

Clinical registries

Achieving sustainable funding

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***“Science tells us what we can do;
Guidelines what we should do;
Registries what we are actually doing.”***

**Ralph Brindis, MP MPH, FACC
Immediate past CMO and chair, ACC National Cardiovascular Registry**

Overview of presentation



- 1. The Australian Cardiac Procedures Registry project**
- 2. The impact of registries on cost and quality**
- 3. Existing funding models**
- 4. The case for sustainable funding of the ACPR**
- 5. Parameters for sustainable funding**
- 6. Elements of a funding framework**

The ACPR project



- 1. Developed through a project sponsored by the Australian Commission for Safety and Quality in Health Care (ACSQHC) and undertaken by Monash University Centre for Research Excellence in Patient Safety (CREPS) and the Australian Society of Cardiothoracic Surgeons**
- 2. Builds on the ASCS Victorian database project and MIG Percutaneous Coronary Intervention (PCI) registry**
- 3. Includes implantable devices such as pacemakers and implantable defibrillators**

The ACPR project



- 1. Minimum dataset of essential epidemiologically sound data items**
- 2. Annual accrual of 85,000-90,000 records**
- 3. Comorbidity data are collected**
- 4. Outcome data are sought routinely**
- 5. 'Opt out' recruitment**
- 6. Strong research environment**
- 7. Robust quality control**
- 8. Strong governance and management**

The ACPR project



Identifying an adequate and reliable funding base is critical to the sustainability and effectiveness of the ACPR

The impact of registries on cost and quality



- **To achieve funding, need to convince potential funders and/or government that the registry will have a sustained positive cost-benefit impact**
- **The most compelling immediate purpose for many decision-makers to fund is quality initiatives in health care is to reduce cost**
- **Quality as an end in itself is, however, important to many**

The impact of registries on cost and quality



- **Extremely challenging to prove that funding a registry will reduce health care costs (at least per patient), but much indirect evidence:**
- **Existing registries used for economic analysis (e.g. *The economic impact of end-stage kidney disease in Australia* (ANZDATA))**
- **Findings of the Australian Orthopaedic Association 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.**

The impact of registries on cost and quality



- **Since its inception in 2001, the Victorian State Trauma Registry has demonstrated a 30% reduction in mortality among trauma victims**

Existing funding models



- **No standard approach**
- **Usually ‘bottom up’ approaches, which often are unsustainable**
- **Small number have achieved consistent external funding, e.g.**
 - **Private operation, mixed public/private funding (e.g. ANZDATA – government, Kidney Health Australia, industry sponsorship – and National Breast Cancer Audit – NBOCC, National Breast Cancer Foundation and Australian Government)**

Existing funding models



- **Small number have achieved consistent external funding, e.g.**
 - **Private operation, Australian Government funding with cost recovery (NJRR)**
 - **Australian Government operations and funding (National Diabetes Registry)**
 - **Private operation, State Government funding (ANZICS Paediatric Intensive Care Registry)**
 - **Private operation and funding (Australian Cystic Fibrosis Data Registry)**

Existing funding models



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 - **Private operation and funding (Australian Cystic Fibrosis Data Registry)**
- **Some concerns about actual/perceived conflict of interest with various funding models**

The case for sustainable funding of the ACPR



- **The burden of disease**
- **Quality improvement potential**
- **Potential economic benefits:**
 - **expenses relating to cardiovascular disease consumed approximately 11% of health expenditure, almost \$6 billion) in 2004-05**
 - **US data suggest that almost 14% of patients experience at least 1 adverse event following CABG**
 - **50,000 Australians a year with hospital admissions for heart failure**
 - **35,000 PCIs annually, 3% with prolonged hospitalisation due to complications**

The case for sustainable funding of the ACPR



Stakeholder support for registries is broadly-based:

- **The Heart Foundation**
- **The AHIA**
- **The review of private health insurance prostheses listing arrangements**
- **The Australian Government Review of Health Technology Assessment in Australia**
- **AIHW has commented on the lack of a registry**
- **Research Australia**
- **AMA**
- **Health consumers**
- **NHHRC**

Parameters for sustainable funding



- **Adequate funding (to cover core infrastructure, data collection, analysis and reporting, patient follow up, quality control, reporting, governance and ‘registry science’)**
- **An acceptable cash flow**
- **Simplicity**
- **An equitable distribution of funding obligation**
- **Assured funding for a reasonable period**
- **A funding approach that aligns with performance objectives**
- **Role clarity**

Elements of a funding framework



Who will benefit (so who might fund)?

- **Payers (e.g. individual consumers, governments, private health insurers)**
- **Providers (e.g. public and private hospitals, clinicians, device and pharmaceutical manufacturers)**
- **Policy makers and regulators**
- **Consumers**

Elements of a funding framework



- **Stakeholder expectations**
 - **Stakeholders (e.g. health insurers, device manufacturers) are interested**
 - **Appropriate standards of operation**
 - **Transparency and accessibility of information**
 - **Engagement in governance**
 - **?A link to regulation**
- **Neither clinicians, consumers or educational/advocacy bodies expect to pay (and we agree)**

Elements of a funding framework



- **A potential national policy framework**
 - **A small number of national registries**
 - **Designated criteria for relevance**
 - **Meet agreed design, operational and governance standards**
 - **‘Centres of excellence’ for central registry functions**
 - **Equitable funding by those who benefit**
 - **Mandated submission of data where public benefit**
 - **Funding of peripheral functions (i.e. data submission) the responsibility of providers**
 - **Participants have the opportunity to engage in registry governance**
 - **?an overall governance role for ACSQHC**

Elements of a funding framework



- **Data interpretation/clinical issues need to continue to be the responsibility of clinicians – this is critical for both credibility and engagement**
- **There needs to be sufficient scrutiny of processes to satisfy stakeholders that they are objective and robust**

Elements of a funding framework



‘Business as usual’ or grant funding

- **‘Business as usual’ would follow usual funding flows – for each procedure performed, data would be collected locally and submitted, together with a payment, to the registry custodian for management**
- **‘Business as usual’ is more logically sustainable, but challenging because:**
- **funding streams are fragmented, complex and interconnected; and**
- **organisations and clinicians will make choices about their investment of time and money depending on where they see the greatest risk and return. The more discretionary participants in a funding system, the more likely is the system to fail**

Elements of a funding framework



‘Business as usual’ may result in:

- **Excessive complexity**
- **Inequitable assumption of responsibility**
- **Inconsistency**
- **Uncertain funding flows**
- **But ‘business as usual’ would strongly align objectives by engaging providers in quality systems**
- **Grant funding would be simpler, but may be less reliable**

Elements of a funding framework



- **As an alternative to ‘business as usual’ funding, a grant-based funding system could be implemented involving:**
 - **Governments**
 - **Device manufacturers**
 - **Health insurers**
- on the basis of proportionate expected benefit and alignment with objectives**

Elements of a funding framework



- **Engagement in peripheral functions is critical to overall success and public benefit**
- **Participation should be mandated where public interest can be shown**
- **Could use regulatory or funding mechanisms**
- **Will need to incorporate mechanisms to ensure quality data (as well as quantity)**

Next steps



- **ACPR report to be submitted to ACSQHC**
- **ACSQHC undertaking further work and discussion with AHMAC**
- **The vision is a small number of well-run, well-governed registries, properly funded, with complete participation, having a substantial influence on the safety and quality of Australian health care**

For discussion

