BCG

The contribution of clinical outcomes registries globally

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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 health care spending generates for each dollar spent – productivity, quality of life, social cohesion and happiness

If we could guarantee value-based health care investment, 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

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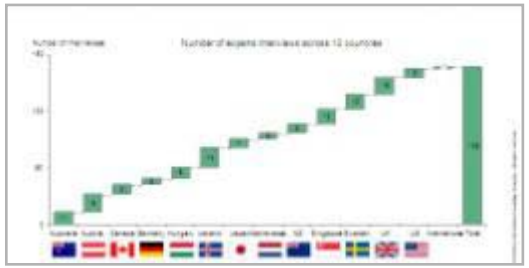
Evaluation of international outcomes data landscape

BCG has sought to address Government's need to understand health outcomes data collection and use

~140 health outcomes data collection experts interviewed



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

12 countries assessed in initial project scope

- 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

Case studies drawn from best-in-class-registries approaches

- 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

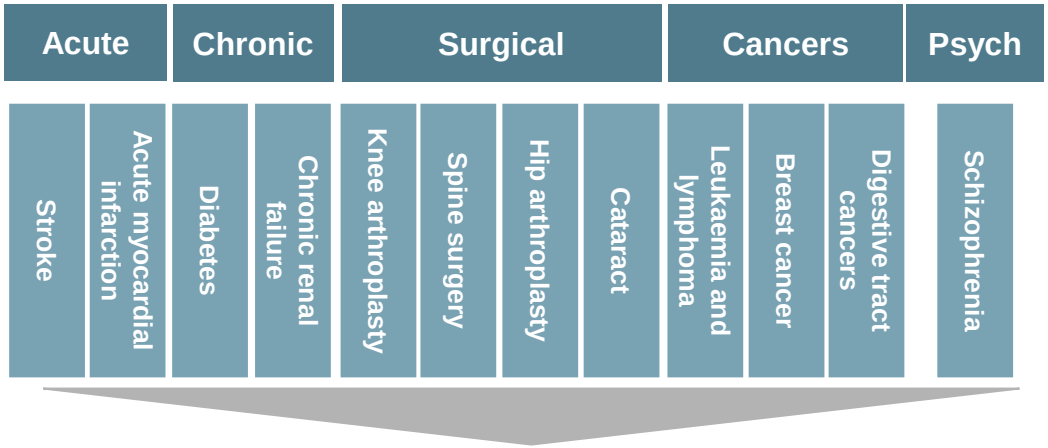
Source: BCG interviews and analysis 2011

BCG's "maturity assessment framework" examines potential to establish Value Based Health Care for a country

A general overview of system preparedness...

National Foundations for Value Based Health care

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



Extent to which <u>National Platforms</u> in place *National Infrastructure & Public and Policy Engagement*

Extent to which <u>Clinician Engagement</u> 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

1 National platforms

Standards
- Systemization 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

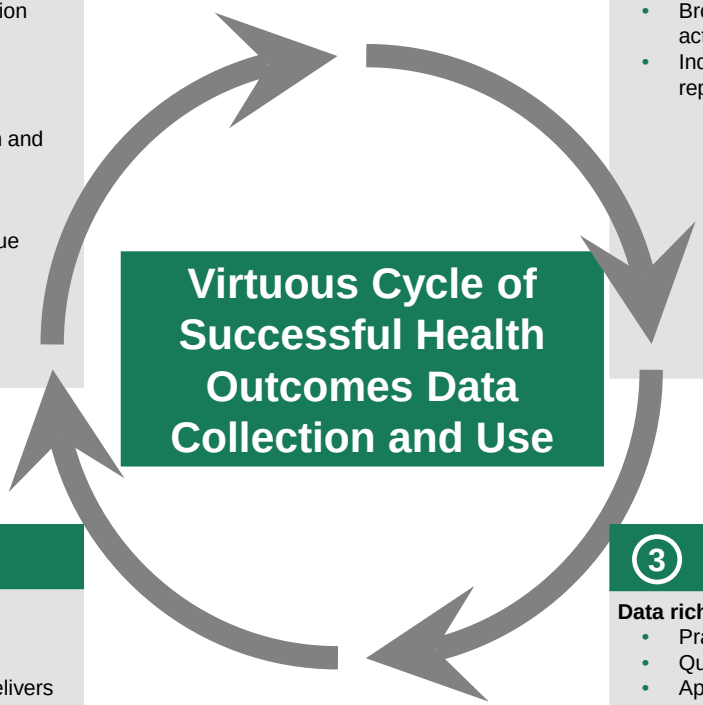
Legal and consent
- A legal and consent framework that supports data collection and use

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

2 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



4 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

3 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)

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

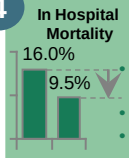
2 Clinician Engagement

- 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

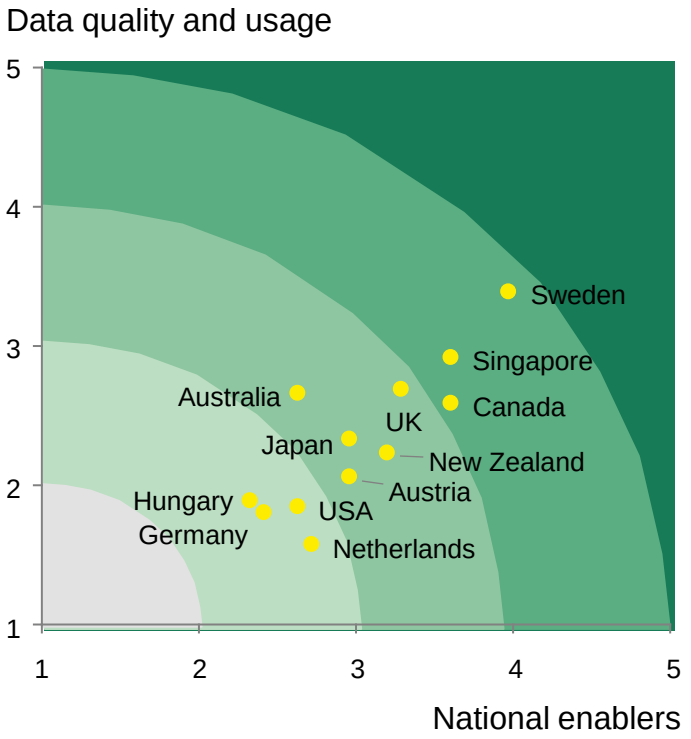
4 Sophistication of Data Use



- 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

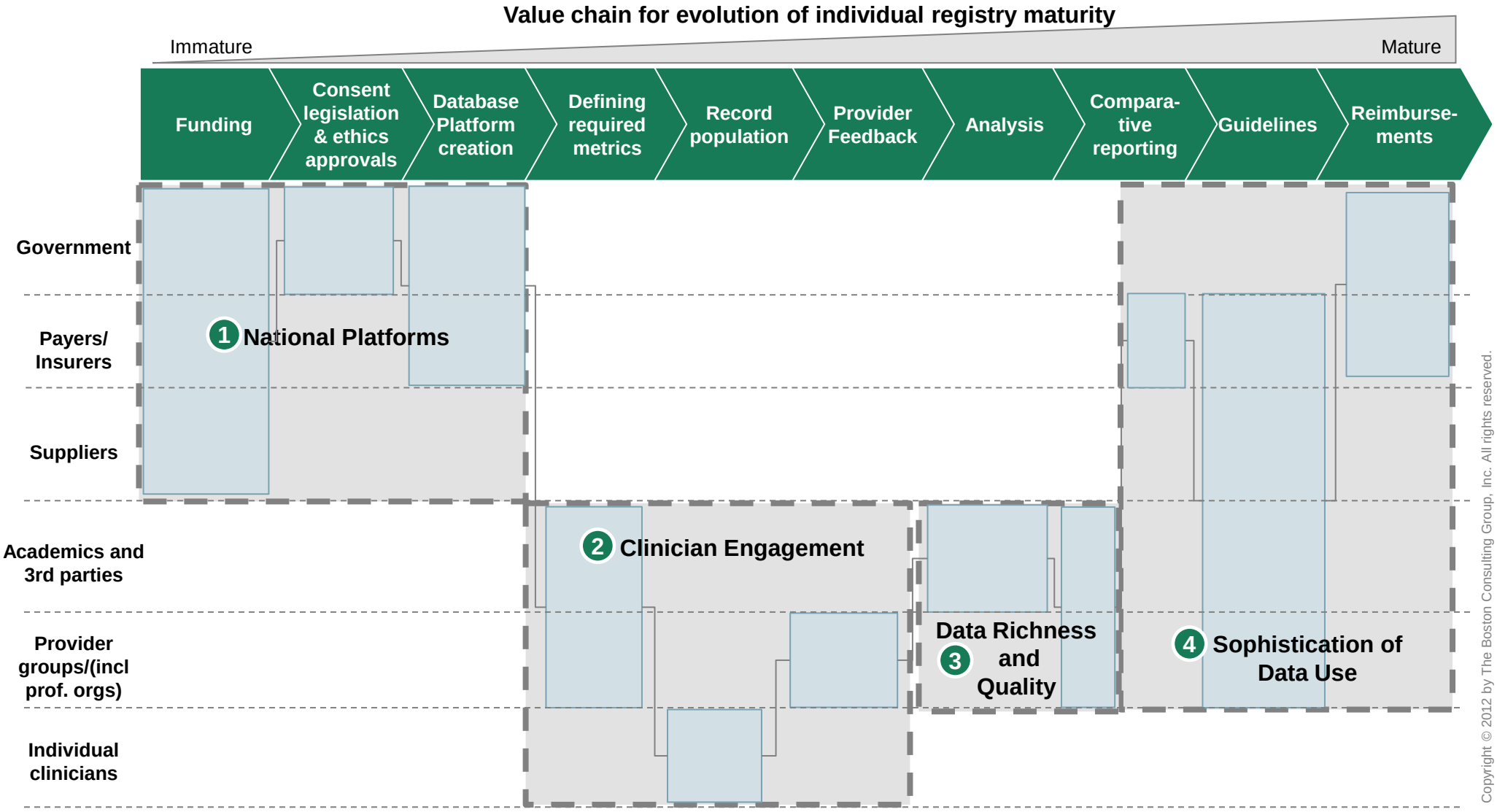
Successful health outcomes data collection and application

Sweden most advanced across maturity assessment in outcomes data collection and use



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



Results segmented along dimensions driving registry success

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

Maturity

Immature → Mature

	Criteria Included	NED	GER	HUN	USA	AUT	JPN	NZ	AUS	UK	CAN	SIN	SWE
National platforms													
• Standards	1b1, 1b2	2.0	3.0	3.0	2.0	3.0	2.5	4.2	2.0	3.5	5.0	4.3	3.5
• IT infrastructure	1b3, 1b4	3.5	2.5	2.0	2.5	2.5	3.0	3.5	3.0	3.0	2.0	3.5	3.5
• Cost linkage	1b5, 2a6	2.0	1.0	2.0	1.8	2.0	2.3	2.4	2.3	1.5	1.6	2.8	3.0
• Legal & Consent	1b6	5.0	3.0	3.0	3.0	3.0	3.0	4.0	2.0	5.0	5.0	4.0	4.0
• Government	1a3-5	2.0	2.3	2.0	3.2	3.7	3.0	2.6	2.3	2.3	3.3	3.3	3.7
• Patients / public engagement	1a6	4.0	2.0	1.0	3.0	3.0	3.0	3.0	2.0	4.0	5.0	4.0	4.0
Clinician engagement													
• Clinicians	1a1, 1a2, 2c4, 2c5	2.3	2.5	2.4	2.6	2.6	3.4	2.9	3.2	3.8	3.6	3.5	4.9
Data richness and quality													
• Data richness & quality	2a (all), 2b (all), 2c1-3	1.7	2.1	2.3	2.0	2.4	2.4	2.6	3.0	3.0	3.0	3.6	3.9
Data utilisation													
• Sophistication of data use	3 (all, except 3.5)	1.4	1.4	1.4	1.6	1.6	2.3	1.7	2.2	2.3	2.0	2.0	2.7
Overall maturity		**2.0**	**2.0**	**2.1**	**2.2**	**2.4**	**2.6**	**2.6**	**2.6**	**2.9**	**3.0**	**3.2**	**3.6**

Level 1 | Level 2 | Level 3 | Level 4 | Level 5

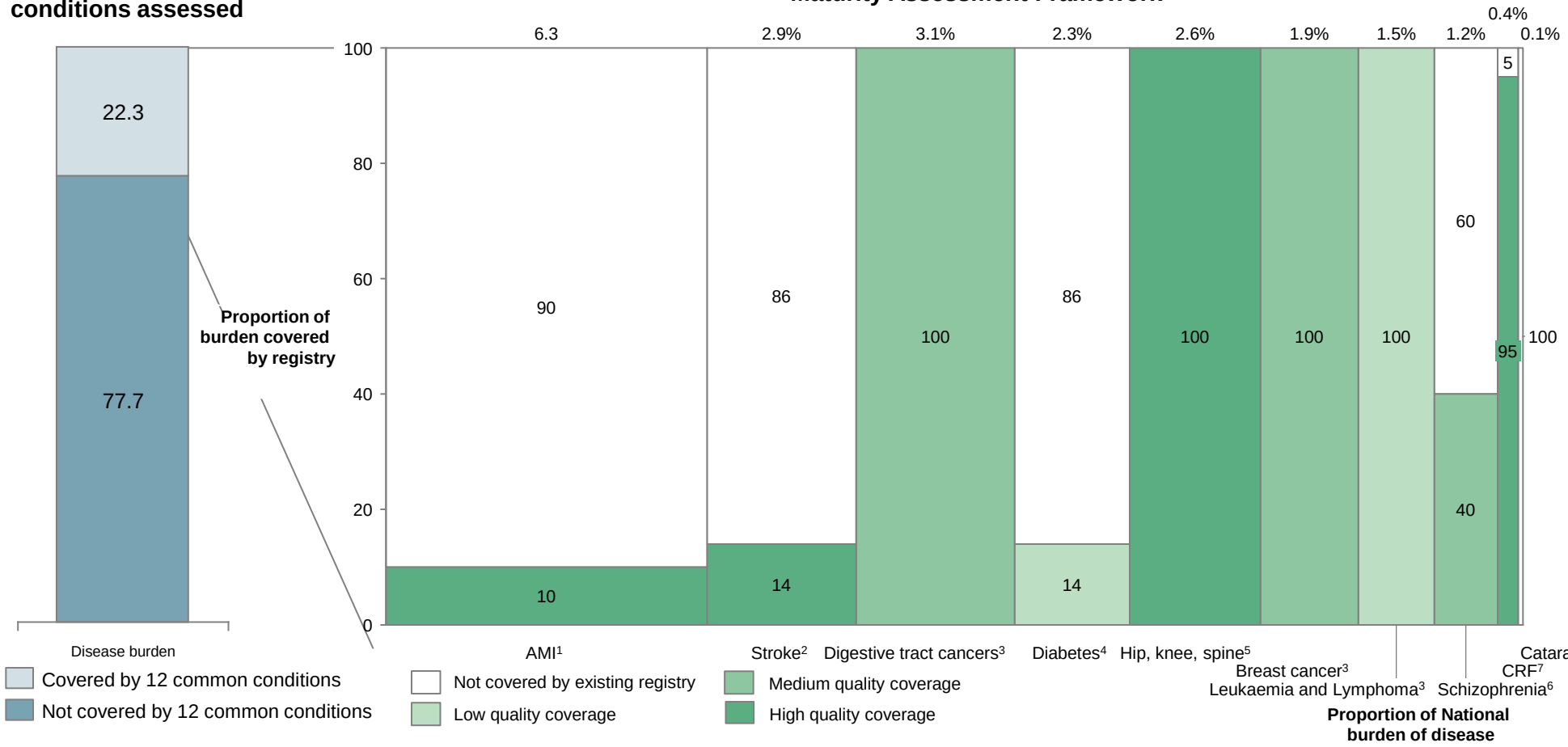
Note: Overall maturity is average of all criteria (except 3.5) with equal weighting

Significant variability exists in both quality and coverage

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

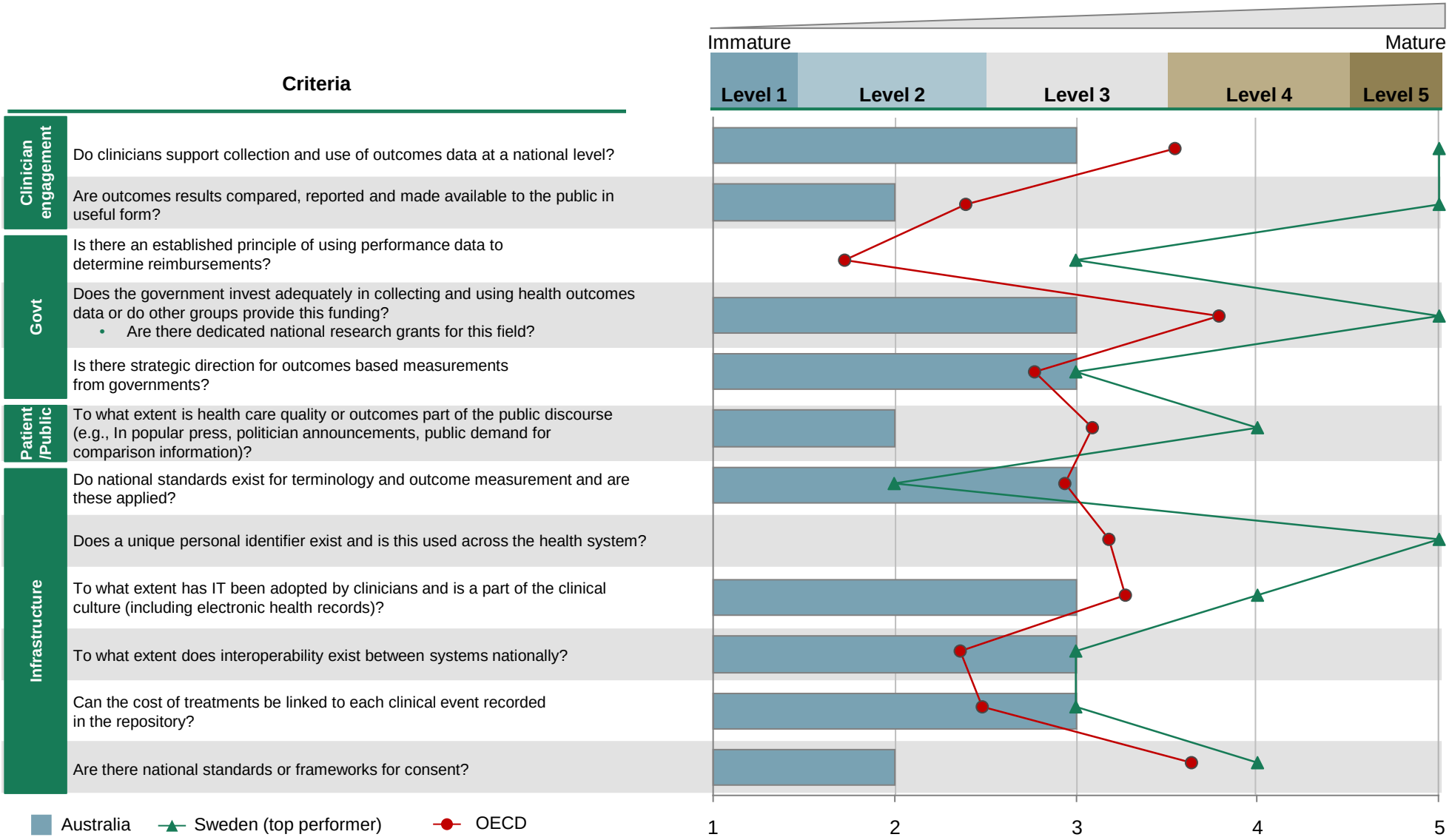
DALY burden coverage for 12 conditions assessed

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



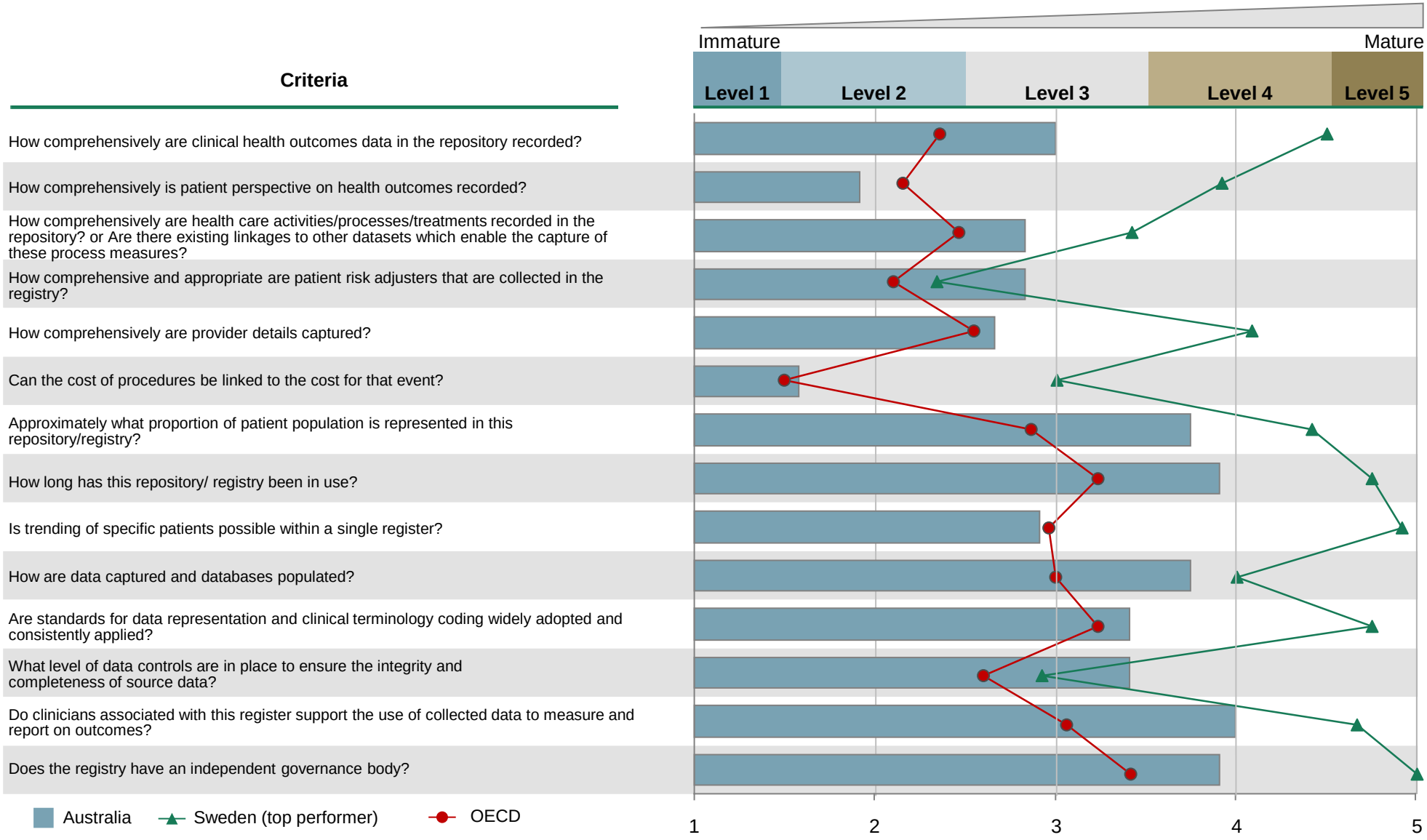
1. AMI: PCI coverage is ~10%, cardiac procedures registry coverage of cardiothoracic surgery is ~60% (from Chris Reid). AMI coverage updated to coverage of PCI (10%). 2. Stroke: estimated 5k events in pilot year at 3 hospitals and year following with a broader roll out in 2011 estimated 60K strokes (http://www.strokefoundation.com.au/facts-figures-and-stats), 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 cancers as this is what the cancer registry in Australia Covers 4. Diabetes: 130k cases on register in 2009 (assumed incidence), national incidence of 900k in 2008 plus gestational diabetes of 12k, therefore assume total incidence in 2009 of ~950k. 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

Australia's national foundations scores indicate substantial opportunities for improvement



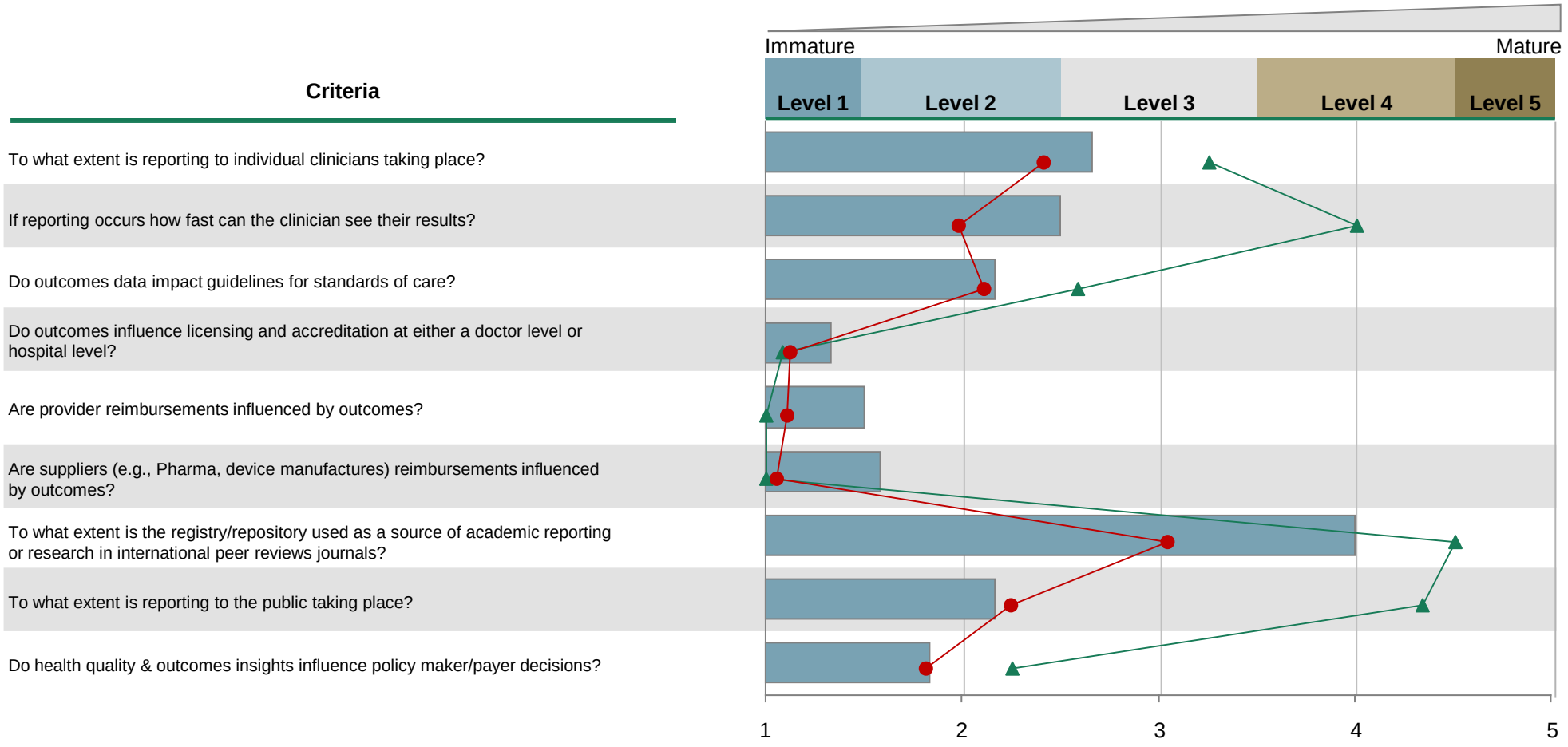
Note: OECD countries include Australia, Austria, Canada, Germany, Hungary, Japan, Netherlands, NZ, Sweden, UK, USA. Source: BCG analysis

Established performance in data collection which is likely to improve as further progress is made on national enablers



Note: OECD countries include Australia, Austria, Canada, Germany, Hungary, Japan, Netherlands, NZ, Sweden, UK, USA. Source: BCG analysis

Use of outcomes data shows opportunities for further improvement supported by enhanced national enablers



Note: Criteria 3.5 (Is the relevant regulatory agency willing to consider/encourage or currently using observational data as part of drug and device approval and post-launch assessment?) is not reported as data not collected for all countries assessed. OECD countries include Australia, Austria, Canada, Germany, Hungary, Japan, Netherlands, NZ, Sweden, UK, USA. Source: 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

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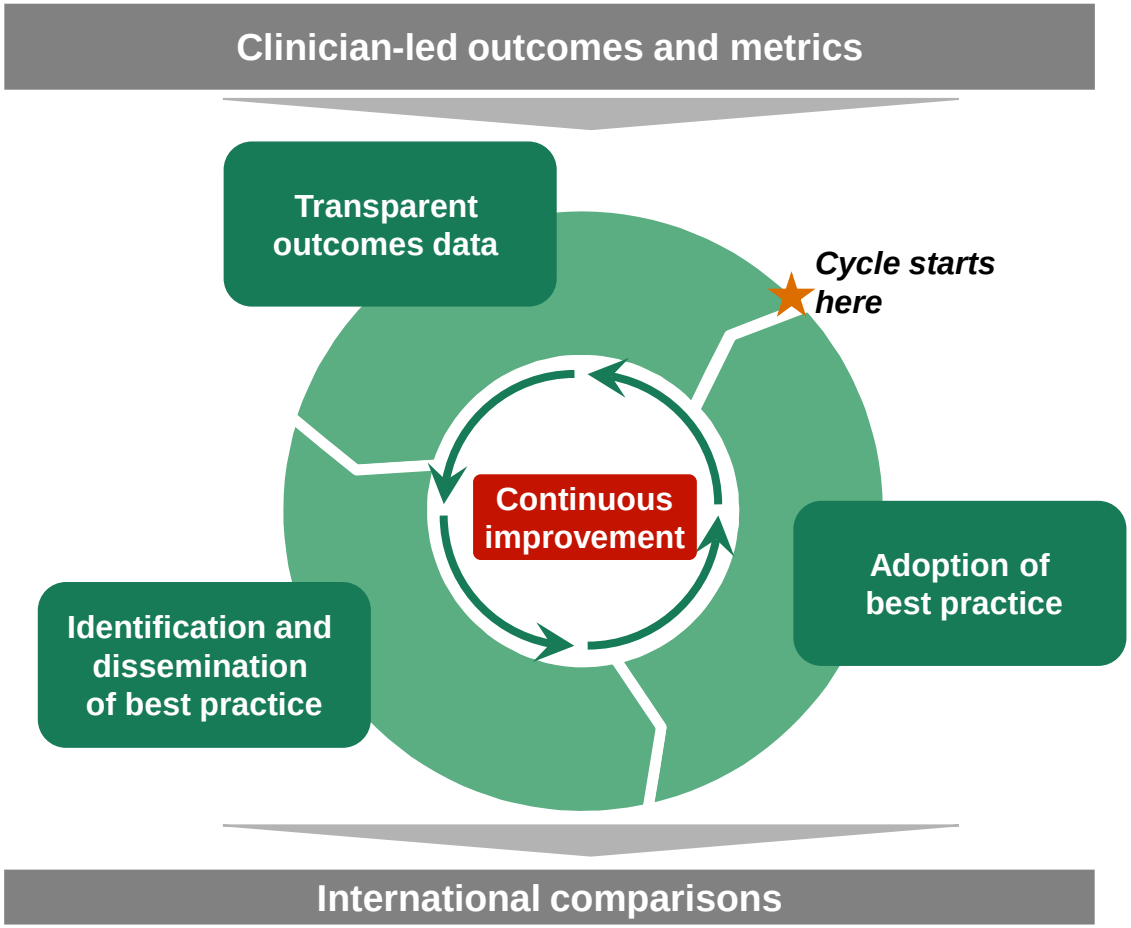
Transparency and best-practice sharing loop leads to improved outcomes, sustainability and risk mitigation

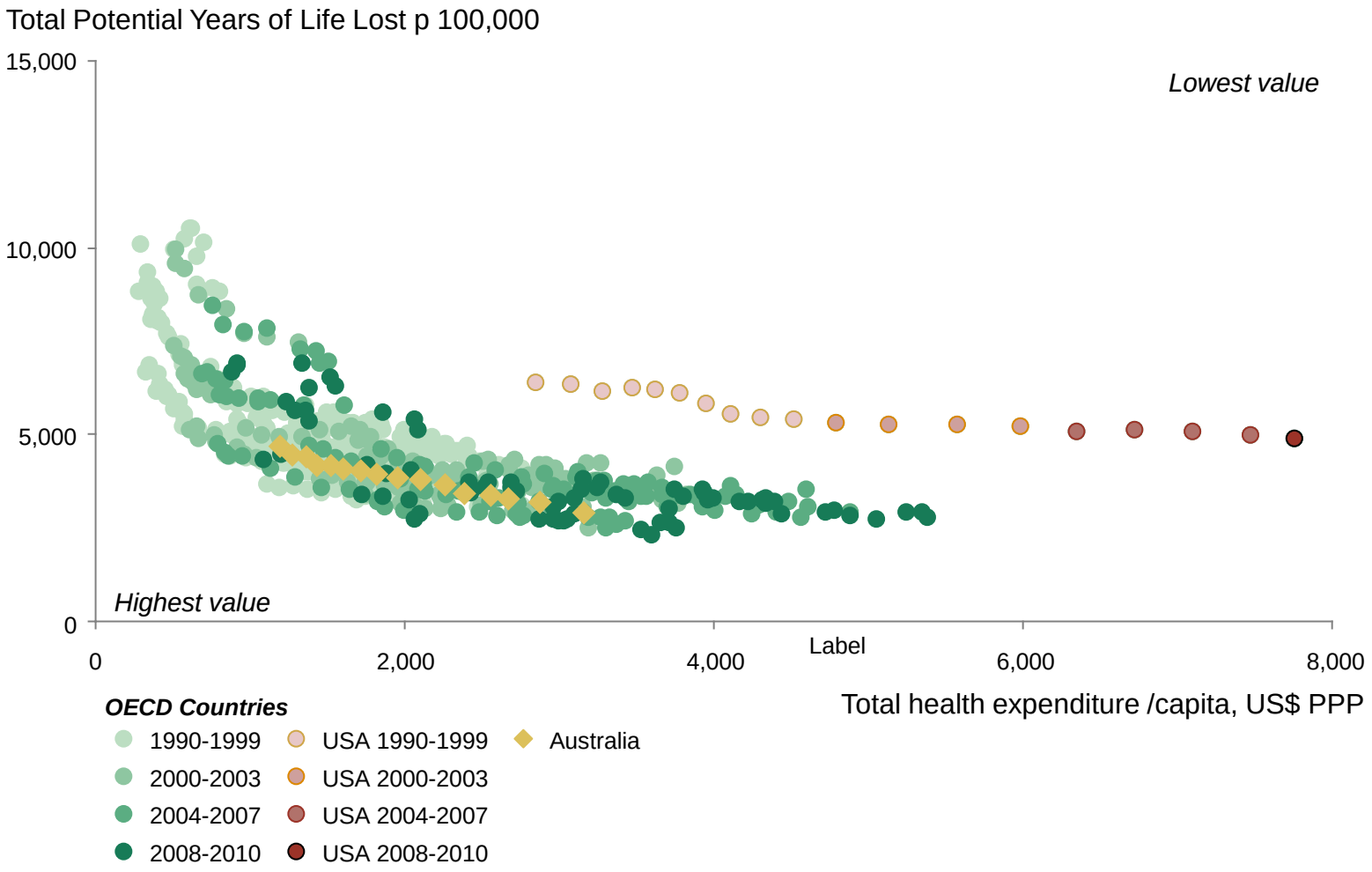
Registries enable a continuous feedback loop …



… which improves

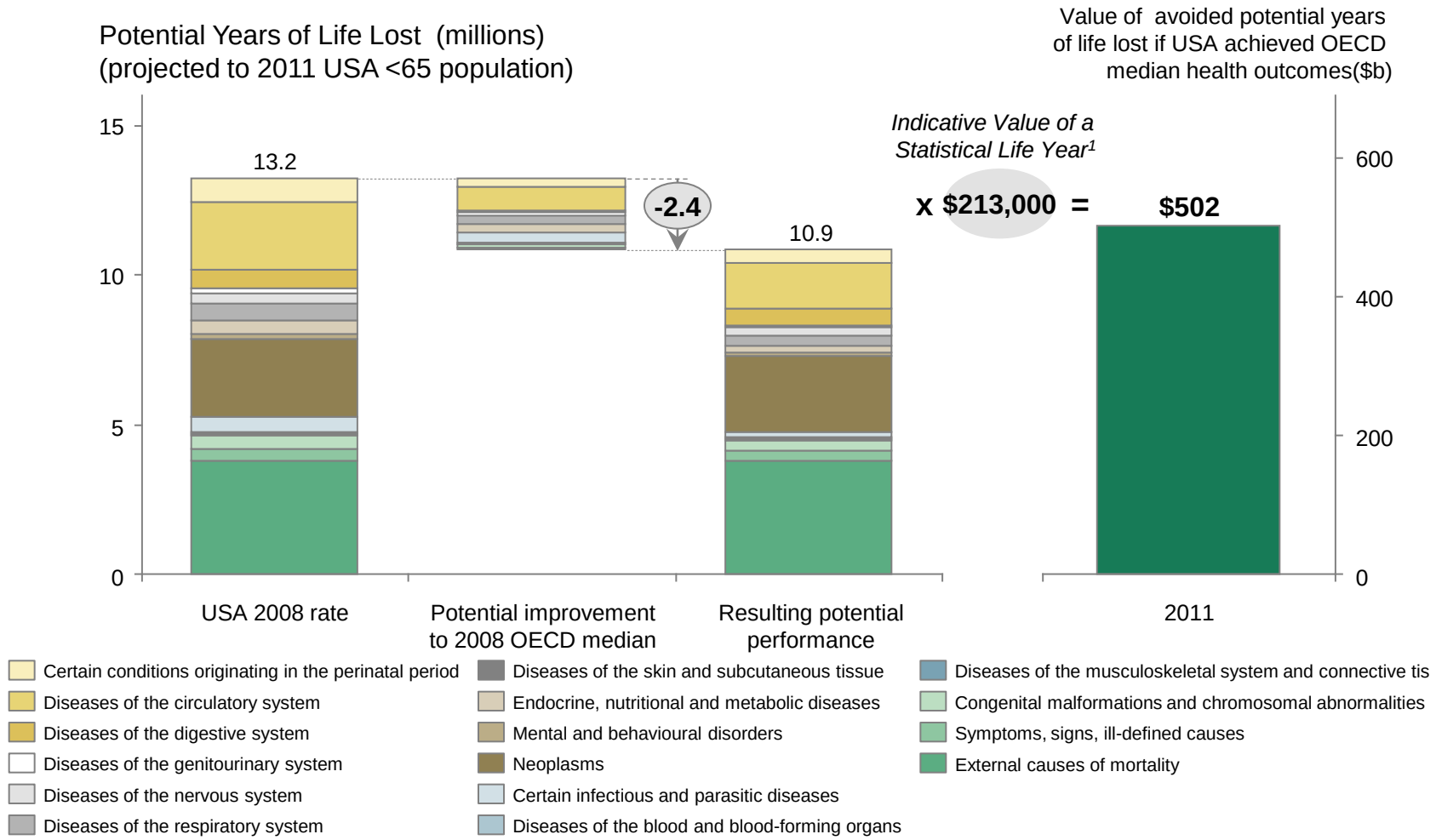
1. Outcomes
2. Sustainability
3. Risk mitigation

Macro-view: USA has poor health outcomes for its high health spend



Source: stats.oecd.org, BCG analysis

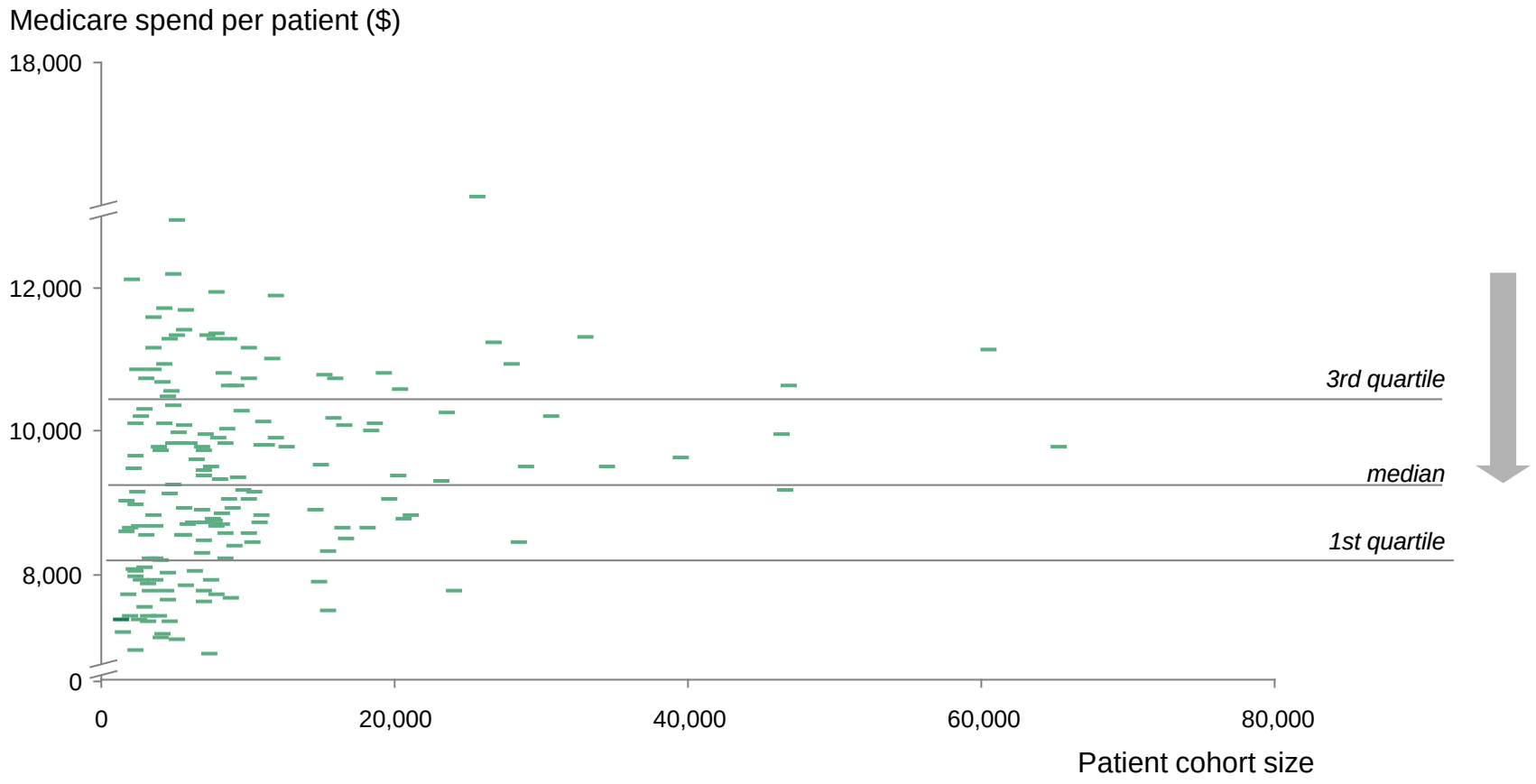
If the USA had OECD median health outcomes, it would deliver 2.4m extra years of life p.a. worth ~$500m



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

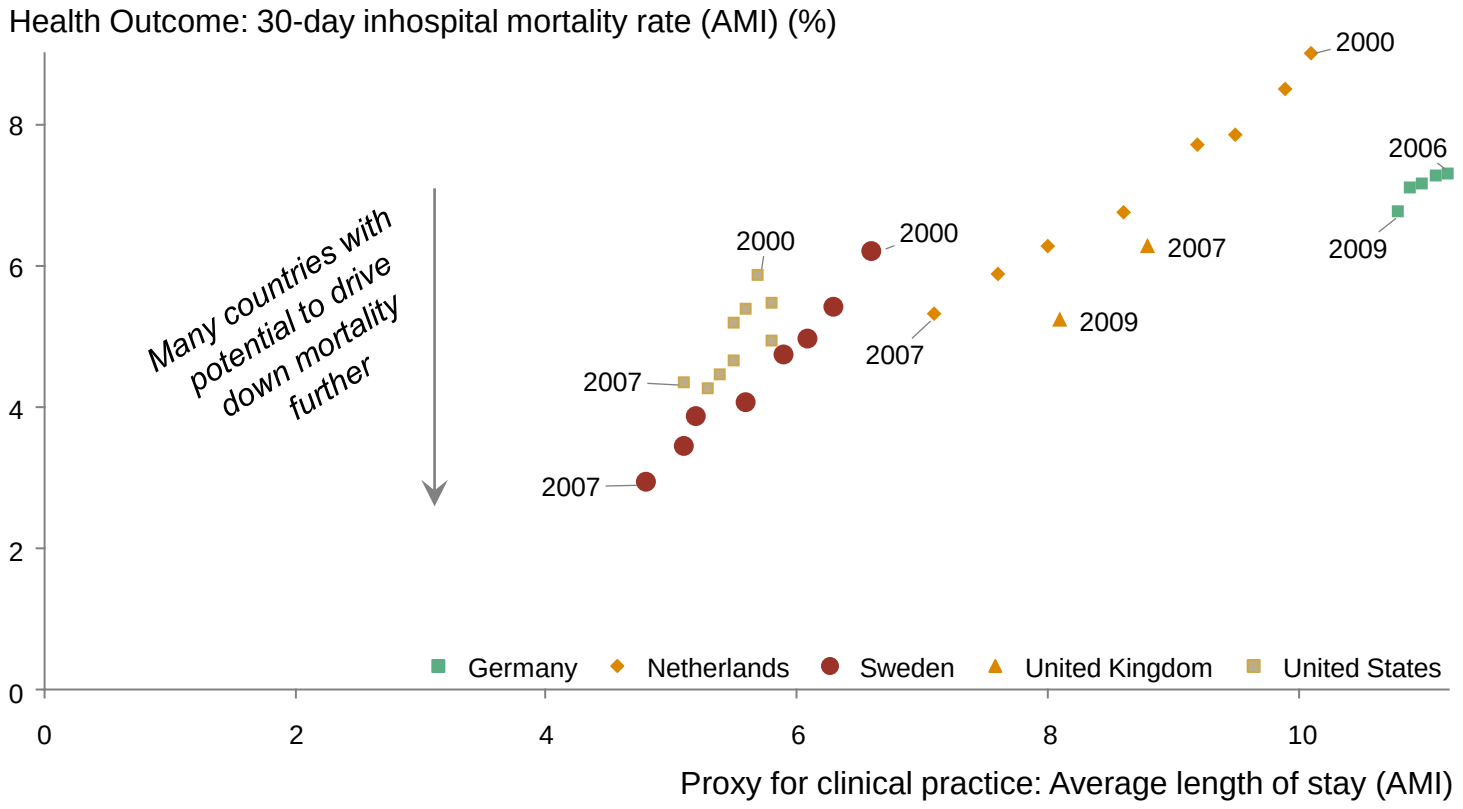
Moving more expensive care to median cost levels worth $200bn p.a. (8% of spend)

Average Medicare spend / patient by US health referral region, 2009



Source: Dartmouth Institute data and research; BCG analysis

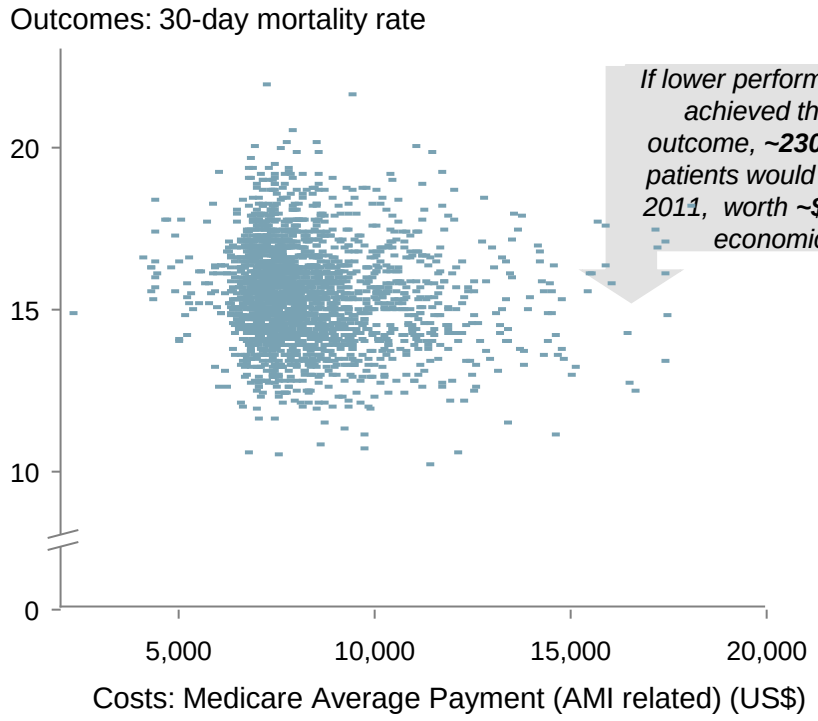
A micro-example – heart attacks



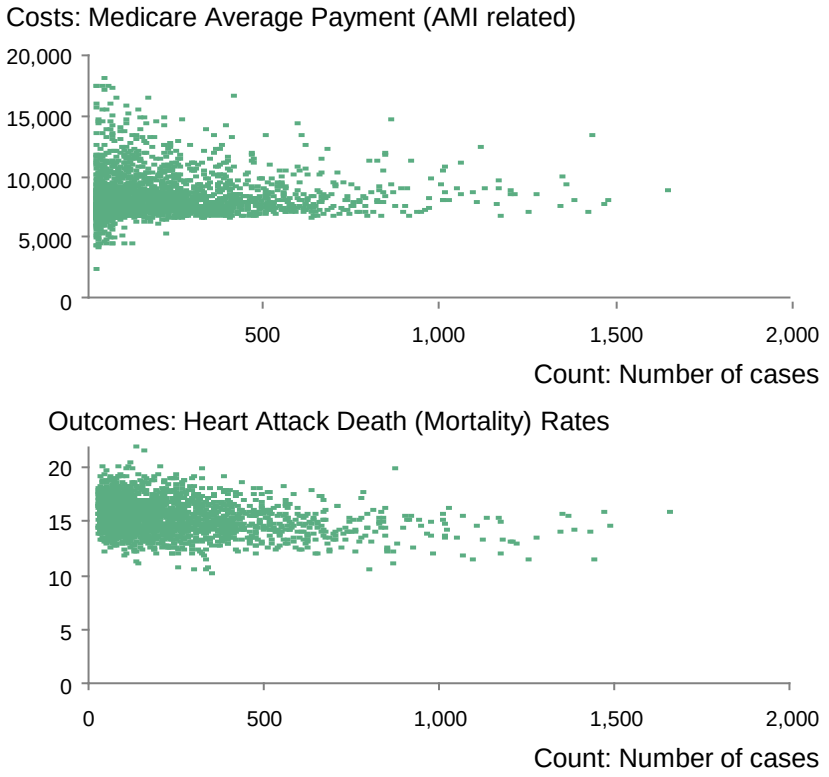
Source: OECD Data, BCG analysis

Heart attacks in the US – significant potential

No obvious relationship between costs and outcomes in Medicare AMI



Unusually, costs and outcomes for AMI do not appear to be related to number of cases



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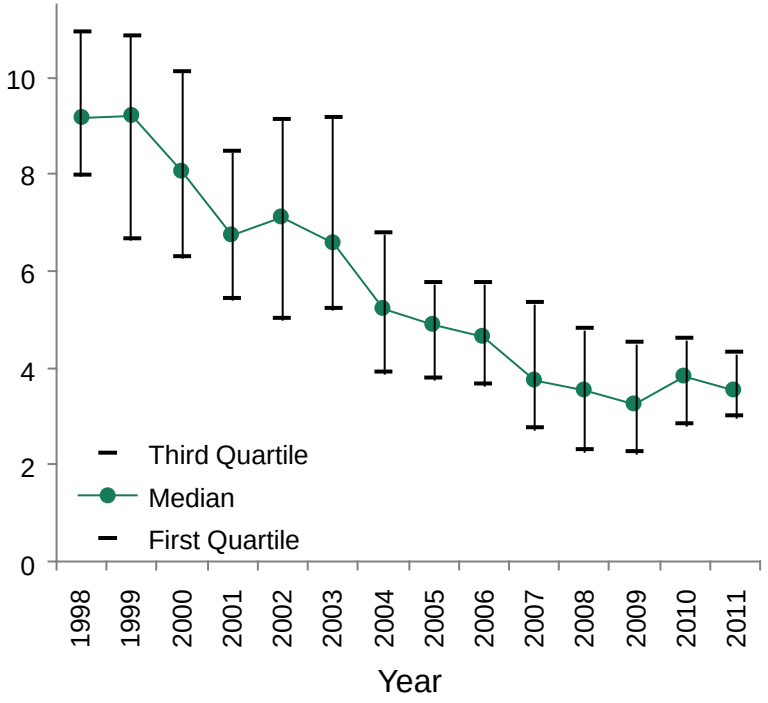
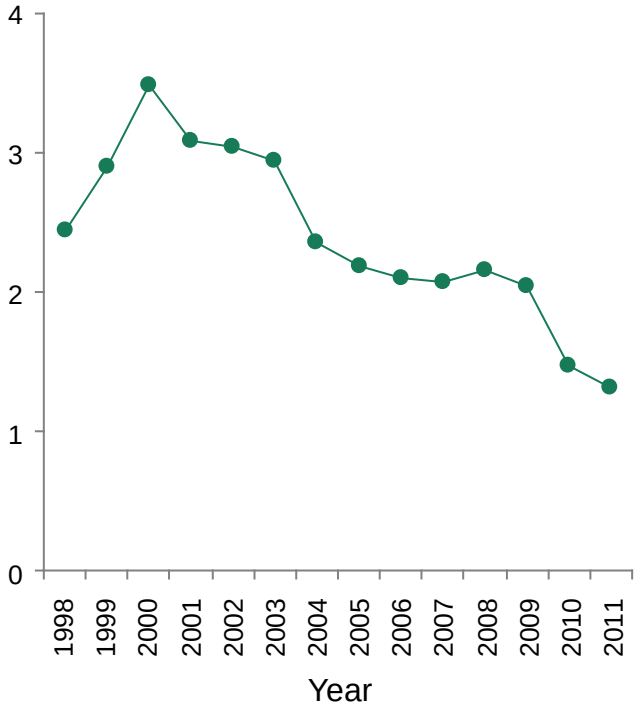
Source: Medicare: http://www.medicare.gov/Download/DownloadDB.asp and https://data.medicare.gov/dataset/Hospital-Medicare-Payment-And-Volume-Measures/7aac-tz9t and https://explore.data.gov/Social-Insurance-and-Human-Services/Medicare-Tools-Downloadable-Databases/vwxh-5b6i , Health, United States 2011, With Special Feature on Socioeconomic Status and Health, CDCP

Swedish AMI registry has seen significant improvement in outcomes

Swedish RIKS-HIA data: % mortality within 30 days after AMI by provider[2]



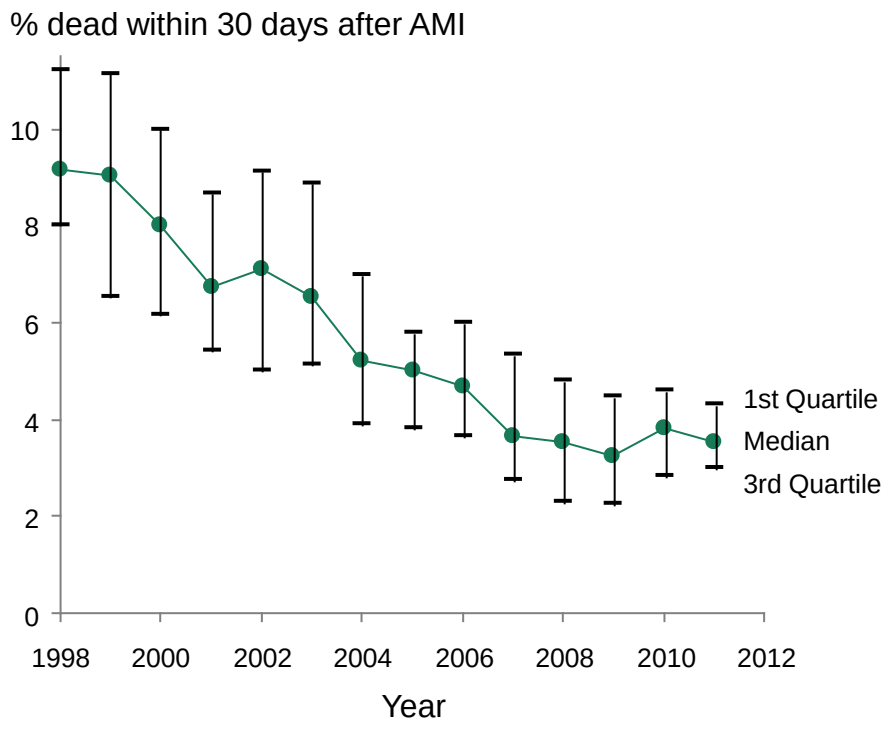
Standard deviation in % mortality within 30 days after AMI by provider[2]



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

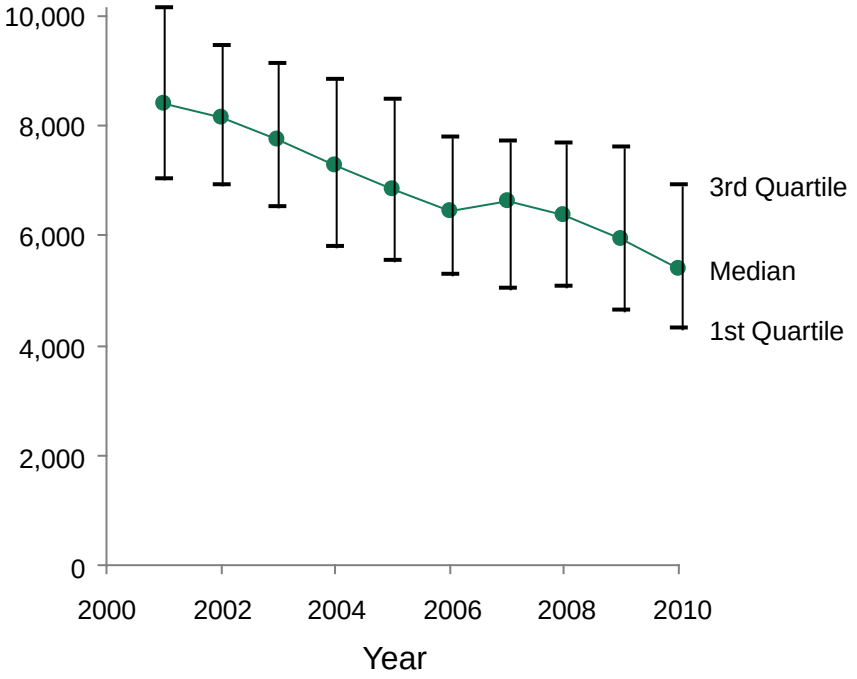
Swedish v UK AMI outcomes

Advanced registry: Sweden



Emerging registry: UK

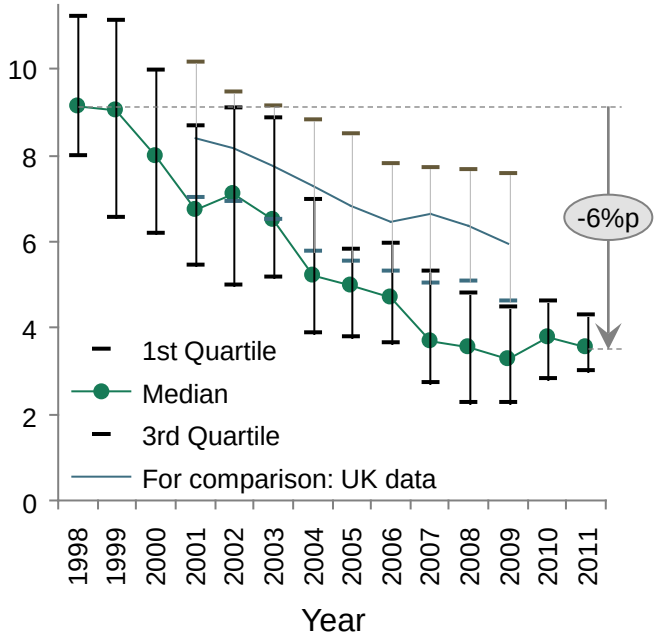
Deaths within 30 days of emergency admission to hospital: myocardial infarction p100,000 males (35-74yo) (age and diagnosis standardised)



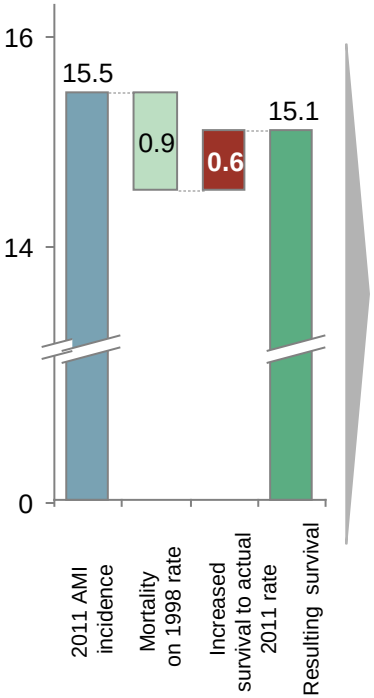
Source: Swedish AMI RIKS-HIA, NHS Indicators

Sweden's AMI registry helped generate $159m p.a. in improved health outcomes by 2011

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

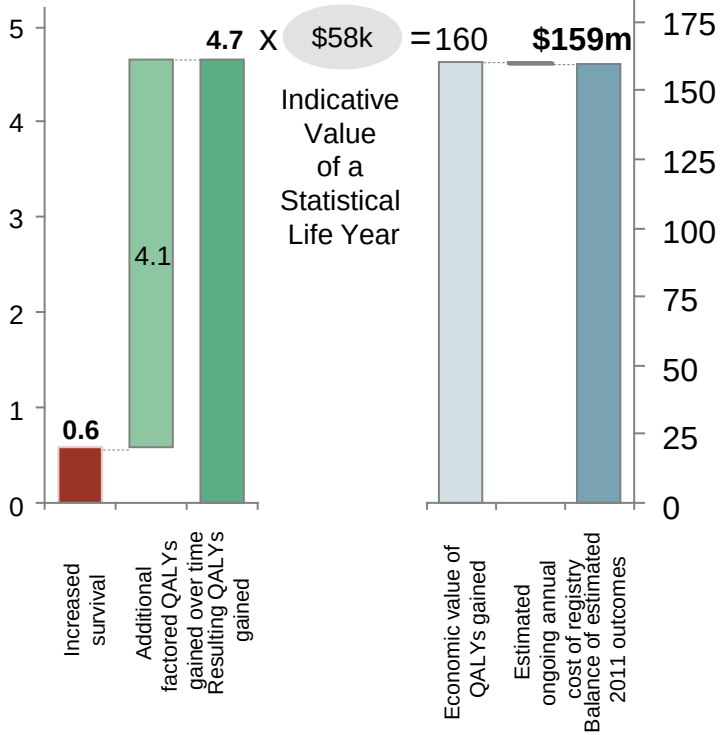


Incidence of AMI in Sweden in 2011 ('000s)



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

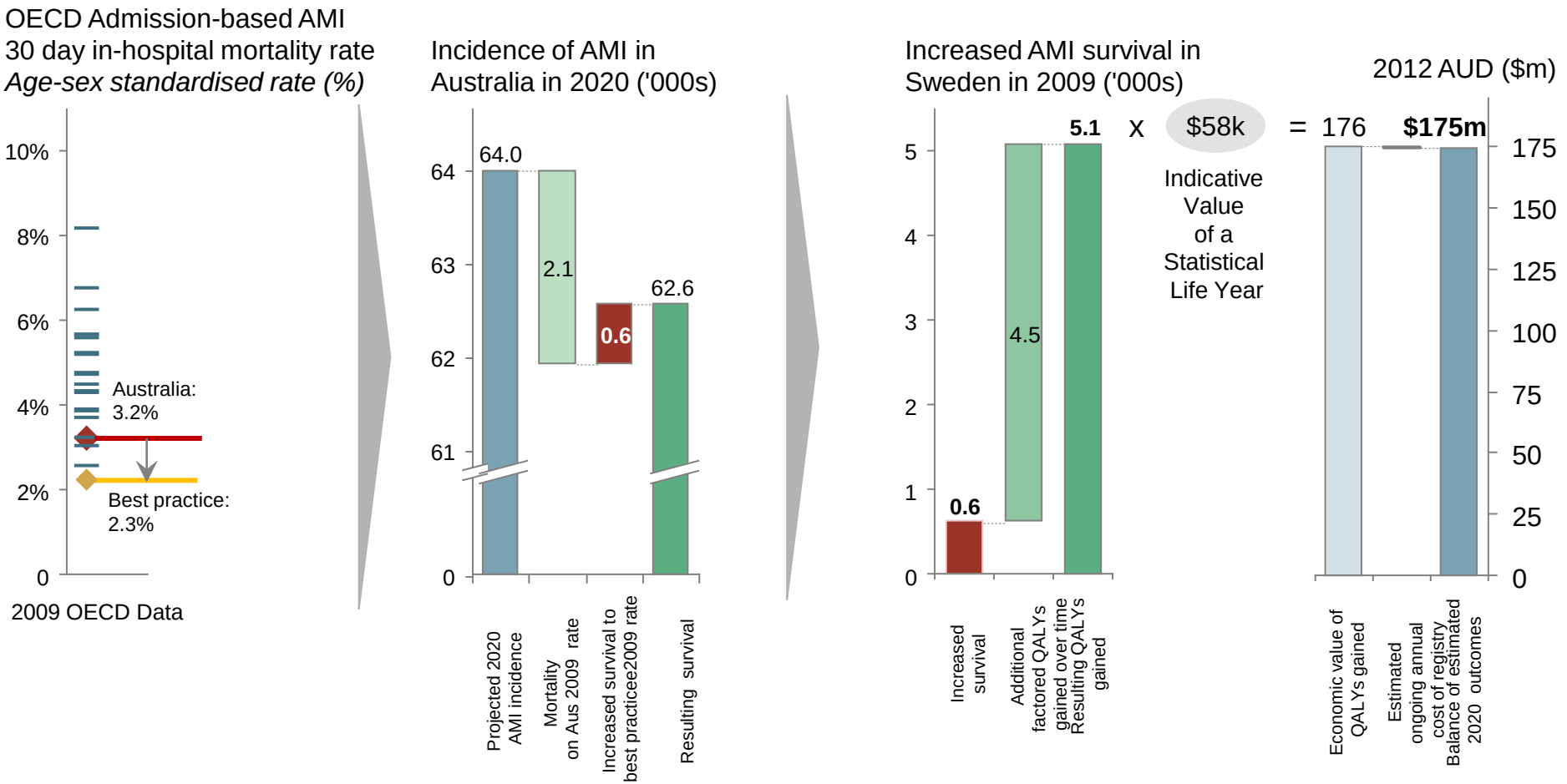
2012 AUD per year ($m)



Source: Swedish RIKS-HIA, The Role of Value for Money in Public Insurance Coverage Decisions for Drugs in Australia: A Retrospective Analysis 1994-2004, Anthony H. Harris, MSc, Suzanne R. Hill, PhD, Geoffrey Chin, MPH, Jing Jing Li, BPharm, Emily Walkom, PhD, Costed infrastructure options for Australian clinical quality registries, Australian Commission on Safety and Quality in Health Care, AIHW The burden of disease and injury in Australia, 2003 YLD by disease.

Australian focus: AMI projection based on OECD comparison

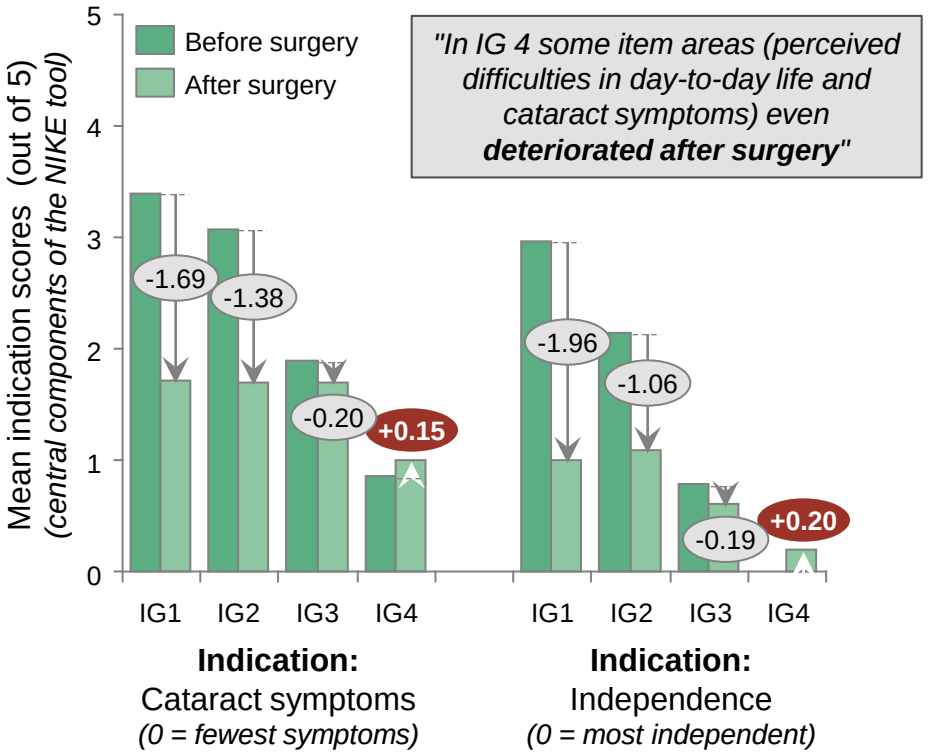
Possible value up to $175m per year



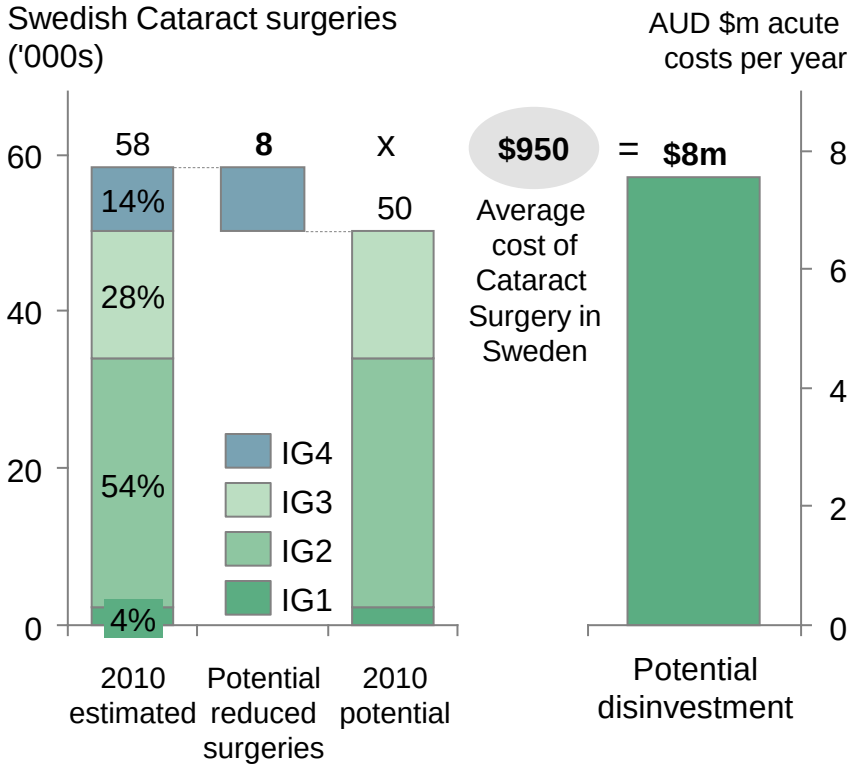
Source: Deloitte Access Economics ACS in Perspective: The importance of secondary prevention 2011, OECD Stats, The Role of Value for Money in Public Insurance Coverage Decisions for Drugs in Australia: A Retrospective Analysis 1994-2004, Anthony H. Harris, MSc, Suzanne R. Hill, PhD, Geoffrey Chin, MPH, Jing Jing Li, BPharm, Emily Walkom, PhD, Costed infrastructure options for Australian clinical quality registries, Australian Commission on Safety and Quality in Health Care, AIHW The burden of disease and injury in Australia, 2003 YLD by disease.

Other value levers: Opportunities for disinvestment

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

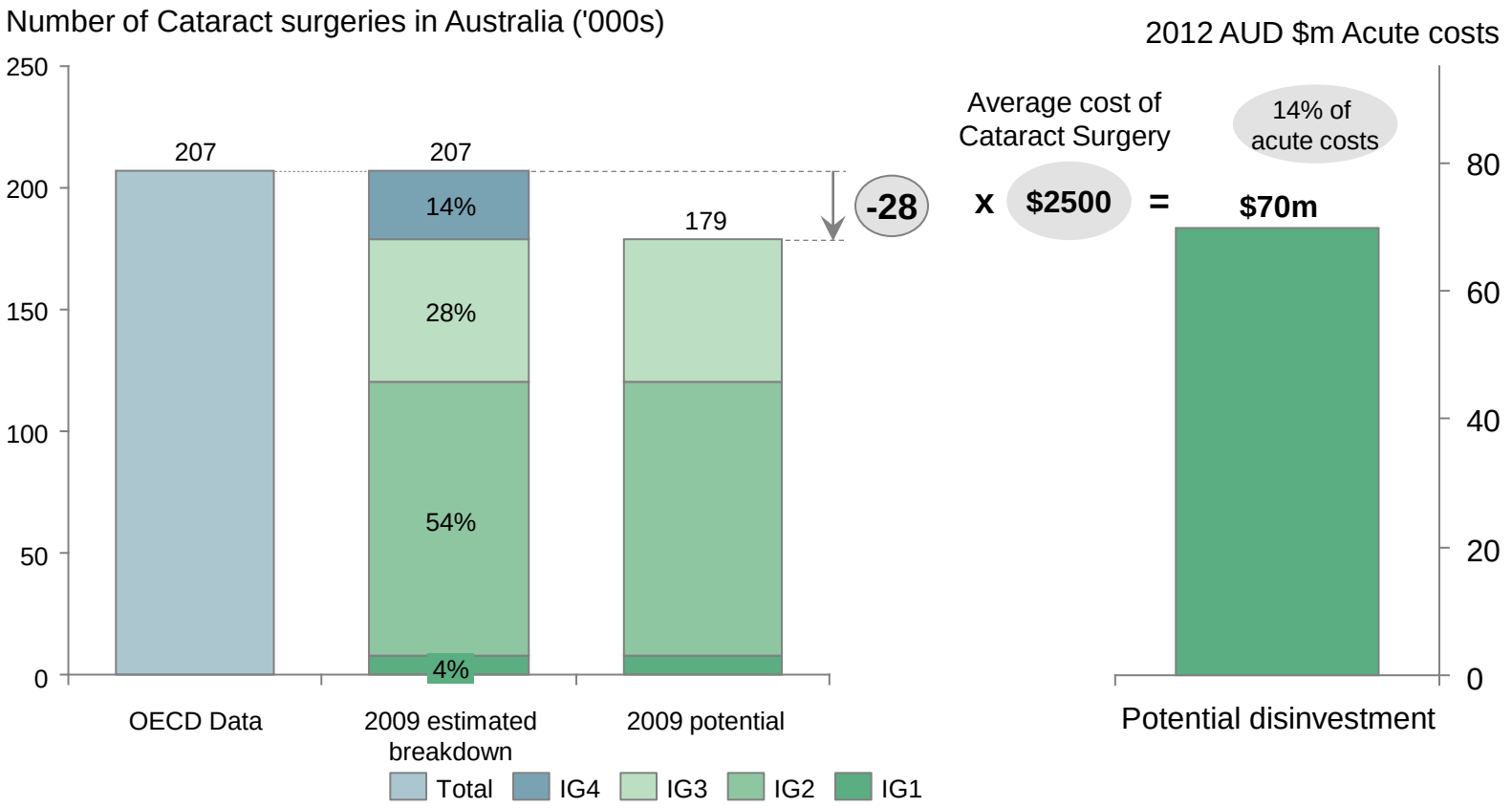


...which created the potential for $8m per year in disinvestment



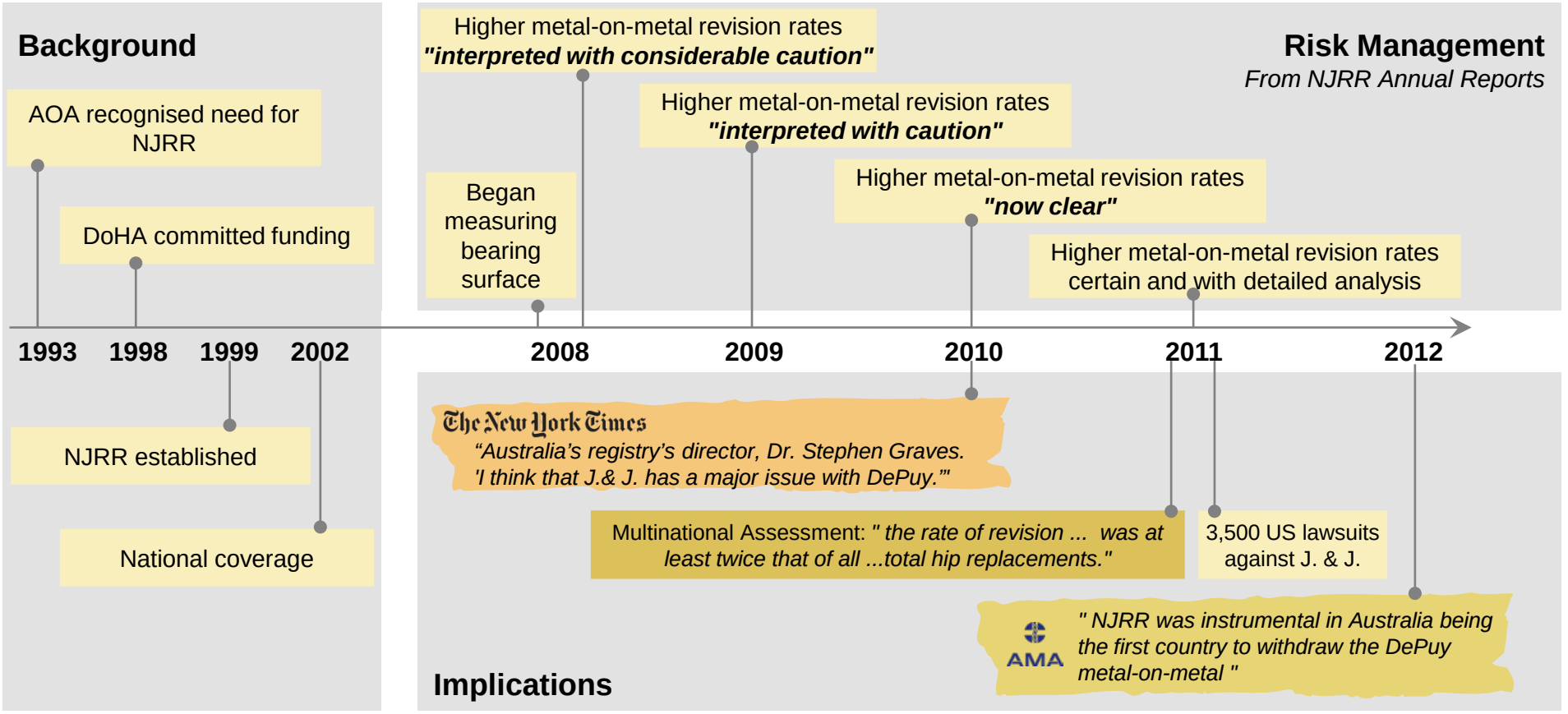
Source: NIKE: a new clinical tool for establishing levels of indications for cataract surgery, Mats Lundstrom, Susanne Albrecht, Ingemar Hakansson, Ragnhild Lorefors, Sven Ohlsson, Werner Polland, Andrea Schmid, Goran Svensson and Eva Wendel, Acta Ophthalmol. Scand. 2006: 84: 495–501, The Role of Value for Money in Public Insurance Coverage Decisions for Drugs in Australia: A Retrospective Analysis 1994-2004, Anthony H. Harris, MSc, Suzanne R. Hill, PhD, Geoffrey Chin, MPH, Jing Jing Li, BPharm, Emily Walkom, PhD, Costed infrastructure options for Australian clinical quality registries, Australian Commission on Safety and Quality in Health Care, AIHW The burden of disease and injury in Australia, 2003 YLD by disease.

Applied to Australia, Cataract surgery represents – up to $70m per year in disinvestment potential



Source: NHCDC, Separation weighted ave across DRGs: C15A, C15B, C16Z, The Role of Value for Money in Public Insurance Coverage Decisions for Drugs in Australia: A Retrospective Analysis 1994-2004, Anthony H. Harris, MSc, Suzanne R. Hill, PhD, Geoffrey Chin, MPH, Jing Jing Li, BPharm, Emily Walkom, PhD, Costed infrastructure options for Australian clinical quality registries, Australian Commission on Safety and Quality in Health Care, AIHW The burden of disease and injury in Australia, 2003 YLD by disease.

Other value levers: Risk management



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

AOA: Australia Orthopaedic Association ,NJRR: National Joint Replacement Registry

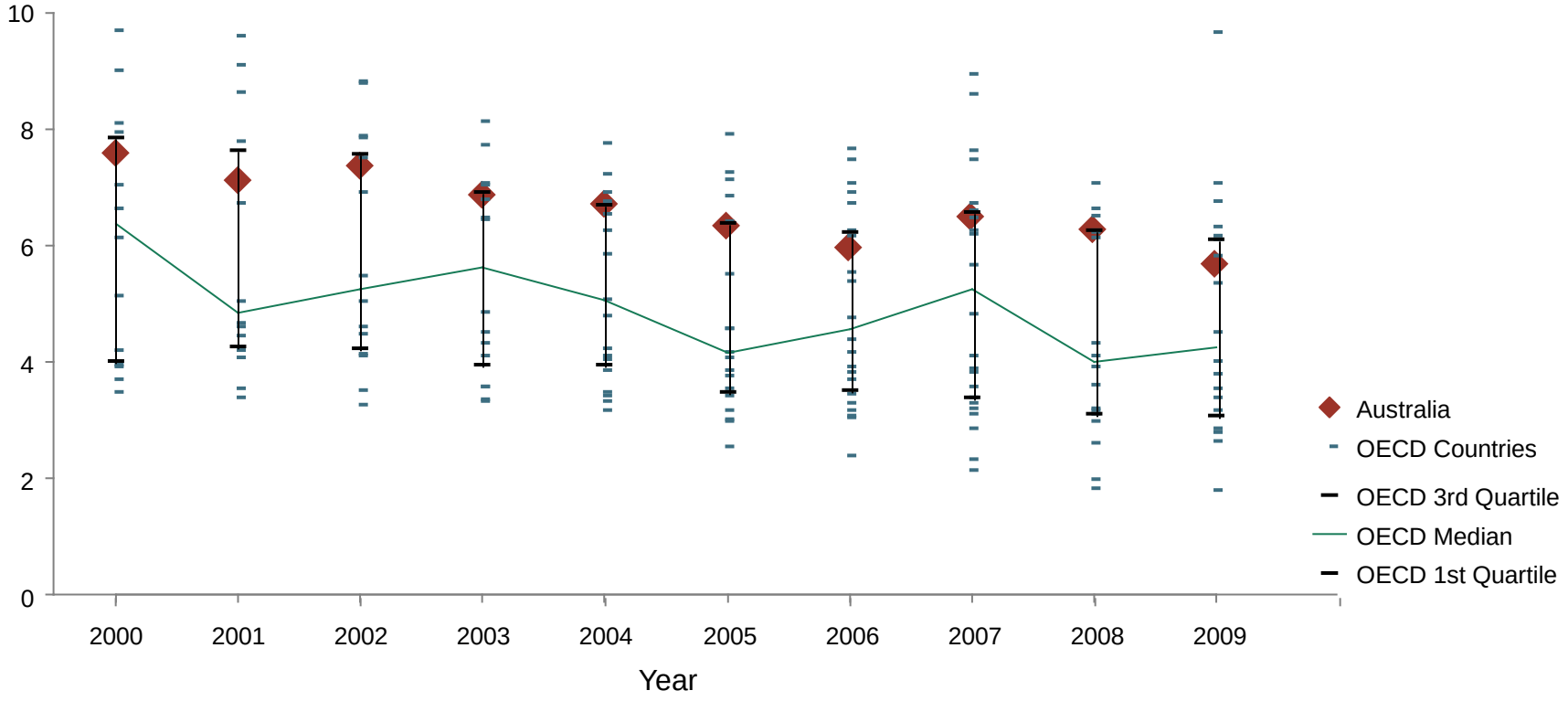
Source: Stephen E. Graves, Alastair Rothwell, Keith Tucker, Joshua J. Jacobs, Art Sedrakyan; A Multinational Assessment of Metal-on-Metal Bearings in Hip Replacement. The Journal of Bone & Joint Surgery. 2011 Dec;93(Supplement_3):43-47, AMA Submission: Regulation of medical devices, The Implants Loophole New York Times 16/12/2010, Australian Orthopaedic Association National Joint Replacement Registry Annual Reports 2008, 2009, 2010, 2011, AOA eNewsletter Health minister's incorrect claims John C Batten, The High Cost of Failing Artificial Hips The New York Times 27/12/2011

Australian focus: Stroke

Appears to be significant opportunity for Australia to improve clinical performance in stroke

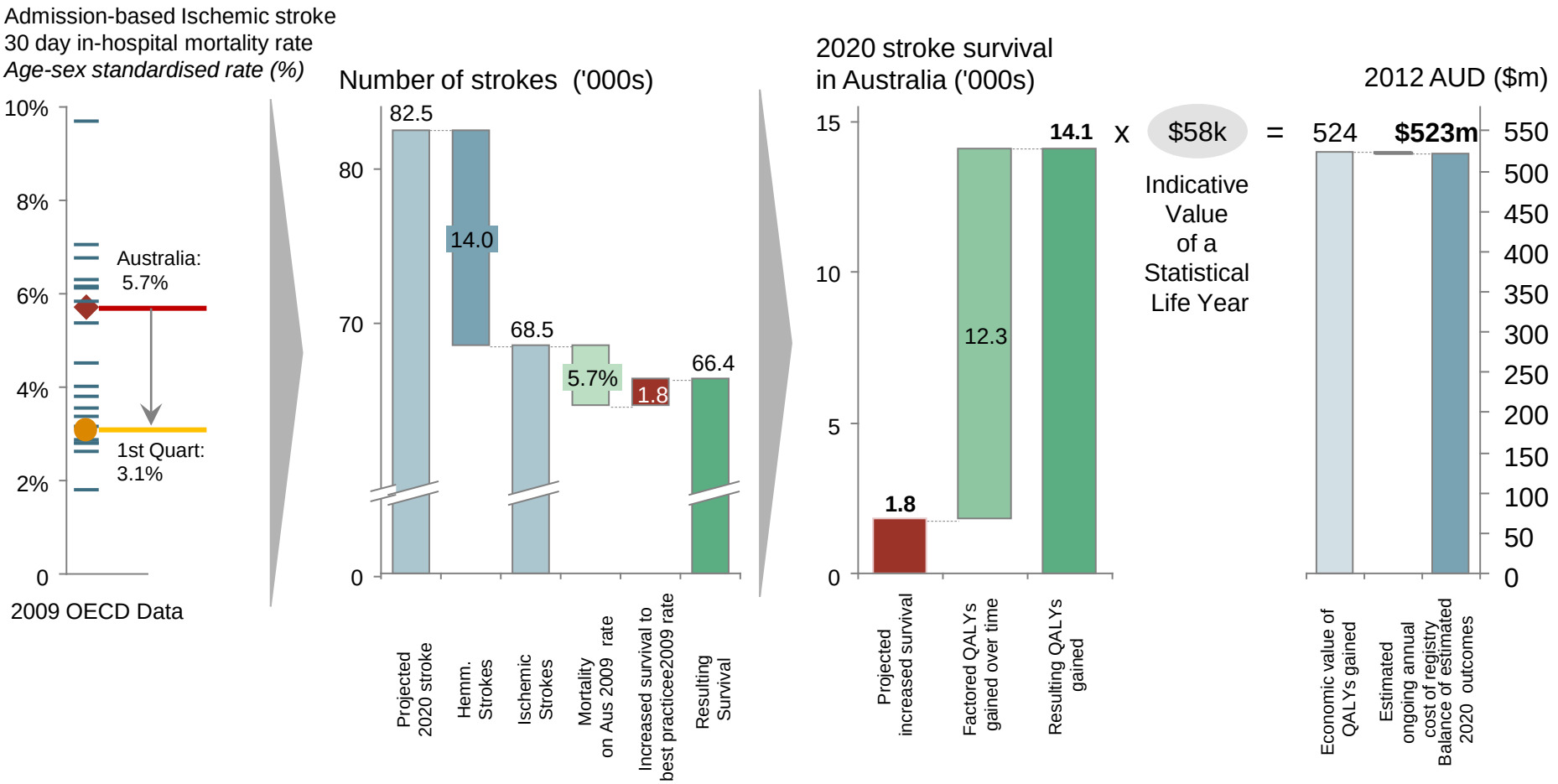
OECD Admission-based Ischemic stroke 30 day in-hospital mortality rate

Age-sex standardised rate (%)



Source: OECD Stats

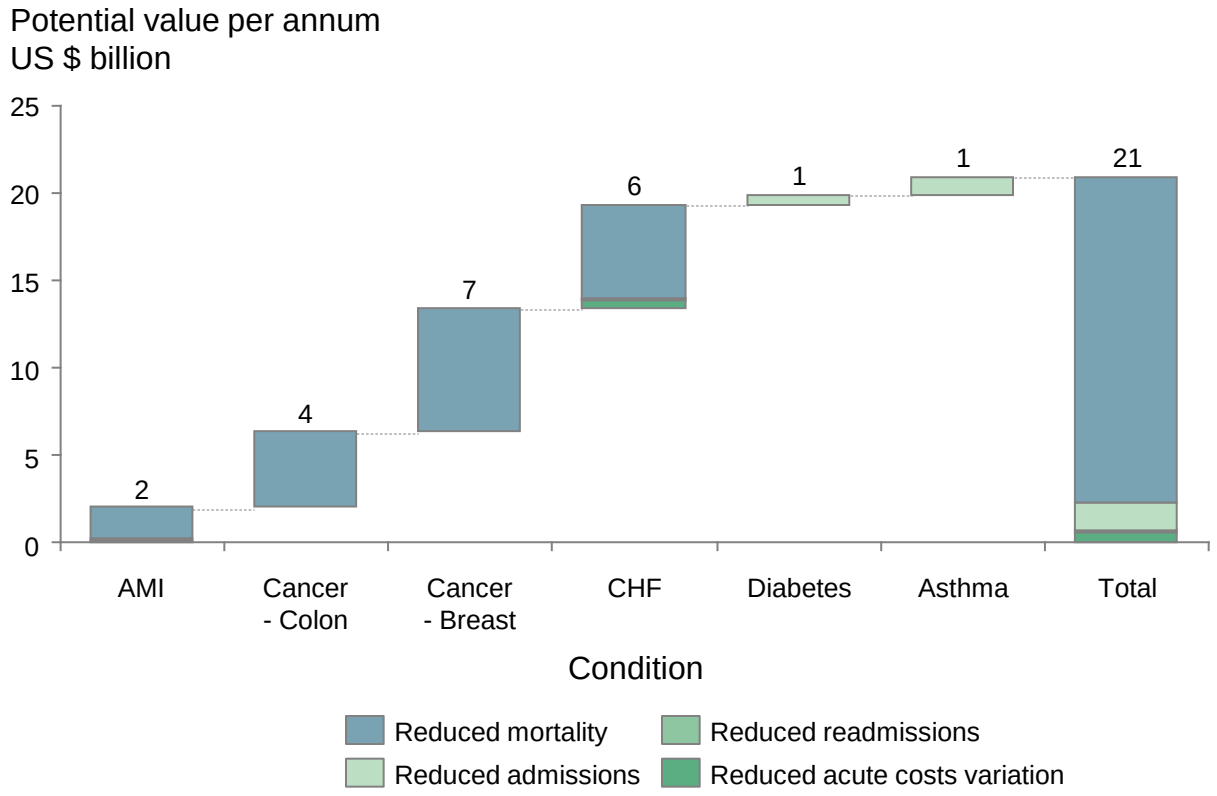
If Australia achieved OECD 1st quartile by 2020, 30-day mortality in 2020 would reduce by ~1800, worth $523m p.a.



Source: OECD Stats, The Role of Value for Money in Public Insurance Coverage Decisions for Drugs in Australia: A Retrospective Analysis 1994-2004, Anthony H. Harris, MSc, Suzanne R. Hill, PhD, Geoffrey Chin, MPH, Jing Jing Li, BPharm, Emily Walkom, PhD, Costed infrastructure options for Australian clinical quality registries, Australian Commission on Safety and Quality in Health Care, AIHW The burden of disease and injury in Australia, 2003 YLD by disease.

Significant gap in registries literature addressing the value of registries to the health system and economy

Selected bottom-up value projections for USA



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.