

## Are Clinical Registries Actually Used? The Level of Medical Staff Participation in Clinical Registries and Reporting within a Major Tertiary Teaching Hospital

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### Abstract

Clinical Registries are established to provide a clinically credible means for monitoring and benchmarking healthcare processes and outcomes, to identify areas for improvement, and drive strategies for improving patient care. Clinical Registries are used to assess changes in clinical practice, appropriateness of care and health outcomes over time. The American Heart Association Policy Statement in April 2011 called for expanding the application for existing and future Clinical Registries, with well-designed Clinical Registry programs. Concurrently, in Australia, and similarly within the United States and United Kingdom, there has been an increased focus on performance measurement for quality and patient safety. Within Victoria, the Victorian Clinical Governance Policy Framework outlines clinical effectiveness as one of the four domains of Clinical Governance

As Clinical Registries evaluate effectiveness and safety of patient care by measuring patient outcomes compared with peers, the use of Clinical Registries data to improve a health service's quality of care seems intuitive. A mixed methods approach was utilised, involving (1) semi-structured interviews and (2) documentation audit in this study conducted at Austin Health, a major tertiary teaching hospital in North-

Eastern metropolitan Melbourne, affiliated with the University of Melbourne and various research institutes within Austin LifeSciences.

Although many studies have highlighted the benefits of data collected via individual Clinical Registries, [5,6] the level of voluntary medical staff participation in Clinical Registries at a health service level is yet to be established. The aim of this study was to document the level of medical staff involvement for Clinical Registries within a major tertiary teaching hospital, and the level of reporting into Quality Committees within the organisation.

This study demonstrates that along with a very high level of medical staff participation in Clinical Registries, there is a lack of systematic reporting of Registries data into quality committees beyond unit level, and utilisation of such data to reflect upon practice and drive quality improvement.

**Abbreviations:** CREPS – Centre for Excellence in Patient Safety; CSU – Clinical Services Unit; HOU – Heads of Unit; VASM – Victorian Audit of Surgical Mortality.

**Key words:** Clinical Registries; benchmarks; improving patient care; clinical practice; outcomes.

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### Background

Clinical Registries are established to 'measure, monitor and identify outcomes through the peer-review process, with the aim to improve patient care'. [1] Registries provide a clinically credible means for monitoring and benchmarking healthcare processes and outcomes, [2] identify areas for improvement, and drive strategies for improving patient care. In addition, Clinical Registries are used to assess changes in clinical practice, appropriateness of care and health outcomes over time. [3] The American Heart Association Policy Statement in

April 2011 called for expanding the application for existing and future Clinical Registries, with well-designed Clinical Registry programs providing 'important mechanisms to monitor patterns of care, evaluate healthcare effectiveness and safety, and improve clinical outcomes'. [4]

Although many studies have highlighted the benefits of data collected via individual Clinical Registries, [5,6] the level of voluntary medical staff participation in Clinical Registries at a health service level is yet to be established.

Concurrently, in Australia, and similarly within the United States and United Kingdom, there has been an increased focus on performance measurement for quality and patient safety. Within Victoria, the Victorian Clinical Governance Policy Framework outlines clinical effectiveness as one of the four domains of Clinical Governance, [7] including:

- Clinical care delivery is evidence-based
- Standards of clinical care are clearly articulated and communicated
- Performance of clinical care processes and clinical outcomes are measures
- Clinical performance measures, peer review and clinical audit are used to evaluate and improve performance
- Quality improvement activities are reviewed externally.

As Clinical Registries evaluate effectiveness and safety of patient care by measuring patient outcomes compared with peers, the use of Clinical Registries data to improve a health service's quality of care seems intuitive.

## Definitions

Clinical quality registries are organisations that systematically monitor the quality (appropriateness and effectiveness) of healthcare, within specific clinical domains, by routinely collecting, analysing and reporting health-related information. The information is used to identify outcome benchmarks, significant outcome variance, and inform improvements in healthcare quality. [8] The Australian Commission on Safety and Quality in Healthcare has defined a Framework, Strategic and Operating Principles, and Technical Guidelines for establishing Clinical Registries within Australia. [8]

Clinical Registries usually encompass patients treated by a single medical specialty group (e.g. Melbourne Interventional Cardiology Group involves patients treated by credentialed Cardiologists only), and hence collation of information is direct from the treating clinicians to the Registry Information in Clinical Registries is captured on an ongoing basis from a defined population. Clinical

Registries provide the most suitable and accurate method of providing monitoring and benchmark data and provide the greatest potential to improve healthcare performance across institutions and providers. [9] The focus of Clinical Registries is to capture data that reflects 'real-world' clinical practice in large patient populations. [6] The data from Clinical Registries 'do not replace the need for traditional randomised controlled trials, rather registries and trials are complementary approaches'. [6]

The relationship between the Clinical Registries and timely, regular feedback to clinicians is essential. The Operating Principles and Technical Standards for Australian Clinical Quality Registries clearly outline the requirement that registries 'must report without delay on risk-adjusted outcome analyses to institutions and clinicians', and ensure a 'publicly-accessible aggregated annual report' is available, detailing 'clinical and corporate findings'. [10]

## Austin Health context

Austin Health is a major tertiary teaching hospital in north-eastern metropolitan Melbourne, affiliated with the University of Melbourne and various research institutes within Austin LifeSciences. Austin Health provides the full range of adult acute medical, surgical, critical care and diagnostic specialties (excluding Gynaecology), sub-acute specialties and general paediatric specialties. Austin Health is world-renowned for its research and specialist work in cancer, liver transplantation, spinal cord injuries, neurology, endocrinology, mental health and rehabilitation. Austin Health encompasses Austin Hospital Heidelberg, Repatriation Hospital Heidelberg, and Royal Talbot Repatriation Centre. During 2008-09, its 6,402 staff treated a record 89,668 inpatients and 155,538 outpatients.

Austin Health established a structure for Quality and Safety Committees, to assist with governance and monitoring patient care across the organisation. The Committee structure includes:

- **Tier 1 - Board Quality and Safety.** This is the highest committee level of governance oversight for Quality and Safety, involving Board members and Executive management. The Board committee discusses strategic quality issues related to whole of organisation.
- **Tier 2 - Executive-level Safety, Quality and Risk Committee.** This is the second highest committee level of governance, involving Executive management, senior clinical and non-clinical leaders throughout the organisation. The Executive Committee discusses operational quality issues relating to whole of organisation.

- **Tier 3 – Quality Committees** dedicated to specific safety areas (such as Falls, Medications, Deteriorating Patient). These committees involve senior clinical leaders with specific quality skills relevant to the area.
- **Tier 4 – Quality Committees** dedicated to specific areas within the health service (such as Surgical Services, Medical Services, Perioperative Services). These multi-disciplinary committees oversee quality issues related to specific areas, with representation from multiple units and medical, nursing, allied health colleagues.

### Aim

To document the level of medical staff involvement for Clinical Registries within a major tertiary teaching hospital, and the level of reporting into Quality Committees within the organisation.

### Methodology

A mixed methods approach was utilised, involving (1) semi-structured interviews and (2) documentation audit.

(1) **Semi-structured interviews** were conducted with clinicians in medical leadership roles within Austin Health, including Medical Clinical Service Units (CSU) Directors, and Heads of Units (HOU). Interviews were conducted throughout August 2011. HOU were asked to comment as to the level of engagement within the relevant Clinical Registry in a 3 point Likert scale (no contribution, partial contribution, full contribution). A list of registries maintained by the Centre for Research Excellence in Patient Safety (CREPS) was used for comparison. [11] In those areas that did not contribute in full, HOU were asked to briefly comment on the reasons behind the limited contribution. In addition, HOU were also asked to comment if they undertook any other forms of external benchmarking of patient outcomes beyond the CREPS list.

Participants were contacted via initial email to Medical CSU Directors with follow-up phone call. For those Units where the Medical CSU Director could not provide comment on the list of Clinical Registries, a further email (with follow up phone call if required) to relevant HOU was undertaken. In addition, any HOU identified by the Medical CSU Director with known additional benchmarking beyond the list were also approached (email then follow up phone call) to clarify the nature of the patient outcome benchmarking.

(2) **Documentation audit of Clinical Registry Reporting within Quality Committees.** A Documentation Audit of the minutes of all Austin Health Quality Committees for a 12 month period (September 2010 to August 2011) was conducted for documentation of reporting of Clinical

Registry information, including:

- (a) Presentation of data itself within the committee
- (b) Analysis of the data to inform quality improvement activities
- (c) Discussions of the framework for utilising Clinical Registry data.

### Results

#### Semi structures interviews for medical staff engagement in Clinical Registries

All Medical Directors of CSUs (seven) responded to the survey. An additional 22 HOU were approached via email or phone call. All 29 participants responded.

Austin Health Medical Units contribute in full to all but one of the benchmarked list of Clinical Registries (Table 1) that are relevant for the organisation. The Clinical Registries encompassed a broad range of surgical, medical, critical care, subacute and psychiatry specialties, and involved a broad representation of clinical conditions/procedural groups and patient cohorts. In addition, it was identified that further peer-reviewed processes for clinical audit with external benchmarking of patient outcomes were undertaken, including Department of Health initiatives, local collaboration with other health services, and unit initiated benchmarking amongst individual clinicians from outside the health service (listed with \*\* in Table 1). Table 2 lists the Clinical Registries that are not relevant for Austin Health.

Of note, there were a number of medical specialties where no Clinical Registry or external benchmarking opportunity currently exist (Endocrinology, General Medicine, Paediatric Medicine, Respiratory Medicine, Spinal Unit, Radiology, Aged Care).

#### Documentation Audit of reporting of Clinical Governance Framework

All tier 1-4 Clinical Governance Committees minutes were reviewed from September 2010 to August 2011. In total, 14 committees were reviewed. Findings included (Figure 1):

##### Tier 1 Committee level

Clinical Registry information was discussed at Tier 1 level (Board Clinical Safety and Quality Committee) on eight separate occasions over six meetings. This included:

- Presentation of Annual Audit results for Anaesthetics as part of Victorian Consultative Council for Anaesthetic Morbidity and Mortality, to identify patient outcomes compared to peers Presentation of Annual Renal Audit including data from Australian and New Zealand Dialysis and Transplant Registry (ANZDATA) report.

**Table 1: Comparison of Medical Specialties within the organisation, clinical registries, and Quality Committee Reporting**

| MEDICAL SPECIALTIES WITHIN THE ORGANISATION  | CLINICAL REGISTRY RELEVANT TO THE SPECIALTY  | QUALITY COMMITTEE RELEVANT TO THE SPECIALTY   |
|--|--|---|
| <p><b>Surgical Specialties</b></p> <ul style="list-style-type: none"> <li>• Cardiac Surgery</li> <li>• General Surgery (4 units)</li> <li>• Maxillofacial Surgery</li> <li>• Neurosurgery</li> <li>• Orthopaedic Surgery</li> <li>• Otolaryngology Surgery</li> <li>• Plastic Surgery</li> <li>• Thoracic Surgery</li> <li>• Urology</li> <li>• Vascular Surgery</li> </ul>  | <p>Victorian Surgical Consultative Council**<br/>                     Victorian Audit of Surgical Mortality (VASM)**<br/>                     ACCORD Comprehensive Cancer Patient Database (Various Surgical Oncology Units with tumour streams)</p> <p>Australian Society of Cardiothoracic Surgeons Database Project (ASCTS)<br/>                     Australian and New Zealand Liver Transplantation Registry (ANZLTR)<br/>                     Bi-National Colorectal Cancer Audit (BCCA)<br/>                     National Bowel Cancer Screening Program</p> <p>Australian Orthopaedic Association (AOA) National Joint Replacement Register (NJRR)<br/>                     Victorian Orthopaedic Trauma Outcomes Registry (VOTOR)</p> <p>Victorian Lung Cancer Registry**<br/>                     Thoracic Surgery Database** (benchmarked with St Vincents Health)<br/>                     Prostate Cancer Clinical Quality Registry<br/>                     Australasian Vascular Audit</p>  | <p>Surgical Audit and Review Committee (all surgical specialties)</p>                                     |
| <p><b>Medical specialties</b></p> <ul style="list-style-type: none"> <li>• Cardiology</li> <li>• Dermatology</li> <li>• Endocrinology</li> <li>• Gastroenterology</li> <li>• General Medicine (5 units)</li> <li>• Infectious Diseases</li> <li>• Nephrology</li> <li>• Neurology</li> <li>• Oncology</li> <li>• Palliative Care</li> <li>• Paediatric Medicine</li> <li>• Respiratory Medicine</li> <li>• Rheumatology</li> <li>• Spinal</li> </ul> | <p>Melbourne Interventional Group (MIG)<br/>                     Interventional Cardiology Registry (PCI)<br/>                     Melbourne Melanoma Collaborative**</p> <p>National Bowel Cancer Screening Program</p> <p>National Creutzfeldt Jacob Disease<br/>                     Victorian Infection Control Nosocomial Infection Surveillance System (VICNISS)<br/>                     Australian and New Zealand Dialysis and Transplantation Registry (ANZDATA)<br/>                     Australian Motor Neuron Disease Registry (AMNDR)<br/>                     Australian Stroke Clinical Registry (AuSCR)<br/>                     ACCORD Comprehensive Cancer Patient Database (Oncology)<br/>                     Bi-National Colorectal Cancer Audit (BCCA)<br/>                     National Breast Cancer Audit (NBCA)<br/>                     Victorian Cancer Registry**<br/>                     Palliative Care Outcomes Collaboration**<br/>                     Palliative Care Consult Services State-wide Minimum dataset**</p> <p>Australian Rheumatology Association Database (ARAD)</p> | <p>Medical Outcomes and Review Committee (all medical specialties)</p> <p>Infection Control Committee</p> |

**Table 1: Comparison of Medical Specialties within the organisation, clinical registries, and Quality Committee Reporting** *continued*

| MEDICAL SPECIALTIES WITHIN THE ORGANISATION   | CLINICAL REGISTRY RELEVANT TO THE SPECIALTY  | QUALITY COMMITTEE RELEVANT TO THE SPECIALTY         |
|---|--|---|
| <b>Critical care specialties</b><br>• Anaesthesia<br>• Emergency Medicine<br>• Intensive Care<br><br>• Organ Donation Service | Victorian Consultative Council for Anaesthetic Morbidity and Mortality (VCCAMM)**<br>National Trauma Registry Consortium (NTRC)<br>Victoria State Trauma Outcomes Registry and Monitoring (VSTORM) Group<br>Australian and New Zealand Intensive Care Unit Society (ANZICS CORE)<br>Consultative Council on Obstetric and Paediatric Mortality and Morbidity (CCOPMM)** – as organization provides Intensive Care services for collocated Maternity Hospital<br>Australian and New Zealand Organ Donation Registry (ANZOD) | Operating Suite Quality Committee (for Anaesthesia) |
| <b>Diagnostic specialties</b><br>• Pathology<br>• Radiology   | National Cytology Registry   |   |
| <b>Subacute specialties</b><br>• Rehabilitation<br>• Aged Care  | Australasian Rehabilitation Outcomes Centre (AROC)   |   |
| <b>Mental Health</b>  | Victorian Mental Health Client Management Interface**<br>Mental Health Mortality Registry**  | Mental Health Safety Quality and Risk Committee     |

\*\* benchmarking opportunities not listed with Centre for Research Excellence in Patient Safety

- Victorian Infection Control Nosocomial Infection Surveillance System (VICNISS) integration into the organisation's suite of clinical indicators was recommended.
- Mental Health Performance Indicators presented regularly at Board Clinical Safety and Quality Committee includes part of Victorian Mental Health Client Management Interface, and Mental Health Mortality Register.
- The framework for integrating Clinical Registries data into the organisation's clinical governance system was discussed on four occasions.

**Tier 2 Committee level**

Integrating Clinical Registry information into the quality committee structures was also discussed on one occasion at the Safety Quality and Risk Committee.

**Tier 3 Committee level**

VICNISS data is reviewed monthly within the Infection Control Committee (Tier 3).

No Registry data was discussed at Clinical Outcomes Review Committee, Drug and Therapeutics Committee, Blood Products Committee or Clinical Policies and Procedures Committee.

**Tier 4 Committee level**

All deaths within surgery for the Victorian Audit of Surgical Mortality (VASM) are reviewed monthly within the Surgical Audit and Review Committee. Seclusion and restraint benchmarking data is reviewed within three meetings of the Mental Health Safety Quality and Risk Committee.

No Registry data was discussed at the Operating Suite Quality Assurance Committee, New Technologies and Clinical Practice Committee, Resuscitation Committee, Medical Outcomes Review Committee, or Clinical Review Committee.

**Table 2: List of clinical registries that are not applicable for the organisation**

| CLINICAL REGISTRY  | DETAILS OF PATIENT GROUP, SURGICAL PROCEDURE OR HEALTH RESOURCE INVOLVED  | CONTRIBUTION TO REGISTRY (OR COMMENTS)   |
|--|---|--|
| Australian and New Zealand Cardiothoracic Organ Transplantation Registry (ANZCOTR) | All individuals who have undergone a heart, a single lung, a double lung or heart lung block transplant operation (with or without any additional organs e.g. kidney, liver, pancreas). | Not relevant for organization ad no heart transplants undertaken.  |
| Australian Cardiac Procedures Registry (ACPR)                                      | All patients who undergo a cardiac surgery, RCI or device procedure at participating hospitals. Ended on 30th November 2009. A number of sites are still collecting data.               | Ceased November 2009.  |
| Australian Corneal Graft Registry  | All individuals who have undergone the surgical procedure of penetrating or lamellar corneal transplantation, anywhere in Australia.  | Not relevant for organisation as no corneal transplants undertaken.  |
| Australian Cystic Fibrosis Data Registry   | Persons diagnosed with Cystic Fibrosis whose condition is managed at a specialist CF treatment centre in an Australian Hospital.  | Not relevant for organisation as no Cystic Fibrosis patients managed at organisation.  |
| Bi-national Burns Registry (Bi-NBR)  | All patients admitted to a Burns Unit with any burn.  | Not relevant for organization as not a designated Burns unit.  |
| Breast Screen Victoria   | Any woman over the age of 40 years who has a mammography in the Breast Screen Australia program.  | No, as the organization is not part of Breast Screen Victoria. Peer review via Breast Multidisciplinary meetings. (Radiology). |
| Centre of National Research on Disability and Rehabilitation Medicine (CONROD)     | All Trauma patients, within Queensland.   | Not relevant for organisation.   |
| Victorian Cardiac Arrest Registry  | The Registry captures all cardiac arrests attended by metropolitan and rural ambulance across Victoria.   | Not relevant as out of hospital arrests.   |

## Discussion and recommendations

### Methodology strengths and limitations

Mixed methods analysis provides the ability to identify Clinical Registries in which the clinicians participated, and subsequently link whether these registries were discussed at Quality Committee level. High respondent rates were achieved through semi-structured interviews. The analysis also identified a number of medical specialties that did not have any relevant registries.

Limitations of the study include the reliance on the documentation within committee minutes for accurate discussions of Registry data.

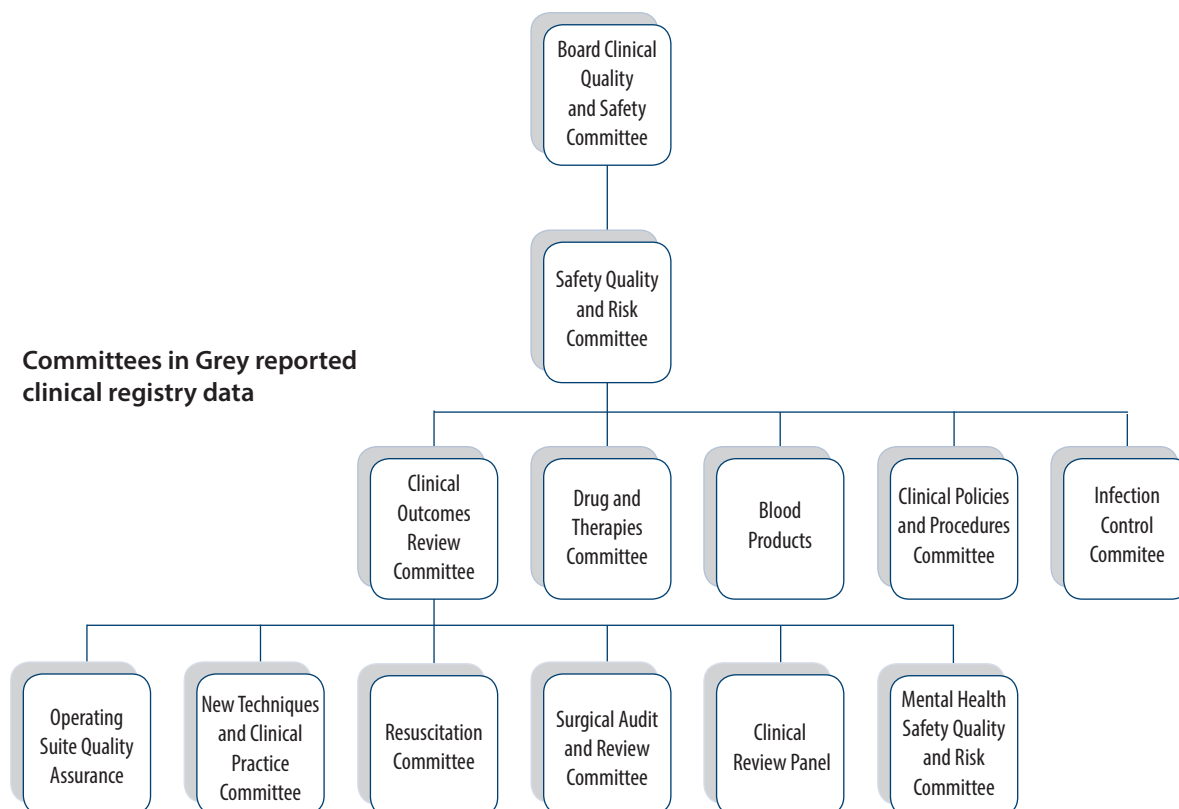
The study did not include educational forums (e.g. Grand Rounds) within its scope. The Division of Surgery holds annual Surgical Forums, where each surgical unit presents its annual clinical audit data. This is presented to the broader organisation via the Division of Surgery. No formal minutes

occur for these presentations, which formally sit underneath the governance of Surgical Audit and Review Committee. A similar educational opportunity occurs within the Division of Medicine Grand Round, with units presenting annually on a rotating weekly basis. Clinical Registry data may be included in these forums, however no formal minutes occur for these presentations.

The study did not include Clinical Trials or Research studies within its scope. Both of these areas would have some ability to measure patient outcomes against other peer organisations, within a trial or research governance framework.

Finally, the study did not include administrative dataset reporting within its scope, including Victorian Admitted Episodes Dataset reporting to the Department of Health Victoria. [12]

Figure 1: Documentation Audit of reporting of Clinical Registries within Quality Committees



### Discussion of comparison to other studies

Clinical Registries are extensively utilised within a tertiary health service as a means of benchmarking patient outcome data with peers and the larger real-world population of patients. Registries allow for timely feedback to clinicians on real-world patients and allow analysis to inform improvements to patient care. We identified almost universal participation in Clinical Registries that were relevant for the organisation. High participation rates were similar to Retegan and colleagues of the VASM independent review, through a survey of 257 individual stakeholders with a 95% agreed participation rate amongst Victorian Fellows of the Royal Australasian College of Surgeons. [13] The analysis of VASM reported cases has also led to further understanding of cross-specialty differences with clinical management issues. [1] High participation rates were also identified in the Australian and New Zealand Intensive Care Society Centre for Outcomes and Resource Evaluation Registries, with 197 adult ICUs (75%) of Australian ICUs contributing to the Registry. [14]

We also identified a number of medical specialties that did not have formal Clinical Registries, including Endocrinology and General Medicine. The National (insulin-treated) Diabetes Register, [15] managed by the Australian Institute of Health and Welfare, collects information about new cases

of insulin-treated diabetes, and managed by the Diabetes Services Scheme, however there is predominantly a register for incidence of diabetes, not clinical outcomes. There are a number of best-practice diabetes management guidelines, available on the Australian Diabetes Society, [16] providing a hypothetical potential to link both via a Clinical Registry. Diabetes Registries have been established in other countries, with the German DiMelli study establishing a diabetes incidence cohort Registry in 2010, [17] which has already generated an increased understanding of the etiology of diabetes, [18] and similarly with the Saudi Arabian National Diabetes Register. [19] Nordic countries are attempting to ensure comparable variables across registries for diabetes, to improve the quality of care for children with diabetes. [20]

International literature in the United States has also identified enhanced understanding of heart failure characteristics, management, outcomes and their predictors through analysis of Heart Failure registries. [21] Lara et al's 2011 study of respiratory disease registries in Spain outlined a number of disease-specific registries that have led to advancements in the management of specific respiratory conditions. [22] An opportunity therefore arises for Australian registries within these general medical conditions.

## Implications for practice

There is significant potential to improve patient care through the timely feedback of clinically relevant information to clinicians' data within local health services. The Surgical Quality Committees reviewed within our organisation had well-established mechanisms for participating in Clinical Registries, and ensuring the data is regularly reviewed within the Surgical Quality Committee beyond unit level within a culture of openness and transparency beyond unit level. As with the learnings across surgical specialties that are arising from analysis at VASM level, [1] cross specialty trends of patient cohorts, treatments and patient outcomes can be realised at the organisation level by sharing of Registry data between specialties.

At present within our organisation, the sharing of broader learnings across physician specialties is lacking (including Nephrology, Cardiology, Emergency, Intensive Care, Anaesthetics) due to the lack of reporting of Registry data beyond Unit level.

As healthcare systems re-focus reform efforts on cost-effectiveness, particularly by evaluating patient outcomes relative to costs, measuring patient outcomes will become increasingly important. An international study of thirteen registries in five countries suggests, 'well managed registries enable medical professionals to engage in continuous learning and to identify and share best clinical practices'. [23]

There is also a corresponding increase in exploring performance measures for patient outcomes derived from routinely recorded administrative data sets, such as The Classification of Hospital Acquired Diagnoses (CHADx), [24] and Hospital Standardised Mortality Ratios [25] within Australia, and within Medicare in the United States. However there are varying opinions of the validity and applicability of such data sets and in general their credibility with clinicians lags substantially behind that of Registry data.

## Implications for further study

To enhance clinician participation in Clinical Registries, it would be valuable to ascertain the factors affecting level of participation to Clinical Registry, particularly any barriers for those areas that were not contributing in full (one Registry). In addition, further study of clinicians' perceptions of the variance in reporting within quality committee structures would be beneficial, to ascertain the factors enhancing surgical reporting, and those barriers to other specialties who do not currently report their Registry data beyond their unit level. In our austere healthcare environments, an economic evaluation of the resource implications for maintaining registries at an organisation would be useful.

## Conclusions

This study demonstrates that along with a very high level of medical staff participation in Clinical Registries, there is a lack of systematic reporting of Registries data into quality committees beyond unit level, and utilisation of such data to reflect upon practice and drive quality improvement. Cross specialty trends of patient cohorts, treatments and patient outcomes could be realised at the organisation level by sharing of Registry data between specialties.

## Competing interests

The authors declare that they have no competing interests.

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