The contribution of clinical outcomes registries globally

February 2013

THE BOSTON CONSULTING GROUP
Agenda

Value based healthcare and outcomes registries

Global comparisons of progress

The size of the prize
Where are we coming from

Countries are very worried about how much money is being spent on healthcare

However, efforts to curb this have been spectacularly unsuccessful, especially in the US, where costs are highest

We would say health expenditure itself is irrelevant - what is relevant is the value that healthcare spending generates for each dollar spent – productivity, quality of life, social cohesion and happiness

If we could guarantee that health spending improved outcomes, individuals and broader society would not be too fussed about the level of health care spending

This broad body of work focuses on how we might use clinical outcomes data to get closer to this "value optimised state".

• A global study of how different countries collect and use health outcomes data
• A methodology and set of early results on the "size of the prize" from clinical outcomes measurement and management
Agenda

Value based healthcare and outcomes registries

Global comparisons of progress

The size of the prize
Evaluation of international outcomes data landscape
BCG has sought to address Government's need to understand health outcomes data collection and use

139 interviews conducted between April and September 2011
- Exposure to national health departments and health outcomes experts
- Detailed understanding of experiences, successes and challenges faced by registry and health repository owners

Results from 12 countries contribute to database of benchmarks and analysis
- New projects in additional countries is continuing to contribute to centralised benchmarking database
- Country specific materials for each of the core countries identifying road blocks and proposed next steps

Case studies and best practices identified
- Recognition of innovative examples of registry development

Best practice case studies can provide examples of successful approaches to overcome typical roadblocks in health outcomes data collection

Source: BCG interviews and analysis 2011
Monash Summary deck 2013 meeting.pptx
BCG's "maturity assessment framework" examines potential to establish Value Based Health Care for a country

A general overview of system preparedness...

... combined with a deep dives into 12 health data repositories or registries

**National Foundations for Value Based Health care**

- Acute
  - Stroke
  - Acute myocardial infarction
  - Diabetes
- Chronic
  - Chronic renal failure
  - Hip arthroplasty
  - Spine surgery
- Surgical
  - Knee arthroplasty
  - Cataract
  - Leukaemia and lymphoma
- Cancers
  - Breast cancer
  - Digestive tract cancers
  - Leukaemia and lymphoma
- Psych
  - Schizophrenia

**Extent to which National Platforms in place National Infrastructure & Public and Policy Engagement**

**Extent to which Clinician Engagement exists**

**Existing Data Richness & Quality**

**Sophistication of Data Use**
The performance against these success factors can be determined using data collected in the maturity assessment.

**National platforms**

- **Standards**
  - Systematization across care settings of what information is recorded
  - Multi-registry platforms to increase coverage
- **IT Infrastructure**
  - Easy to use (IT) interface for data collection and dissemination
  - Easy to collect data and share results
- **Cost linkage**
  - Cost of procedures can be accurately tracked
- **Legal and consent**
  - A legal and consent framework that supports data collection and use
- **Government engagement**
  - Access for clinicians to a sufficient, stable funding source
  - Commitment from Government to improving health care value
  - A willingness by government to let go of some elements of outcomes measurement control
- **Patient / Public engagement**
  - Patients actively seek cost and quality information and use it in their decision making processes

**Clinician engagement**

- **Clinicians**
  - Passionate core team from the affected discipline with shared responsibility, common vision, strong leadership and an entrepreneurial spirit
  - Broader ongoing commitment from specialists and clinicians with active engagement in data quality and risk adjustment
  - Independent registry governance with relevant stakeholder representatives

**Data richness & quality**

- **Data richness & quality**
  - Practical
  - Quality Controlled
  - Appropriate risk adjustment possible and clinician identified
  - Designed with a view to being able to answer research question(s)

**Sophistication of data use**

- **Sophistication of data use**
  - Systematic, fast feedback of results
  - Learnings linked to feedback
  - Use of data in the clinic and in publications by physicians delivers increased confidence
  - Incentives to keep pushing the growth of registry participation
  - Cooperative national agenda that places outcomes based assessment of HC on the National Agenda

**Virtuous Cycle of Successful Health Outcomes Data Collection and Use**
Assessments have provided a comparative view of country progress and suggest four key success factors...

Four broad themes are essential components to successfully collect and use health outcomes data

1. **National Platforms**
   - Common national standards and IT infrastructure
   - National legal and consent frameworks
   - Cost-linkage capability
   - Government and public/patient engagement

2. **Clinician Engagement**
   - Passionate core team with a broader ongoing commitment and independent governance structure
   - Value of data collection understood and shared by clinician group
   - Data collection not perceived as unnecessary burden

3. **Data Quality**
   - Practical, quality controlled rich data collections
   - Clinician identified risk adjustors collected and applied
   - Coverage and penetration of patient group

4. **Sophistication of Data Use**
   - Systematic, regular reporting of results linked to feedback
   - Data used in the clinic and in public reporting
   - Incentives aligned with outcomes and reporting of data

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Note: National enablers is average of scores for 1a(all), 1b (all); Data richness and quality and sophistication of use is average of 2a (all), 2b (all), 2c1–3, and 3 (all, except 3.5).

Source: BCG interviews and analysis 2011
Government actions focused at early stage of registry maturity value chain – other players best placed to act later

Value chain for evolution of individual registry maturity

<table>
<thead>
<tr>
<th>Immature</th>
<th>Mature</th>
</tr>
</thead>
<tbody>
<tr>
<td>Funding</td>
<td>Consent legislation &amp; ethics approvals</td>
</tr>
<tr>
<td>Database Platform creation</td>
<td>Defining required metrics</td>
</tr>
<tr>
<td>Record population</td>
<td>Provider Feedback</td>
</tr>
<tr>
<td>Analysis</td>
<td>Comparative reporting</td>
</tr>
<tr>
<td>Guidelines</td>
<td>Reimbursements</td>
</tr>
</tbody>
</table>

Government

Payers/Insurers

Suppliers

Academics and 3rd parties

Provider groups/(incl prof. orgs)

Individual clinicians

1 National Platforms

2 Clinician Engagement

3 Data Richness and Quality

4 Sophistication of Data Use

Recommended responsible group
### Results segmented along dimensions driving registry success

Australia has opportunity to improve government engagement, legal & consent and data use

<table>
<thead>
<tr>
<th>Criteria Included</th>
<th>NED</th>
<th>GER</th>
<th>HUN</th>
<th>USA</th>
<th>AUT</th>
<th>JPN</th>
<th>NZ</th>
<th>AUS</th>
<th>UK</th>
<th>CAN</th>
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</tr>
<tr>
<td>• Standards</td>
<td>1b1, 1b2</td>
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<td>3.0</td>
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<td>3.0</td>
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<td>3.5</td>
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<td>• Cost linkage</td>
<td>1b5, 2a6</td>
<td>2.0</td>
<td>1.0</td>
<td>2.0</td>
<td>1.8</td>
<td>2.0</td>
<td>2.3</td>
<td>2.4</td>
<td>2.3</td>
<td>1.5</td>
<td>1.6</td>
<td>2.8</td>
</tr>
<tr>
<td>• Legal &amp; Consent</td>
<td>1b6</td>
<td>5.0</td>
<td>3.0</td>
<td>3.0</td>
<td>3.0</td>
<td>3.0</td>
<td>4.0</td>
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<td>4.0</td>
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<tr>
<td>• Government</td>
<td>1a3-5</td>
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<td>2.3</td>
<td>2.3</td>
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<tr>
<td>• Patients / public engagement</td>
<td>1a6</td>
<td>4.0</td>
<td>2.0</td>
<td>1.0</td>
<td>3.0</td>
<td>3.0</td>
<td>3.0</td>
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<td>2.0</td>
<td>4.0</td>
<td>5.0</td>
<td>4.0</td>
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<td><strong>Clinician engagement</strong></td>
<td>1a1, 1a2, 2c4, 2c5</td>
<td>2.3</td>
<td>2.5</td>
<td>2.4</td>
<td>2.6</td>
<td>2.6</td>
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<td>3.2</td>
<td>3.8</td>
<td>3.6</td>
<td>3.5</td>
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<tr>
<td><strong>Data richness and quality</strong></td>
<td>2a (all), 2b (all), 2c1-3</td>
<td>1.7</td>
<td>2.1</td>
<td>2.3</td>
<td>2.0</td>
<td>2.4</td>
<td>2.4</td>
<td>2.6</td>
<td>3.0</td>
<td>3.0</td>
<td>3.0</td>
<td>3.6</td>
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<tr>
<td><strong>Data utilisation</strong></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>• Sophistication of data use</td>
<td>3 (all, except 3.5)</td>
<td>1.4</td>
<td>1.4</td>
<td>1.4</td>
<td>1.6</td>
<td>1.6</td>
<td>2.3</td>
<td>1.7</td>
<td>2.2</td>
<td>2.3</td>
<td>2.0</td>
<td>2.0</td>
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<tr>
<td><strong>Overall maturity</strong></td>
<td>2.0</td>
<td>2.0</td>
<td>2.1</td>
<td>2.2</td>
<td>2.4</td>
<td>2.6</td>
<td>2.6</td>
<td>2.6</td>
<td>2.9</td>
<td>3.0</td>
<td>3.2</td>
<td>3.6</td>
</tr>
</tbody>
</table>

Note: Overall maturity is average of all criteria (except 3.5) with equal weighting.
Significant variability exists in both quality and coverage

In Australia, successful registries emerge where profession is contained and clinicians highly motivated.

**Health data repository coverage of 12 conditions assessed using the Maturity Assessment Framework**

<table>
<thead>
<tr>
<th>Disease burden</th>
<th>Proportion of burden covered by registry</th>
<th>Proportion of National burden of disease</th>
</tr>
</thead>
<tbody>
<tr>
<td>AMI$^1$</td>
<td>10%</td>
<td>60</td>
</tr>
<tr>
<td>Stroke$^2$</td>
<td>86%</td>
<td>60</td>
</tr>
<tr>
<td>Digestive tract cancers$^3$</td>
<td>100%</td>
<td>95</td>
</tr>
<tr>
<td>Diabetes$^4$</td>
<td>14%</td>
<td>40</td>
</tr>
<tr>
<td>Hip, knee, spine$^5$</td>
<td>100%</td>
<td>95</td>
</tr>
<tr>
<td>Breast cancer$^3$</td>
<td>60%</td>
<td>100</td>
</tr>
<tr>
<td>Leukaemia and Lymphoma$^3$</td>
<td>100%</td>
<td>100</td>
</tr>
<tr>
<td>Schizophrenia$^6$</td>
<td>5%</td>
<td>100</td>
</tr>
<tr>
<td>Cataracts$^7$</td>
<td>0.4%</td>
<td>0%</td>
</tr>
</tbody>
</table>

1. AMI: PCI coverage is ~10%, cardiac procedures registry coverage of cardiothoracic surgery is ~60% (from Chris Reid). AMI coverage updated to coverage of PCI (10%). 2. Stroke: estimated 5k events in pilot year at 3 hospitals and year following with a broader roll out in 2011 estimated 60k strokes (http://www.strokefoundation.com.au/facts-figures-and-stats), indicates a coverage of ~8% of all events nationally however of hospitalised events coverage is 14% with a plan to expand to 30k of 35k of hospitalised incidents in the coming year. 3. All cancers were taken from the Australian cancer clearing house which has 100% coverage of cancers identified however it is only in state level data sets that some capture outcomes. Digestive tract cancers coverage was the proportion of these cancers classified as bowel cancer as this is what the cancer registry in Australia covers. 4. Diabetes: 130k cases on register in 2009 (assumed incidence), national incidence of 90k in 2008 plus gestational diabetes of 12k, therefore assume total incidence in 2009 of ~95k. Coverage = 14%. 5. Hip, Knee and Spine has 99.96% coverage of Hip and Knee procedures in Australia and increasing coverage of spine, however only a proportion of Hip, Knee and Spine result in arthroplasty. Coverage is assumed at 100%. 6. Schizophrenia: Estimated coverage is ~40% of the total population, coverage is much higher in high risk patients and those diagnosed in childhood. Coverage is geographically driven major east coast cities incl Orange, Newcastle and some rural coverage also covers family members. 7. 100% of surgeons captured and 100% of dialysis and transplant patients captured. Does not cover untreated CRF. Note: Registry quality score is average of maturity assessment criteria 2a1-5, 2b2-3 and 2c2-3. An average score of “1” is “Not covered by existing registry”, “1.1-2.5” is assigned “Low quality of coverage”, “2.6-3.5” is “Medium quality coverage”, “3.6-5” is “High quality coverage”. Source: WHO (Feb 2009, Estimated total DALYs (‘000), by cause and WHO Member State, 2004), BCG analysis.
Three major challenges for Australia to address to improve health outcomes data collection and usage

1. **Fragmentation**
   - **Australia’s health system is highly fragmented which has led to**
     - Differing health priorities emerging between States and a lack of national alignment in health care
     - Registries are being established at the State or hospital system-level with limited communication across jurisdictions leading to
       - A proliferation of registries competing for the same resources
       - Data collected using different standards with limited opportunities for interoperability
       - Data collected with a different focus which further limit interoperability or consolidation to form a single national dataset

2. **Consent legislation**
   - **Achieving coverage and linking existing data is a significant challenge in a fragmented system such as Australia’s**
     - Lack of currently active personal health identifier presents challenges for linking datasets to add further richness of the data collected e.g. deaths linkage, cross-condition linkage
     - Achieving high-level of coverage nationally can be a significant challenge, particularly for new registries as a national system for ethics approval to collect data is absent

3. **Funding**
   - **To date health data collection has not been a national priority in Australia**
     - Registries are often significantly underfunded and exist as 'cottage industries' due to fragmented funding
     - Some registry owners have established independent funding approaches however, where this relies on State government funding data collection which propagates increasingly localised registries
     - Insufficient funding paired with limited visibility of the national data collection agenda, can lead to custom builds for data collection and storage, wasting resources and increasing challenges for linking datasets
Agenda

Value based healthcare and outcomes registries

Global comparisons of progress

The size of the prize
Transparency and best-practice sharing loop leads to improved outcomes, sustainability and risk mitigation

Registries enable a continuous feedback loop ...  

... which improves

1. Outcomes
2. Sustainability
3. Risk mitigation

Clinician-led outcomes and metrics

- Transparent outcomes data
- Cycle starts here
- Continuous improvement
- Adoption of best practice
- Identification and dissemination of best practice

International comparisons
Macro-view: Outcomes in the USA are as poor as costs are high

Source: stats.oecd.org, BCG analysis
If the USA had OECD median health outcomes, it would deliver 2.4m extra years of life p.a. worth ~$500m

Potential Years of Life Lost (millions) (projected to 2011 USA <65 population)

- USA 2008 rate
- Potential improvement to 2008 OECD median
- Resulting potential performance

Value of avoided potential years of life lost if USA achieved OECD median health outcomes ($b)

Indicative Value of a Statistical Life Year

x $213,000 = $502

1. Moderately conservative option from FDA based on $7.9m Value of a Statistical Life as used by the FDA in 2011 [http://www.fda.gov/downloads/Food/LabelingNutrition/UCM249278.pdf]

Note: External causes of mortality were not projected to the median as they are too significantly driven by non-health system factors.

Source: Stats.oecd, BCG analysis

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A micro-example – heart attacks

Health Outcome: 30-day in-hospital mortality rate (AMI) (%)

Proxy for resource intensity: Average length of stay (AMI)

Source: OECD Data, BCG analysis
Swedish AMI registry has seen significant improvement in outcomes

Swedish RIKS-HIA data: % mortality within 30 days after AMI by provider

Standard deviation in % mortality within 30 days after AMI by provider

Note: Sweden’s population ~9m
1. Only hospitals with >20 patients over 80 years old in 2010
2. Source: Swedish AMI RIKS-HIA.
Swedish v UK AMI outcomes

Advanced registry: Sweden

Emerging registry: UK

Deaths within 30 days of emergency admission to hospital: myocardial infarction per 100,000 males (35-74yo) (age and diagnosis standardised)

Source: Swedish AMI RIKS-HIA, NHS Indicators

Monash Summary deck 2013 meeting.pptx
Sweden's AMI registry helped generate $159m p.a. in improved health outcomes in 2011.

Swedish RIKS-HIA data: % mortality within 30 days after AMI by provider.

Incidence of AMI in Sweden in 2011 ('000s)

Increased AMI survival in Sweden in 2011 ('000s)

2012 AUD per year ($m)

Other value levers: Opportunities for disinvestment

NIKE identified four indication groups (IGs) with common responses to surgery...

...which created the potential for $8m per year in disinvestment

Swedish Cataract surgeries (’000s)

<table>
<thead>
<tr>
<th>Indication: Cataract symptoms (0 = fewest symptoms)</th>
<th>Indication: Independence (0 = most independent)</th>
</tr>
</thead>
<tbody>
<tr>
<td>-1.69 IG1, -1.38 IG2, -0.20 IG3, +0.15 IG4</td>
<td>-1.96 IG1, -1.06 IG2, -0.19 IG3, +0.20 IG4</td>
</tr>
</tbody>
</table>

"In IG 4 some item areas (perceived difficulties in day-to-day life and cataract symptoms) even deteriorated after surgery"

If applied to Australia, could represent an up to $70m per year savings potential

Number of Cataract surgeries in Australia ('000s)

- OECD Data: 207
- 2009 estimated breakdown:
  - IG4: 28%
  - IG3: 54%
  - IG2: 14%
- 2009 potential: 179
- Potential disinvestment: $2500 x 14% = $70m

14% of acute costs

Other value levers: Risk management

**Background**
- AOA recognised need for NJRR
- DoHA committed funding
- NJRR established
- National coverage

**Risk Management**

From NJRR Annual Reports

1993 1998 1999 2002

- 2008
  - Higher metal-on-metal revision rates
  - "interpreted with considerable caution"

- 2009
  - Began measuring bearing surface
  - Higher metal-on-metal revision rates
  - "interpreted with caution"

- 2010
  - Higher metal-on-metal revision rates
  - "now clear"

- 2011
  - Higher metal-on-metal revision rates certain and with detailed analysis

**Implications**

**The New York Times**
"Australia’s registry’s director, Dr. Stephen Graves. ‘I think that J. & J. has a major issue with DePuy.’"

Multinational Assessment: "the rate of revision ... was at least twice that of all ...total hip replacements."

3,500 US lawsuits against J. & J.

"NJRR was instrumental in Australia being the first country to withdraw the DePuy metal-on-metal"

**NJRR was critical to assessing the risks posed by metal-on-metal hip replacements**

AOA: Australia Orthopaedic Association, NJRR: National Joint Replacement Registry
Australian focus: Stroke
Appears to be significant opportunity for Australia to improve clinical performance in stroke

OECD Admission-based Ischemic stroke 30 day in-hospital mortality rate
*Age-sex standardised rate (%)*

Source: OECD Stats
Monash Summary deck 2013 meeting.pptx
If Australia achieved OECD 1st quartile by 2020, 30-day mortality in 2020 would reduce by ~1800, worth $0.5b p.a.
Significant gap in registries literature addressing the value of registries to the health system and economy

Selected bottom-up value projections for USA

<table>
<thead>
<tr>
<th>Condition</th>
<th>Potential value per annum US $ billion</th>
</tr>
</thead>
<tbody>
<tr>
<td>AMI</td>
<td>2</td>
</tr>
<tr>
<td>Cancer - Colon</td>
<td>4</td>
</tr>
<tr>
<td>Cancer - Breast</td>
<td>7</td>
</tr>
<tr>
<td>CHF</td>
<td>6</td>
</tr>
<tr>
<td>Diabetes</td>
<td>1</td>
</tr>
<tr>
<td>Asthma</td>
<td>1</td>
</tr>
<tr>
<td>Total</td>
<td>21</td>
</tr>
</tbody>
</table>

Challenges

- Accessing variation of outcomes data
- Accessing variation of costs data
- Accessing outcomes data other than mortality and readmission
- Finding examples of existing value demonstrations from registries
  - e.g. NJRR $44.6m

1. VSLY = Value of a Statistical Life Year. 2. Medicare 3. AHRQ, 4. CDC
Note: All projected to the median. Opportunity to expand to other cancers: Brain and Other Nervous System, Cervix, Colon and Rectum, Corpus and Uterus, NOS, Esophagus, Female Breast, Female Breast (in situ), Hodgkin Lymphoma, Kaposi Sarcoma, Kidney and Renal Pelvis, Larynx, Leukemias, Liver and Intrahepatic Bile Duct, Lung and Bronchus, Melanomas of the Skin, Mesothelioma, Myeloma, Non-Hodgkin Lymphoma, Oral Cavity and Pharynx, Ovary, Pancreas, Prostate, Stomach, Testis, Thyroid, Urinary Bladder.