Funding and sustaining activities for Clinical Quality Registries

Prof Christopher Reid

Outline

1. DLA Phillips Fox Report - Strategy

2. International Funding Models

3. Australian Examples
ACPR Pilot Project

- ACSQHC Project
- Operating Principles and Technical Standards
- Established a patient based cardiac registry
  - Governance
  - Performance Monitoring

- Sustainable Funding Model Recommendations
  (H. Wellington)

1. National Policy

- Designation of a small number of registries
  - Mandatory participation
  - Design, standards and governance
  - Data access/use, & clinician/stakeholder balance

- Mandatory submission of data
  - HCP organisations & clinicians

- Establish regulatory/funding mechanisms
  - Ensure participation in complete & effective
Recommendations

- ACSQHC – key role
- Participation reinforced via policy and purchasing mechanisms
- Independent mechanism to ensure compliance by providers with data quality
- Providers operate under a business as usual model for peripheral data collection
- Broad stakeholder consultation

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Recommendations

- Equitable funding by a range of stakeholders
  - Hospitals
  - Health Insurers
  - Governments
  - Manufacturers
- Assess private/public distribution of procedures to enable consideration of funding responsibility

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# Funding of central registry functions

<table>
<thead>
<tr>
<th>Funding approach</th>
<th>Benefits</th>
<th>Risks</th>
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<tbody>
<tr>
<td><strong>Health service pays</strong></td>
<td>• registry becomes core function of health service</td>
<td>• setting appropriate price</td>
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<td></td>
<td>• costs proportional to volume</td>
<td>• complexity to model</td>
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<td></td>
<td>• reinforces responsibilities of health providers for QA</td>
<td></td>
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<tr>
<td><strong>Shared funding by hospitals, health insurers, govt, device manufacturers</strong></td>
<td>• engages all interested parties</td>
<td>• setting appropriate price</td>
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<td></td>
<td>• establishes broad base for governance</td>
<td>• equitable division of funding among stakeholders</td>
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<tr>
<td></td>
<td></td>
<td>• complex</td>
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<tr>
<td><strong>Govt funding</strong></td>
<td>• simple to manage</td>
<td>• potentially disenfranchise some of the interested parties</td>
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Adapted from: Funding for Clinical Quality Registries – the Australian Cardiac Procedures Registry. H. Wellington, DLA Phillips Fox, 2011

## Characteristics of a registry

- **Hospital 1**
- **Hospital 2**
- **Hospital 3**
- **Hospital 4** etc

**Governance process**

**Central data collation**
- identical collection methods
- identical definitions

**Quality control**

**Systematic outcome assessment**

Victorian Cardiac Outcomes Registry (VCOR)

Monash University

CCRE Therapeutics
International Funding Models

A system of about 100 national quality registries dating back to the 1970s.
A unique opportunity to monitor the results and quality of health care services

Originally a resource reserved for a small group in the medical professions, the registries have now become one of the foremost tools for improvement efforts and quality follow-up within Swedish health care.

International Funding Models

Since 1990, the Swedish Government and the county councils have allocated special funding to quality registries.
In 2011, the Swedish Government decided together with the Swedish Association of Local Authorities and Regions (SALAR) to increase the funding to the quality registries;
  • substantially with the aim of increasing the quality of data as well as the percentage of patients participating
  • This is to create a system in which quality registries are the core in terms of measuring health outcomes, conducting research and improving the quality of care.
Hospital scores on the RIKS-HIA Swedish Coronary Care Registry Quality Index, 2005-09

Quality index | Index rankings became public
--- | ---
6 | 5
5 | 4
4 | 3
3 | 2
2005 | 2006 | 2007 | 2008 | 2009
--- | --- | --- | --- | ---
All hospitals (n=69) | Below average hospitals in 2007 (n=34)

RIKS-HIA annual reports 2005-09

Research registries?

THE NEW ENGLAND JOURNAL OF MEDICINE

ORIGINAL ARTICLE

Thrombus Aspiration during ST-Segment Elevation Myocardial Infarction

Ole Fröbert, M.D., Ph.D., Bo Lagerqvist, M.D., Ph.D., Göran K. Olvecrona, M.D., Ph.D., Elmir Omerovic, M.D., Ph.D., Thorarinn Guðnason, M.D., Ph.D., Michael Maeng, M.D., Ph.D., Mikael Aasa, M.D., Ph.D., Oskar Angerås, M.D., Fredrik Calais, M.D., Mikael Danielewicz, M.D., David Erlinge, M.D., Ph.D., Lars Hellsten, M.D., Ulf Jensen, M.D., Ph.D., Agnete C. Johansson, M.D., Amra Kåregren, M.D., Johan Nilsson, M.D., Ph.D., Lotta Robertson, M.D., Lennart Sandhall, M.D., Ivar Sjögren, M.D., Ollie Östlund, Ph.D., Jan Harnek, M.D., Ph.D., and Stefan K. James, M.D., Ph.D.

NEJM, 1st September 2013
Research registries?

METHODS

We conducted a multicenter, prospective, randomized, controlled, open-label clinical trial, with enrollment of patients from the national comprehensive Swedish Coronary Angiography and Angioplasty Registry (SCAAR) and end points evaluated through national registries. A total of 7244 patients with STEMI undergoing PCI were randomly assigned to manual thrombus aspiration followed by PCI or to PCI only. The primary end point was all-cause mortality at 30 days.

Results

0 – lost to follow-up
2.8% v 3.0% - P=0.63
RTA – no effect on mortality

NEJM, Sept 1st 2013

What’s the future for Registry Research Initiatives?

The Randomized Registry Trial — The Next Disruptive Technology in Clinical Research?

Michael S. Lauer, M.D., and Ralph B. D’Agostino, Sr., Ph.D.

The randomized trial is one of the most powerful tools clinical researchers possess, a tool that enables them to evaluate the effectiveness of new (or established) therapies while accounting for United States and abroad have collected vast amounts of data from patients with acute coronary syndromes, stable coronary disease, and heart failure, as well as from patients with rare diseases

Transforms existing standards, procedures and cost structured
International Funding Models

Directly funds > 20 registries
Not focussed on “Clinical quality registries”
Voluntary participation
Clinical Trial recruitment

International Funding Models

Consortium of funding
Major focus on Quality, Safety and Benchmarking
Voluntary participation - pay for participation

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Operational Since 2001

28/48 surgical units involved nationally, 10/14 in Victoria (all publics collecting since inception)

Governance

- ACSRIL Pty Ltd
  - Board of Directors (ANZSCTS)
  - Registry Steering Committee
  - Peer Review Committee
  - Research Committee
  - Contracts Running of registry to SPHPM

Consortium of Funders

- DHS Vic (since 2001) – 3 year cycle
  - 6 Victorian Public Hospitals
  - Current contract remains under review
- Clinical Excellence Commission (NSW)
  - 8 NSW Area Health Services
  - Annual Contract – always behind
- Individual Private Hospital Funding
  - 3 year contracts

Deliverables

- Public / National / State / Hospital Annual Reports
- Quarterly KPI reviews
VCOR Registry

- Operational Since 2012
- 22/29 Victorian PCI units involved
- Governance
  - Steering Committee
    - Stakeholder Representation (Funders + Hospitals)
    - Quality Review Committee
    - Contracts Running of registry to SPHPM

VCOR Registry

- Consortium of Funders
  - DHS Vic – 3 year funding
    - Victorian Public Hospitals
    - Regional non PCI AMI module
  - Medibank Private – 3 year funding

- Deliverables
  - State / Hospital Annual Reports
  - Quarterly KPI reviews
Progress in Australia

NJRR – Device Manufacturers funding

National Prostate Cancer Registry- Movember

AuSCR – consortium Stroke Society, Florey and George Institutes - partnership funding with NHMRC

Breast Implant – Plastic Surgeons Society (DOH)

Bariatric Surgery - Medicare / Bariatric Surgeons

Colorectal Surgery Registry – CSSANZ

2013 DOHA Tender for 2 Clinical Quality Registries

High Risk Cardiac Implantable devices
Breast Device Registries

~$5 M for 2 years

After the 2 year funding from DOHA – Device Companies?
Summary

- **Consortium of Funders**
  - Highly desirable
  - Achievable
  - Sustainable

- **Issues**
  - Site funding models
    - Public versus Private
  - Longer term sustainability

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