The economic impact of clinical quality registries – Do they pay their way?

Research conducted Jointly by Monash University and QHO, with support from the Australian Commission for Safety and Quality in Healthcare

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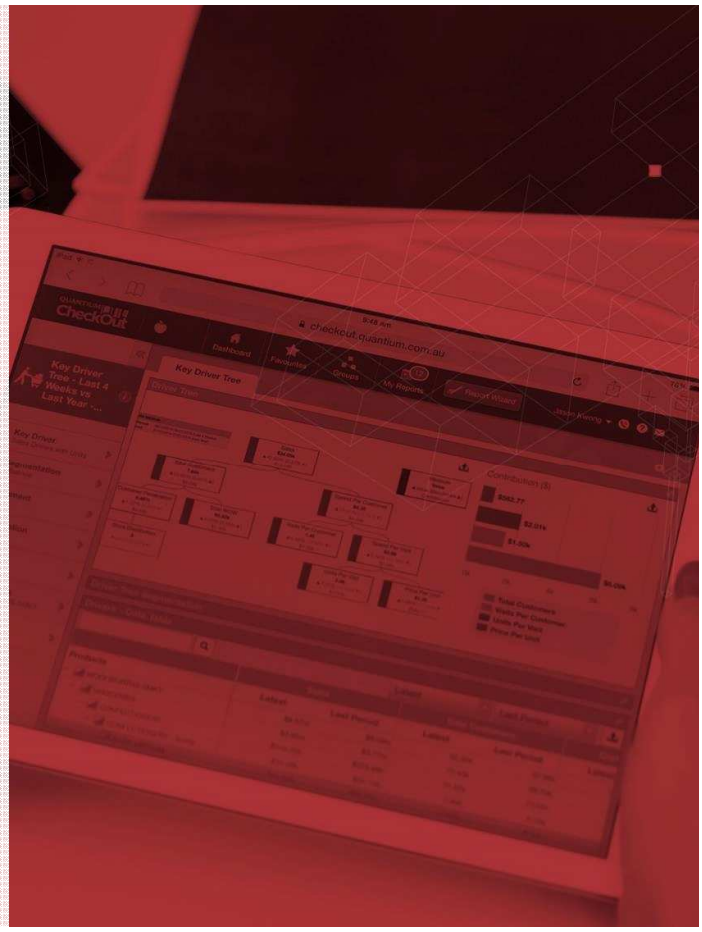

Why we did this project

Increasingly broad acknowledgement that clinical quality registries are powerful tools…

- For initiating new research streams
- For identifying best and worst practices
- For changing clinical practice via personal feedback

However

…Some scepticism about the business case for widespread rollout:

- Surely we can just learn from the trials and registries operated overseas?
- They don't provide much more information than we already get from routine sources
- Their cost is 'prohibitive'

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The project evaluated a selection of Australian Clinical Quality Registries

Registry type	Purpose	Info collected	Example(s)
Epidemiological	▪ Measure incidence of condition / disease, e.g. for policy planning, forecasting, surveillance etc.	▪ Basic patient identifiers ▪ Disease state / severity	▪ Australian National CJD registry ▪ National Cancer Statistics clearing house
Post-marketing surveillance	Track users of medical products, e.g. ▪ Adverse event reporting for medicines ▪ Patients with implants in event of recall	▪ Patient identifiers for follow-up ▪ Adverse events	▪ Australian Breast Implant Registry
Clinical quality registry	▪ Track progress of patients ▪ Analyse and feed back into clinical practice and decision-making	▪ Case-mix data for risk-adjustment ▪ Longitudinal outcomes data ▪ Treatments given	▪ Victorian Prostate Cancer Registry

Focus of this project

Registries were shortlisted for inclusion based on meeting the principles set out in the ACSQHC Framework of Clinical Quality Registries, availability of participation and other factors. Selected registries track and measure indicators that are considered to be the most important and relevant for the clinical specialty

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Five registries were selected for investigation

Selected Clinical Quality Registries were of sufficient maturity to show evidence of change in clinical practice and outcomes, that could be attributed to registry activity, and where the economic value of that change was measureable

	Registry	Hosted by	Evidence of impact (Selected based on availability of data)
1	Victorian Prostate Cancer Registry (Victorian PCR)	Monash University	▪ Compliance with guidelines that prevent active intervention in low risk patients (PRIAS) ▪ Positive surgical margin reduction - better survival and avoided need for secondary therapy
2	Victorian State Trauma Registry (VSTR)	Monash University	▪ Reduced in-hospital mortality ▪ Reduced average length of stay
3	ANZICS adult patient database (ANZICS APD)	ANZIC-RC	▪ Reduced Intensive Care Unit standardised mortality rates ▪ Reduced Intensive Care Unit Length of stay
4	ANZ Dialysis and Transplantation Registry (ANZDATA)	Royal Adelaide Hospital	▪ Reduced dialysis mortality ▪ Reduced transplant graft loss rate ▪ Reduced rates of complications (e.g. incidence of peritoneal infection 'peritonitis')
5	AOA National Joint Registry (AOANJRR)	University of Adelaide	▪ Reduced burden of revision in hip and knee arthroplasty ▪ Early identification and withdrawal from the market of prostheses with a higher than expected rate of revision

Evaluated indicators were not comprehensive – but rather a selection of readily available ones

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Registries generate value in three ways

Contribution	Example metrics	Mechanism of action
1 More effective	▪ Decreased mortality	▪ Well designed and run registries **identify outcome indicators**, like mortality**, enable** feedback loops to improve these outcomes
	▪ Enhanced quality of life / decreased diminished quality of life	▪ **Variation in harder to track metrics**, including quality of life, PROMS, patterns of care (e.g. time to diagnosis and treatment), morbidity related indicators are also measured and fed back
2 More efficient	▪ Decreased avoidable events (reduced infections, readmissions)	▪ Where poor outcomes drive costs in the health system (e.g., a readmission), registries can reduce expenditure through feedback of information
	▪ Opportunities for disinvestment (reducing number of procedures for the same or better outcomes)	▪ By capturing patient profiles and co-morbidities as well as outcomes, registries can identify healthcare activity which is not improving patient outcomes, **allowing disinvestment**
3 More appropriate	▪ Compliance with guidelines and standards	▪ Where best practices are set out through guidelines and agreed standards, registries **enable benchmarking** and tracking of compliance against these benchmarks
	▪ Improved visibility of outlying performers	▪ As a central repository, registries are able to identify and feed back to **outlying performers**, providing opportunities for actions to be taken to improve performance

Value is delivered through greater effectivity, efficiency and more appropriate care

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Economic Evaluation of five CQRs shows between 2-7 times benefit to cost ratio at current patient coverage levels

Analysis of economic benefit based on current coverage

Registry	Period of analysis	Gross attributed benefit (total)		Registry costs	Benefit to cost ratio	Internal rate of return
		Costs Avoided	QALYs Saved			
Victorian Prostate Cancer Registry (PCR)	2009-13	**$5.2m**		$2.7m	2:1	52%
		$1.4m	$3.8m			
Victorian State Trauma Registry (VSTR)	2005-13	**$36m**		$6.5m	6:1	51%
		$1.2m	$35m			
ANZICS Adult Patient Database (ANZICS APD)	2000-13	**$36m**		$9.8m	4:1	23%
		$32m	$4m			
ANZDATA Registry (ANZDATA)	2004-13	**$58m**		$8.8m	7:1	48%
		$14m	$44m			
AOA National Joint Replacement Registry (AOA NJRR)	≤2002-14	**$65m**		$13m	5:1	25%
		$36m	$29m			

Benefit to cost ratios if each registry had full national coverage

Registry	Extrapolated BCR
Victorian PCR	5:1
VSTR**	12:1
ANZICS	4:1
ANZDATA	7:1
AOA NJRR	5:1

** Crude estimate due to different definitions of 'major trauma' in different jurisdictions and broad assumption of starting from zero coverage in other states when we know in reality there is some existing coverage. BCR – Benefits to Costs Ratio

ANZDATA and AOANJRR are considered to already have full national coverage

Cost and benefit units in 2014 dollars. All figures are discounted at an annual discount rate of 3% to reflect private present time preference. Columns may not sum due to rounding

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Methodology to evaluate benefits from registry

Evaluation of observed changes clinical practice, corrected for confounding factors

Identify indicators of changed practice	Infer change in outcome (if required)	Compare to control group	Assess economic value of change
Find relevant indicators: Process quality measures; ▪ Compliance with clinical guidelines ▪ Measures of clinical quality ▪ Length of stay Patient outcomes ▪ Morbidity ▪ Mortality ▪ Long-term function	Infer impact of improved process measures based on published evidence or observed outcomes ▪ e.g. decreased life expectancy following PSMs	Interview expert clinicians to understand ▪ Impact and extent of use of registry ▪ Confounding changes over time period Control for confounding changes by comparing to a group with no / less feedback e.g. ▪ Later registry contributors ▪ Groups not receiving or accessing feedback	Improvements in life expectancy and quality of life ▪ Based on value of a statistical life year and burden of disease Changes to cost of medical care ▪ Avoided / alternative cost of treatment
Evidence of changed clinical practice	Quantification of impact	Impact attributed to registry	Value of benefits associated with registry

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Benefits are measured through reduction in service costs or preserved quality of life

Registry	Indicators of changed practice	Compare to control group	Assess economic value	
Victorian Prostate Cancer Registry (Victorian PCR)	PSM rate PRIAS compliance	**Case:** Early registry contributors **Control:** Later registry contributors	Avoided treatment costs	Quality of life preserved
Victorian State Trauma Registry (VSTR)	Trauma length of stay In-hospital mortality	**Case:** Recipients of outlier feedback **Control:** Non-recipients of outlier feedback	Avoided treatment costs	Quality of life preserved
ANZICS adult patient database (ANZICS APD)	ICU length of stay ICU mortality rate	**Case:** Recipients of outlier feedback **Control:** Non-recipients of outlier feedback	Avoided treatment costs	Quality of life preserved
ANZ Dialysis and Transplantation Registry (ANZDATA)	Dialysis mortality Transplant graft loss Peritonitis incidence	**Case:** Hospitals that access online feedback **Control:** Hospitals that do not access online feedback	Avoided treatment costs	Quality of life preserved
AOA National Joint Replacement Registry (AOANJRR)	Revision rate (burden of revision)	**Case:** Surgeons who access their individual outcomes data **Control:** Surgeons who do not access their individual outcomes data	Avoided treatment costs	Quality of life preserved

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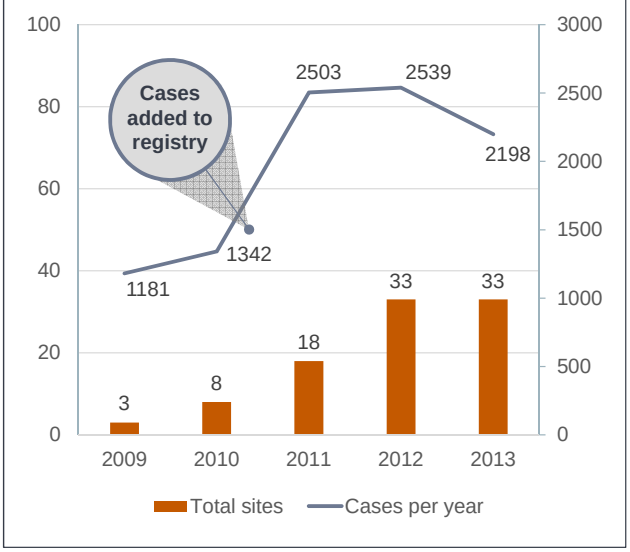
Example: Victorian Prostate Cancer Clinical Registry (Vic PCR) Background

Victorian PCR founded in 2009 and has grown to 33 sites



Has achieved coverage of 75% of Victorian incident cases

Patient coverage: Prostate cancer, opt-out (<3% opt-out rate)

Managed by: Monash University

Funding sources: Government (Federal and State), Cancer organisations (e.g. Cancer Australia, Movember Foundation)

Principal Metrics: Mortality, morbidity, surgical outcomes, patterns of care (and variations thereof), PROMS related to quality of life and disease impact.

Analysis: Quality control, data cleaning and auditing conducted by program staff, cross-checks against admin data. Risk-adjustments

Feedback processes: 11 indicators are fed back to hospitals and urologists every 6 months through benchmarking reports. Annual report released to public

Source Victorian PCR 5-year report (published 2015 Monash University)

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We looked at two sources of benefit – Better initial surgery and reduction in inappropriate intervention

	Indicator of changed clinical practice	Control(s)	Patient outcome	Conversion to economic value	Comment
1a	**Positive Surgical Margin (PSM) rates**	Comparison of sites: Early contributors to the registry versus more recent	Mortality **Morbidity (PROMS)** Reduced need for secondary treatment	Mortality ($ / life year) Morbidity (Weighted $ / Life Yr.) Avoided secondary Tx cost $ / change in quality of Life	Data accessed and analysed
1b	**Rates of Intervention when pt. PRIAS criteria**		Avoided surgery and complications (incontinence, sexual dysfunction)	Avoided costs of procedures $ / change in quality of Life	
1c	**Earlier treatment**	Compared to other states (South Australia / NSW) Outliers within state (Gippsland project)	**Improved outcomes**	Mortality ($ / life year) $ / change in quality of Life	
1d	Other changes in patterns of care	Compared to other states Rate of improvement compared to registry adoption	**Patient reported outcomes (PROMS)**	$ / change in quality of Life	PROMS included in PRIAS evaluation

Indicators for evaluation

Measured by the registry directly

Source: Health Outcomes Australia analysis

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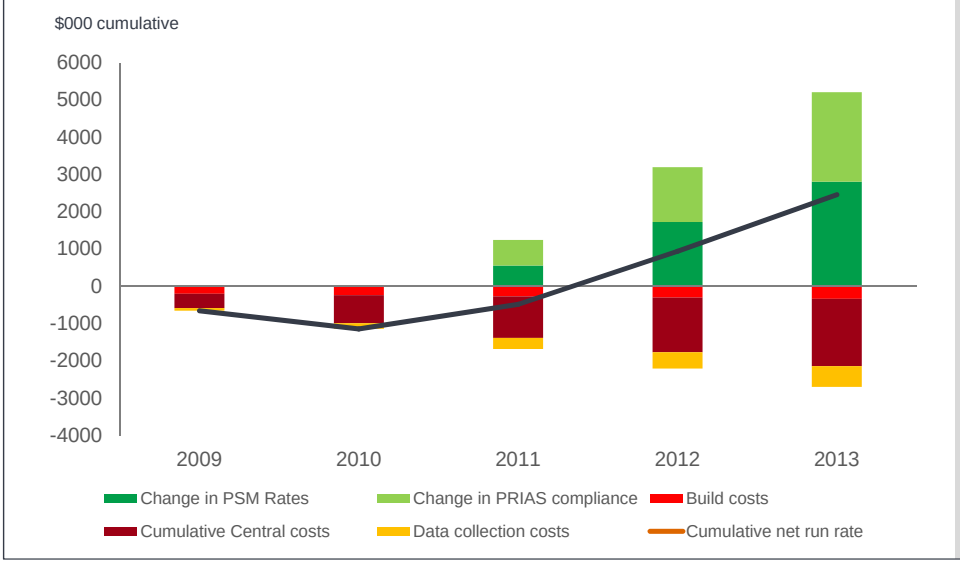
Victorian PCR shows a net benefit of $2.4 million based on a comparison of early versus late registry adopters

Cumulative benefits & costs attributed to Victorian PCR



Over period 2009-2013

Net return attributed
Internal Rate of Return 52%

Total benefits
$5.2m

Total costs
$2.7m

Year	Benefit to cost ratio
2009-2013	2:1

Note: Discounted by 3% p.a.; Cost units in 2014 dollars. VSLY unit calculated per annum. Values may not exactly sum due to rounding
Source Health Outcomes analysis. OBPR protocol

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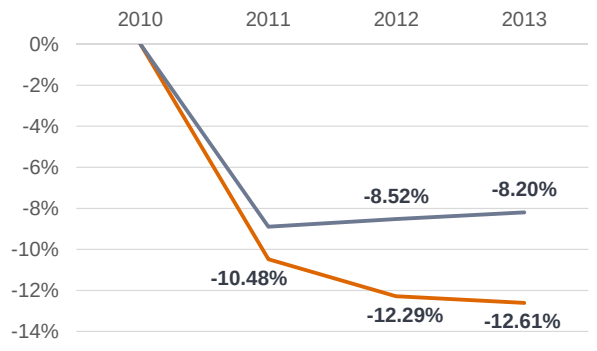
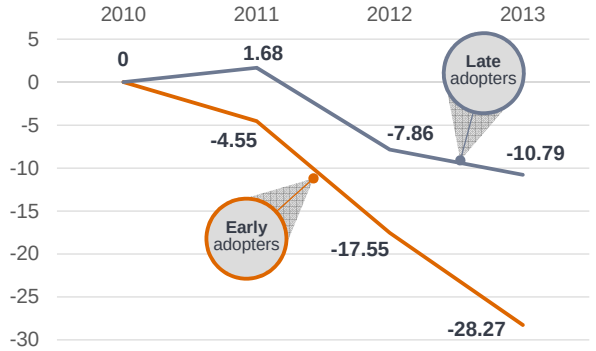
Impact assessed by comparing early and late adopters

Reduction in PSM rates



Rates of change in reduction in positive surgical margins, and (therefore improvements in practice / outcomes) are greater in hospitals that are early contributors to the registry compared to later contributors

Reduction in active treatment of PRIAS patients



Rates of change in reduction in positive surgical margins, and (therefore improvements in practice / outcomes) are greater in hospitals that are early contributors to the registry compared to later contributors

Source: Health Outcomes Australia Analysis. Registry data. For the purpose of the PRIAS analysis the first 5 contributing units were identified as early contributors to enable sufficient case volume for comparison. In practice these 5 units started providing data to the registry demonstrably earlier than subsequent units

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Victorian PCR costs amount to $2.7m from inception to 2013 after discounting

Cost heading	Responsible for cost	2009	2010	2011	2012	2013	Total 09-13
Development and maintenance*		**$200,000**	**$36,050**	**$36,050**	**$36,050**	**$36,050**	**$344,200**
▪ Initial build costs	Monash	$200,000					**$200,000**
▪ Ongoing maintenance (IT & infrastructure)	Monash		$36,050	$36,050	$36,050	$36,050	**$144,200**
Central costs		**$383,254**	**$383,254**	**$383,254**	**$383,254**	**$383,254**	**$1,916,270**
▪ Lead	Monash	$34,561	$34,561	$34,561	$34,561	$34,561	**$172,805**
▪ Biostatistics and analysis	Monash	$38,074	$38,074	$38,074	$38,074	$38,074	**$190,370**
▪ Research and administration	Monash	$129,364	$129,364	$129,364	$129,364	$129,364	**$646,820**
▪ Casual staff	Monash	$68,538	$68,538	$68,538	$68,538	$68,538	**$342,690**
▪ Overheads	Monash	$112,717	$112,717	$112,717	$112,717	$112,717	**$563,585**
Peripheral (data collection) costs[1]		**$72,181**	**$82,021**	**$152,980**	**$155,181**	**$134,339**	**$596,702**
▪ Data collection metro & regional	Monash	$40,736	$46,289	$86,335	$87,577	$75,815	**$336,752**
▪ Data collection (outcomes)	Monash	$31,445	$35,732	$66,645	$67,603	$58,524	**$259,949**
Total cost per annum		**$655,435**	**$501,325**	**$572,284**	**$574,484**	**$553,643**	**$2,857,000**
Number of cases in registry		1,181	1,342	2,503	2,539	2,198	9763

Annual running costs between $500k to 700k p.a., and scale with the amount of case load

[1] Varies based on case load

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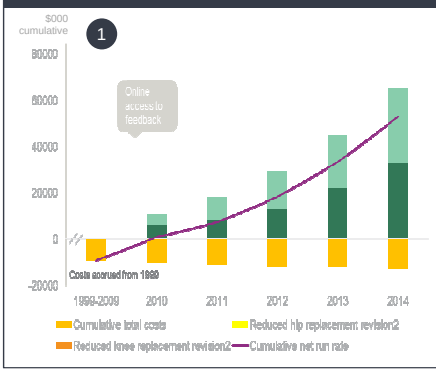
Each registry showed positive benefit to cost ratio despite conservative estimates of benefits through isolated registry functions

Cumulative benefits & costs attributed to AOANJRR



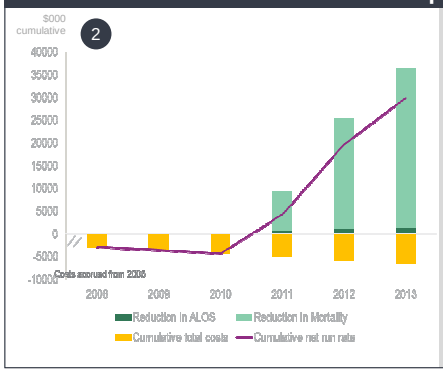
Net return attributed
Internal Rate of Return 25%

Total benefits
$65m

Total costs (from 1999)
$13m

Year	Benefit to cost ratio
1999-2014	5:1

Cumulative benefits & costs attributed to VSTR Post CRG feedback period



Net return attributed
Taking costs for the whole period post 2005;

Internal Rate of Return 51%
Annual Run rate (plotted) benefits realised from 2011

Total benefits
$36m

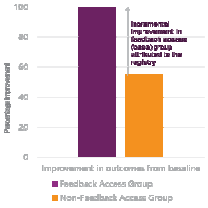
Total costs (from 2005)
$6.5m

Year	Benefit to cost ratio
2005-2013	6:1

Benefits were conservatively attributed through isolated registry function: accessing individual clinician level registry feedback

Outcomes were compared between surgeons that accessed individual outcomes feedback and those that did not

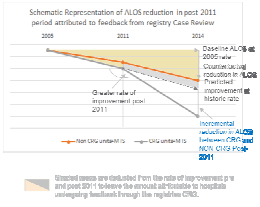
Only the incremental benefit in the former group was attributed to the registry



Benefits were conservatively attributed through isolated registry functions. i.e.: structured registry feedback to outliers

Outcomes were compared between hospitals that received structured outlier feedback and those that did not

Only the incremental benefit in the former group was attributed to the registry



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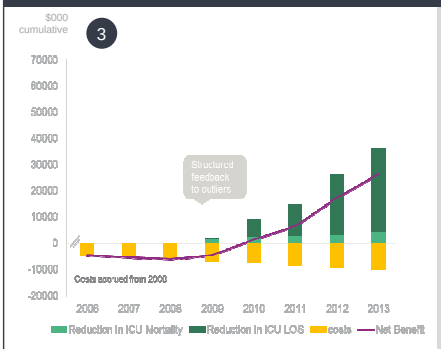
Each registry showed positive benefit to cost ratio despite conservative estimates of benefits through isolated registry functions

Benefits and costs attributed to ANZICS APD



Net return attributed
Internal Rate of Return 23%
Annual Run rate (plotted) benefits realised from 2010

Total benefits
$36m

Total costs (from 2000)
$9.8m

Year	Benefit to cost ratio (cumulative)
2000-2013	4:1

Benefits and costs attributed to accessing ANZDATA registry feedback

Net return attributed
Internal Rate of Return 48%
Annual Run rate (plotted) benefits realised from 2011

Total benefits
$58m

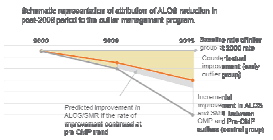
Total costs (from 2004)
$8.8m

Year	Benefit to cost ratio (cumulative)
2004-2013	7:1

Benefits were conservatively attributed through isolated registry functions, i.e.: structured registry feedback to outliers

Outcomes were compared between outliers that received structured feedback and those that did not

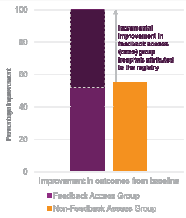
Only the incremental benefit in the former group was attributed to the registry



Benefits were conservatively attributed through isolated registry functions, i.e.: accessing registry feedback

Outcomes were compared between hospitals that accessed feedback reports and those that did not

Only the incremental benefit in the former group was attributed to the registry



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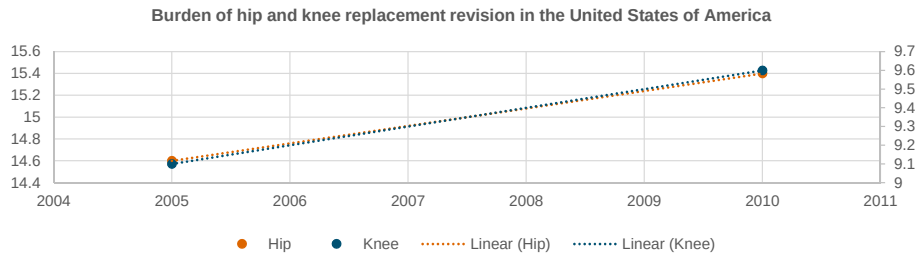
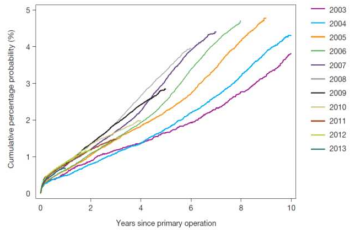
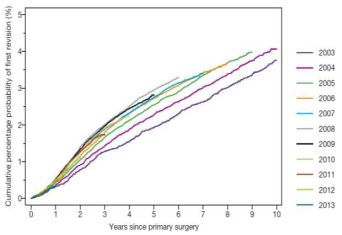
Whole country comparisons suggest an even greater impact of CQRs

USA and UK Revision rates for hip and knee arthroplasty have increased from 2003 to 2014





UK: Temporal changes in revision rates after primary hip replacement



UK: Temporal changes in revision rates after primary knee replacement

The annual burden of revision for hip and knee surgery from October 2005 to December 2010 in America increased 5.5% (14.6% to 15.4% and 9.1% to 9.6% respectively). In a similar period in Australia (December 2004 to December 2010) an 8% and 5.5% improvement was observed in revision burden in Hip and Knee arthroplasty respectively

In the United Kingdom, cumulative percent revision for hip arthroplasty has increased each year from 2003 to 2009 in the first four years after primary joint replacement. Data for more recent years suggest the year on year revision rate is getting progressively higher. A similar trend is observed in the first three years post-knee arthroplasty

Source: Bozic K. J., (2015) and NJR for England, Wales, Northern Ireland, and Isle of Man 2015. UK rates are cumulative percent probability of revision for each year

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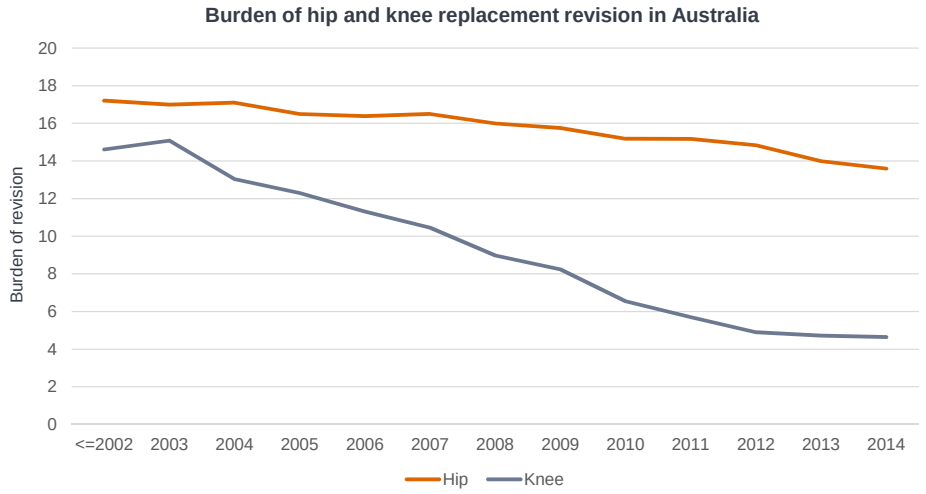
In the same period the revision rate has decreased in Australia

The overall reduction in revisions of hip and knee arthroplasties is equivalent to a benefit of $618 million from 2003 to 2014



If the full reduction in revision burden between 2002 to 2014 were to be attributed to the AOANJRR, this would be equivalent to a benefit of **$361 million and $257 million for avoided hip and knee arthroplasty revisions respectively**

Source: Registry data and Health Outcomes Australia analysis

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Registry costs were typically around $1 million per annum*, with varying degree of national / state-wide coverage and functions

Cost heading	Responsible for cost	1 Year
Development and maintenance of database	**Largely fixed:**	70%
▪ Information Technology costs	Usually met by the registry with charity / government funding	
Central	**Largely fixed with some variable element**	
▪ Research and administrative staffing costs	Usually a combination of government, charity and specialty group funding	
▪ Overheads	In kind support from academic institutions is significant	
▪ Data Analysis costs		
Peripheral	**Largely variable, driven by case load**	30%
▪ Data Collection costs (including validation and data entry)	Variation – sometimes met by the registry itself, at other times met by participating clinical units / hospitals as a cost of regular business	
Total cost per annum		**$0.6 to $1million**

In 3 case studies, data collection costs are met by participating hospitals. This is not uniformly the case

* Before discounting at 3% per annum

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