Developing national clinical quality registries

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• Independent, statutory authority
• Established under the *National Health Reform Act 2011*.
• Funding – AHMAC model
• **Role:** to lead and coordinate improvements in safety and quality in health care across Australia.

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National Health Reform Act 2011

Functions of the Commission include to:

- promote, support and encourage the implementation of arrangements, programs and initiatives relating to health care safety and quality matters;
- collect, analyse, interpret and disseminate information relating to health care safety and quality matters;
- publish reports relating to health care safety and quality matters;
- formulate standards, guidelines and indicators;
- promote, support and monitor the implementation of standards, guidelines and indicators;
- formulate model national schemes that:
  (i) provide for the accreditation of health care organisations; and
  (ii) relate to health care safety and quality matters;
- consult and co-operate with other persons, organizations and governments on health care safety and quality matters;
Q: Why does Australia need clinical quality registries?
A: Limited capacity (beyond audits) to monitor and report the appropriateness and effectiveness of healthcare within specific clinical domains (eg: Stroke care, #NOF, Acute coronary syndrome etc)
CQRs: An effective and efficient solution.
STUDY by Larssson et al (2012) 13 CQRs in 5 countries:

Findings:

- Effective continuous learning for clinicians
- Improved health outcomes at lower cost
- Hypothetical eg: if US had a hip replacement registry comparable to that in Sweden, the US would avoid $2 billion of an expected $24 billion in total costs for these surgeries in 2015.

Source: Larsson S et al *Health Affairs* Jan 2012
How do good CQRs work?

COLLECT ➔ ANALYSE ➔ REPORT

- Routinely **collect** health data
  - patient, diagnosis, intervention, outcome
- **Analyse** and risk-adjust
- Generate comparative **reports**
  ➔ FOR clinicians, hospitals, health departments and private hospital groups
  ➔ TO compare the processes and outcomes of health care and assess performance against peers, standards and benchmarks
  ➔ WHICH drives improvements in care
The CQR stakeholder ‘contract’

INPUTS

$$$
Data

OUTPUTS

Funders

Registry

Clinicians and Hospitals

Hospital level reports

Risk-adjusted, comparative reports
Australian experience

- Australia: 28 identified clinical (quality) registries
- Currently, few have national coverage
- Examples of national registries with high (>90%) participation rates:
  1. NJRR
  2. ANZDATA (ESRF incl kidney t/plant and renal dialysis)
  3. ANZICS APD (ICU)
  4. PCOC (Pall Care)
  5. AROC (Inpatient Rehab)
  + Perinatal NMDS (AIHW)
• The US and UK have a broad range of clinical registries.
• > 70 clinical registries in Sweden
  – Over 20 greater than 85% patient coverage
  – ‘Bang for Buck’: Conditions tracked represent 25% of national health care spending.

Barriers to CQR development

1. Funding
2. Data entry (collection) of source data
3. Poor interoperability between CIS
4. Technical systems development and support
5. ‘Data governance’ (restrictions on data disclosure, collection, and use)

Commission addressing points 2 – 5 below
CQRs need to routinely collect **individually identifying data** over time (linkage and f/u)

- Variable **jurisdictional legislation**, regulations and principles (public healthcare organisations)

- **Federal Privacy Act**
  Section 95 (Commonwealth agencies and ACT)
  Section 95A (private healthcare organisations)
  + associated guidelines issued by the NHMRC
Existing arrangements for CQR:

**National**
The Privacy Act 1988 (Section 95) including Information Privacy Principles [Applicable to Commonwealth agencies and the ACT. Not applicable to other States and Territories].

**Private Health Sector**
The Privacy Act 1988 (Section 95A) including National Privacy Principles [Applicable to all health service providers in the private health sector].

**Australian Capital Territory**
Privacy Act 1988
Health Records (Privacy and Access) Act 1997

**New South Wales**
Health Records and Information Privacy Act 2002

**Northern Territory**
Information Act 2002

**Queensland**
Information Privacy Act 2009
Health and Hospitals Network Act 2011
Private Health Facilities Act 1999
Public Health Act 2005

**South Australia**
Cabinet Administrative Instruction 1/89: Information Privacy Principles 1, 2 & 3; Code of Fair Information Practice

**Tasmania**
Personal Information Protection Act 2004

**Victoria**
Health Records Act 2001
Health Services Act 1988
Mental Health Act 1986

**Western Australia**
Hospital and Health Services Act 1927
The requirement for opt-in patient consent (opt-out not recognised by some Ethics Committees and NHMRC)

- case selection bias
- unrepresentative data
- reduced data validity
- limits power to inform quality improvements

Burden of HREC applications and reports
CQR Advisory Committee convened 2007

Health Ministers (Nov 2010):
1. Endorsed *Strategic and Operating Principles* for a national approach to CQR development
2. Accepted ACSQHC recommendations to:
   • develop national health information arrangements for CQRs.
   • provide a costed infrastructure plan for high-cost, high-variance clinical CQRs.
Possible Option:
Use of the National Health Information Agreement (NHIA)

NHIA: An agreement between health authorities to improve, maintain and share national health information.

NHIPPC → NHIPPC Working Group
Costed infrastructure options (draft) for best practice technical design and operation of clinical quality registries.

- Partnership with NeHTA
- Relevant committees / groups
  - Registry Expert Group
  - Clinical Quality Registries Advisory Committee
  - Information Strategy Committee
  - Inter-Jurisdictional Committee
  - National E-Health Information Principal Committee
    (+National Health CIO Forum)
  - Australian Health Ministers Advisory Council

AHMAC Deliverable 2: Costed Infrastructure Plan

ACSQHC
Include features to:

- Limit interoperability problems and data entry duplication
  (incl: ‘PULL’ and batch upload capabilities from hospital and admin systems)
- Support technical systems development and on-going maintenance.
Option 1: Centralised
   (Single centre houses and manages all registries)

Option 2a: Centres of Excellence
   (Co-located data hosting services)

Option 2b: Centres of Excellence
   (Centralised data hosting services, single platform)

Option 3: Stand-alone registries
Option 2b
Centres of Excellence
(Centralised data hosting services, single platform)
1. Technical and operational requirements specification
2. Logical architecture and design
3. Architecture and technical standards
4. Security certification framework (draft)

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Minimum Requirements (draft)

- Demonstrated clinical need
- Purpose and scope
- Organised clinical leadership and governance
- Indicators
- Data Set Specification (METeOR, AIHW)
- Data collection (succinct, not overly burdensome)
- Data quality (accuracy and ascertainment)
- Data custodianship (jurisdictional, private sector, NHIA)
- Ethics and privacy
- Reporting (routine and ad-hoc to funders, jurisdictions, clinicians, healthcare organisations etc.)
- Certification of secure data hosting (technical) services
Possible assessment/accreditation models:

a) Self assessment

b) Accreditation or certification to an endorsed peer committee, organisation or similar

c) Establishment or designation of a publicly accountable agency
Clinical Relevance Criteria

- Condition / device / procedure is associated with a high cost to the health system.
- There are serious consequences for the patient associated with poor quality.
- An evidence-based sequence of care improves patient outcomes for the clinical condition.
- Unwanted variation from the sequence of care can be identified and addressed.
Feasibility Criteria

• The clinical condition / event is able to be systematically recognised.

• There is national clinician support for the (proposed) registry.

• The governance requirements for a successful registry can be met.

• There are sufficient resources available for the sustainable operation of the registry.
Feasibility Criteria (contd):

The **information requirements** for a successful registry can be met:

- The entire eligible population can be captured.
- The necessary data set is able to be specified and captured.
- Validated indicators of quality can be defined.
- There is potential for reliable risk adjustment and/or stratification.
- Clinical information systems can support data collection and reporting.
What does good look like?

Source: ANZDATA Registry Report 2010
hypothesised example of deaths following cardiac surgery

HOSPITALS WITH AN UNEXPECTEDLY HIGH PROPORTION OF DEATHS

HOSPITALS WITH AN UNEXPECTEDLY LOW PROPORTION OF DEATHS

Observed proportion of deaths consistent with a true underlying mortality of 5%

What does good look like?

### Possible reports under national arrangements

<table>
<thead>
<tr>
<th>Report</th>
<th>Frequency</th>
<th>Generator</th>
<th>Content</th>
<th>Stakeholder Recipient</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Routine annual registry reports</td>
<td>Annually</td>
<td>Registry</td>
<td>Aggregated clinical and registry findings; national trends in outcomes and patterns of practice</td>
<td>Open to the public</td>
</tr>
<tr>
<td>2 Routine jurisdiction reports</td>
<td>Quarterly</td>
<td>Registry</td>
<td>Risk-adjusted unit level data by jurisdiction and private hospital ownership group (clinicians and patients not identified)</td>
<td>Jurisdiction and private hospital ownership groups</td>
</tr>
<tr>
<td>3 Routine unit Reports</td>
<td>Quarterly</td>
<td>Registry</td>
<td>Risk-adjusted granular data limited to the contributing unit with comparators at national / jurisdictional / peer group level</td>
<td>Confidential to the contributing provider unit</td>
</tr>
<tr>
<td>4 Routine clinician reports</td>
<td>Quarterly</td>
<td>Registry</td>
<td>Risk-adjusted granular data limited to the contributing clinician with comparators at national / peer group level (patients identified)</td>
<td>Confidential to the contributing clinician</td>
</tr>
<tr>
<td>5 Ad hoc jurisdiction reports</td>
<td>Ad hoc</td>
<td>Registry</td>
<td>Risk-adjusted unit-level data limited to the jurisdiction with comparators at national/jurisdictional/peer group level (clinicians and patients not identified)</td>
<td>Not for publication</td>
</tr>
<tr>
<td>6 Ad hoc unit reports</td>
<td>Ad hoc</td>
<td>Authorised unit staff</td>
<td>Risk-adjusted granular data limited to the querying unit</td>
<td>Confidential to the contributing unit</td>
</tr>
<tr>
<td>7 Ad hoc clinician reports</td>
<td>Ad hoc</td>
<td>Authorised clinician</td>
<td>Risk-adjusted granular data limited to the querying clinician (patients identified)</td>
<td>Confidential to the contributing clinician</td>
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