Clinical Quality Registries

Associate Professor Sue Evans
Director, Clinical Registry Unit
Department of Epidemiology and Preventive Medicine
• What registries may be collecting data in your health service?
Australian Clinical Registries

Diseases/events captured by Australian registries

Cardiovascular disease

- Australia New Zealand Society of Cardiac and Thoracic Surgeons (ANZSCTS) Cardiac Surgery Database Programme
- Coronary Angiogram Database of South Australia (CADOSA)
- Australian Stroke Clinical Registry (AuSCR)
- Australasian Vascular Audit
- Victorian Cardiac Outcomes Registry (VCOR)
- Victorian Ambulance Cardiac Arrest Registry (VACAR)
Australian Clinical Registries

Diseases/events captured by Australian registries

Critical care and infection control

- The Victorian State Trauma Registry (VSTR)
- Victorian Orthopaedics Trauma Outcome Registry (VOTOR)
- Australian and New Zealand Intensive Care Society (ANZICS): Adult Patient Database (APD)
- Australian and New Zealand Paediatric Care (ANZPIC) Registry
- Australian and New Zealand Massive Transfusion Registry
- Australian and New Zealand Intensive Care Society (ANZICS): Central Line Associated Blood Stream Infection (CLABSI) Surveillance System
- Victorian Healthcare Associated Infection Surveillance System (VICNISS)
- Burns Registry of Australia and New Zealand (BRANZ)
Australian Clinical Registries

Diseases/events captured by Australian registries

Chronic disease and rehab

- Australian Cystic Fibrosis Data Registry (ACFDR)
- Australian Motor Neuron Disease Registry (AMNDR)
- Spleen Registry Australia
- Australian Bleeding Disorders Registry (ABDR)
- Australasian Rehabilitation Outcomes Centre (AROC)
- Australian Rheumatology Association Database (ARAD)
Australian Clinical Registries

Diseases/events captured by Australian registries

Procedure and device

- Australian Breast Device Registry
- Australian Orthopaedic Association National Joint Replacement Registry (AOANJRR).
- Breast Surgery Australia New Zealand Quality Audit
- Bariatric Surgery Clinical Quality Registry
- Australian Corneal Graft Registry
Australian Clinical Registries

Diseases/events captured by Australian registries

Transplant

• Australasian Bone Marrow Transplant Recipient Registry (ABMTRR)/Australasian Stem cell Transplants Online (ASTRO)
• Australia and New Zealand Liver Transplant Registry (ANZLTR)
• Australia New Zealand Dialysis and Transplantation Registry (ANZDATA)
Australian Clinical Registries

Diseases/events captured by Australian registries

Cancer

- Prostate Cancer Outcome Registry- Australia and New Zealand (PCOR-ANZ)
- Victorian Lung Cancer Registry (VLCR)
- Binational Colorectal Cancer Audit (BCCA)
- South Australian Metastatic Colorectal Cancer Registry
- Australian Thyroid Cancer Audit
- Australian Paediatric Cancer Registry (APCR)
- Upper GI Cancer Registry
Monash Clinical Registries - History

2001 VSTR
2002 ARAD
2003 VOTOR
2004 MIG
2005 ANZCTS
2008 TTP, NAIT
2008 Australian Operating Principles for CQRs (ACSQHC)
2009 BSR, PCOR
2010 VLCR, BRANZ
2011 ABDR, MTR, AAR
2012 VCOR, Myeloma
2013 ROKD,
2014 PCOR -ANZ
2015 UGI Ca Registry
2016 CF, ATR, PCO-CRV Global
2017 Spine Surgery Registry
2017 Thyroid Cancer Registry
Monash Clinical Quality Registries

Currently operate 25 clinical and clinical quality registries – the leading provider of clinical registries in Australia
What are clinical registries?
CQRs as defined by the Australian Commission on Safety and Quality in Health Care:

[CQRS 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 is used to identify benchmarks, significant outcome variance, and inform improvements in healthcare quality.”
## Difference between a clinical registry, clinical trial and CQR?

<table>
<thead>
<tr>
<th></th>
<th>Clinical registry</th>
<th>Clinical trial</th>
<th>CQR</th>
</tr>
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<tbody>
<tr>
<td>Collects incidence data</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td><em>how many cases are there?</em></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Reports patterns of care</td>
<td>+/-</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Observational</td>
<td>✓</td>
<td>-</td>
<td>✓</td>
</tr>
<tr>
<td>Collects patient reported outcomes</td>
<td>-</td>
<td>+/-</td>
<td>✓</td>
</tr>
<tr>
<td>Interventional</td>
<td>-</td>
<td>✓</td>
<td>-</td>
</tr>
<tr>
<td>Collects health outcomes</td>
<td>+/-</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Collects population-level data</td>
<td>-</td>
<td>-</td>
<td>✓</td>
</tr>
<tr>
<td>Minimal information</td>
<td>+/-</td>
<td>-</td>
<td>✓</td>
</tr>
<tr>
<td>Monitors quality of care using indicators</td>
<td>-</td>
<td>-</td>
<td>✓</td>
</tr>
<tr>
<td>Provides feedback to hospitals/clinicians</td>
<td>-</td>
<td>-</td>
<td>✓</td>
</tr>
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</table>
Clinical Quality Registry Process Overview

- Hospital 1
- Hospital 2
- Hospital 3
- Hospital 4...etc

Central data collation
Registry services provider
High security

- Governance process*
- Quality control*

Quality related outcomes

- Benchmarking reports

Process measures

IDENTICAL
Minimum data-set
Registry Governance and Funding

- **Auspicing body**
  - Often consortium of funders e.g. state/commonwealth government; government agencies e.g. TGA; medical specialty societies, consumer organisations, industry.

- **Steering committee**
  - Independent chair & representatives of professional groups, registry staff, funders, consumers.

- **Operations committee**
  - Strong research environment
  - Independent of providers
  - ISO27001/2 & NEHTA accredited for data

- **Quality of care committee**

**REGISTRY**

Central registry: includes quality assurance, reporting,
Peripheral data collection: initial data & outcome collection:
Clinical Quality Registry Minimum Dataset

**DATA SPINE**
from everyone
minimal
epidemiologically sound
no clinical judgement
unchanging
identifiable
linkable
risk adjustable
bench-markable

**DATA RIB**
may be time limited from interested centres typically requires funding

Measurement is foundational to advancing healthcare improvement
Importance of good data

Some administrative data are excellent e.g. Procedure codes

But, others are poor e.g. comorbidities and risk factors. Patient-reported outcomes

### Data and infrastructure

<table>
<thead>
<tr>
<th>Priority</th>
<th>Detail</th>
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<tbody>
<tr>
<td>Clinical quality registries</td>
<td>Provide start-up investment in disease or therapy-focused clinical registries supported by a national framework to maximise interoperability and value of research to clinical practice.</td>
</tr>
</tbody>
</table>

#### Recommendation 3.4:

That departmental monitoring of safety and quality includes monitoring against a comprehensive range of outcome indicators using hospital routine data and data from clinical registries.

#### Recommendation 3.7:

That:

3.7.1. the funding contracts for clinical quality registries funded by the department be renegotiated to provide:

- an explicit requirement for all performance metrics to be provided to hospital chief executives (or their designated nominee) and to the department at the same time as they are fed back to clinical units
- for registries that have been in existence for more than a decade, a full dataset of registry data to the department (the new Victorian Health Performance Authority when established) at least annually to allow matching to, and incorporation in, the relevant routine dataset (the data provided should have the names of individual clinicians removed)

3.7.2. the new Victorian Health Performance Authority publishes metrics derived from clinical registries in its quarterly public report
Exploring one registry- PCOR-Vic
Prostate cancer is:

- The **most** common non-skin cancer in Australian men
- The **second** most common cause of death, behind lung cancer.
- The **most** costly of all cancer types; almost **twice** that of the next two most costly combined, more than **twice** the economic cost of breast cancer, and **more than three times** the economic cost of lung cancer.
- A chronic disease, with 5 year survival at >92% in Australia
- A debilitating disease of older men, associated with a significantly higher risk of suicide compared to men without prostate cancer.
Prostate Cancer Outcome Registry-Victoria

§ Treatment pathways for prostate cancer:
- Surgery
- Radiotherapy
- Active surveillance.

§ Active Surveillance (AS) increasingly being used in the management of low risk prostate cancer.

§ Primary aim of active surveillance – avoid unnecessary treatment of men with low risk disease and monitor them in a manner that enables recognition of signs of progression with the intent of deferred treatment being curative.
§ Established in 2009 to understand reasons for variation in survival and monitor treatment and outcomes

§ Men in rural regions of Australia have a statistically significant and increasing age standardised mortality compared to metro counterparts

   • Victorian data

   • Melbourne Metro 5-year survival = 86%
   • Rest of Victoria 5-year survival = 80%
   • Within rural ICS, 3-fold difference in mortality.


Prostate cancer management according to where you live....

<table>
<thead>
<tr>
<th>Region</th>
<th>Asymptomatic</th>
<th>Symptomatic</th>
<th>Unknown</th>
</tr>
</thead>
<tbody>
<tr>
<td>REGIONAL</td>
<td>74.5%</td>
<td>24.1%</td>
<td>1.4%</td>
</tr>
<tr>
<td>METRO</td>
<td>79.6%</td>
<td>17.8%</td>
<td>2.6%</td>
</tr>
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</table>

Surgical treatment 2008-13

[Heatmap chart showing surgical treatment by year of diagnosis and region]
... and your socioeconomic status

Over-treatment? Under-treatment?
So… more advanced disease is regional patients; less treatment for men in regional Victoria, more treatment in men from high socioeconomic class and in private hospitals….what does all this mean?
### Understanding what good care looks like

<table>
<thead>
<tr>
<th>Good care</th>
<th>(indicators) Measured by...</th>
</tr>
</thead>
<tbody>
<tr>
<td>Good documentation</td>
<td>PSA at diagnosis</td>
</tr>
<tr>
<td></td>
<td>cT documented in medical record</td>
</tr>
<tr>
<td>Treatment is timely</td>
<td>Time from diagnosis to treatment for high-risk disease</td>
</tr>
<tr>
<td></td>
<td>Time from referral to diagnosis</td>
</tr>
<tr>
<td>Treatment is appropriate</td>
<td>Evidence of high-risk men receiving treatment</td>
</tr>
<tr>
<td></td>
<td>Evidence of low-risk men on active surveillance</td>
</tr>
<tr>
<td>Treatment is effective</td>
<td>Risk-adjusted positive surgical margins</td>
</tr>
<tr>
<td></td>
<td>Five-year biochemical recurrence rate</td>
</tr>
<tr>
<td>Treatment is safe</td>
<td>In-hospital death from surgical complication</td>
</tr>
<tr>
<td>Care is patient-centred and</td>
<td>Urinary, bowel and sexual bother by treatments</td>
</tr>
<tr>
<td>responsive</td>
<td></td>
</tr>
</tbody>
</table>

+++ evidence also demonstrates that men should receive adequate info to make informed management choice and receive sexual counselling + more...
Examples of quality improvement - PCOR-Vic
To: Prostate Cancer Foundation of Australia

For: Why are mortality rates for men with prostate cancer higher in Gippsland than in most other Victorian Integrated Cancer Services?

Multiple factors
MDTs are now conducted in the region
Funding provided for radiotherapy equipment and enhanced services
TrueNTH Care Coordination project underway
Lobbying for change to the Red Book on PSA testing
5% more men with high-risk disease having treatment within 12 months of diagnosis.
50% reduction in positive surgical margins in pT2 disease
Reduction in positive surgical margins =

Avoiding 20 PSMS

...is predicted to avoid ~1 premature death,

+5 years $860,000 +

and almost $200,000 in avoided secondary treatment costs

$182,000
Three-fold reduction in men with low risk disease undergoing surgery (currently at 14%)
Reduction in active treatment =

Reducing 10 active treatments in PRIAS patients

...prevents poorer quality of life in 6 patients

1 QALY
$182,000

and results in benefits of $155,000 in avoided treatment costs.

* (not including $ benefits improved Quality of Life)
A (rib) study off PCOR-Vic has identified that

- Only 26.5% of men are receiving surveillance in accordance with minimal requirements
- Men on AS in private hospitals are 80% more likely to have adequate AS compared to men in public hospitals
- Why?

- Registries are platforms for future research
Recommendation 1: Universal contribution to PCOR Vic and share data with local clinical group
Much work still to be done

- More efficient data collection
Much work still to be done

- More efficient data collection
- Better data integration and display

**Indicators**

1. Risk-adjusted survival at 5 years
2. PSA taken at Dx
3. PSA taken post prostatectomy
4. Documentation of cT in medical record
5. Advanced disease and active surveillance (risk adjusted)
6. Percentage of men with high risk disease receiving treatment within 90 days
Much work still to be done

- More efficient data collection
- Better data integration and display
- Balancing transparency with confidentiality

DHHS requirement for reporting

Voluntary nature of registries
Much work still to be done

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- More widespread promotion of registries to quality managers
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- Balancing transparency with confidentiality
- More widespread promotion of registries to quality managers
- Facilitating distribution of registry reports to relevant committees within health services
- Sustained funding
- International benchmarking of quality of care
Summary & Next Steps

- Clinical Registries have proven benefits for increasing knowledge of diseases; for improving clinical care; and for providing a platform for clinical research.

- Australia can learn from international examples where:
  - Registries are embedded into clinical care
  - Registries are embedded into funding mechanisms
  - Registry international benchmarking is core business

- National clinical registry strategy needs to be co-ordinated with jurisdictions and private stakeholders

- Ongoing strategy for sustainable infrastructure and funding required
Many thanks to.....