MONASH University

Clinical Quality Registries

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Director, Clinical Registry Unit
Department of Epidemiology and Preventive Medicine

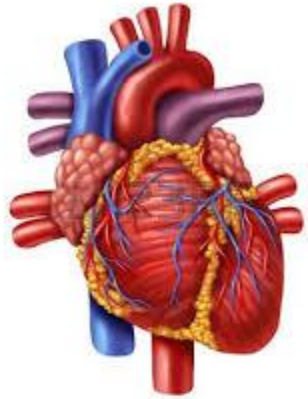
GROUP OF EIGHT AUSTRALIA

Australian Clinical Registries

- What registries may be collecting data in your health service?

Diseases/events captured by Australian registries

Cardiovascular disease



- Australia New Zealand Society of Cardiac and Thoracic Surgeons (ANZSCTS) Cardiac Surgery Database Programme
- Coronary Angiogram Database of South Australia (CADOSA)
- Australian Stroke Clinical Registry (AuSCR)
- Australasian Vascular Audit
- Victorian Cardiac Outcomes Registry (VCOR)
- Victorian Ambulance Cardiac Arrest Registry (VACAR)

Diseases/events captured by Australian registries

Critical care and infection control

- The Victorian State Trauma Registry (VSTR)
- Victorian Orthopaedics Trauma Outcome Registry (VOTOR)
- Australian and New Zealand Intensive Care Society (ANZICS): Adult Patient Database (APD)
- Australian and New Zealand Paediatric Care (ANZPIC) Registry
- Australian and New Zealand Massive Transfusion Registry
- Australian and New Zealand Intensive Care Society (ANZICS): Central Line Associated Blood Stream Infection (CLABSI) Surveillance System
- Victorian Healthcare Associated Infection Surveillance System (VICNISS)
- Burns Registry of Australia and New Zealand (BRANZ)

Diseases/events captured by Australian registries

Chronic disease and rehab

- Australian Cystic Fibrosis Data Registry (ACFDR)
- Australian Motor Neuron Disease Registry (AMNDR)
- Spleen Registry Australia
- Australian Bleeding Disorders Registry (ABDR)
- Australasian Rehabilitation Outcomes Centre (AROC)
- Australian Rheumatology Association Database (ARAD)

Diseases/events captured by Australian registries

Procedure and device

- Australian Breast Device Registry
- Australian Orthopaedic Association National Joint Replacement Registry (AOANJRR).
- Breast Surgery Australia New Zealand Quality Audit
- Bariatric Surgery Clinical Quality Registry
- Australian Corneal Graft Registry

Diseases/events captured by Australian registries

Transplant

- Australasian Bone Marrow Transplant Recipient Registry (ABMTRR)/ Australasian Stem cell Transplants Online (ASTRO)
- Australia and New Zealand Liver Transplant Registry (ANZLTR)
- Australia New Zealand Dialysis and Transplantation Registry (ANZDATA)

Diseases/events captured by Australian registries

Cancer

- Prostate Cancer Outcome Registry- Australia and New Zealand (PCOR-ANZ)
- Victorian Lung Cancer Registry (VLCR)
- Binational Colorectal Cancer Audit (BCCA)
- South Australian Metastatic Colorectal Cancer Registry
- Australian Thyroid Cancer Audit
- Australian Paediatric Cancer Registry (APCR)
- Upper GI Cancer Registry

Monash Clinical Registries - History

2001 VSTR

2002 ARAD

2003 VOTOR

2004 MIG

2005 ANZCTS

2008TTP, NAIT

2008 Australian Operating Principles for CQRs (ACSQHC)

2009 BSR, PCOR

2010 VLCR, BRANZ

2011 ABDR, MTR, AAR

2012 VCOR, Myeloma

2013 ROKD,

2014 PCOR -ANZ

2015 UGI Ca Registry

2016 CF, ATR, PCO-CRV Global

2017 Spine Surgery Registry

2017 Thyroid Cancer Registry

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2017 Spine Surgery Registry

2017 Thyroid Cancer Registry

Monash Clinical Quality Registries

Currently operate 25 clinical and clinical quality registries – the leading provider of clinical registries in Australia

AUSTRALIAN
Breast
Device
REGISTRY

massive
transfusion registry

VLCR
Victorian Lung Cancer Registry

PROSTATE
CANCER
OUTCOMES
REGISTRY
AUSTRALIA &
NEW ZEALAND

BSR
BARIATRIC SURGERY REGISTRY

VCOR
VICTORIAN CARDIAC OUTCOMES REGISTRY

vstorm

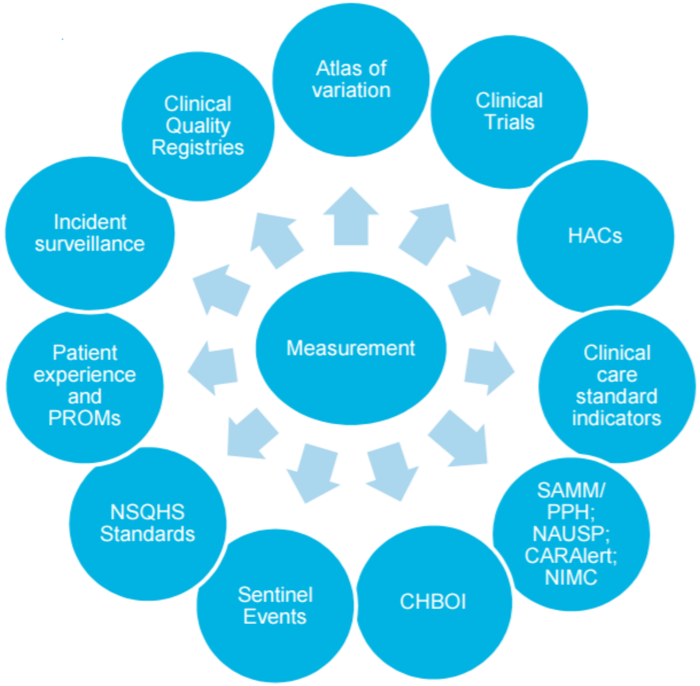
State Government Victoria Department of Health
TAC TRANSPORT ACCIDENT COMMISSION
MONASH University
Medicine, Nursing and Health Sciences

What are clinical registries?

Monash Clinical Quality Registries (CQRs)

CQRs as defined by the Australian Commission on Safety and Quality in Health Care:

> *[CQRS are] "organisations that systematically monitor the quality (appropriateness and effectiveness) of health care, within specific clinical domains, by routinely collecting, analysing and reporting health-related information. The information is used to identify benchmarks, significant outcome variance, and inform improvements in healthcare quality."*



Measurement

Atlas of variation

Clinical Trials

HACs

Clinical care standard indicators

SAMM/ PPH; NAUSP; CARAlert; NIMC

CHBOI

Sentinel Events

NSQHS Standards

Patient experience and PROMs

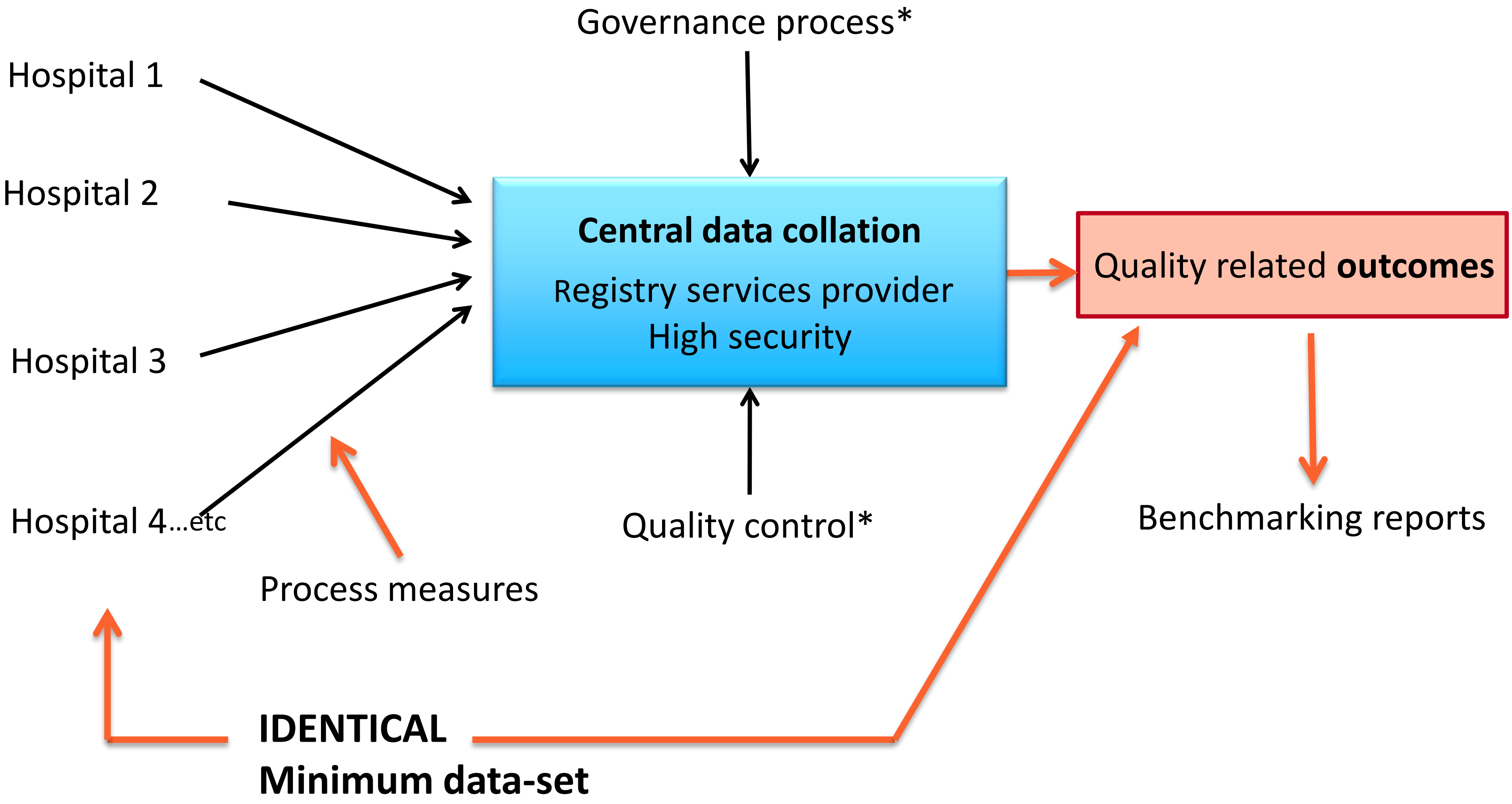
Incident surveillance

Clinical Quality Registries

Difference between a clinical registry, clinical trial and CQR?

	Clinical registry	Clinical trial	CQR
Collects incidence data *how many cases are there?	✓	✓	✓
Reports patterns of care	+/-	✓	✓
Observational	✓	-	✓
Collects patient reported outcomes	-	+/-	✓
Interventional	-	✓	-
Collects health outcomes	+/-	✓	✓
Collects population-level data	-	-	✓
Minimal information	+/-	-	✓
Monitors quality of care using indicators	-	-	✓
Provides feedback to hospitals/clinicians	-	-	✓

Clinical Quality Registry Process Overview



Governance process*

Hospital 1

Hospital 2

Hospital 3

Hospital 4…etc

Central data collation

Registry services provider

High security

Quality related **outcomes**

Benchmarking reports

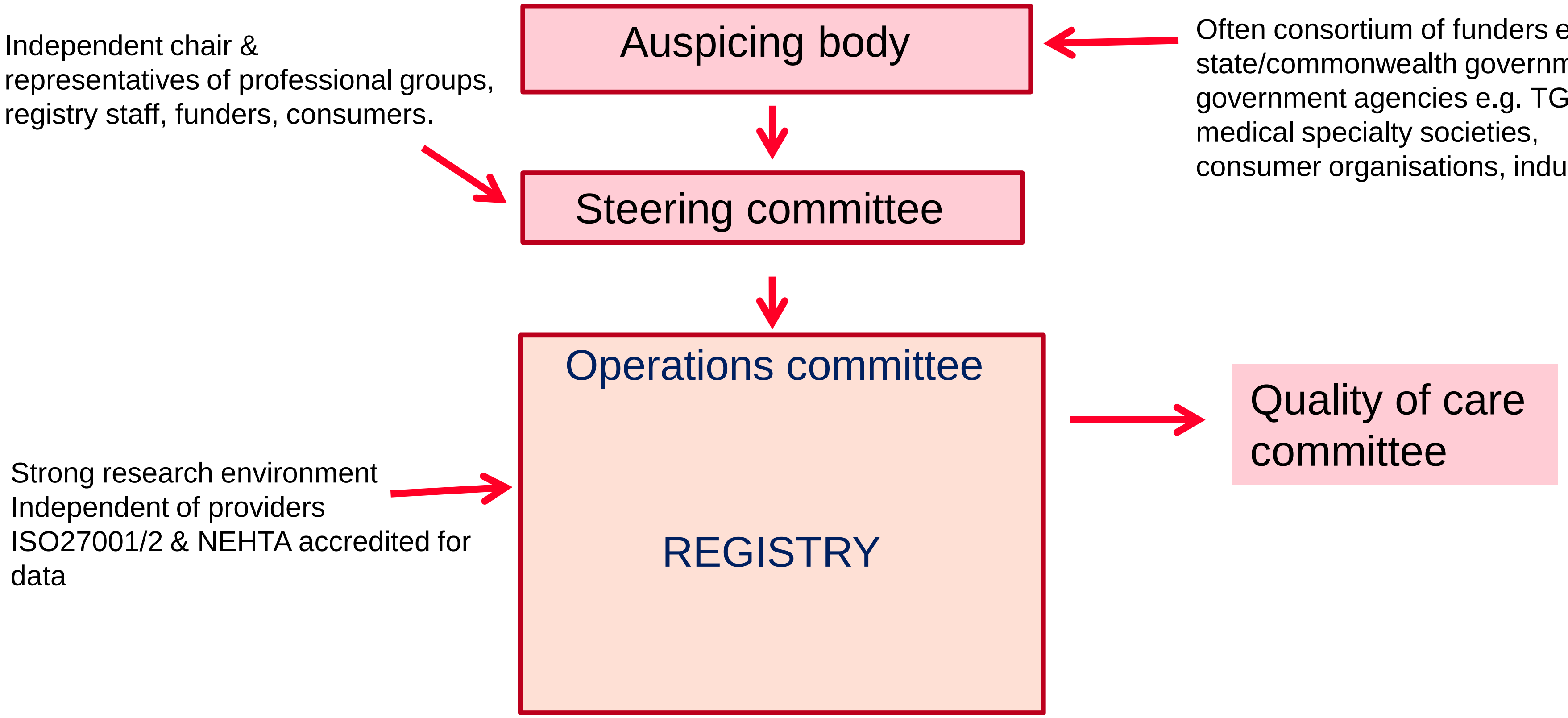
Quality control*

Process measures

IDENTICAL

Minimum data-set

Registry Governance and Funding



Independent chair & representatives of professional groups, registry staff, funders, consumers.

Auspicing body

Often consortium of funders e.g. state/commonwealth government; government agencies e.g. TGA; medical specialty societies, consumer organisations, industry.

Steering committee

Strong research environment
Independent of providers
ISO27001/2 & NEHTA accredited for data

Operations committee

REGISTRY

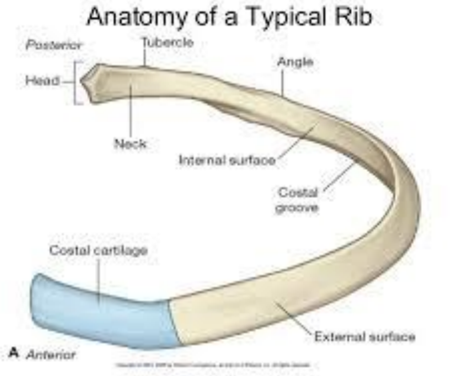
Quality of care committee

Central registry: includes quality assurance, reporting,
Peripheral data collection: initial data & outcome collection:

Clinical Quality Registry Minimum Dataset

DATA SPINE

from everyone
minimal
epidemiologically sound
no clinical judgement
unchanging
identifiable
linkable
risk adjustable
bench-markable



DATA RIB

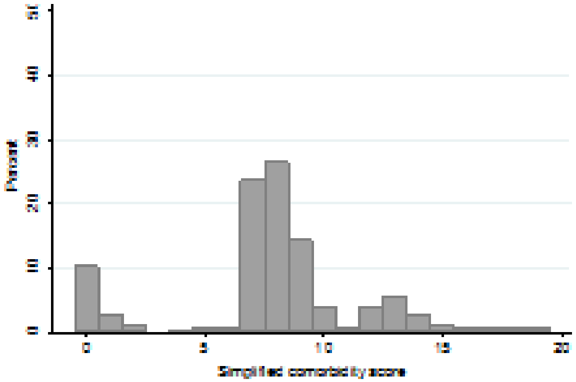
may be time
limited from
interested
centres typically
requires funding

Measurement is foundational to advancing healthcare improvement

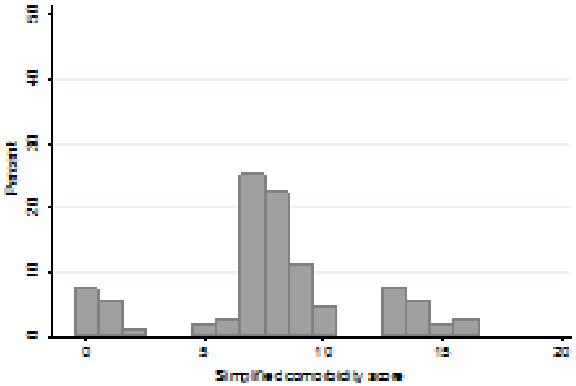
Importance of good data

Some administrative data are excellent e.g. **Procedure codes**

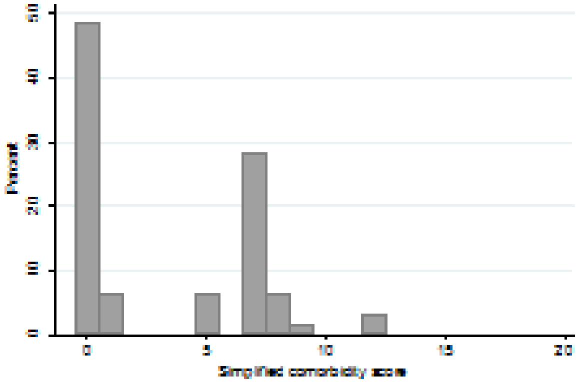
But, others are poor e.g. comorbidities and risk factors.
Patient-reported outcomes



A) Registry data



B) Medical record review



C) ICD coded data

Alexander M, Wolfe R, Ball D, Evans SM MJA 2017: In Press

Australian Government

Medical Research
Future Fund

Targeting zero
Supporting the Victorian hospital system to eliminate avoidable harm and strengthen quality of care
Report of the Review of Hospital Safety and Quality Assurance in Victoria

Data and infrastructure

Priority	Detail
Clinical quality registries	Provide start-up investment in disease or therapy-focussed clinical registries supported by a national framework to maximise interoperability and value of research to clinical practice.

Recommendation 3.4:

That departmental monitoring of safety and quality includes monitoring against a comprehensive range of outcome indicators using hospital routine data and data from clinical registries.

Recommendation 3.7:

That:

3.7.1. the funding contracts for clinical quality registries funded by the department be renegotiated to provide:

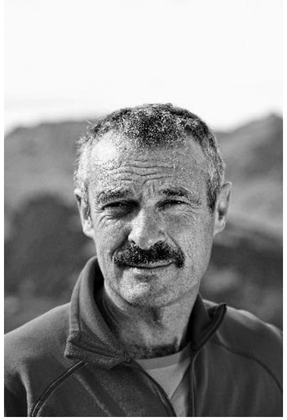
- an explicit requirement for all performance metrics to be provided to hospital chief executives (or their designated nominee) and to the department at the same time as they are fed back to clinical units
- for registries that have been in existence for more than a decade, a full dataset of registry data to the department (the new Victorian Health Performance Authority when established) at least annually to allow matching to, and incorporation in, the relevant routine dataset (the data provided should have the names of individual clinicians removed)

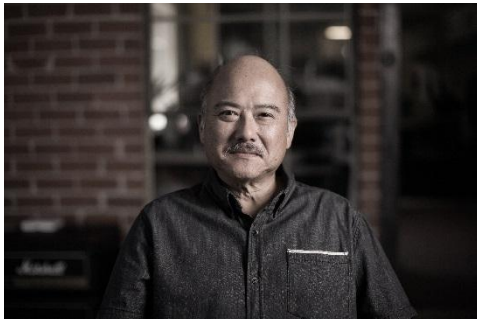
3.7.2. the new Victorian Health Performance Authority publishes metrics derived from clinical registries in its quarterly public report

Exploring one registry- PCOR-Vic

Prostate Cancer Outcome Registry-Victoria

- Prostate cancer is:
  - the **most** common non-skin cancer in Australian men
  - the **second** most common cause of death, behind lung cancer.
  - the **most** costly of all cancer types; almost **twice** that of the next two most costly combined, more than **twice** the economic cost of breast cancer, and **more than three times** the economic cost of lung cancer
  - A chronic disease, with 5 year survival at >92% in Australia
  - A debilitating disease of older men, associated with a significantly higher risk of suicide compared to men without prostate cancer.





Prostate Cancer Outcome Registry-Victoria

- Treatment pathways for prostate cancer:
    - Surgery
    - Radiotherapy
    - Active surveillance.
- Active Surveillance (AS) increasingly being used in the management of low risk prostate cancer.
- Primary aim of active surveillance – avoid unnecessary treatment of men with low risk disease and monitor them in a manner that enables recognition of signs of progression with the intent of deferred treatment being curative.

Prostate Cancer Outcome Registry-Victoria

§ Established in 2009 to understand reasons for variation in survival and monitor treatment and outcomes

§ Men in rural regions of Australia have a statistically significant and increasing age standardised mortality compared to metro counterparts [1]

- Victorian data [2]
    - Melbourne Metro 5-year survival = 86%
    - Rest of Victoria 5-year survival = 80%
    - Within rural ICS, 3-fold difference in mortality.

1. Coory MD, Baade PD. Urban–rural differences in prostate cancer mortality, radical prostatectomy and prostate-specific antigen testing in Australia. Med J Aust 2005; 182:112-5.
2. English D, Farrugia H, Thursfield V, Chang P, Giles GG. Cancer Survival, Victoria 2007. Melbourne: The Cancer Council Victoria. 2007.

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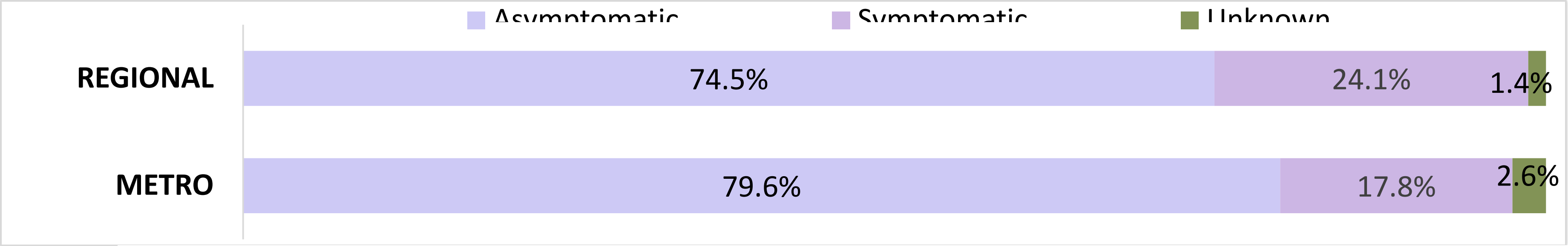
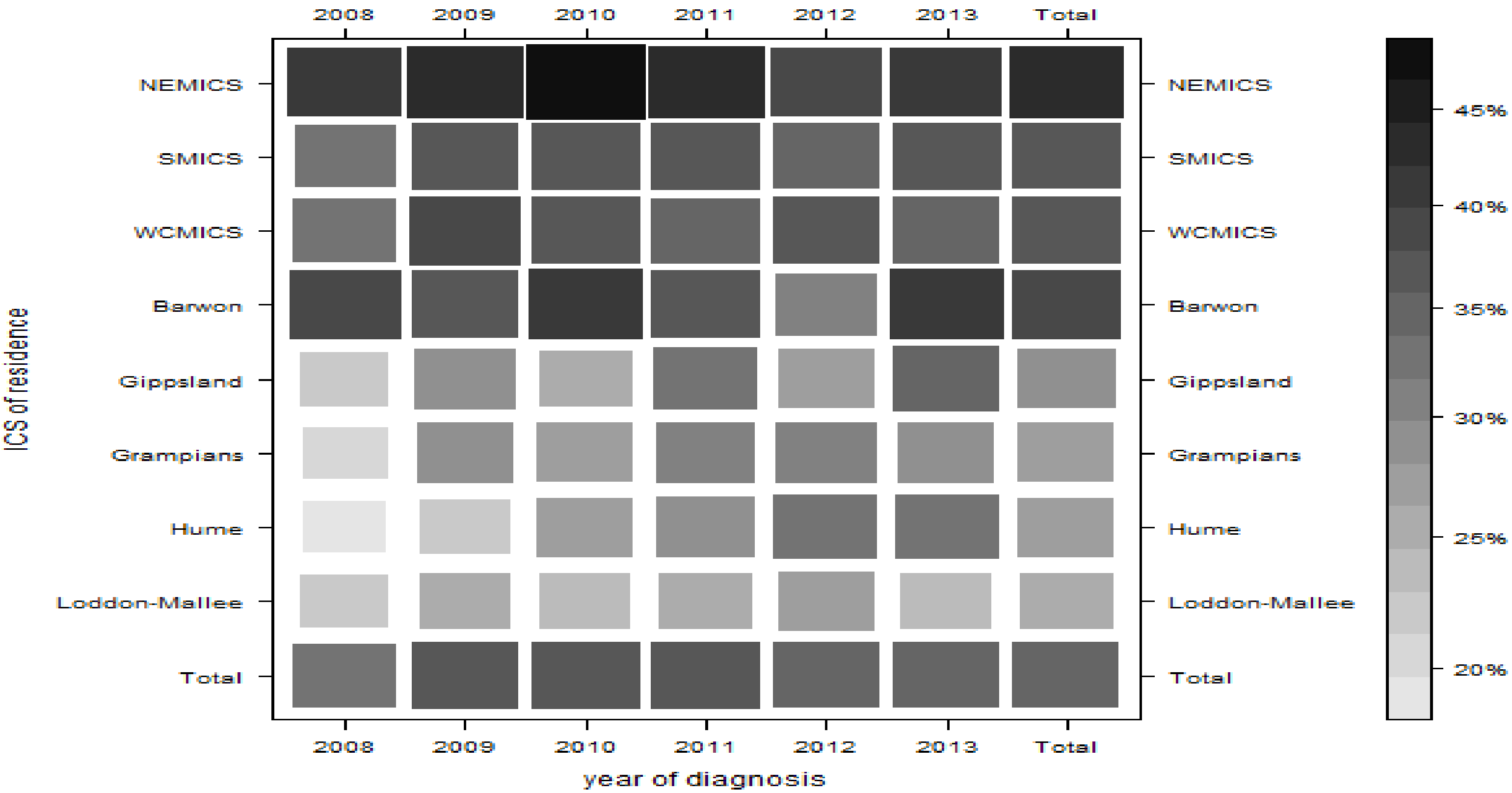
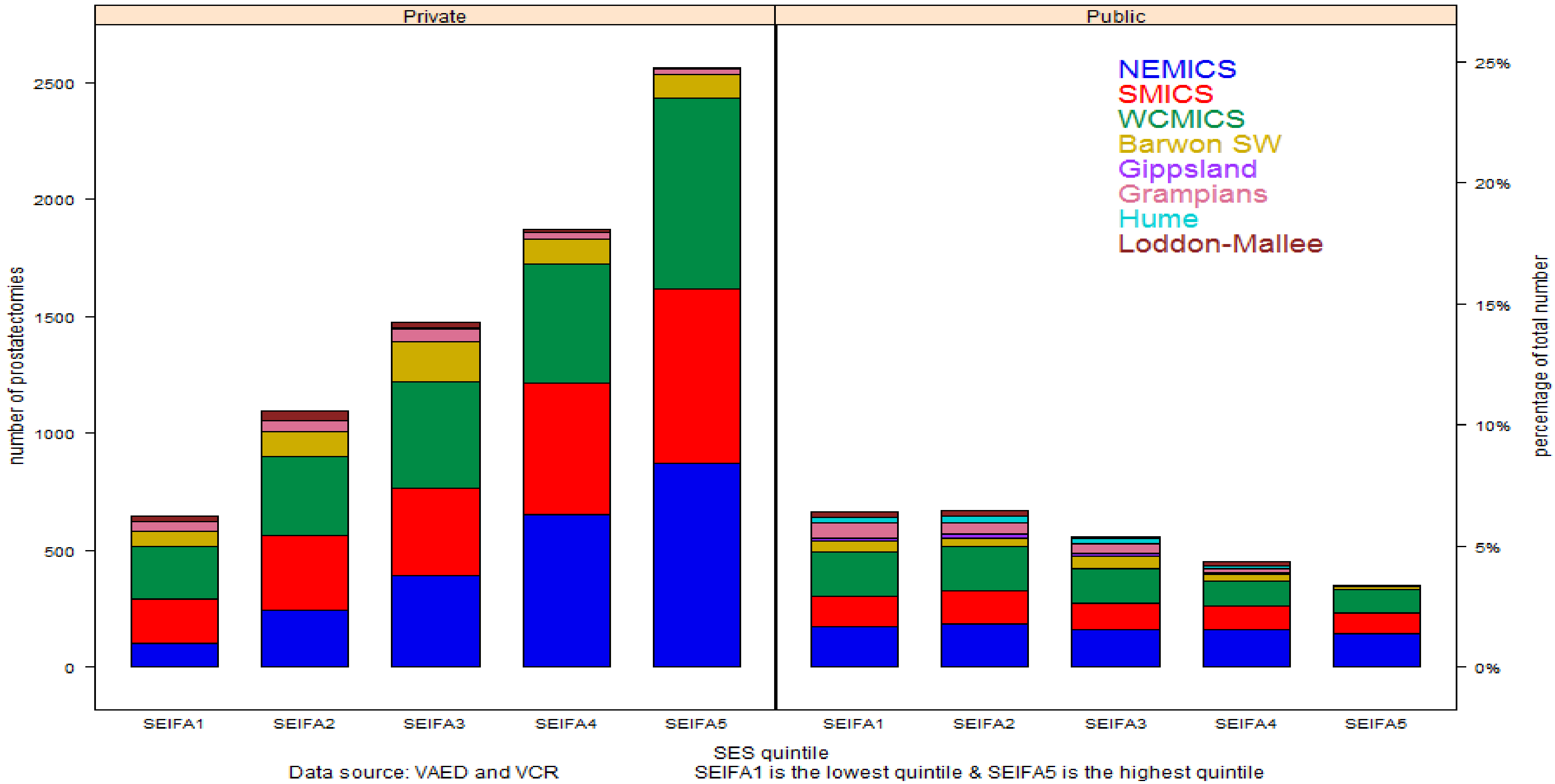
Prostate cancer management according to where you live….



Surgical treatment 2008-13



… and your socioeconomic status



Data source: VAED and VCR

Over-treatment? Under-treatment?

So… more advanced disease is regional patients; less treatment for men in regional Victoria, more treatment in men from high socioeconomic class and in private hospitals….what does all this mean?

Understanding what good care looks like

Good care	(indicators) Measured by…
Good documentation	PSA at diagnosis cT documented in medical record
Treatment is timely	Time from diagnosis to treatment for high-risk disease Time from referral to diagnosis
Treatment is appropriate	Evidence of high-risk men receiving treatment Evidence of low-risk men on active surveillance
Treatment is effective	Risk-adjusted positive surgical margins Five-year biochemical recurrence rate
Treatment is safe	In-hospital death from surgical complication
Care is patient-centred and responsive	Urinary, bowel and sexual bother by treatments

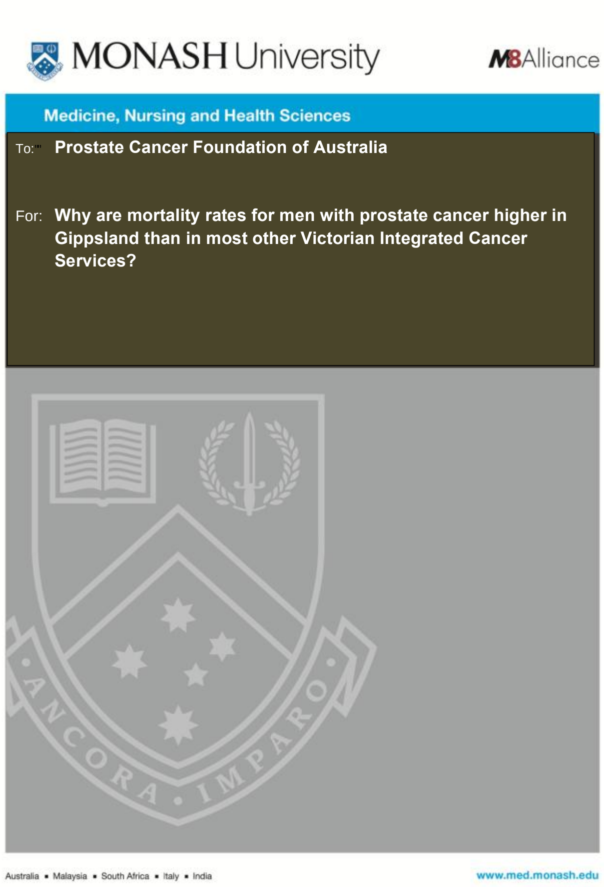
+++ evidence also demonstrates that men should receive adequate info to make informed management choice and receive sexual counselling + more…

MOVEMBER FOUNDATION | PROSTATE CANCER OUTCOMES | REGISTRY AUSTRALIA & NEW ZEALAND

Examples of quality improvement- PCOR-Vic

PROSTATE
CANCER
OUTCOMES

REGISTRY
AUSTRALIA &
NEW ZEALAND



MONASH University

M8 Alliance

Medicine, Nursing and Health Sciences

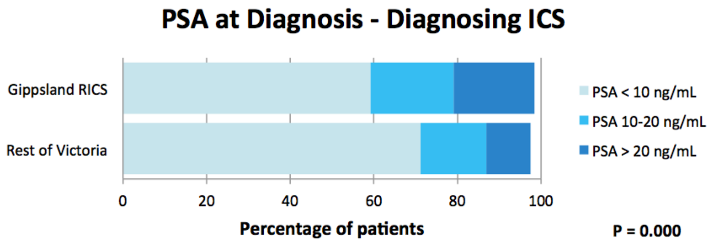
To: **Prostate Cancer Foundation of Australia**

For: **Why are mortality rates for men with prostate cancer higher in Gippsland than in most other Victorian Integrated Cancer Services?**

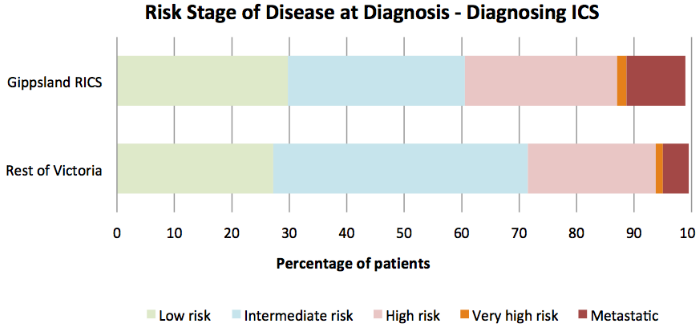
Australia • Malaysia • South Africa • Italy • India

www.med.monash.edu

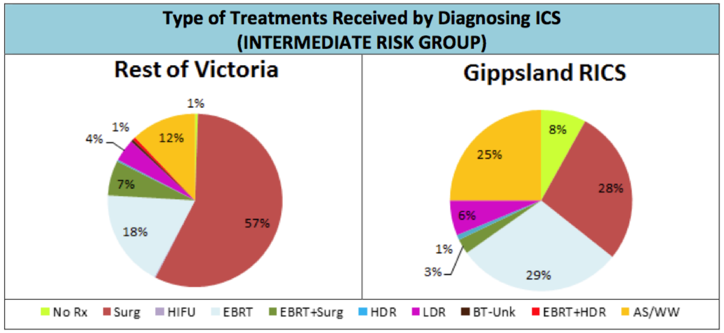
Multiple factors



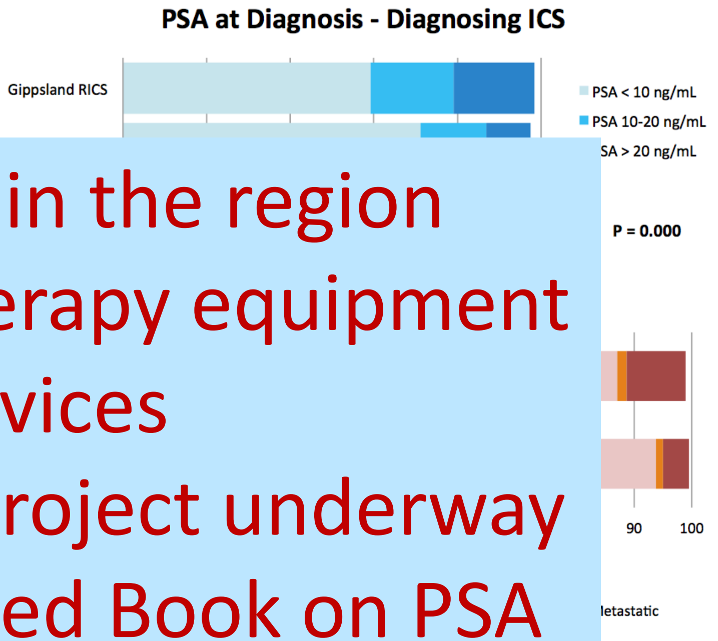
PSA at Diagnosis - Diagnosing ICS

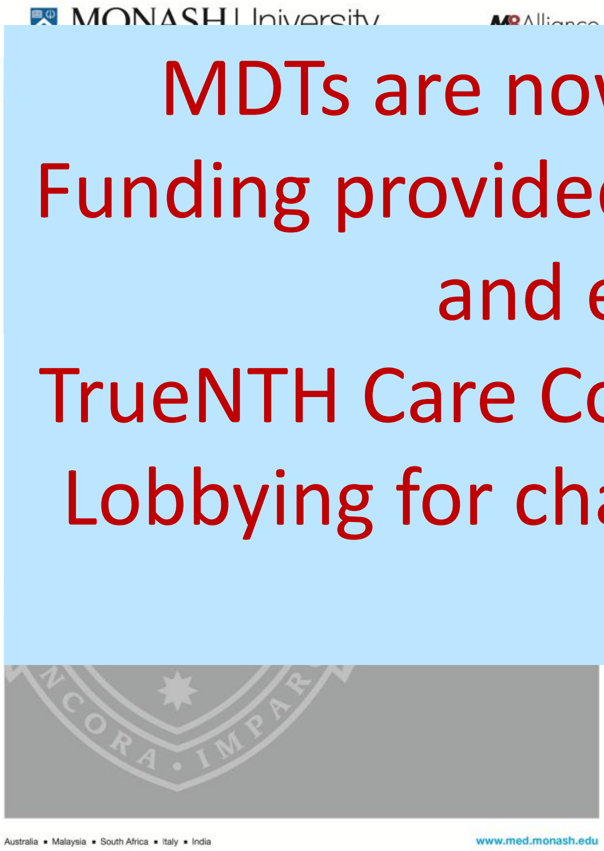


Risk Stage of Disease at Diagnosis - Diagnosing ICS



Type of Treatments Received by Diagnosing ICS (INTERMEDIATE RISK GROUP)



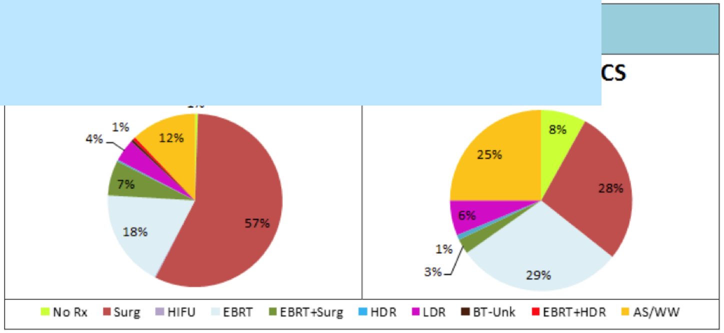


MDTs are now conducted in the region

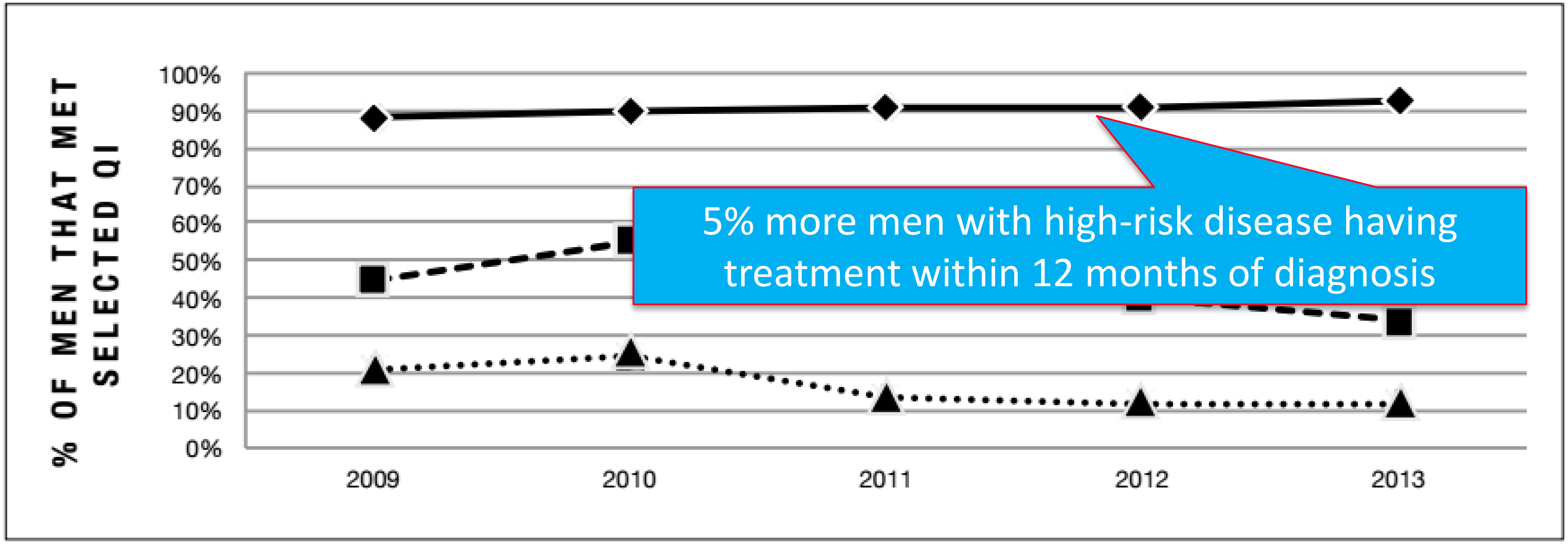
Funding provided for radiotherapy equipment and enhanced services

TrueNTH Care Coordination project underway

Lobbying for change to the Red Book on PSA testing



TREND IN QUALITY CARE IMPROVEMENT IN VICTORIA



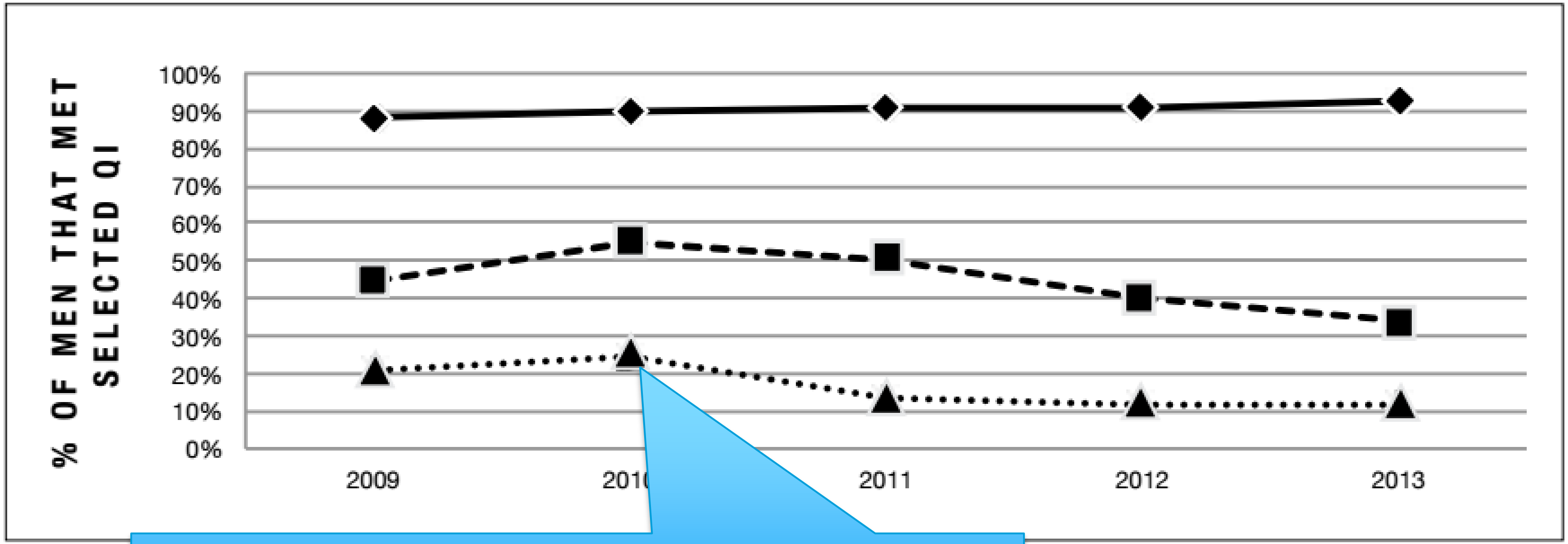
5% more men with high-risk disease having treatment within 12 months of diagnosis

Quality of care achievements of the Prostate Cancer Outcomes Registry–Victoria

Fanny Sampurno, Arul Earnest, Patabendi B Kumari, Jeremy L Millar, Ian D Davis, Declan G Murphy, Mark Frydenberg, Paul A Kearns and Sue M Evans

Med J Aust 2016; 204 (8): 319.

TREND IN QUALITY CARE IMPROVEMENT IN VICTORIA



50% reduction in positive surgical margins in pT2 disease

Qua
Prostate Cancer Outcomes Registry–
Victoria

Fanny Sampurno, Arul Earnest, Patabendi B Kumari, Jeremy L Millar, Ian D Davis, Declan G Murphy, Mark Frydenberg, Paul A Kearns and Sue M Evans

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PROSTATE CANCER OUTCOMES
REGISTRY AUSTRALIA & NEW ZEALAND

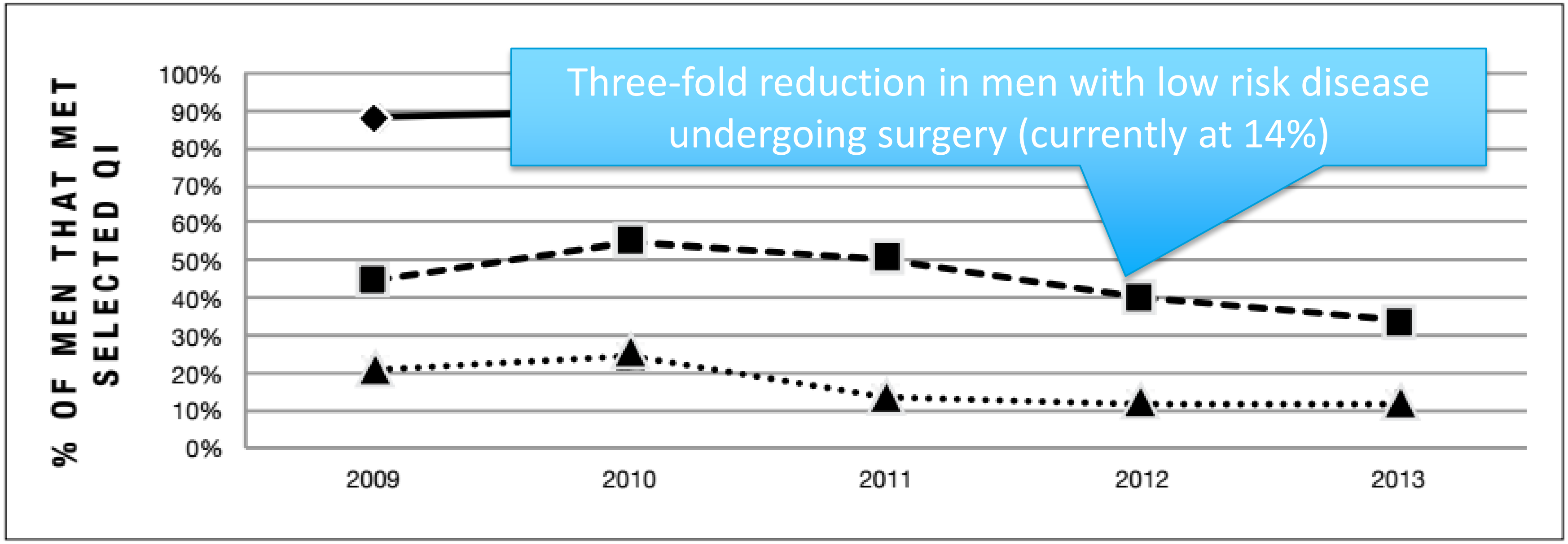
Reduction in positive surgical margins =

Avoiding 20 PSMS

…is predicted to avoid ~1 premature death,

and almost $200,000 in avoided secondary treatment costs

TREND IN QUALITY CARE IMPROVEMENT IN VICTORIA



Three-fold reduction in men with low risk disease undergoing surgery (currently at 14%)

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PROSTATE CANCER OUTCOMES

REGISTRY AUSTRALIA & NEW ZEALAND

Reduction in active treatment=

Reducing 10 active treatments in PRIAS patients

…prevents poorer quality of life in 6 patients

1 QALY

$182,000

and results in benefits of $155,000 in avoided treatment costs.

➕ $155,000

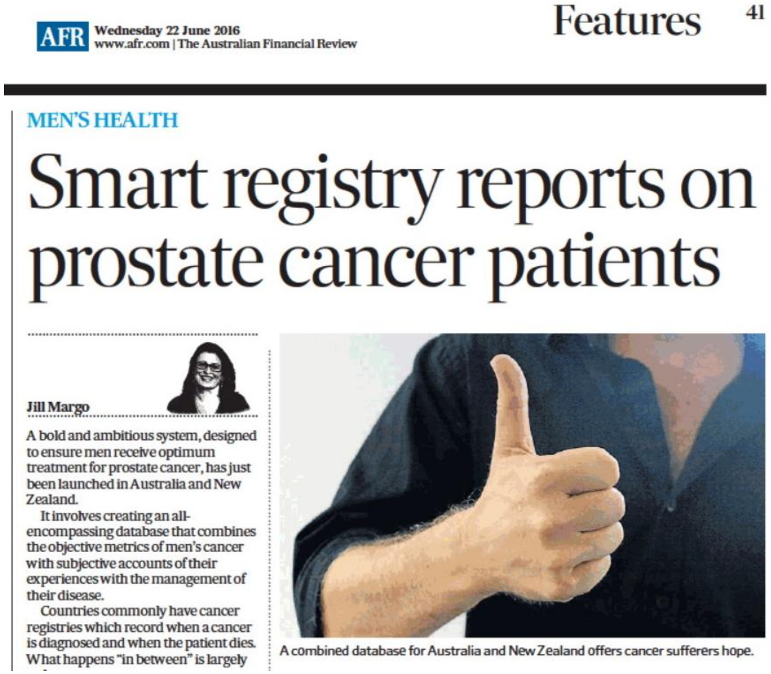
* (not including $ benefits improved Quality of Life)

But…..

- A (rib) study off PCOR-Vic has identified that
  - Only 26.5% of men are receiving surveillance in accordance with minimal requirements
  - Men on AS in private hospitals are 80% more likely to have adequate AS compared to men in public hospitals
  - Why?
  - Registries are platforms for future research

PROSTATE CANCER OUTCOMES | REGISTRY AUSTRALIA & NEW ZEALAND

Prostate cancer summit 2016



AFR Wednesday 22 June 2016
www.afr.com | The Australian Financial Review

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MEN'S HEALTH

Smart registry reports on prostate cancer patients

Jill Margo

A bold and ambitious system, designed to ensure men receive optimum treatment for prostate cancer, has just been launched in Australia and New Zealand.

It involves creating an all-encompassing database that combines the objective metrics of men's cancer with subjective accounts of their experiences with the management of their disease.

Countries commonly have cancer registries which record when a cancer is diagnosed and when the patient dies. What happens "in between" is largely

A combined database for Australia and New Zealand offers cancer sufferers hope.

Recommendation 1: Universal contribution to PCOR Vic and share data with local clinical group

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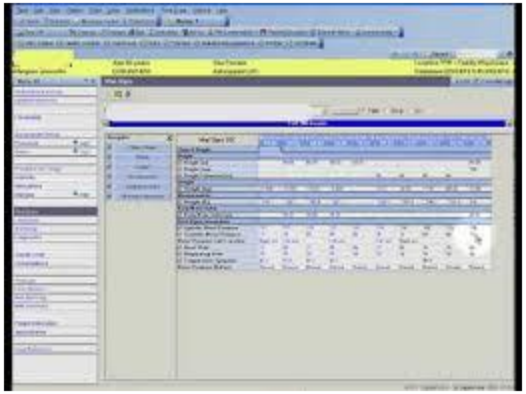
PROSTATE CANCER OUTCOMES
REGISTRY AUSTRALIA & NEW ZEALAND

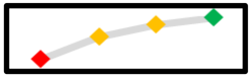
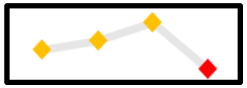
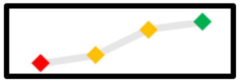
Much work still to be done

- More efficient data collection



Much work still to be done

- More efficient data collection
- Better data integration and display

Indicators	Progression	Current Performance
1. Risk-adjusted survival at 5 years		🟢
2. PSA taken at Dx		🟡
3. PSA taken post prostatectomy		🟡
4. Documentation of cT in medical record		🟢
5. Advanced disease and active surveillance (risk adjusted)		🔴
6. Percentage of men with high risk disease receiving treatment within 90 days		🟢

Much work still to be done

- More efficient data collection
- Better data integration and display
- Balancing transparency with confidentiality

DHHS
requirement
for reporting

Voluntary
nature of
registries

Much work still to be done

- More efficient data collection
- Better data integration and display
- Balancing transparency with confidentiality
- More widespread promotion of registries to quality managers

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- More widespread promotion of registries to quality managers
- Facilitating distribution of registry reports to relevant committees within health services

PROSTATE
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Much work still to be done

- More efficient data collection
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- More widespread promotion of registries to quality managers
- Facilitating distribution of registry reports to relevant committees within health services
- Sustained funding

Much work still to be done

- More efficient data collection
- Better data integration and display
- Balancing transparency with confidentiality
- More widespread promotion of registries to quality managers
- Facilitating distribution of registry reports to relevant committees within health services
- Sustained funding
- International benchmarking of quality of care

Summary & Next Steps

- Clinical Registries have proven benefits for increasing knowledge of diseases; for improving clinical care; and for providing a platform for clinical research.
- Australia can learn from international examples where:
  - Registries are embedded into clinical care
  - Registries are embedded into funding mechanisms
  - Registry international benchmarking is core business
- National clinical registry strategy needs to be co-ordinated with jurisdictions and private stakeholders
- Ongoing strategy for sustainable infrastructure and funding required

Many thanks to…..

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CHANGING THE FACE OF MEN'S HEALTH

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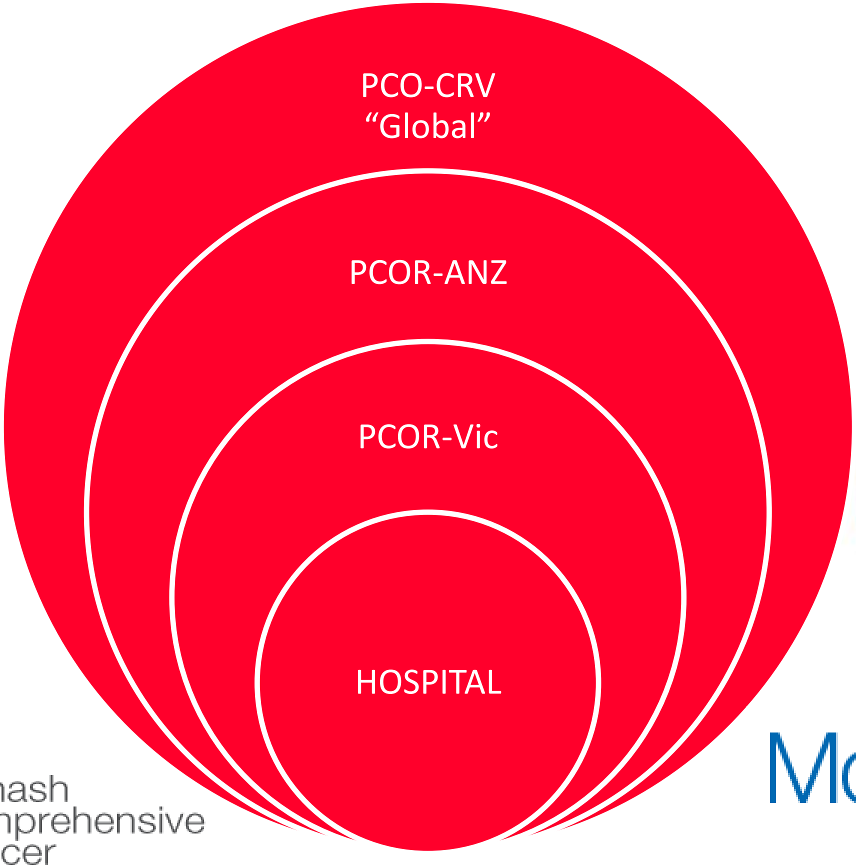
Medicine, Nursing and Health Sciences

Monash Partners
Academic Health Science Centre



PCO-CRV
“Global”

PCOR-ANZ

PCOR-Vic

HOSPITAL

Cabrini

theAlfred

Victorian Cancer Registry
Cancer Council Victoria

Victorian Cancer Agency

Monash Comprehensive Cancer Consortium

MonashHealth