.

Clinical-quality registries are an important development in monitoring and benchmarking quality of clinical care. Registries systematically and uniformly collect information from people who undergo a procedure, are diagnosed with a disease or use a health care resource. They are particularly appropriate for monitoring and benchmarking processes and outcomes of care where there is known variation and where poor performance results in high additional cost (eg, renal transplantation) or poor quality of life. Before outcomes are benchmarked, data must be statistically adjusted to isolate quality of care from prognostic factors that are beyond the influence of clinicians. Variables such as age and clinical comorbidities are typically included in risk-adjustment models.

Registries are ongoing data-collection exercises, and the validity of their results relies on near-complete inclusion of all eligible patients. To achieve this goal, use of an “opt-out” consent process is recommended. Where registries have used “opt-in” consent, recruitment rates have been as low as one in six of those eligible, making data unreliable for benchmarking, and rendering the registry ineffective.² Where an opt-out approach has been used in the United States, recruitment rates as high as 97% have been achieved,³ with even higher rates in Australia (< 1% opt-out in the Australian Orthopaedic Association [AOA] National Joint Replacement Registry and Victorian State Trauma Registry).

Clinical-quality registries aim to improve quality of care through benchmarking clinical outcomes and stimulating competition in achieving best practice. The registry set up by the Danish Lung Cancer Group exemplifies what can be achieved. Feedback of indicators of high-quality care derived from registry data to those delivering care has been largely responsible for improvement in 30-day, 1-year and 2-year survival rates for people with lung cancer of 1.6%, 8% and 10%, respectively.⁴

In addition to providing information on safety and efficacy of treatment, data from registries can also be used to determine whether patients have timely access to care,⁵ and whether care is delivered in line with best practice and evidence-based guidelines.^{4,6} Process measures are frequently built into clinical-quality registries to detect variations in clinical approach and explore differences in outcomes. For example, stroke registries established in Canada routinely collect data to assess speed and appropriateness of thrombolytic treatment.⁷

Collection and feedback of data must be underpinned by an effective central governance structure for the registry, with strong clinical leadership, and a regulatory framework providing incentives for quality improvement and proactive approaches for managing poor performance. There must also be strong local clinical leaders who are accountable for ensuring that registry outcomes drive quality improvement. The impact of poor registry governance was highlighted in an inquiry into cardiac surgery at the

Bristol Royal Infirmary in the United Kingdom.⁸ Since the inquiry, improvements have been made to ensure that findings from the Central Cardiac Audit Database are provided to surgeons and are also publicly reported.

Clinical-quality registries can improve safety and reduce costs. Findings of the AOA National Joint Replacement Registry show a decline in the rate of hip and knee revision surgery over a 4-year period from 14.8% to 11.1% and from 10.4% to 7.9%, respectively, with an associated annual cost saving of \$44.6 million.⁹ Since its inception in 2001, the Victorian State Trauma Registry has shown a 30% reduction in mortality among trauma victims.¹⁰ These improvements may be attributed at least in part to a monitoring system that provides ongoing feedback to contributing sites, detailing their risk-adjusted outcomes relative to those of peer organisations, and to the institution of remedial processes to manage outliers.

International momentum is gathering to develop new clinical registries as quality-improvement measures. For example, Sweden has established a network of more than 70 quality registries and has made available resources to assist in establishing new registries.¹¹ In the UK, a national directory of registries has been established to enhance the usefulness of registries in monitoring quality of care.^{12,13} The US Agency for Healthcare Research and Quality has produced a guide to the design, operation, analysis and evaluation of patient registries.¹⁴ In Australia, the document *Operating principles and technical standards for Australian clinical quality registries* has been developed under the auspices of the Australian Commission on Safety and Quality in Health Care and is now being evaluated.¹⁵ Australia has 28 clinical registries, which continuously collect patient-level health-related data, including outcomes, and operate across many health care sites.¹⁶

In Australia, new registries are required in a range of areas where improved quality of care is likely to lead to significant improvements in safety and outcomes. A national registry of cardiac procedures and devices has been widely advocated.¹⁷ New registries should be established in strong clinical research environments with access to people skilled in clinical epidemiology, biostatistics and clinical data management. Registry custodians must ensure that their registries collect complete data from as many eligible patients as possible; give accurate and timely feedback to clinicians and organisations; and have well-functioning governance structures. They must ensure that lessons are shared among contributors and that data are continuously used to drive improvement in practice. With high-quality data from clinical registries, there is a strong potential to engage clinicians more intensely in quality improvement activities.

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Competing interests

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