

HEALTH DATA  
CONFERENCE  
21st JULY 2017

USING  
CLINICAL  
DATA TO  
TRANSFORM  
CANCER CARE

FLIPPING

the

RECORD

#IMPSCI  
COMMUNITY  
OF PRACTICE

# WELCOME

On behalf of our conference partners:

- Sydney West TCRC
- CONCERT TCRC
- Translational Cancer Research Network
- Hunter Cancer Research Alliance
- Sydney Vital TCRC
- Kids Cancer Alliance
- Sydney Catalyst TCRC
- and
- The Cancer Institute NSW



# INTRODUCTION

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## Setting the Scene

by **Professor Tim Shaw**

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**PROFESSOR OF HEALTH, DIRECTOR**  
RESEARCH IN IMPLEMENTATION  
SCIENCE AND eHEALTH GROUP,  
THE UNIVERSITY OF SYDNEY

# KEYNOTE

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The Cancer Institute  
NSW vision for data  
usage in health care



by **Professor David Currow**

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CHIEF CANCER OFFICER, NSW AND  
CHIEF EXECUTIVE OFFICER,  
CANCER INSTITUTE NSW



# A vision for the optimal use of health data

**Prof David Currow**

**Cancer Institute NSW**

**July, 2017**

E17/08244



## Optimal use of health data

**Half-life of knowledge: the time in which knowledge may be superceded or be shown to be untrue**

Fritz Machlup, 1962;

Knowledge Production and Distribution in the United States. Princeton University Press

**Half-life of facts: the time for half the facts in a discipline to become obsolete**

Samuel Arbesman, 2012;

The Half-Life of Facts: Why Everything We Know Has An Expiration Date



# Optimal use of health data

1. What principles underpin our use of data?
2. What progress have we made?
3. What can the future look like?

# Optimal use of health data

**1. What principles underpin our use of data?**

2. What progress have we made?

3. What can the future look like?

# Optimal use of health data

## Whose data?

- ❖ Data belong to the people about whom they are collected
- ❖ We need open and honest conversations across the community about the collection and use of data
- ❖ **People need to be assured that these data are being used appropriately to improve their care and care for people subsequently**

# Optimal use of health data

## Whose data?

- ❖ **There is an ethical imperative to use all available data to ensure that we are improving care for people systematically**
- ❖ **There is therefore also an imperative to make these data as widely available to clinicians and researchers as possible**



# Optimal use of health data

## *The status quo*

- ❖ **Data rich**
- ❖ **Information poor**
- ❖ **Little local knowledge**
- ❖ **Poor integration across clinical data / information technology systems**

# Optimal use of health data

## *The status quo*

- ❖ **How little information clinicians and health service planners actually have**
- ❖ **Individual clinician's performance reports on clinical outcomes adequately adjusted and benchmarked are incredibly rare**

# Optimal use of health data

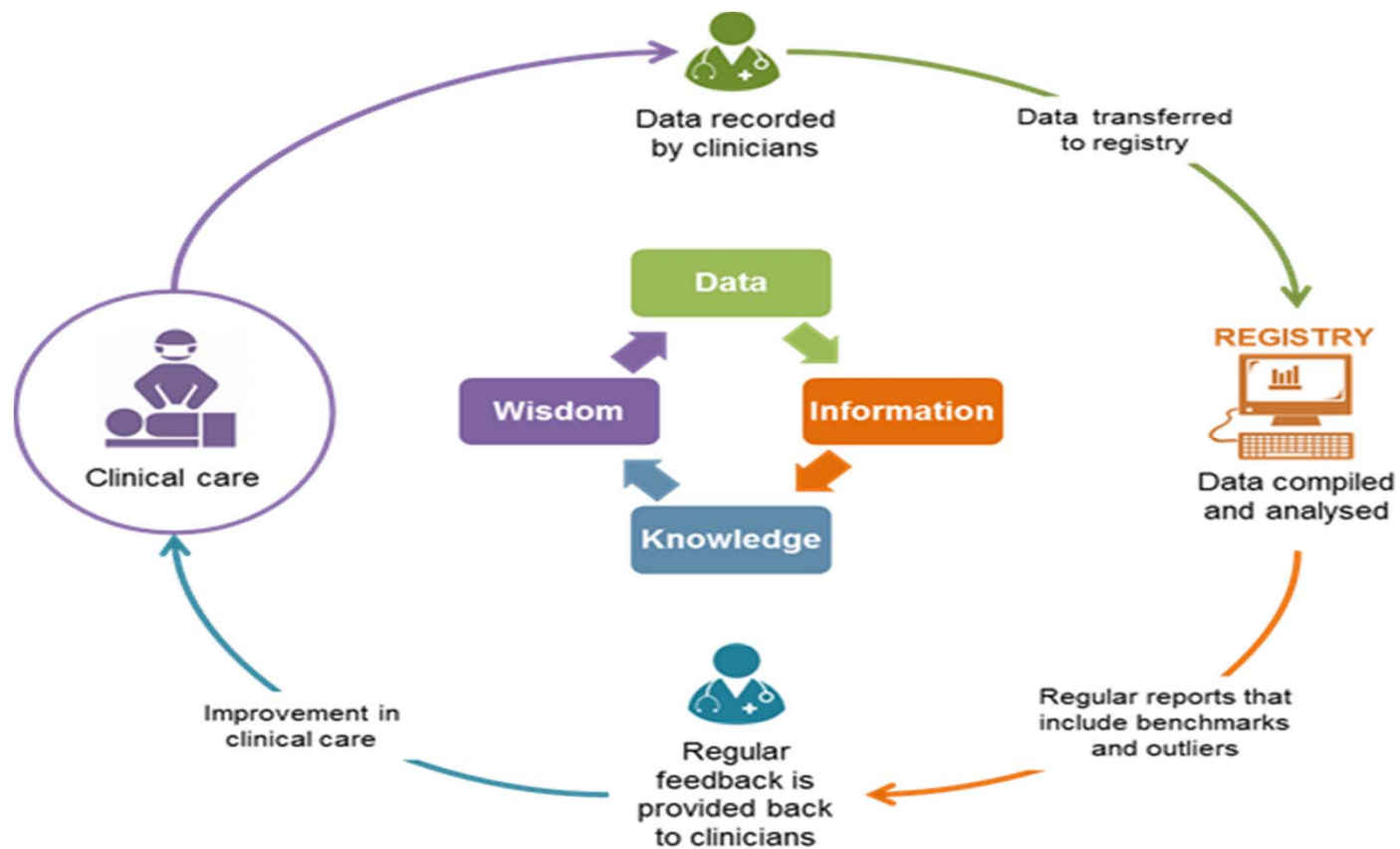
## The leaders today

- ❖ **Data harvesting**
- ❖ **Data linkage**
- ❖ **Data analysis**
- ❖ **Data presentation**

# Optimal use of health data



# Optimal use of health data



# Optimal use of health data

1. What principles underpin our use of data?
2. What progress have we made?
3. What can the future look like?



# Optimal use of health data

## Local knowledge

- **Results adjusted for:**
  - **age;**
  - **sex;**
  - **co-morbidities;**
  - **pre-operative level of function;**
  - **extent of spread at presentation;**
  - **urgency of admission;**
  - **private / public; and**
  - **year of separation.**
- **Results presented by hospital volume.**

## Optimal use of health data

**Mortality (30, 90 day)**

**Survival (1 year conditional (survived 30 days), 1 & 5 year survival)**

**\*Percentage of people with length of stay >21 days**

**\*Readmission within 28 days of episode of care**

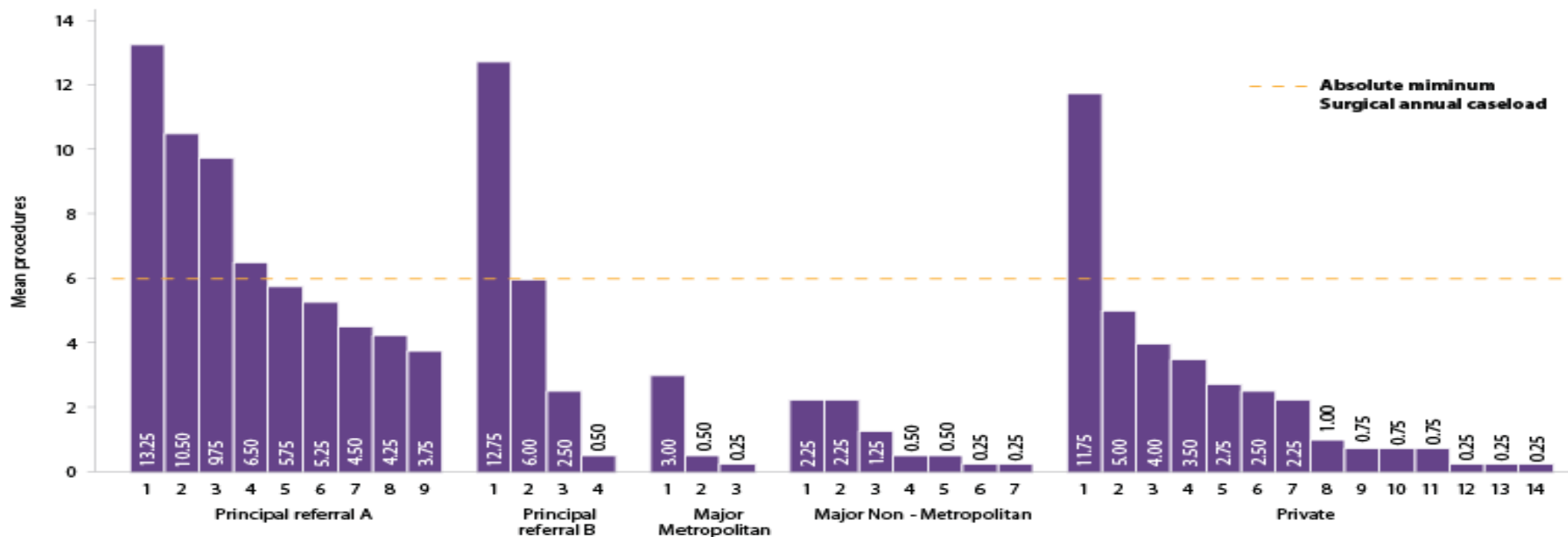
(Definitions are taken from the Ministry of Health or Australian Council on Healthcare Standards)

\*Across the whole state – not limited to care in the original institution



# OESOPHAGUS CANCER SURGERIES

Mean procedure volume in NSW, 2005-2008

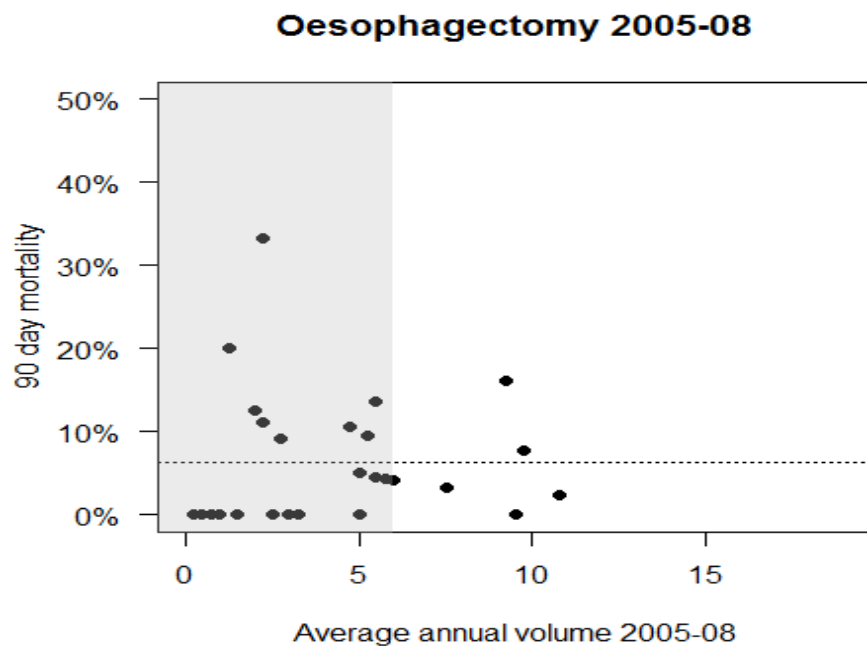


## Oesophagus – mortality by average annual hospital volume, NSW, 2005-2008

Average annual volume	Procedures (n)	Facilities (n)	30-day mortality ( %)	90-day mortality ( % )	1 year conditional survival
<b>0-3</b>	<b>20</b>	<b>19</b>	<b>4.6</b>	<b>9.4</b>	76.1
<b>&gt;3-6</b>	<b>32</b>	<b>8</b>	<b>3.2</b>	<b>4.7</b>	72.8
<b>&gt;6</b>	<b>41</b>	<b>5</b>	<b>2.7</b>	<b>5.5</b>	81.2

# Oesophagectomy

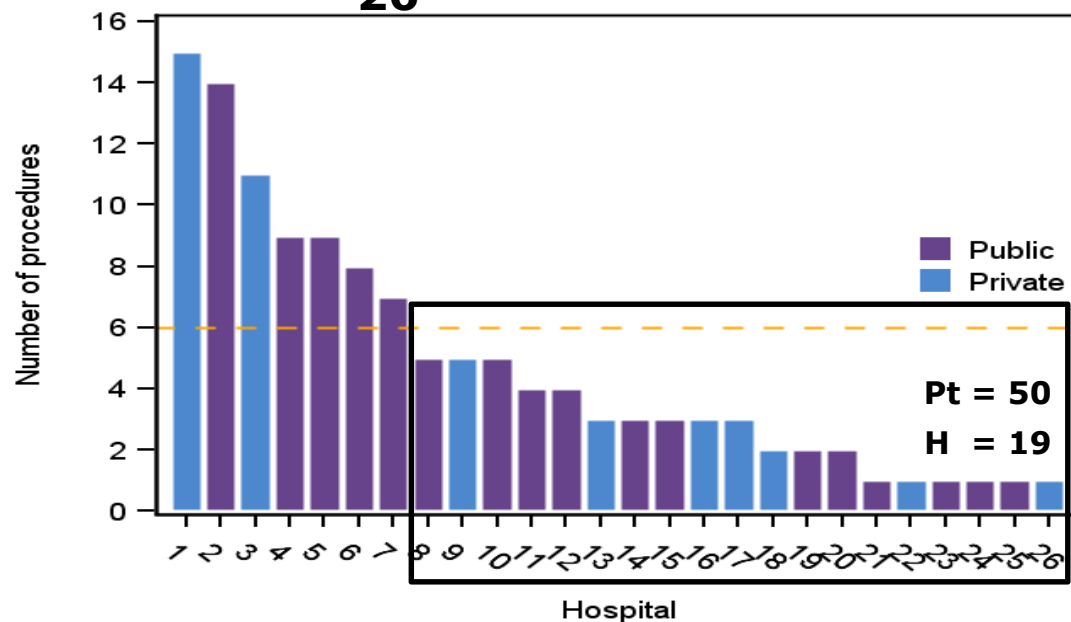
## 90-day mortality by volume



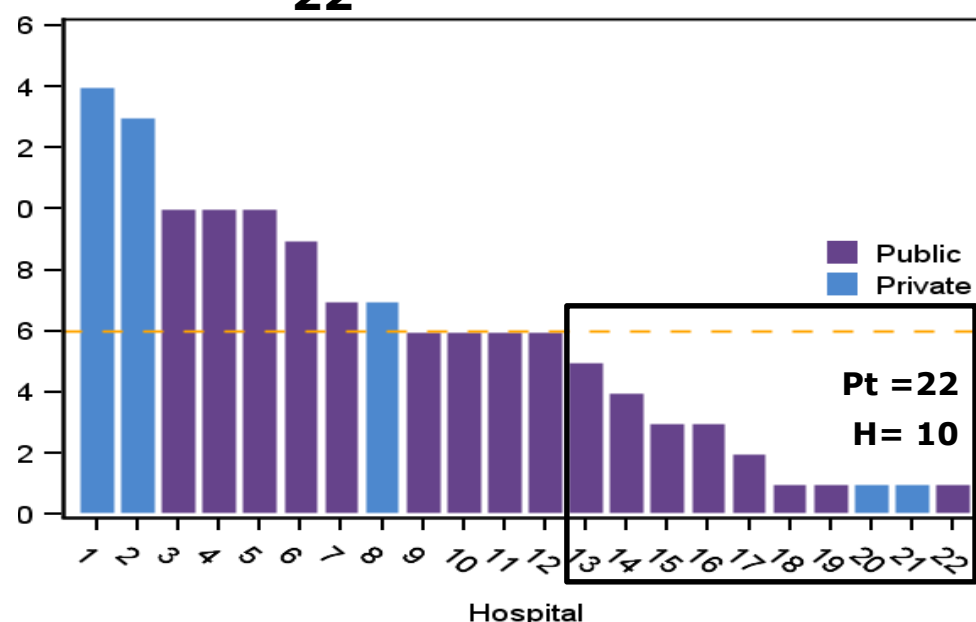
# Hospitals performing these procedures at very low volume

Oesophagectomy for invasive oesophago-gastric cancer

2009, n = 123, h = 26



2013, n = 126, h = 22

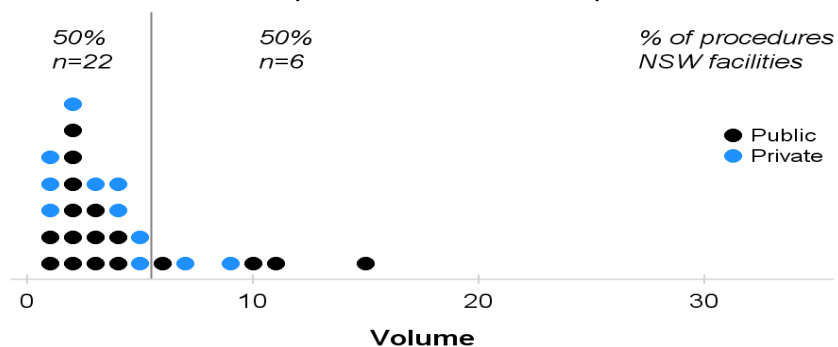




# 2005 compared to 2014

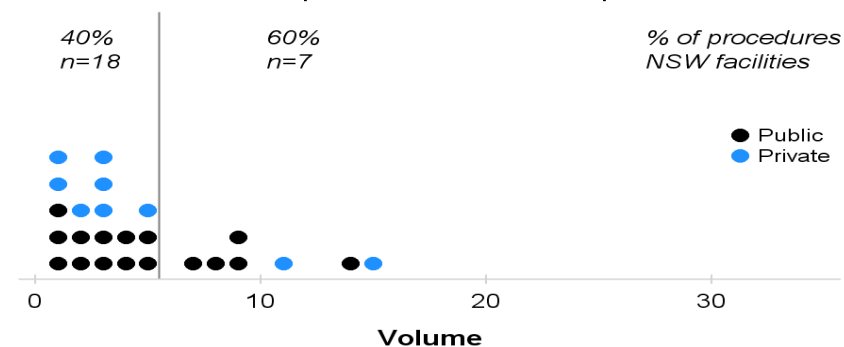
## Oesophagectomy, 2005

N = 115 procedures; N = 28 hospitals



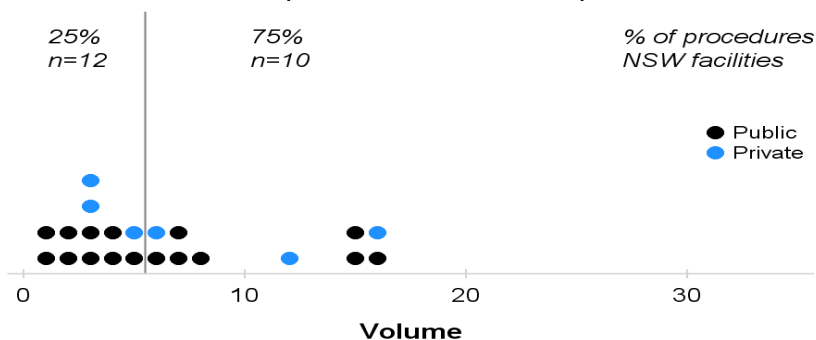
## Oesophagectomy, 2009

N = 122 procedures; N = 25 hospitals



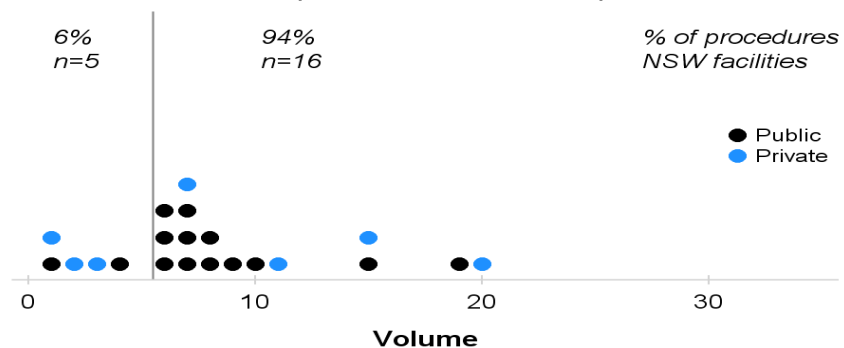
## Oesophagectomy, 2011

N = 144 procedures; N = 22 hospitals



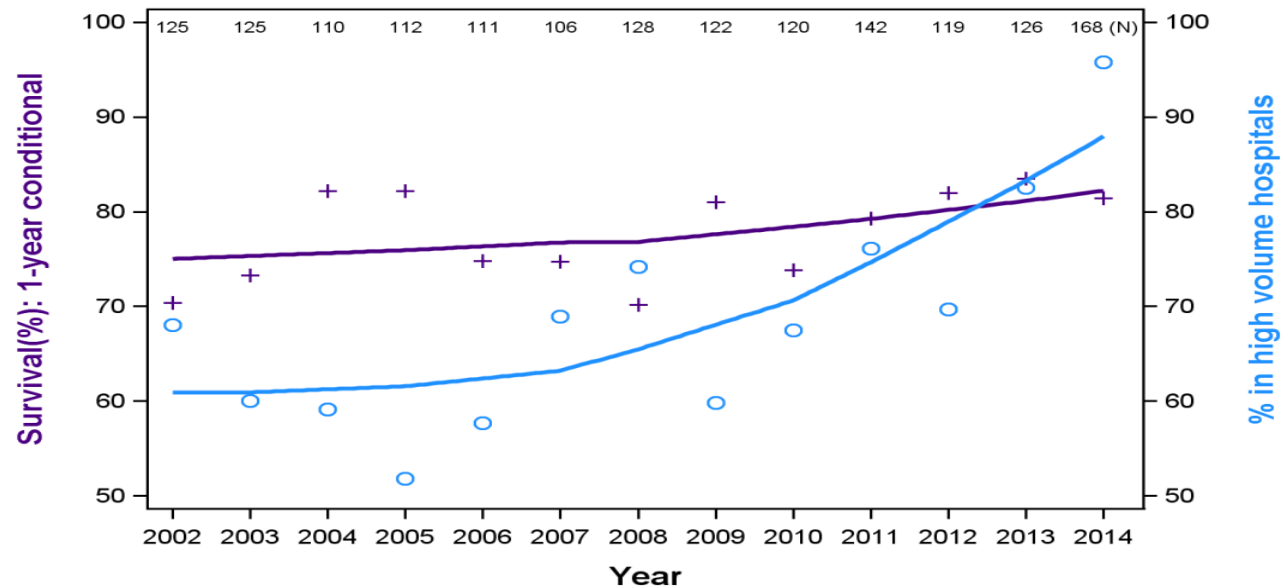
## Oesophagectomy, 2014

N = 172 procedures; N = 21 hospitals



# One year conditional post-operative survival, 2002-2014

## Oesophagectomy



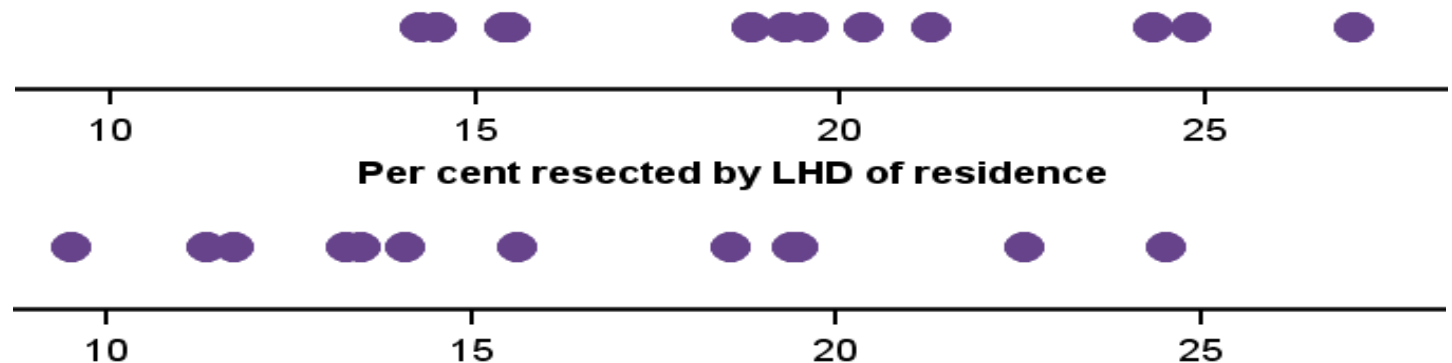
- **One-year conditional survival** (conditional on surviving 30 days)
- **% of resections in higher volume ( $\geq 6$  per year) hospitals**

## Percent resected by LHD of residence with curative intent, 2010-2012

- For people with a first admission for cancer between 2010 and 2012:
- 14-27% for oesophagus
- 9-24% for pancreas

Oesophageal & cardia cancer

Pancreatic & ampullary cancer

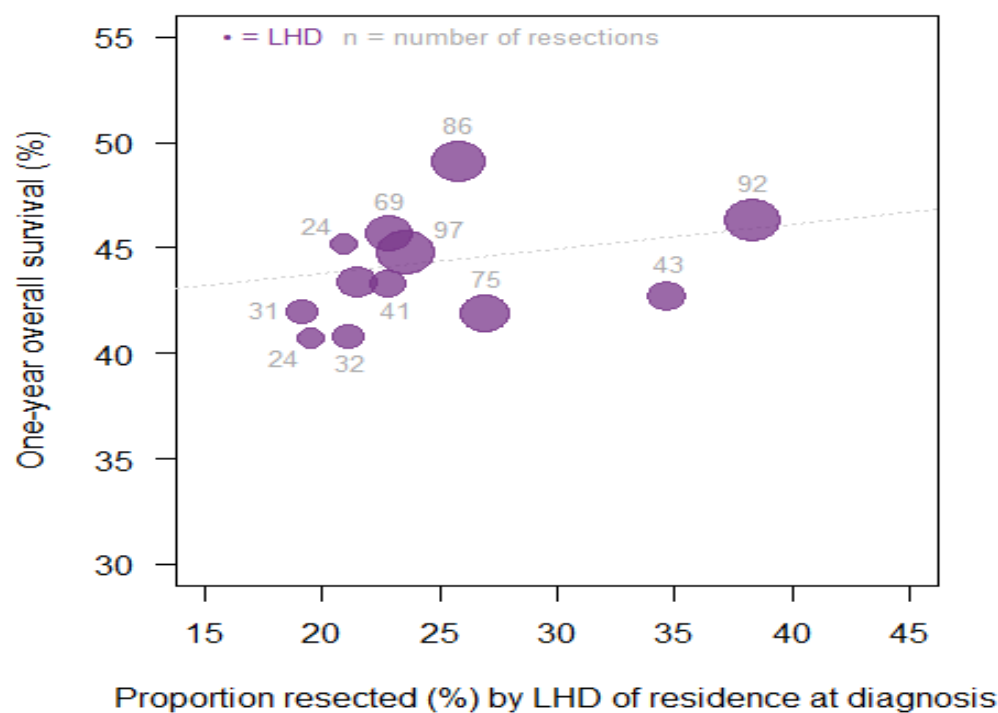


Northern NSW, Southern NSW and Far West LHDs are excluded.



# Oesophagus: per cent resected and one-year survival

Oesophageal and cardia cancer cases 2005-09

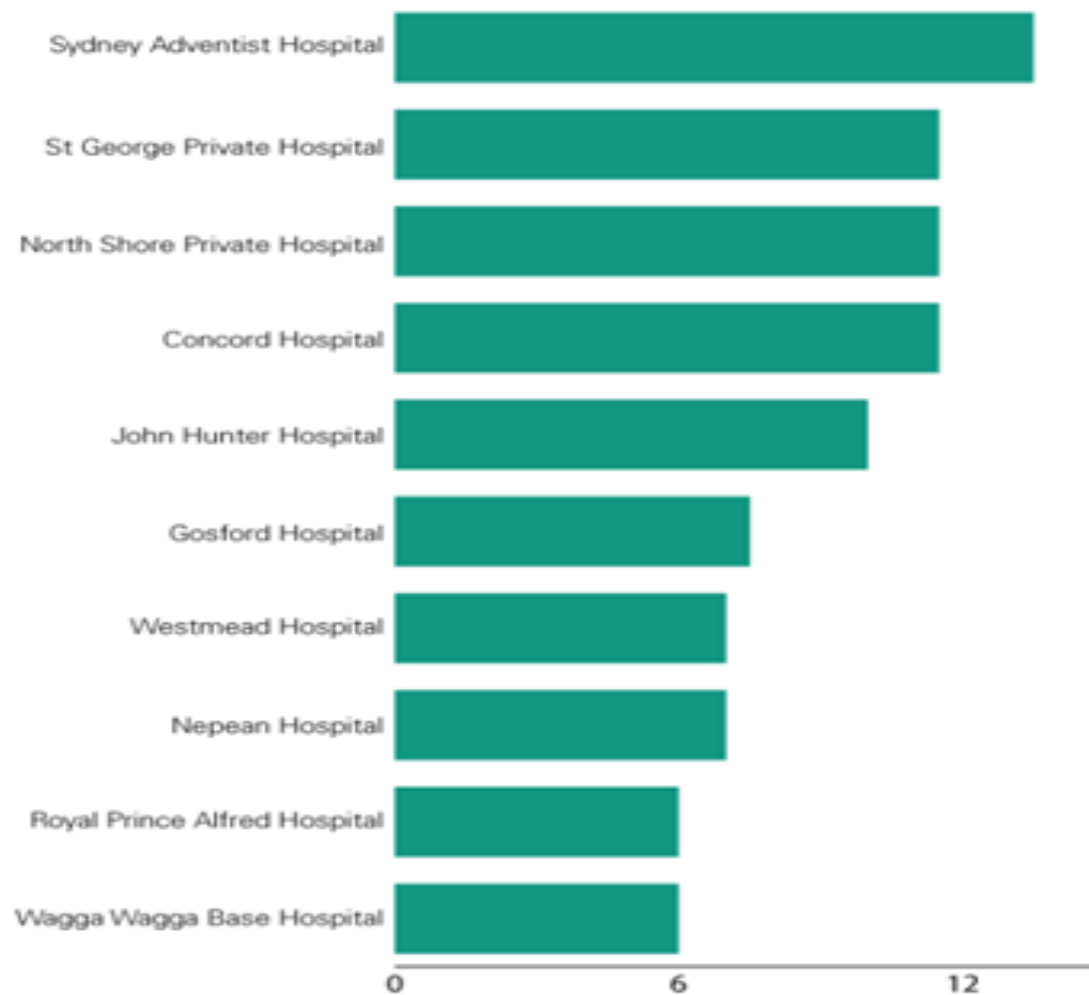


One-year survival following oesophagectomy was associated\* with the per cent resected

\* Proportional hazard model with risk adjustment

Data source: Central Cancer Registry linked to the Admitted Patient Data Collection and the Registry of Births, Deaths and Marriages. Excluding Northern NSW, Southern NSW and Far West LHDs.

Average annual procedural volume of higher-volume hospitals, oesophagectomy for cancer,  
NSW, Financial Year 2012/13-2013/14



## **Optimal use of health data**

**Current program – Reporting Better Cancer Outcomes (RBCO)**

**Annual cycle of Chief Executive / Directors of Cancer Services meetings. All now jointly with the relevant Primary Health Network (PHN)**

- 7th year**
- Year 5 – public reporting by de-identified Local Health District (LHD)**
- Year 6 – public reporting by identified LHD**



## Developments in 2016: Co-located public-private campus reports

- Five co-located, campus-level public-private RBCO meetings



**Report pages  
43-46**

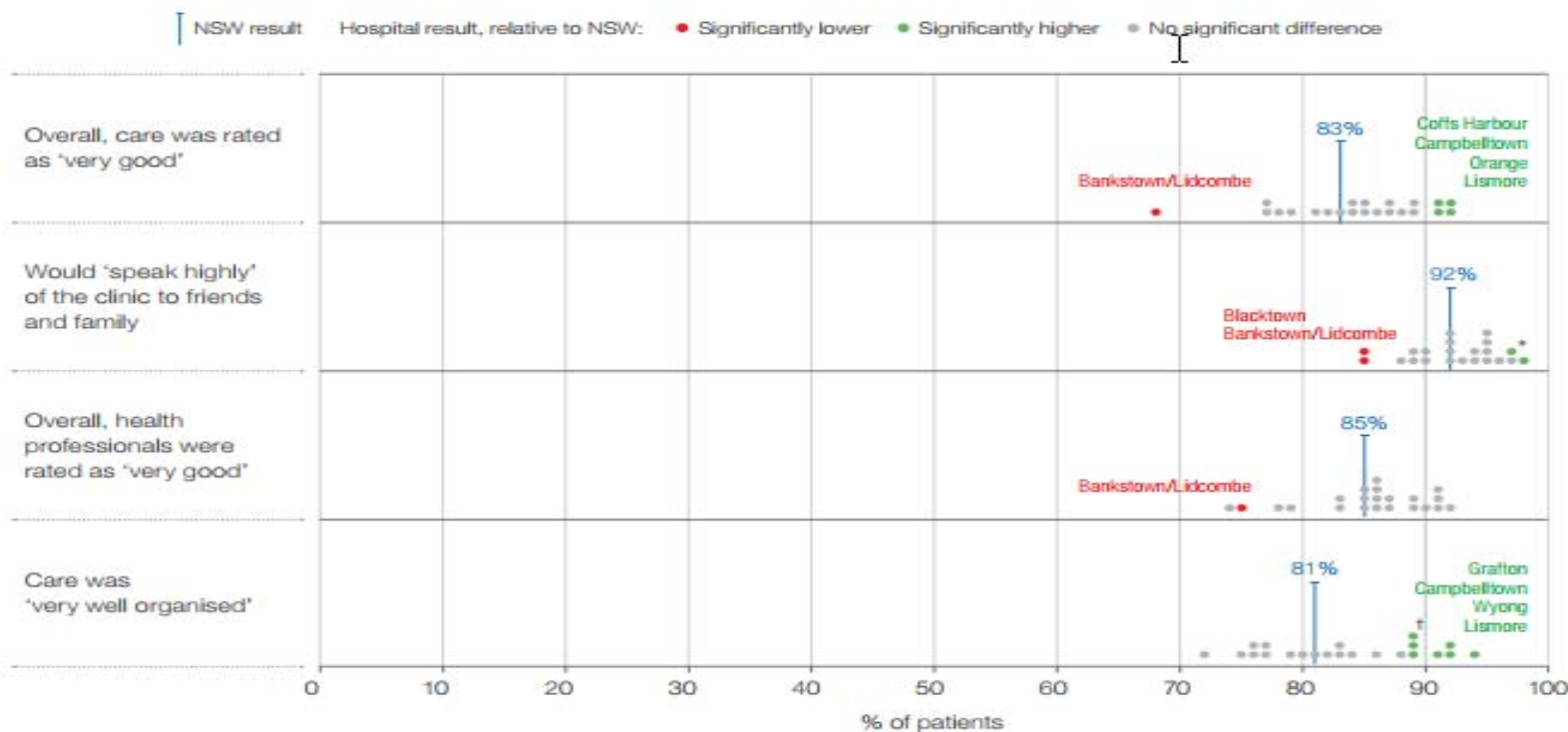


## Experiences and outcomes of care February and March 2015



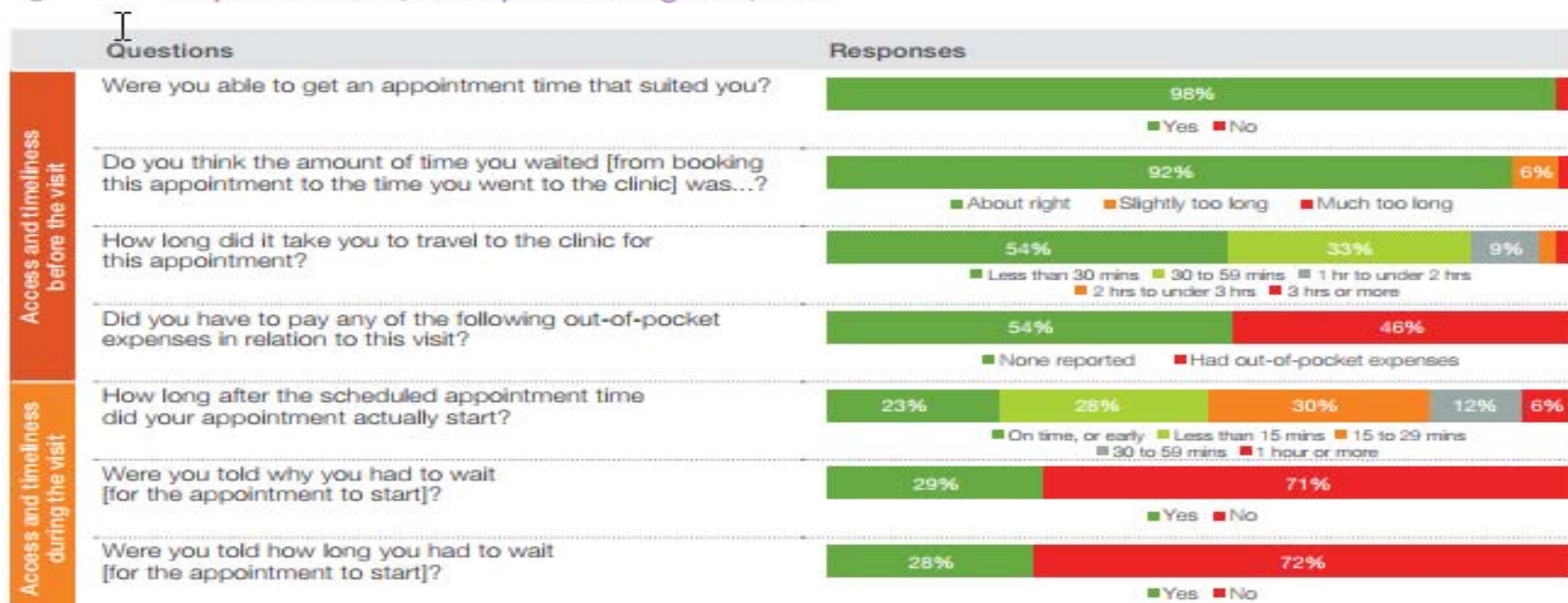
# Optimal use of health data

Overall experience of care, percentage of patients who selected the most positive response category, hospital results relative to NSW



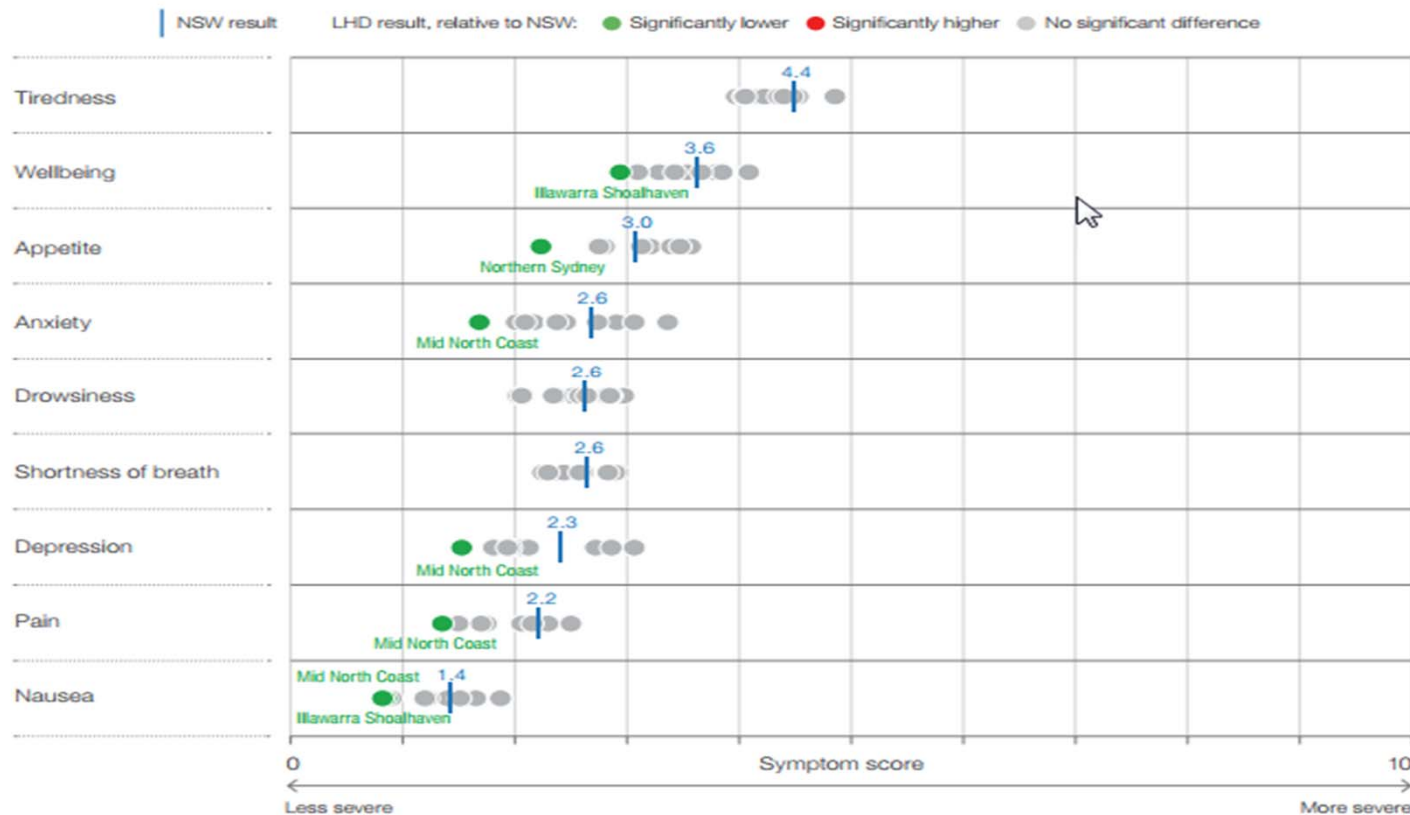
# Optimal use of health data

## Aspects of care, all response categories, NSW



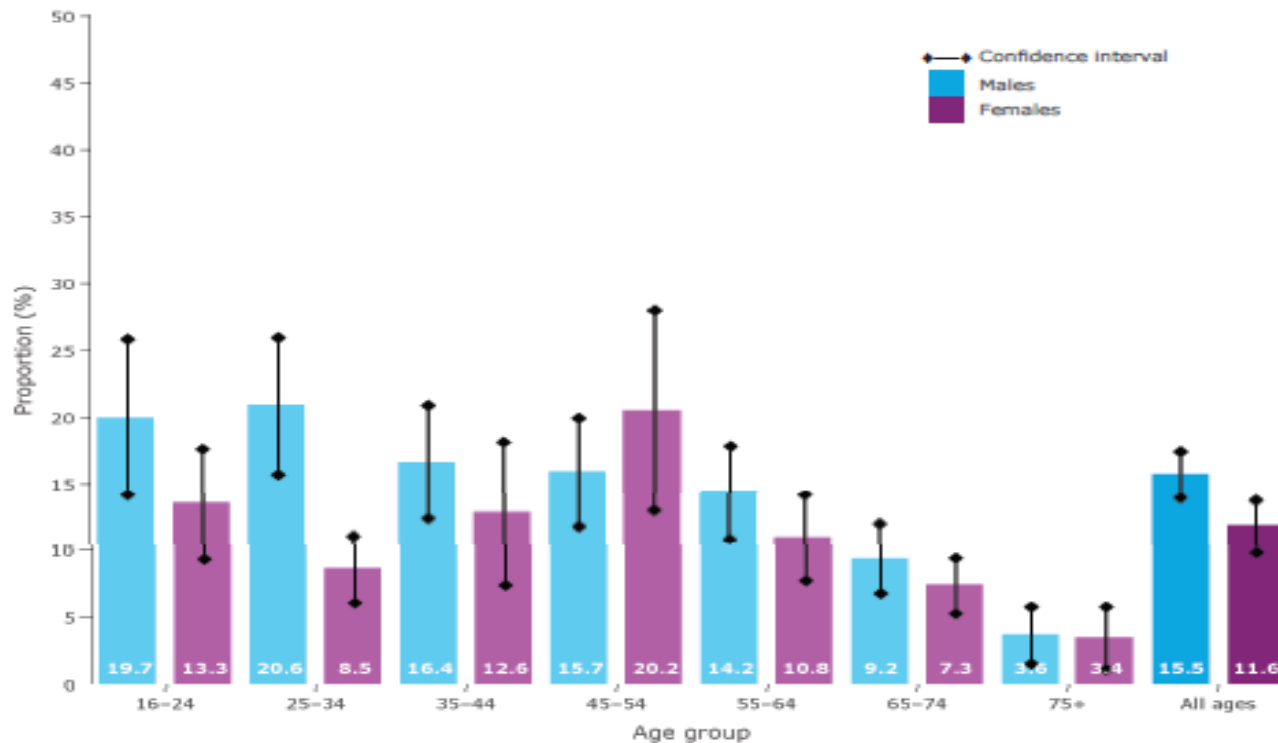
# Optimal use of health data

Symptom severity score at time of survey completion, patients in active treatment phase,  
LHD results relative to NSW



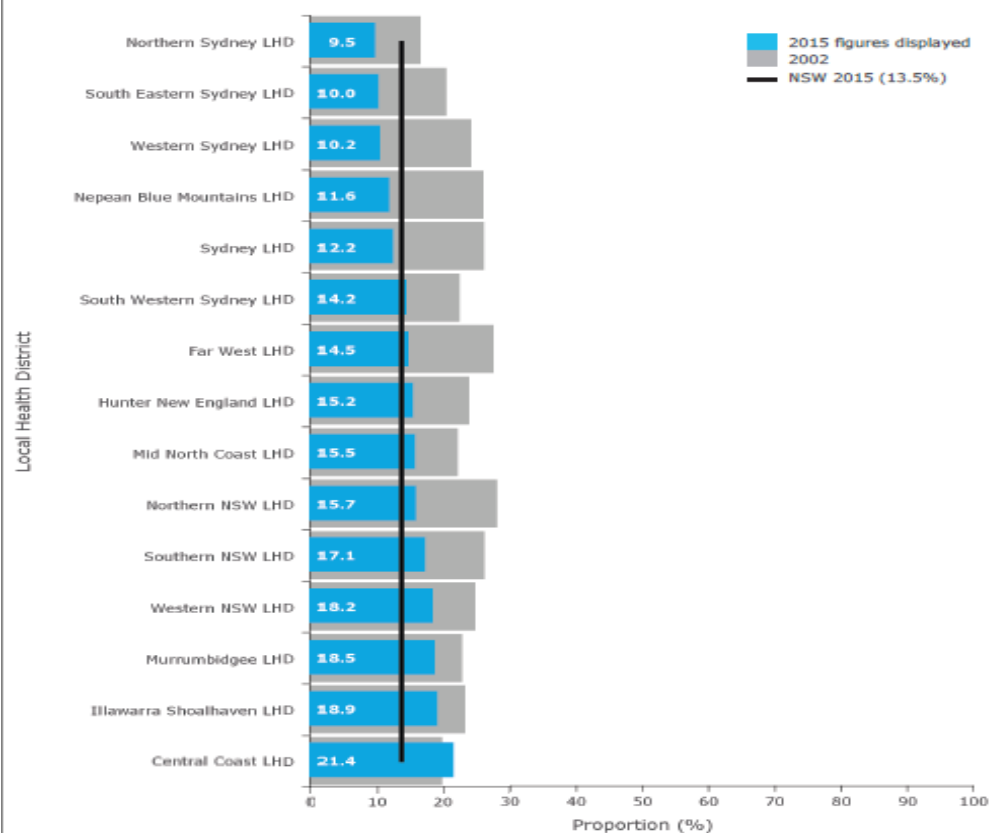
# Optimal use of health data

Current smoking prevalence in adults\*, by gender and age, NSW, 2015



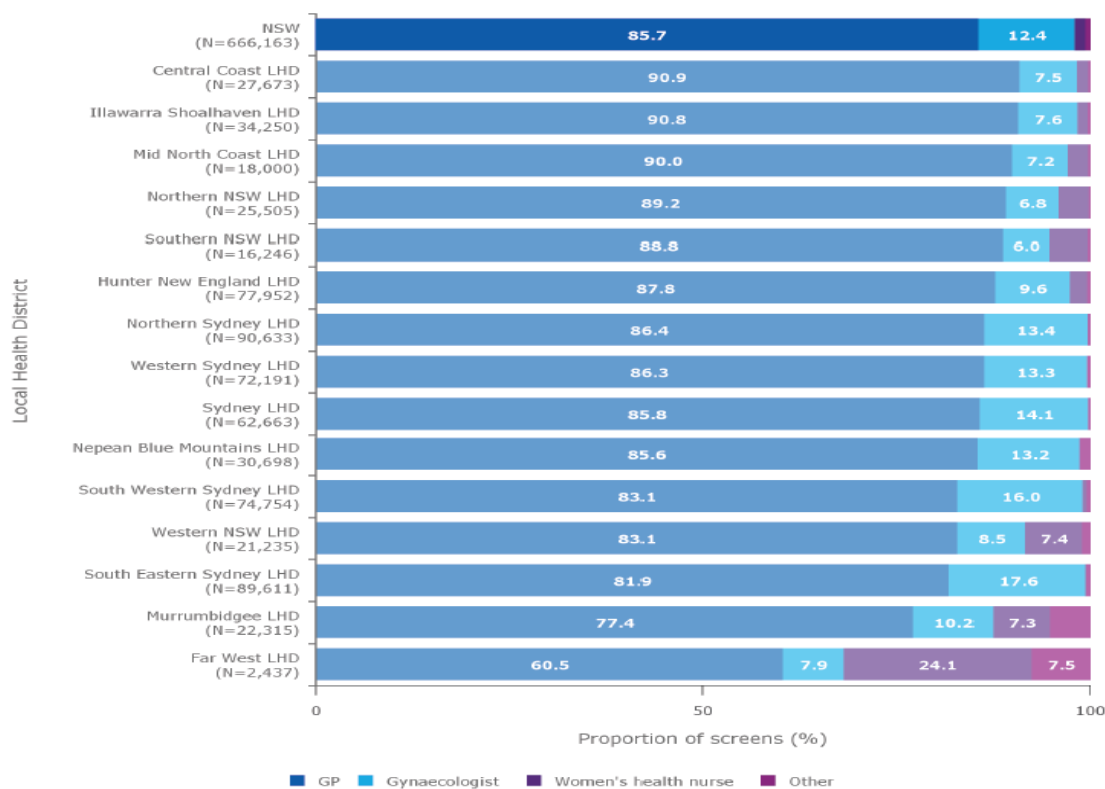
# RBCO 2016: Areas of progress, smoking

Smoking prevalence in adults\*, by LHD (ranked), 2002 and 2015



# Optimal use of health data

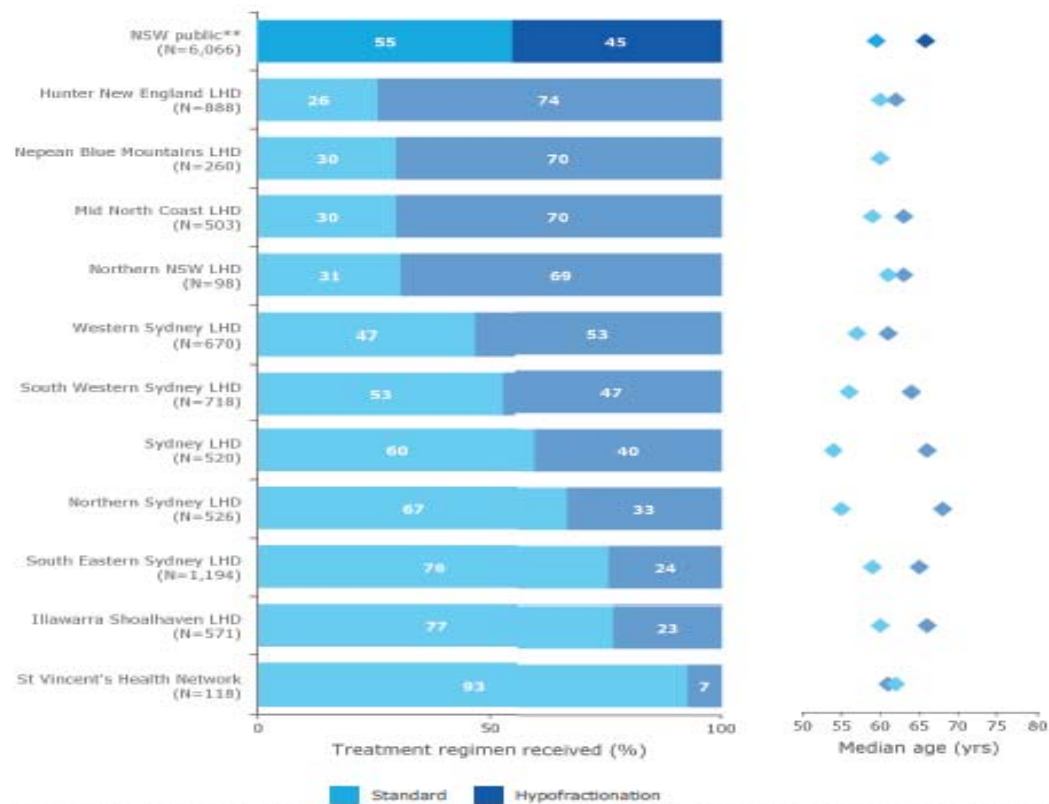
Cervical screening activity for NSW women aged 20–69, by provider type, by LHD (ranked), 2015





# Optimal use of health data

Proportion of early-stage breast cancer\* patients receiving standard or hypofractionated regimens of external beam radiotherapy in NSW public facilities, with median age, by LHD (ranked), 2008–2012



# Colon cancer resections, surgical inflow and outflow, 2011–2015

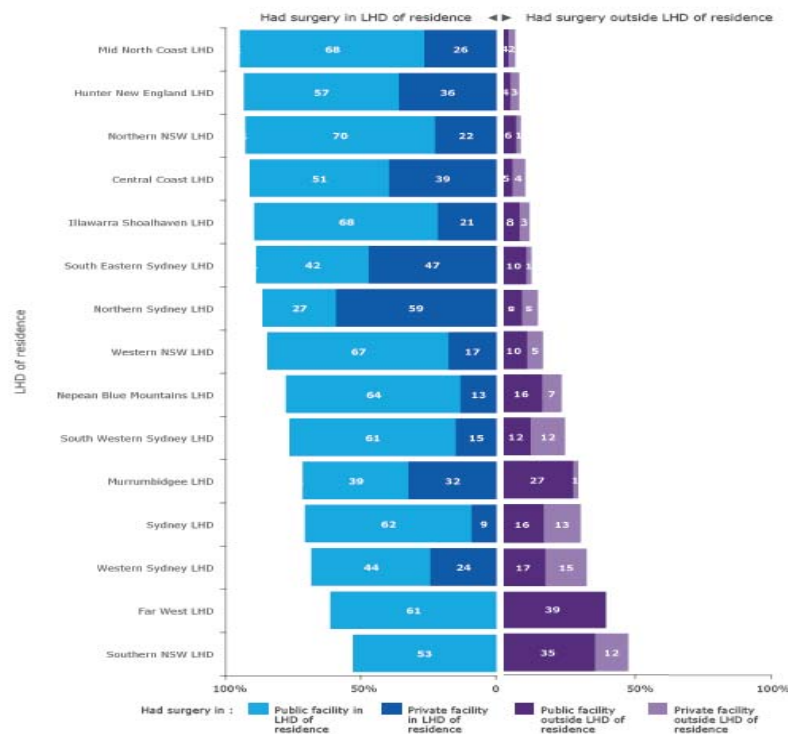
Average annual flows of people for resection for colon cancer, 2011–2015\*

Resections	LHD of treatment																	
LHD of residence	CC	FW	HNE	IS	MNC	Murr	NBM	NwV	NNSW	NS	SES	SNSW	SWS	Sydney	WNSW	WS	Inter state	StVHN **
Central Coast LHD	92		1			<1				2	3		<1	2			<1	<1
Far West LHD		6															4	
Hunter New England LHD	4		239		<1		<1		<1	<1	5		<1	2	<1	<1	2	1
Illawarra Shoalhaven LHD				118					<1		6	1		4	<1	<1		1
Mid North Coast LHD			1		87						3			<1			<1	
Murrumbidgee LHD			<1	<1		41		16		<1	2	<1		1	<1		6	<1
Nepean Blue Mountains LHD							81				2		<1	5	7	6		
Network with Victoria								8									<1	
Northern NSW LHD			<1	<1	2				84		2						3	
Northern Sydney LHD	<1		<1		<1		<1			89	6		<1	13		3	<1	4
South Eastern Sydney LHD											123		4	7	<1	<1	<1	18
Southern NSW LHD	<1						<1	<1			3	42	<1	1				<1
South Western Sydney LHD	<1		<1	<1		<1	3			<1	10		161	11		4		2
Sydney LHD										1	13		5	100	<1	1		7
Western NSW LHD		<1	1			<1	<1			<1	2		<1	5	74	<1	<1	<1
Western Sydney LHD	<1						9			7	4		7	10		98		<1
Interstate	<1	<1	<1					19	12	<1	6	<1	<1	<1	<1			<1
Unknown	<1	<1	1				<1	1		<1	4		<1	2	<1	2		<1
ACT Health											5			1				<1
Total	97	7	245	119	90	42	95	44	96	101	196	44	179	163	83	115	18	36

# Optimal use of health data

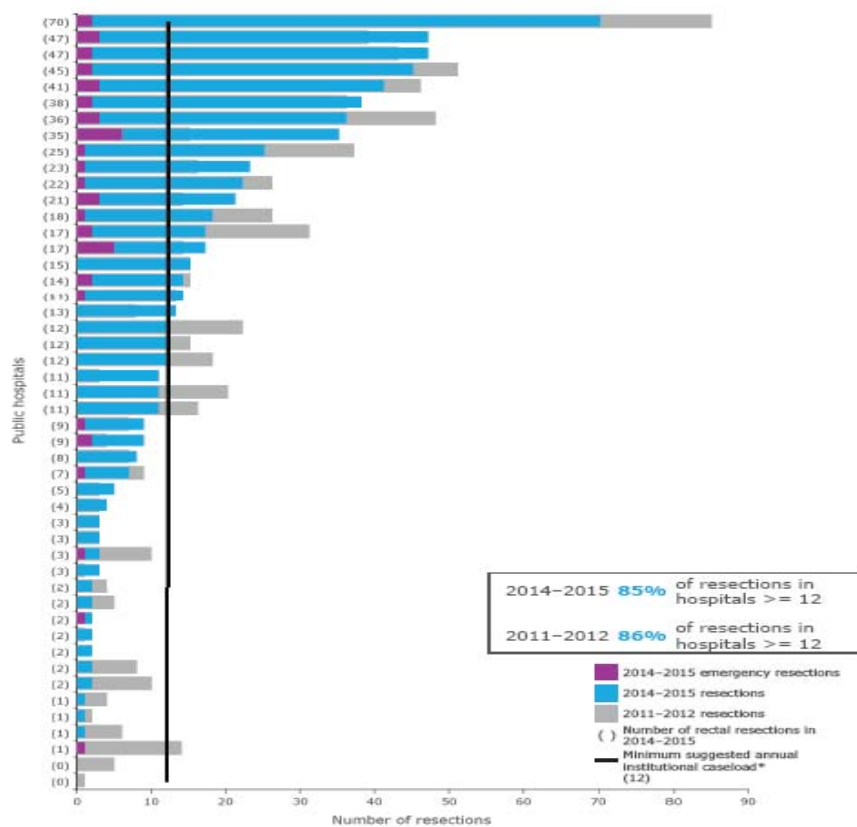
## Colon cancer

Average annual flows of people for colon cancer resections, by LHD of residence, FY 2011–2015



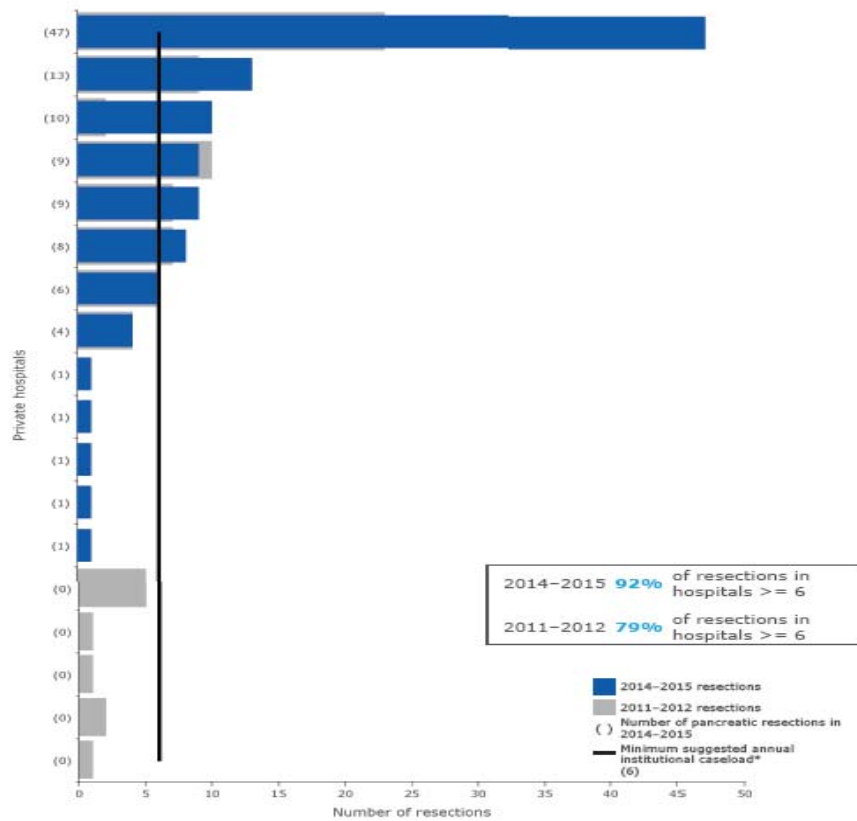
# Optimal use of health data

Rectal cancer resections in NSW public hospitals, FY 2011–2012 and FY 2014–2015

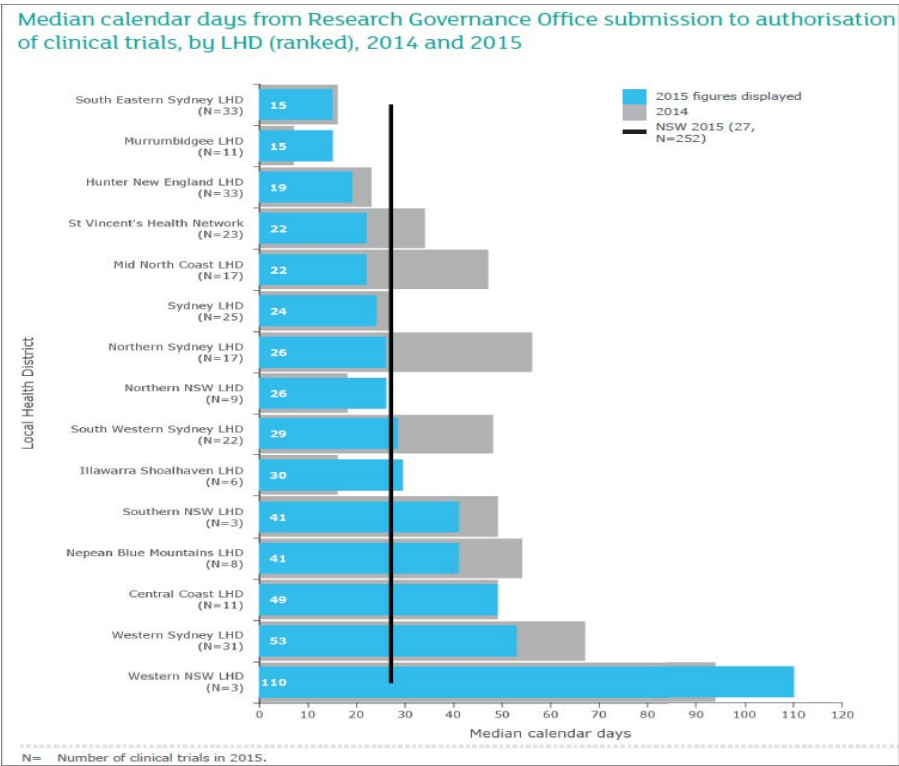
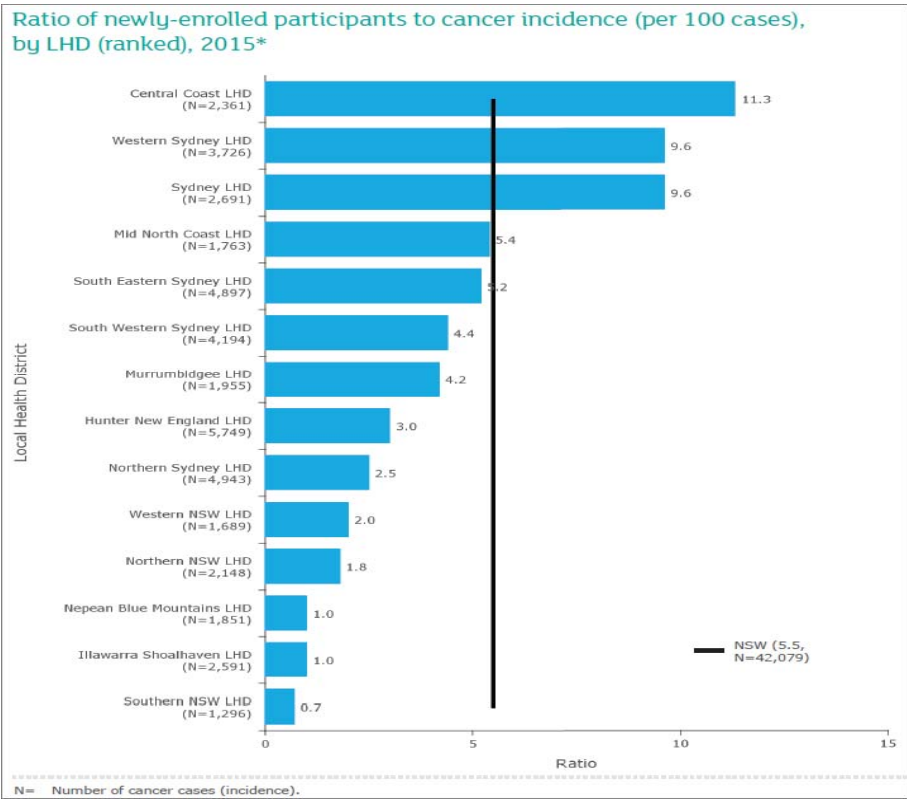


## Optimal use of health data

### Pancreatic cancer resections in NSW private hospitals, FY 2011–2012 and FY 2014–2015



# Clinical trials: Areas of progress



# Optimal use of health data

1. What principles underpin our use of data?
2. What progress have we made?
- 3. What can the future look like?**

# Optimal use of health data

## The future

- ❖ **Improve outcomes across the population**
- ❖ **Improve outcomes specifically for sub-populations with poorer outcomes: Aboriginal and Torres Strait Islanders; people from culturally and linguistically diverse backgrounds; people who are socio-economically disadvantaged; people from rural and remote areas**

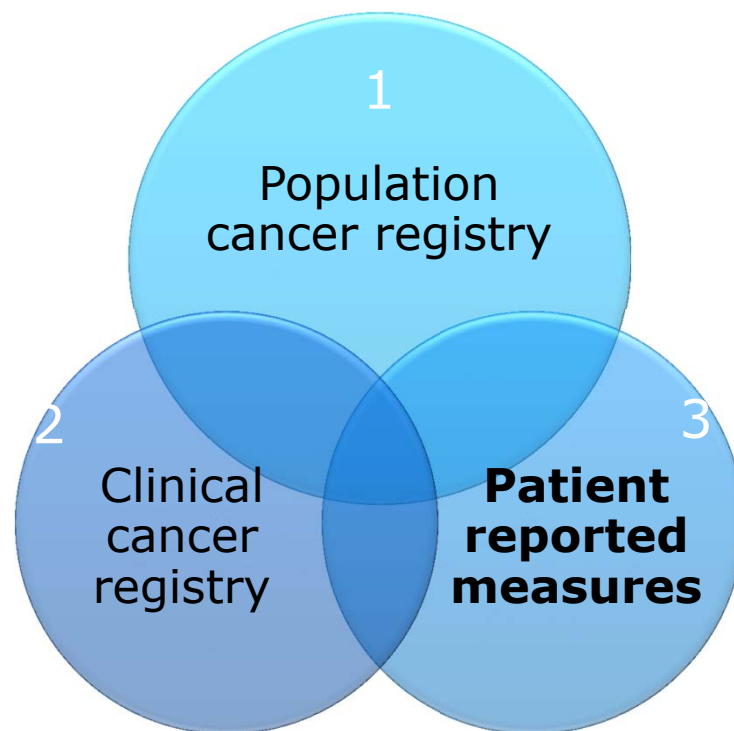


# Optimal use of health data

## The future

- ❖ **Investment in structured reporting as a key way forward – across electronic medical records (given the move to an opt-out national health record). College of Pathologists / CA / CINSW**
- ❖ **A clear distinction between quality assurance / business as usual (BAU) and research**

# Optimal use of health data



# Optimal use of health data

## Timely feedback...

- ❖...to clinicians about their performance
- ❖...that is contextualised in performance more broadly
- ❖... that genuinely compares like-with-like (adjusted analyses)

# Optimal use of health data

*The future...*

## Linked data

**\*Population cancer registry**

**\*Clinical cancer registry**

**\*Admitted patient data set**

**Emergency department data**

**Screening registry data**

**\*Death Index**

**Public and private radiotherapy**

**Viral hepatitis register**



# Optimal use of health data

## *The future...*

### **Linked data**

**\*Population cancer registry**

**\*Clinical cancer registry**

**\*Admitted patient data set**

**Emergency department data**

**Screening registry data**

**\*Death Index**

**Viral hepatitis register**

**Patient reported measures**

**Public and private radiotherapy**

**Pharmaceutical Benefits Schedule (PBS) data**

**Medicare Benefits Schedule (MBS) data**

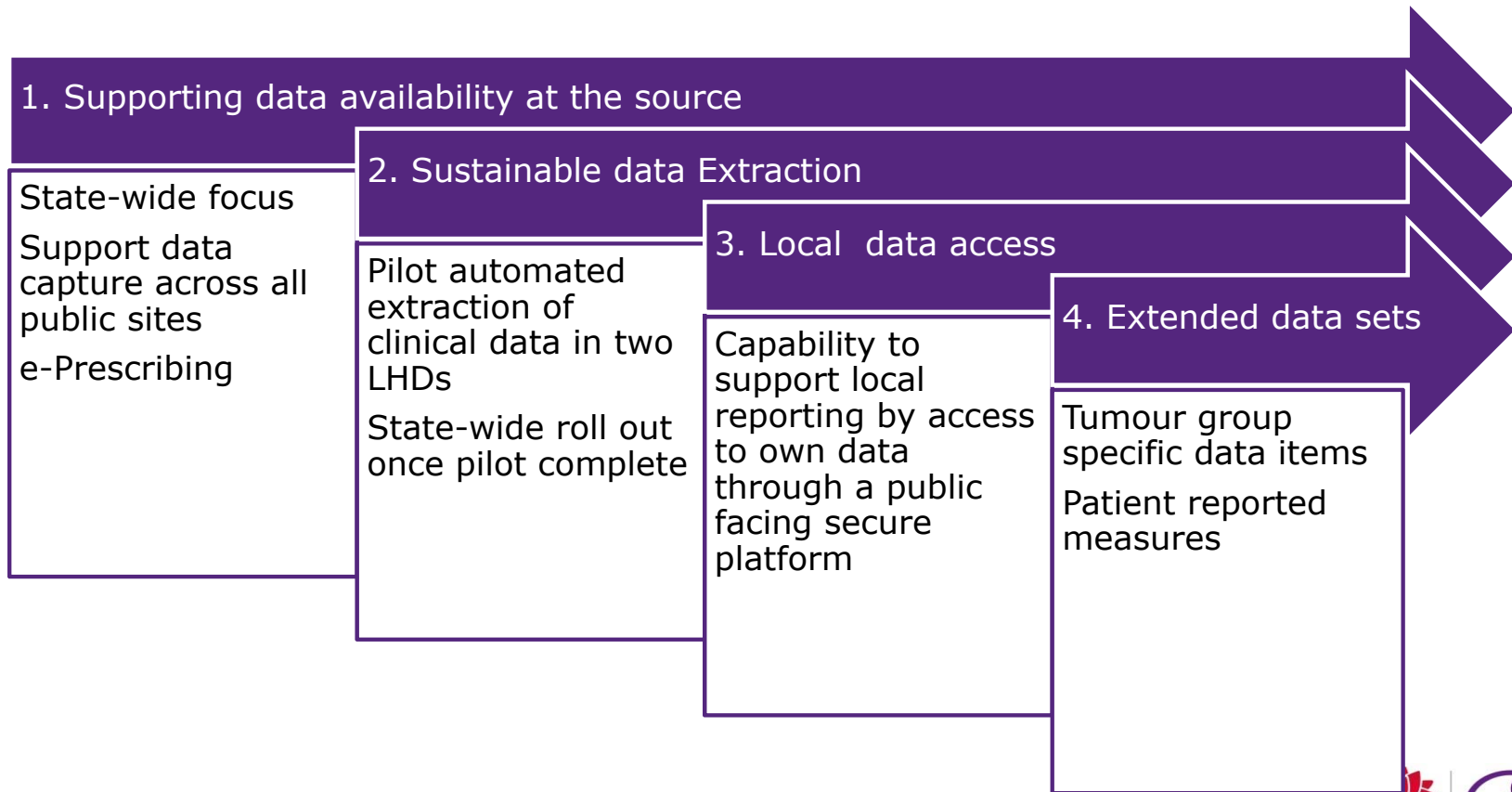


# Optimal use of health data

## In 5 years, success will...

- ❖ ... have strong clinician leadership as clinicians increasingly understand and use big data sets
- ❖ ... **high quality knowledge is routinely part of service planning and performance (outcomes) reporting**
- ❖ ... timeliness of data feeding into analyses is more current
- ❖ ... analytic plans will be harmonised as widely as possible
- ❖ ... data capture will be using source data captured once, used many times
- ❖ ... standardised data items

# Increasing access to data



# **Optimal use of health data**

**Who takes ownership of a cancer stream?**

**We have the data sets to take a whole-of-population approach**

**The need for clinical ownership even of people who have not been seen or referred**



# Optimal use of health data

1. What principles underlie our use of data
2. What progress have we made?
3. What can the future look like?

# Patient Reported Measures (PRMs)

To collect PRMs at each Local Health District

Build upon funded work

- PROMPT (in 2 local health districts (LHDs) as of 2017)
- ADAPT (Commencing engagement of up to 12 sites)

## Approach

- Web based form
- Transfer of data into oncology information systems (OMIS)
- Utilise data extraction process from OMIS
- Clinician report at point of care
- Patient resources

## Status

- Commenced initial build using the PROMPT concept

# Optimal use of health data

1. What principles underlie our use of data
2. What progress have we made?
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by **Dr Alastair MacGregor**

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**ASSOCIATE CHIEF MEDICAL  
INFORMATION OFFICER**

MOFFITT CANCER CENTER AND  
RESEARCH CENTER (MCC), TAMPA FL

# KEYNOTE

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The Everest Sized  
Challenges for Oncology  
Applications –  
Lessons Learned



# **“The Everest Sized Challenges for Oncology Applications – Lessons Learned”**

Dr. Alastair MacGregor MB ChB

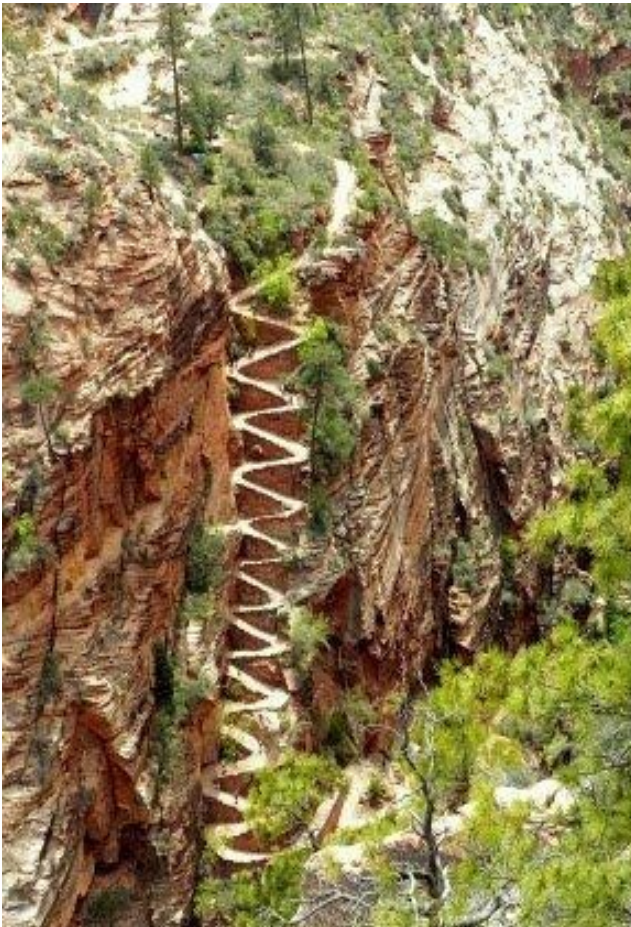
Associate CMIO Moffitt Cancer Center, Tampa, FL,  
USA

# Agenda

- Personal International Informatics Journey
- Moffitt Cancer Center –
  - Who we are
  - The “Everest” sized journey to base camp
  - Applied Informatics, IT, Research – Data base camp
- Route from Base Camp
- Lessons Learned and Brief Observations



# A Thirty Six Year International Journey in Informatics



## **Scotland/UK 1974-1995:**

Anesthesiologist, General Practitioner, Consultant in primary care informatics for a health region,  
Exec. medical officer for all Scottish Mountain Rescue.

## **Canada 1995-1998:**

Consultant to Ministry of Health of BC,  
Medical Director, Clinidata Inc. including consulting engagements with Provincial Health Ministries and Medical Associations

## **USA 1998 - 2017:**

**1998-2009:** Cerner Consulting Physician Executive, outsourced as CMIO to 'bleeding edge' projects

**2009-2015** Combined CIO/CMIO to Methodist Healthcare, Memphis TN, eight hospitals 1600 beds, 2000 specialty doctors, 370 ambulatory doctors,  
Leader for 230 IT staff

**2016-2017 Interim CMIO then Associate CMIO**  
**H. Lee Moffitt Cancer Center, Tampa FL**

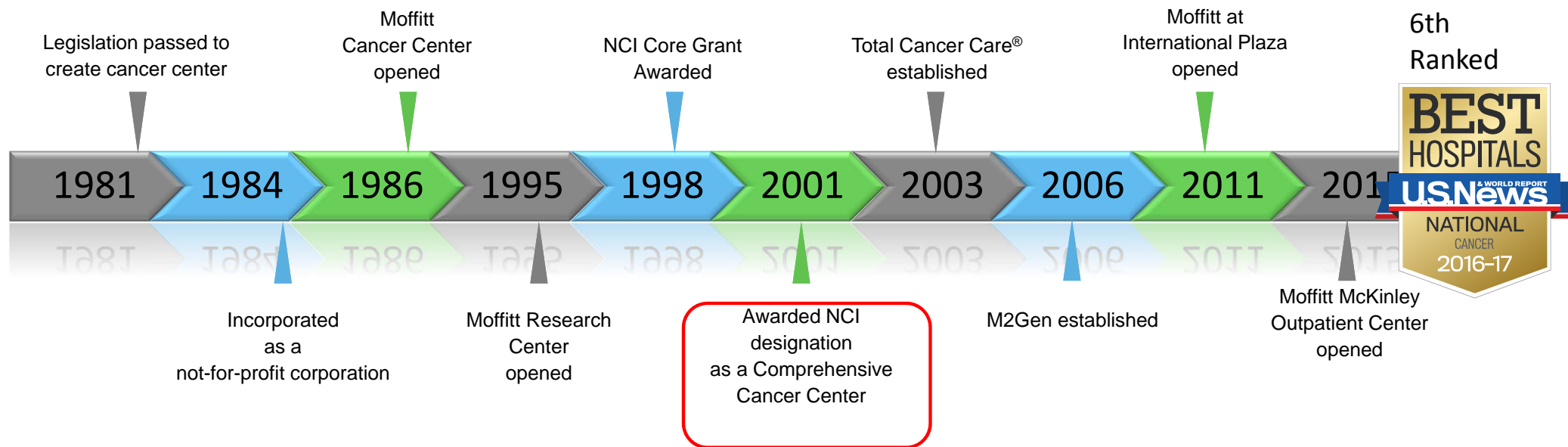


# WE BEGAN THIRTY YEARS AGO WITH A SINGULAR MISSION

- Moffitt's mission was and still is...  
“to contribute to the prevention and cure of cancer.”
- Moffitt's vision is  
“to transform cancer care through service, science and partnership.”

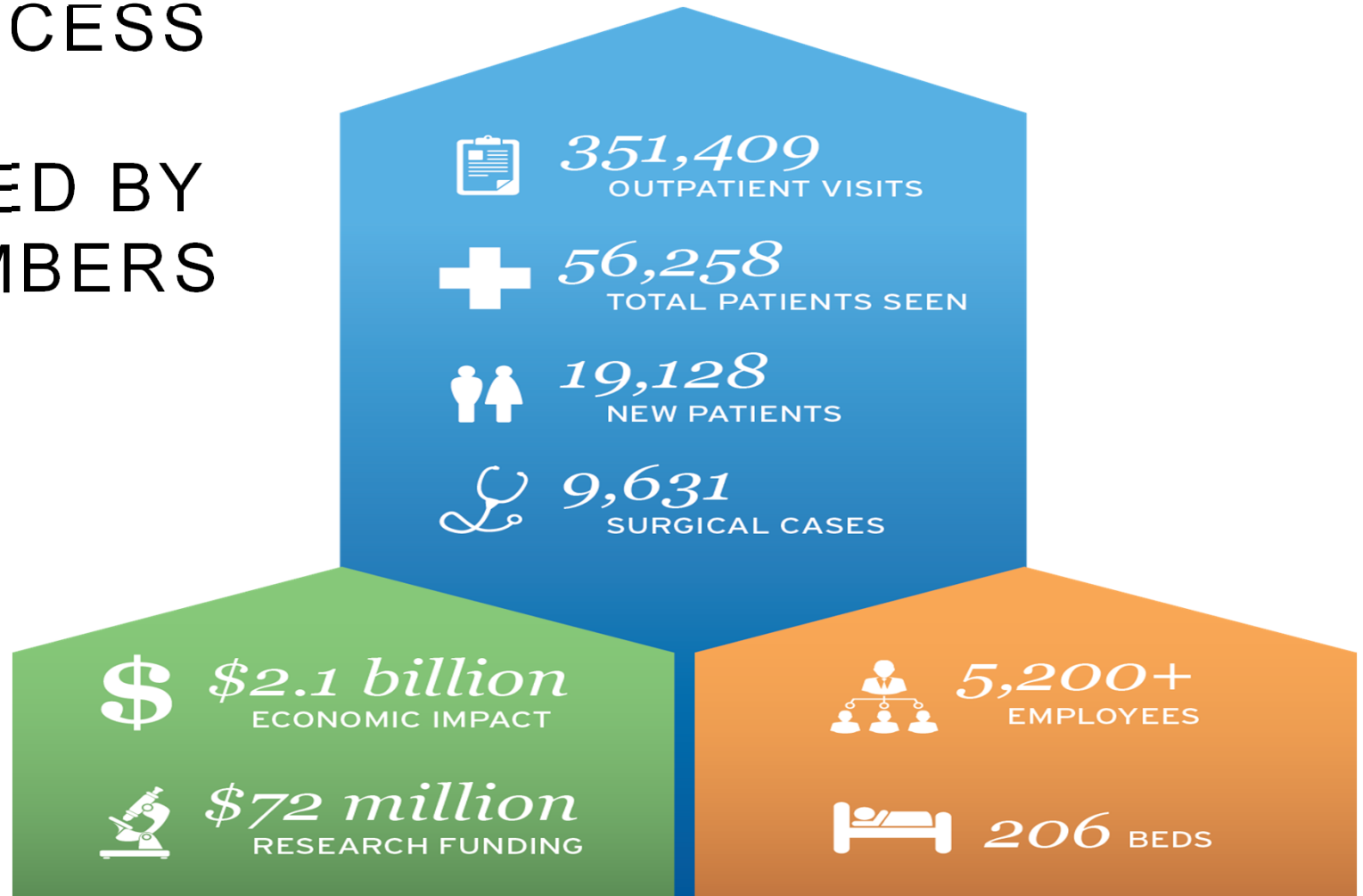


# THE 30 YEAR JOURNEY - EVERY STEP BRINGS US CLOSER TO A CURE



# OUR SUCCESS CAN BE MEASURED BY OUR NUMBERS

Total Patient Infusions  
**per day** across three  
sites  
**~260 patients**



## RANKED 6<sup>TH</sup> for Cancer in the Nation based on U.S. News & World Report's 2016-17 "Best Hospitals" List

- Highest ranking achieved since joining list in 1999
- Up from No. 18 in 2015
- Moffitt's ranking places it in top 1% of 902 hospitals evaluated for cancer care ranking
- Factors that boosted Moffitt's ranking to No. 6 include its achievement of nurse Magnet recognition and its continued superior outcomes
- U.S. News also ranks Moffitt in the top 4% in Urology, and high performing in Gastroenterology and GI Surgery, Colon Cancer Surgery, and Lung Cancer Surgery



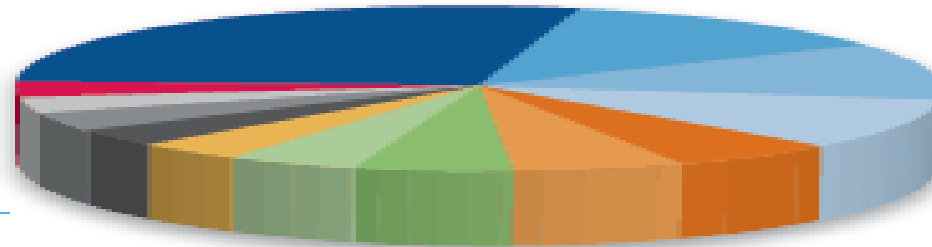
Ranking Methodology:

<http://health.usnews.com/health-care/best-hospitals/articles/faq-how-and-why-we-rank-and-rate-hospitals>

:

# Patients Neoplastic Disease Distributions

## 2015 12 MOST FREQUENT CANCER SITES\*



Breast	12.5%	Kidney and renal pelvis	3.6%
Skin**	11.2%	Myeloma	3.5%
Bronchus and lung	9.9%	Pancreas	3.4%
Prostate	6.0%	Other Hematopoietic	3.2%
Leukemia	5.9%	Colon	2.9%
Non-Hodgkin Lymphoma	5.2%	Other sites+	28.3%
Bladder	4.3%		

\*Includes analytic and non-analytic cases for accession year 2015

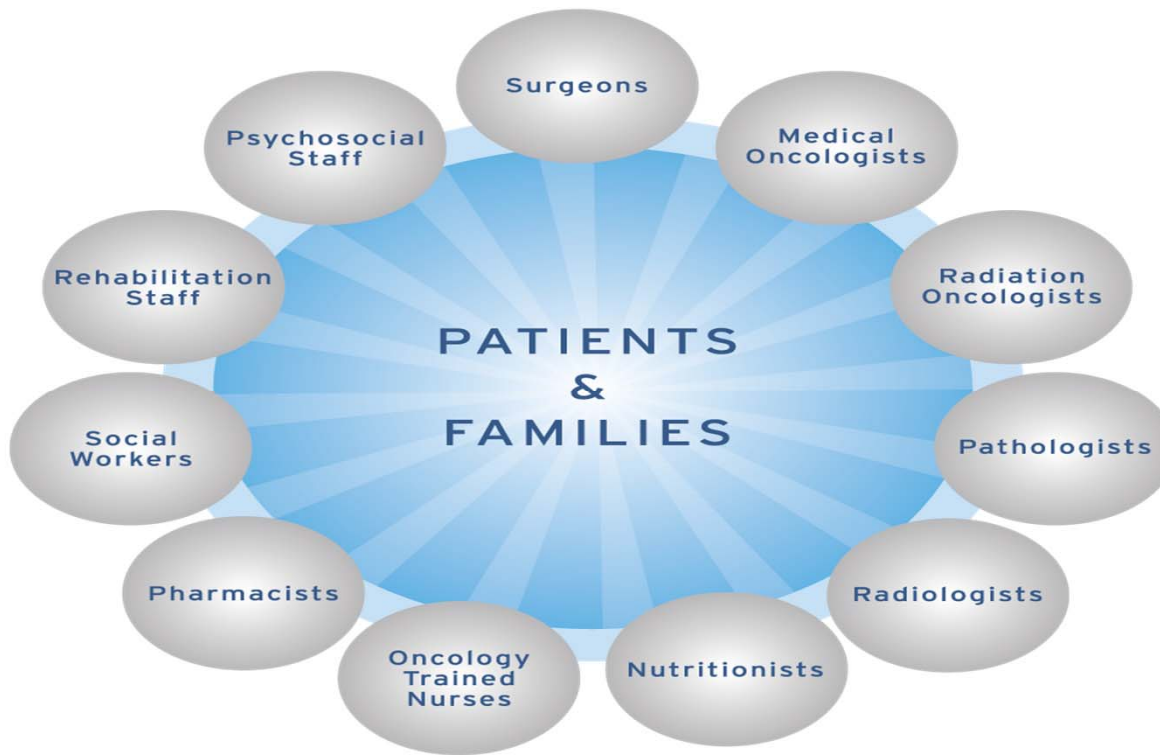
There were a total of 9735 analytic and non-analytic cases for accession year 2015

\*\* Excludes basal cell and squamous cell carcinoma

+ does not include historical case count [n=1555]

Source: Cancer Registry

# MOFFITT MULTISPECIALTY CARE TEAM:

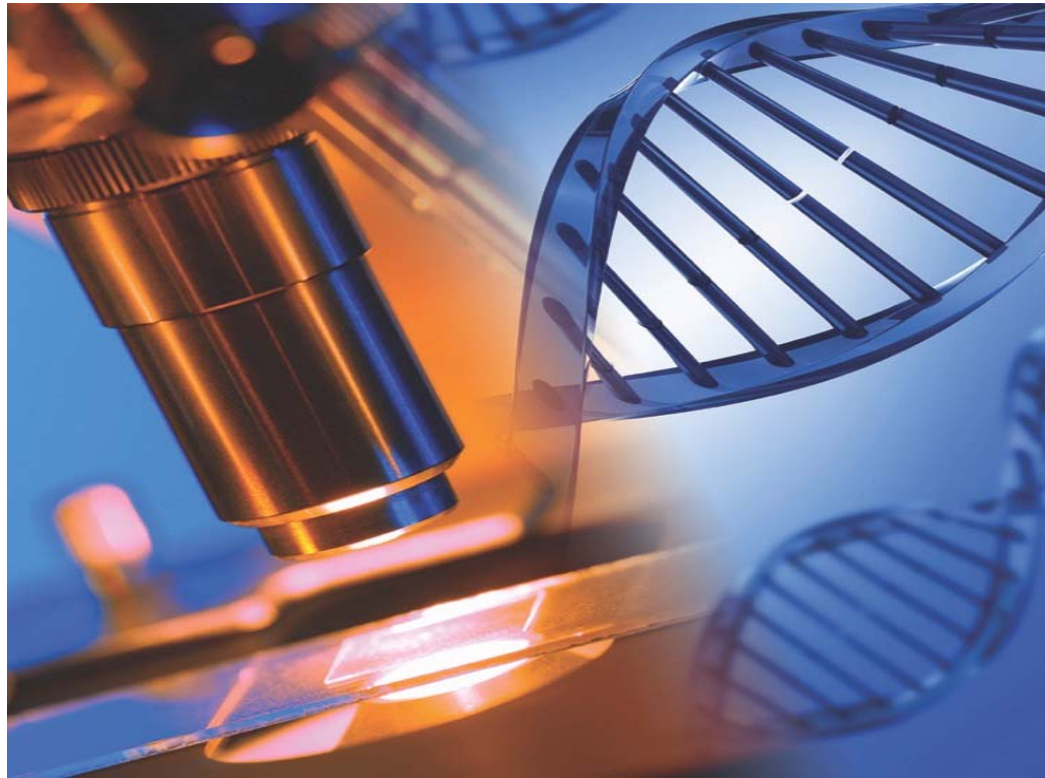


## X 12 Clinical Oncology Disease Programs:

- Malignant Hematology
- BMT
- Sarcoma
- Pulmonary
- GI
- GU
- Cutaneous
- Breast
- Neuro
- Head and Neck
- Supportive Care
- Internal Medicine – In Patient hospitalists

# HOW WE DO IT:

- Individual investigators organized into five programs that span research:
  - At the bench
  - At the bedside
  - In the community
- Commitment to fundamental discovery with relevance
- Close integration between the clinicians and the scientists (**and some are both**)





Total Cancer Care ©

O.R.I.E.N. ©

# The Total Cancer Care: A Patient-Centric Approach to Cancer Research and Care

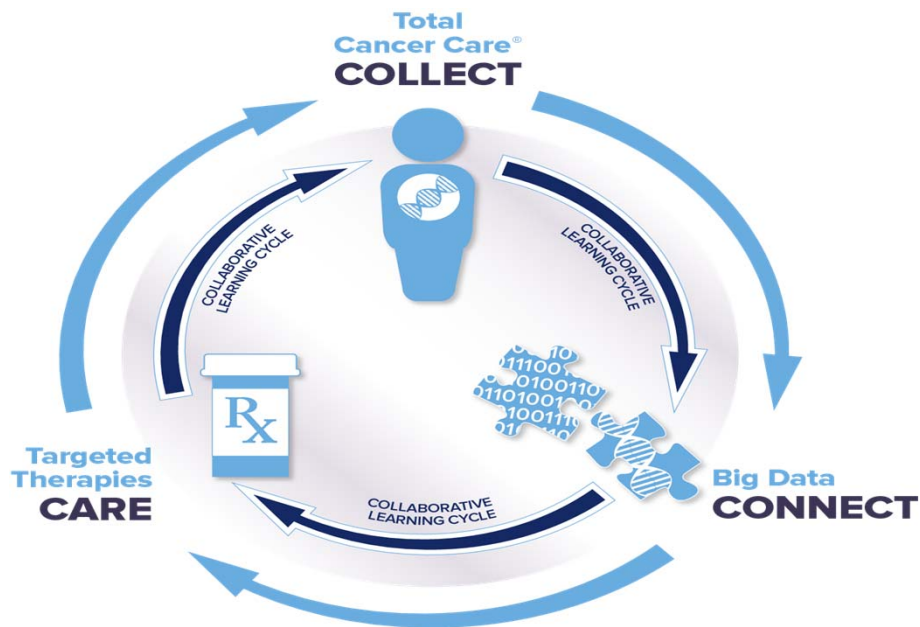


## Total Cancer Care aims to:

- Identify the needs of the patient & their families
- Develop an evidence-based approach to meet those needs
- Develop markers to predict need so they can be prevented



# Benefits of Total Cancer Care “Opt In” Approach



Continuous improvement  
based on evidence and value

- Patients active partners in a life-long study of their disease
- Enables ongoing ability to match patients to clinical trials and re-contact patients when there is a therapy that may benefit them
- Allows for ongoing collection of clinical, outcomes and self reported data from patients and their health providers
- Enables data sharing and promotes a rapid and continuous learning environment

# Creating an In Silico Avatar: Patient Genotype and Phenotype

***Patients will be profiled and tracked using clinical and molecular data to inform biomarker/target discovery and assess eligibility for clinical trials***

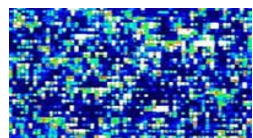


## Phenotype:



- Diagnosis
- Stage of disease
- Comorbidities
- Demographics
- Prior treatments/procedures
- Performance Status
- Specimen availability

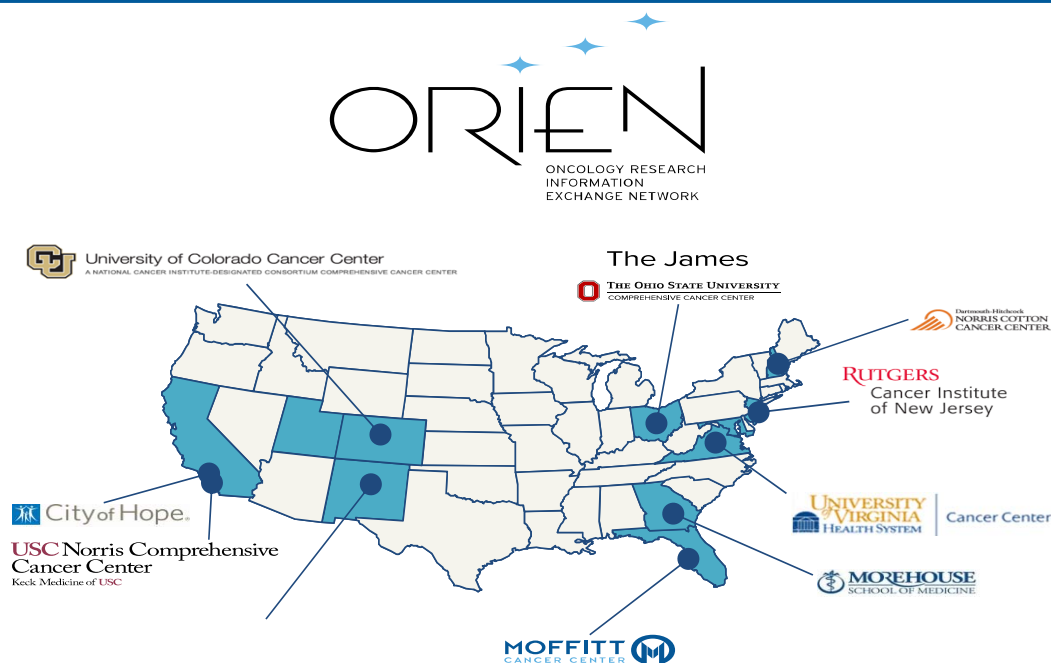
## Genotype:



- Mutation
- Gene expression
- Copy number variations
- Protein expression
- Pathway analysis

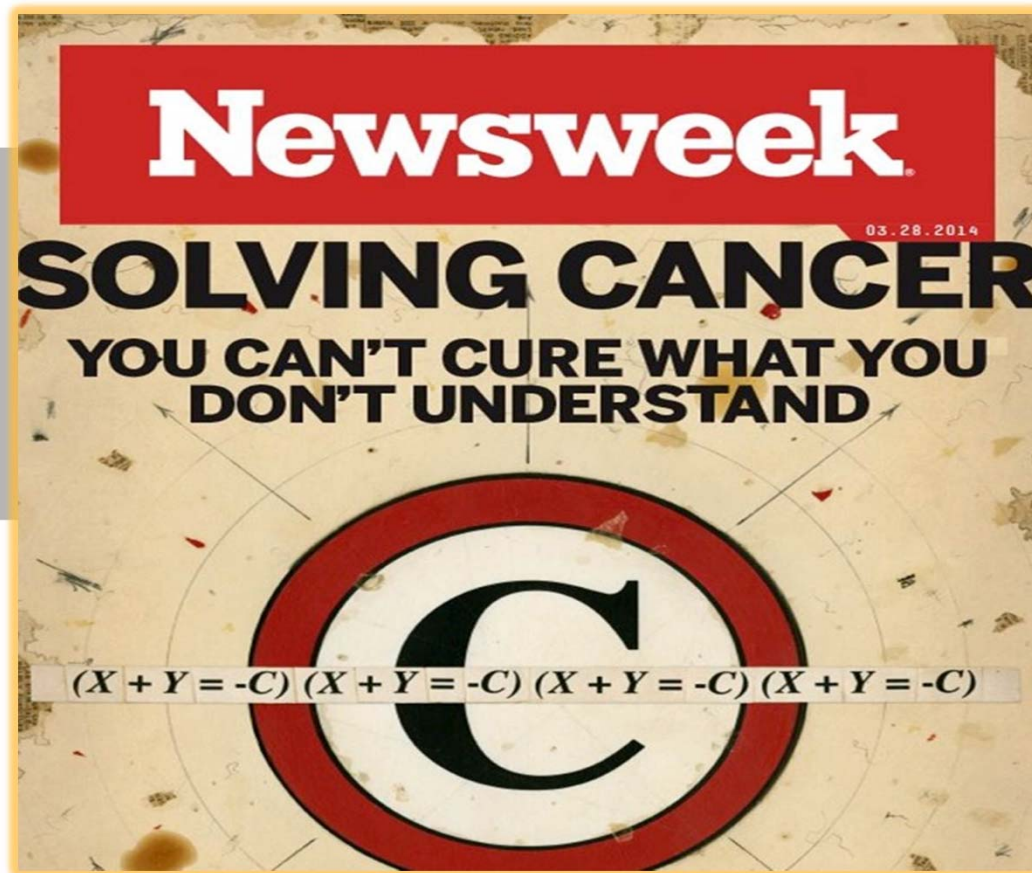
# Oncology Research Information Exchange Network (ORIEN)

*M2Gen currently partners with eleven of the nation's leading cancer centers to deliver informatics based solutions to accelerate drug discovery and development via the Oncology Research Information Exchange Network (ORIEN)*



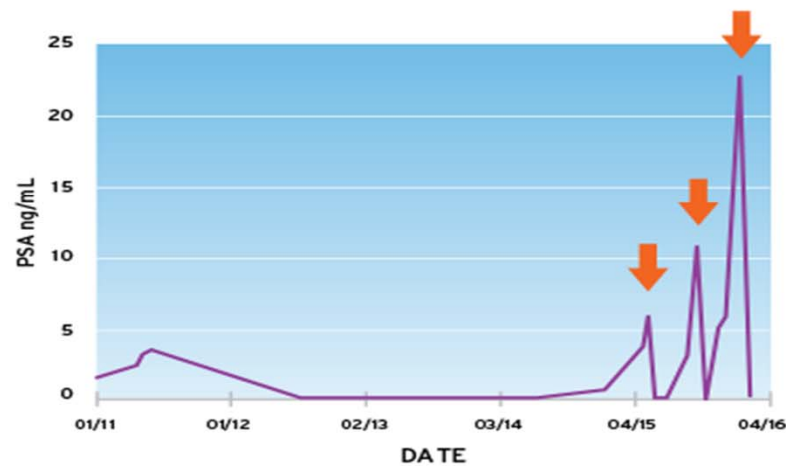
- A National Cancer Center Alliance to integrate “Big Data” and Data Sharing For Cancer Research and Care
- All ORIEN Members agree to operationalize the TCC Protocol, and share the resulting data
- Potential to consent more than 50,000 new patients annually into TCC
- **M2Gen maintains exclusive commercialization rights to data shared amongst ORIEN Members from TCC Protocol**

# Integrated Mathematical Oncology



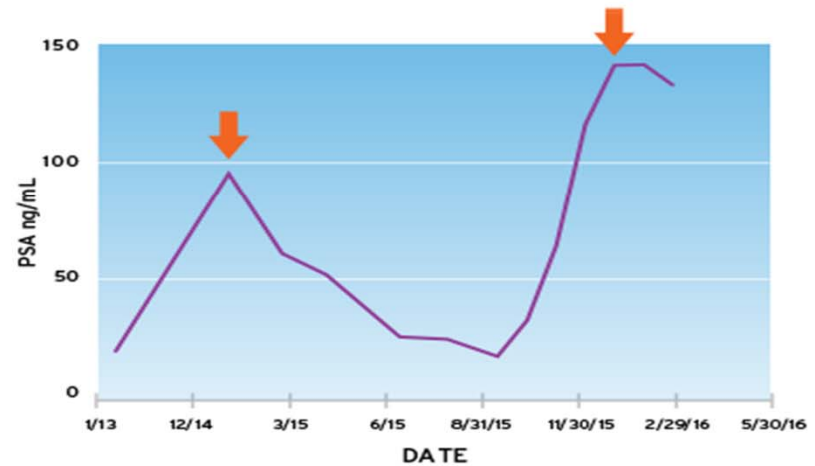
Bob Gatenby, MD

# Adaptive Prostate Cancer Therapy



## IMMEDIATE RESULTS:

- Reduced dose by more than half
- Improved quality of life



## GOAL:

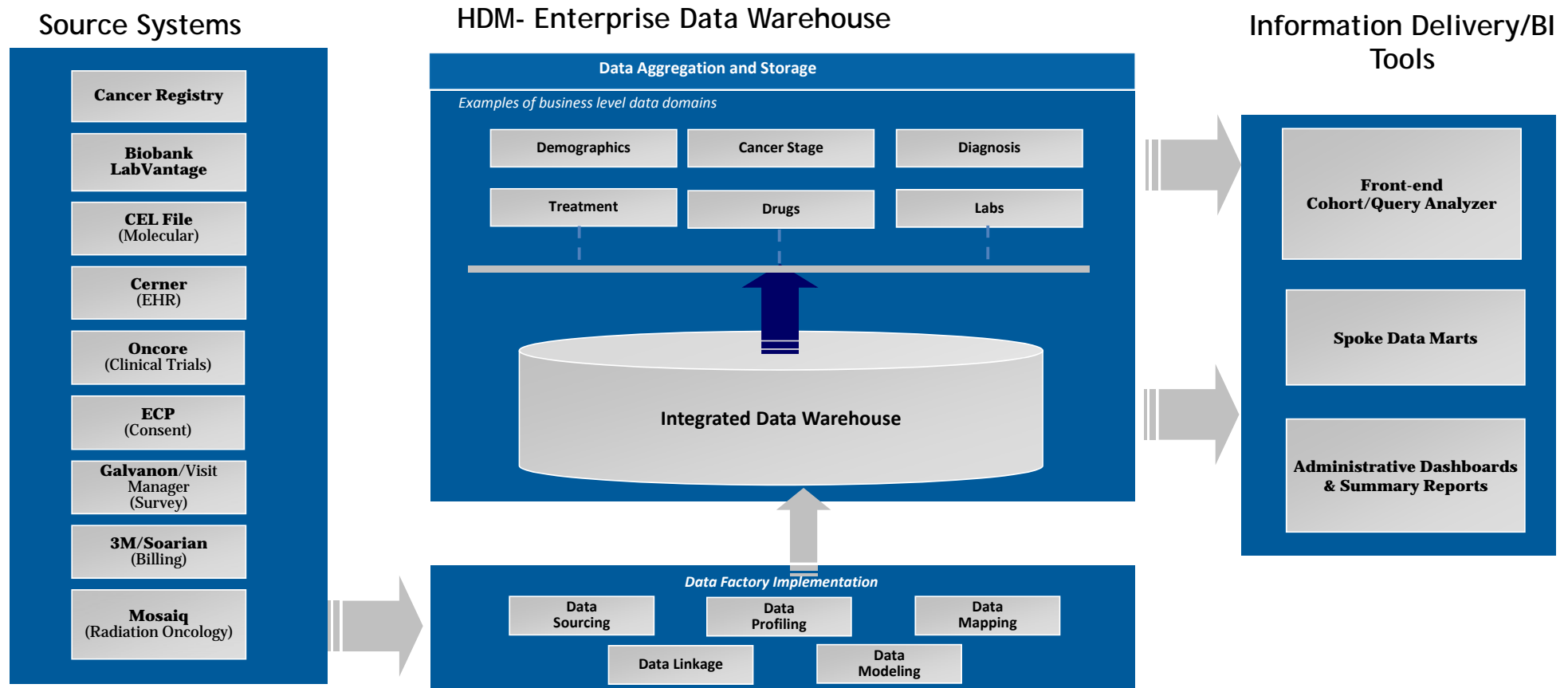
Eliminate prostate cancer as cause of death



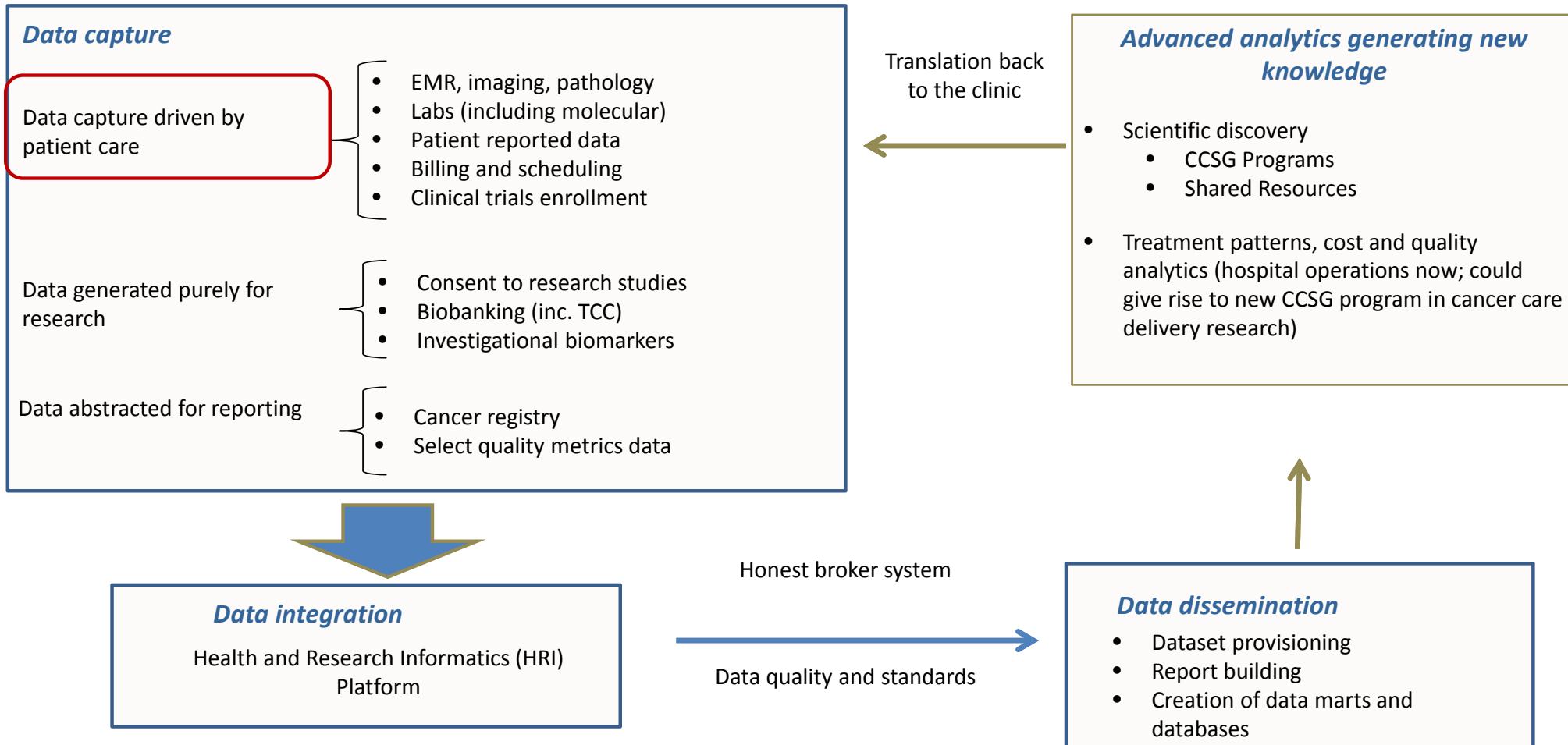
# The IT, Research and Applied Informatics Base Camp



# Health and Research Informatics (HRI) Platform: Information Architecture



# Ecosystem of Enterprise Analytics

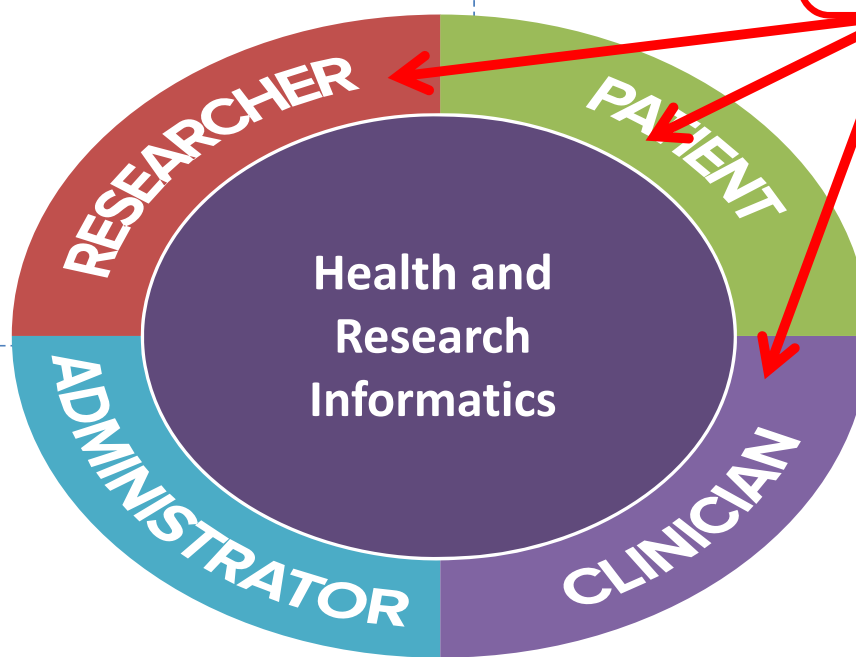




# Information Stakeholders Across the Moffitt Cancer Center

- Cohort identification
- Molecular profiling
- Biomarker discovery
- Comparative effectiveness

- Operational dashboards
- Quality & safety reporting
- Health outcomes & cost of care analysis



## Role and impact areas of Clinical Informatics

- Patient Portal
- Personal health record
- Longitudinal follow-up
- Personalized search

- EHR; Results, CPOE, Documentation,
- Decision support, synchronous and asynchronous reports
- Clinical pathways
- Clinical trial matching
- Access for affiliate network

# Exponential Explosion of Patient Care Data and Perceived Burden of Additional Research Data Entry

## **Research requirements:**

- Currently minimal Cerner discrete documentation is flowing to the Research Database

## **Clinical:**

- Increasing complexity of clinical data required to deliver care and support research in a tertiary care oncology center institute e.g. Precision medicine, genomics, tumor board
- Increasing volume of data being added to longitudinal EHR needing physician review:
  - Patients via PRO surveys, eMessages via Portal , telephone messages actions,
  - Medical monitoring devices ;internal and remote
  - Non PACs Digital image media
  - Referring health organizations patient data through health information exchanges
  - Patient specific internal messages across MCC providers and clinicians

## **Regulatory requirements – quality and completeness of documentation:**

- National Cancer Center Network
- Government regulatory reporting requirements
- Payors pre-approval
- Research Governance Groups

## Moffitt Cancer Center “Summit Route Plan”

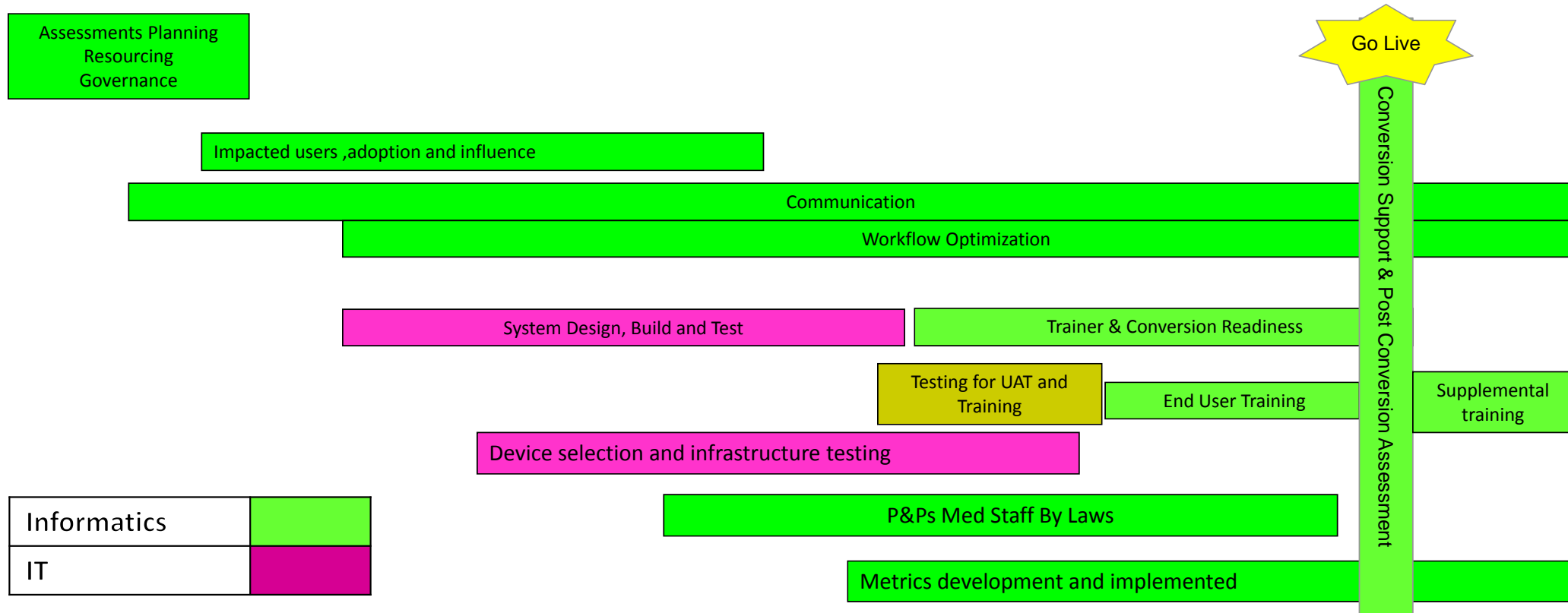


## Informatics “Summit Route Plan”

<b>Project Planning Scoping And Resourcing</b>	<b>Governance; Corporate Facility, Program</b>	<b>Targeted Impacted Users for Adoption, Influence, Support</b>
<b>Communications: Impacted users Leadership, Modalities</b>	<b>Workflow Assessment; Optimization and Future State design</b>	<b>Solutions Design by Role</b>
<b>Training and Learning Task Analysis</b>	<b>System Design Validation and User Acceptance Testing</b>	<b>Metrics; Utilization, Process Changes, Clinical Outcomes</b>
<b>Testing; IT User Acceptance Testing</b>	<b>Medical Staff Bylaw P&amp;P changes Downtime Planning, IT SOP</b>	<b>Device Planning and Infrastructure Assessment</b>
<b>Pre implementation Readiness Activation Plan</b>	<b>Peri-implementation Issue, Enhancement Management</b>	<b>Continuous Post Implementation Adoption Management</b>

# “Summit Plan Logistics” to Go Live Summit Bid!

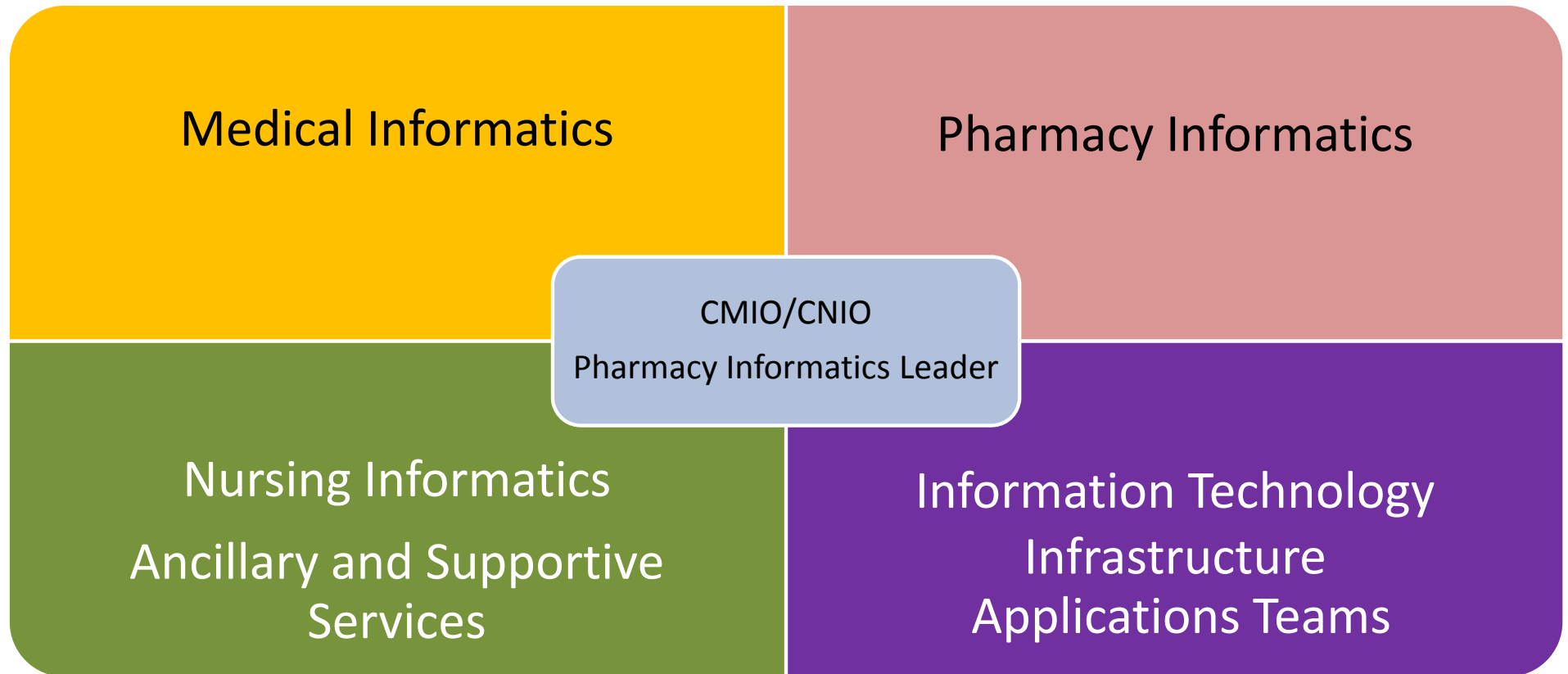
Project Preparation	Project Kick Off	Design Phase	Configure & Test	Conversion Preparation	Testing 1	Testing 2	Conversion	Audit
---------------------	------------------	--------------	------------------	------------------------	-----------	-----------	------------	-------



Define your essential “Summit Team” of Leaders



# Proposed “Summit Team”



## Clinical Informatics Leader (s) Role and Responsibilities

***“Is to balance the needs of the many,  
over the needs of the voluble few  
and  
bring speed to value for  
all patients.”***



NSW Oncology Journey to Base  
Camp - Moffitt Lessons Learned  
and Sydney Observations



# MCC 'Lessons Learned'

## Optimization:

- **Workflows**
  - Identify impacted users and engage them in design
  - Understand hybrid manual and electronic workflow variation by user roles
  - Where appropriate reduce hybrid documentation and ordering
  - Plan for an automated future state workflow NOT replication of paper workflow
- **Review current IT state and implement optimization plan for:**
  - Code upgrades required not just 'like for like' installs
  - Infrastructure: Wireless, Ethernet, PCs and servers
- **Review and standardize current manual state:**
  - Completeness of paper order sets
  - Medical Staff By laws and policy and procedures including changes in scope of practice

# MCC 'Lessons Learned'

## **Application Design:**

- Review and adopt with critical thinking Cerner's recommendations:

Oncology PowerChart:

<https://wiki.ucern.com/display/reference/PowerChart+Oncology+Reference+Pages>

Oncology Model:

<https://wiki.ucern.com/pages/releaseview.action?spaceKey=ModelExperience&title=Oncology+Service+Line>

- Sydney observations; add new enhancements:
  - Dynamic Doc
  - PowerPlans/Regimens
  - Chart Search
  - Orders Related Results
  - Patient Portal
  - ?Interoperability application 'Resonance'

# MCC 'Lessons Learned'



## **Resource Planning:**

- Identify, engage and commit appropriate resources from Clinical Applications, Informatics, Subject Matter Experts; medical, pharmacy, nursing and scheduling (especially infusion centers)
- Identify number of chemo plans and regimens required at go live

## **Test Plan:**

- Include users - Integration, Testing User Acceptance , PROD build from CERT – EVERY CHEMO POWERPLAN.

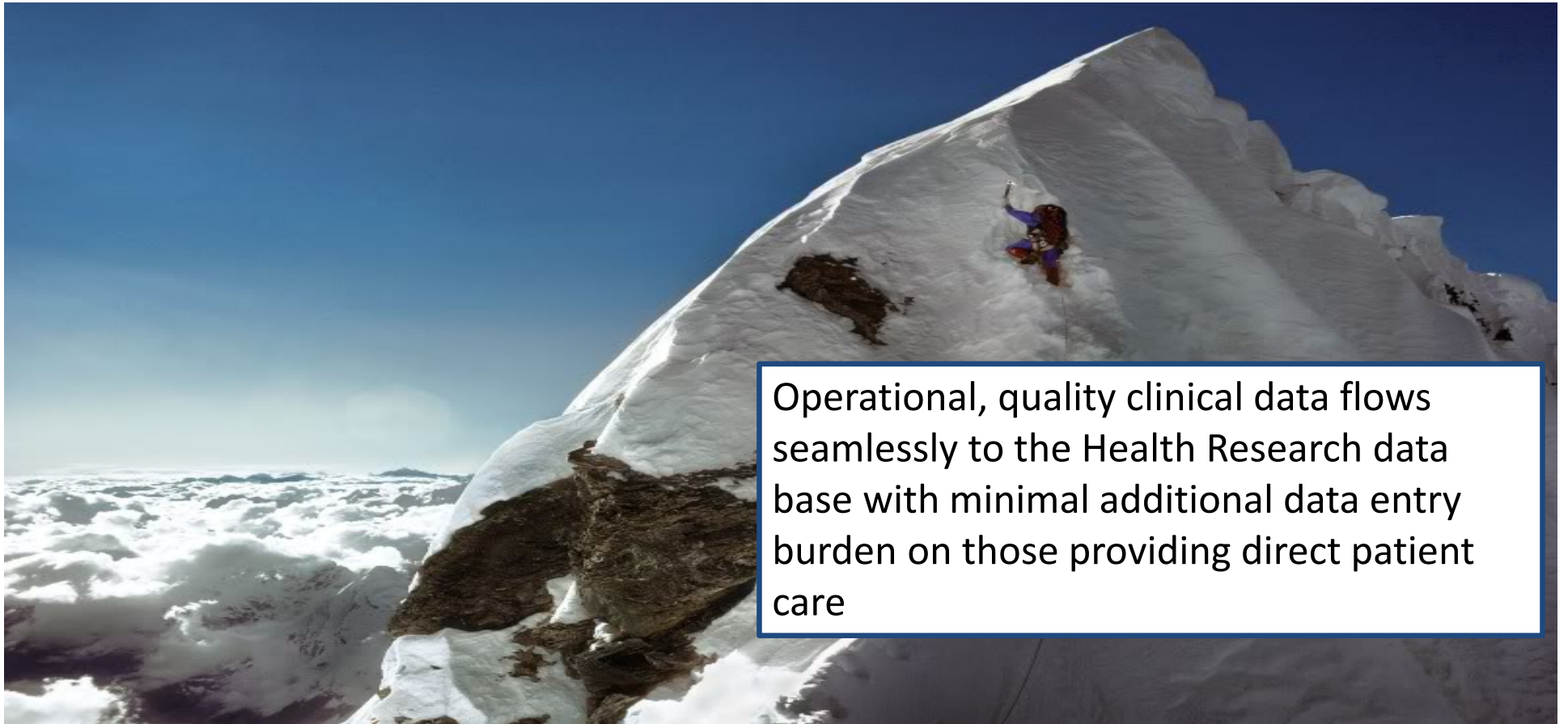
## **Metrics:**

Define success measures and develop reports by user position for:

- User utilization adoption
- Track workflow adoption changes
- Process/Clinical outcomes

**Define Guiding Principles early in the project life cycle**

# The Final Step Before the Summit



Operational, quality clinical data flows seamlessly to the Health Research data base with minimal additional data entry burden on those providing direct patient care

# Moffitt Cancer Center Acknowledgements

- Dr. Dana Rollison, VP and Chief Data Officer, PhD, Department of Cancer Epidemiology  
[Dana.Rollison@moffitt.org](mailto:Dana.Rollison@moffitt.org)
- Dr. Howard L. McLeod, Medical Director, MD, PhD, The DeBartolo Family Personalized Medicine Institute, Division of Population Sciences  
[Howard.McLeod@moffitt.org](mailto:Howard.McLeod@moffitt.org)
- Dr. J. Kevin Hicks, Pharm D, PhD The DeBartolo Family Personalized Medicine Institute, Division of Population Sciences  
[James.Hicks@moffitt.org](mailto:James.Hicks@moffitt.org)
- Dr. Robert Gatenby, Chair of Diagnostic and Interventional Radiology, Applied mathematical Oncology  
[Robert.Gatenby@moffitt.org](mailto:Robert.Gatenby@moffitt.org)
- Dr. William Dalton MD PhD, CEO, M2Gen  
[William.Dalton@m2gen.com](mailto:William.Dalton@m2gen.com)
- **Louis B. Harrison, MD, FASTRO Chair Department of Radiation Oncology, Senior Member, Department of Integrated Mathematical Oncology, Deputy Physician in Chief** [Louis.Harrison@moffitt.org](mailto:Louis.Harrison@moffitt.org)
- Information Technology:
- Jennifer Greenman BSc, CIO,  
[Jennifer.Greenman@moffitt.org](mailto:Jennifer.Greenman@moffitt.org)
- Randa M Perkins MD, CMIO  
[Randa.Perkins@Moffitt.org](mailto:Randa.Perkins@Moffitt.org)

# Thank You!

Questions / Comments?





# Informatics Resources

- AMIA
  - Informatics programs:
    - <https://www.amia.org/programs>
  - eNews: <https://www.amia.org/news-and-publications/amia-enews>
- HIMSS
  - Informatics programs
    - <http://www.himss.org/library/clinical-informatics>
  - eNewsletters:
    - <http://www.himss.org/newsletters>
- Cerner uCern
  - [www.ucern.com](http://www.ucern.com)
- Journal Clinical Cancer Informatics (JCO)
  - <http://cci.jco.org/>
- Gartner Group (Healthcare)
  - <http://www.gartner.com/technology/consulting/healthcare-providers.jsp>

**FLIPPING**

**the**

**RECORD**

• 10:15 - 10:45 AM

**MORNING  
TEA**

#IMPSCI  
COMMUNITY  
OF PRACTICE

# **RAPID-FIRE**

## P R E S E N T A T I O N S

SELECTED SPEAKERS SHOWCASING  
EXAMPLES OF DATA USAGE TO  
IMPROVE HEALTH CARE

**Meaningful use of EHR data  
to improve the quality of  
breast cancer care; a proof-  
ofconcept in data  
visualisation**

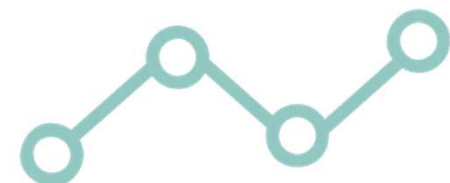
**PRESENTED BY ELISABETH ELDER**  
WESTMEAD BREAST CANCER INSTITUTE

# Meaningful use of EHR data to improve the quality of breast cancer care

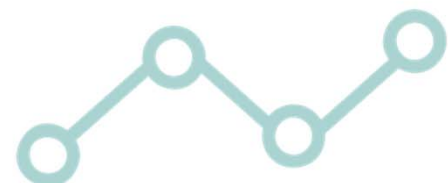
Presented by A/Prof. Elisabeth Elder

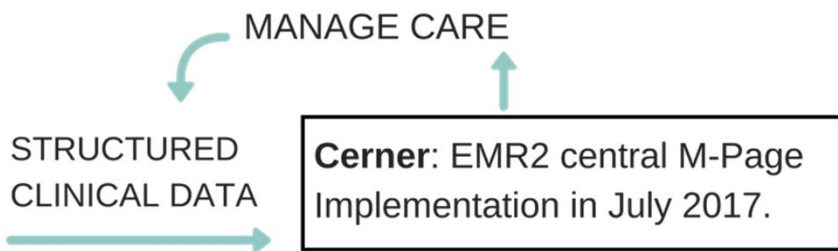


A Westmead Breast Cancer Institute,  
Research in Implementation Science &  
eHealth and Centre for Translational  
Data Science collaboration



**Project Team:** A/Prof. Elisabeth Elder, A/Prof. Nirmala Pathmanathan, Candice Kielly-Carroll, Dr. Aldo Saavedra, Joshua Stretton, Dr. Phuong Dinh, Prof. Judy Kay, Masrura Kabir, Anna Janssen, Prof. Tim Shaw





BCI-Breast Assessment - Test, BCI Patient 1

\*Performed on: 17/07/2017 1103

### Presenting Symptoms

Initial Assessment Date: 08/06/2017 1547 Category: [Dropdown]

**Presenting Complaint**  
Symptomatic [Dropdown]

**Description of Complaint**  
Segoe UI 9 [Dropdown] [Icons] [Rich Text Editor]  
test

**Breast Symptoms**  
☐ Yes ☒ No

**Breast Lump**  
☐ Yes ☐ No

Site	Duration	Diagnosis By:	Change In Size
[Dropdown]	[Dropdown]	[Dropdown]	[Dropdown]
[Dropdown]	[Dropdown]	[Dropdown]	[Dropdown]
[Dropdown]	[Dropdown]	[Dropdown]	[Dropdown]
[Dropdown]	[Dropdown]	[Dropdown]	[Dropdown]

**Nipple Discharge** ☐ Yes ☐ No  
Discharge Site: [Dropdown]  
Duration: [Dropdown] [Dropdown]  
Duct Discharge: [Dropdown]  
Spontaneous: [Dropdown]  
Discharge Colour: [Dropdown]

**Mastalgia** ☐ Yes ☐ No  
Mastalgia Site: [Dropdown]  
Duration: [Dropdown] [Dropdown]  
Cyclical: [Dropdown]  
Severity: [Dropdown]  
Distribution: [Dropdown]

**Breast Inflammation** ☐ Yes ☐ No  
Inflammation Site: [Dropdown]  
Duration: [Dropdown] [Dropdown]



\*Performed on: 17/07/2017 1103

- Presenting Symptoms
- Gynae\_Homonal Hx
- Family Hx
- Medical Hx
- Medication and Allergy
- Psychosocial Hx
- Breast Examination
- Investigations
- Management Plan

## Presenting Symptoms

Initial Assessment Date 08/06/2017 1547 Category

Presenting Complaint Symptomatic

Description of Complaint Segoe UI 9

test

Breast Symptoms ☐ Yes ☒ No

Breast Lump ☐ Yes ☐ No

Site	Duration	Diagnosis By:	Change In Size

Nipple Discharge ☐ Yes ☐ No

Discharge Site

Duration

Duct Discharge

Spontaneous

Discharge Colour

Mastalgia ☐ Yes ☐ No

Mastalgia Site

Duration

Cyclical

Severity

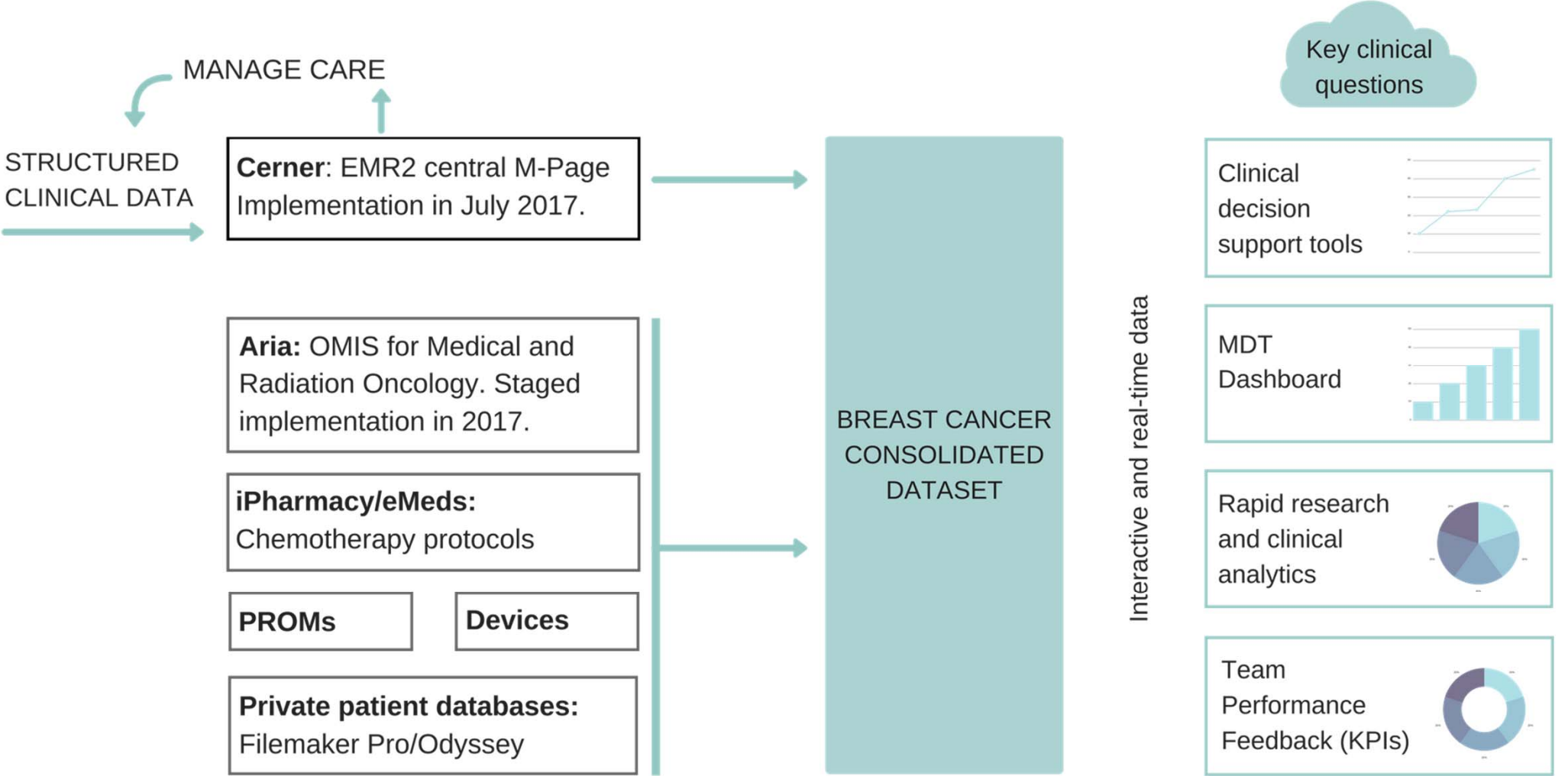
Distribution

Breast Inflammation ☐ Yes ☐ No

Inflammation Site

Duration

Multiple heterogenous data sources → Data extracted into integrated database → Downstream utilisation of data





# **Distributed learning for Non-Small Cell Lung Cancer using the Australian Computer Aided Theragnostics (OzCAT) network**

**PRESENTED BY A/PROF SHALINI VINOD**

CANCER THERAPY CENTRE, LIVERPOOL HOSPITAL

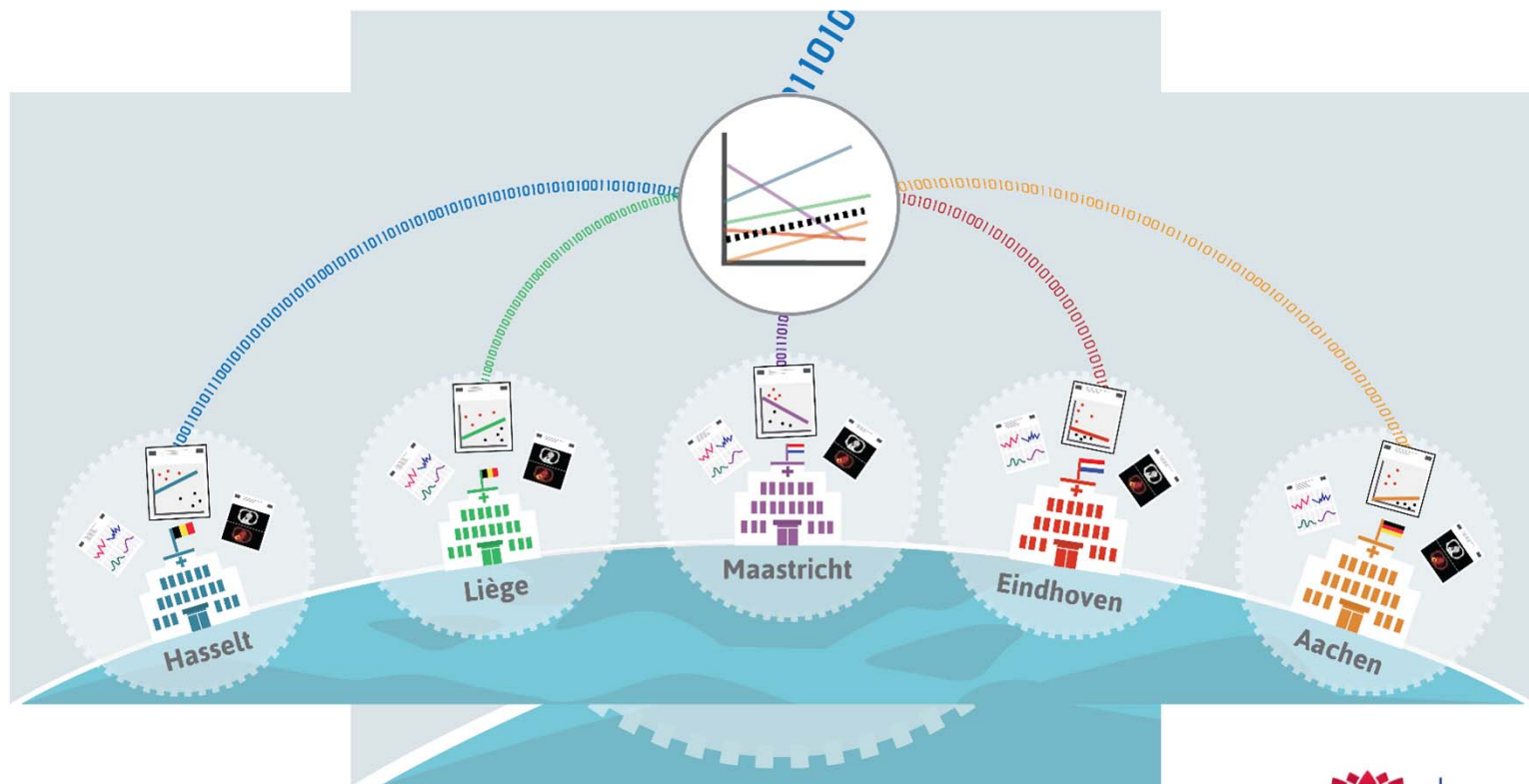


# Distributed learning for Non-Small Cell Lung Cancer using the Australian Computer Aided Theragnostics (OzCAT) network

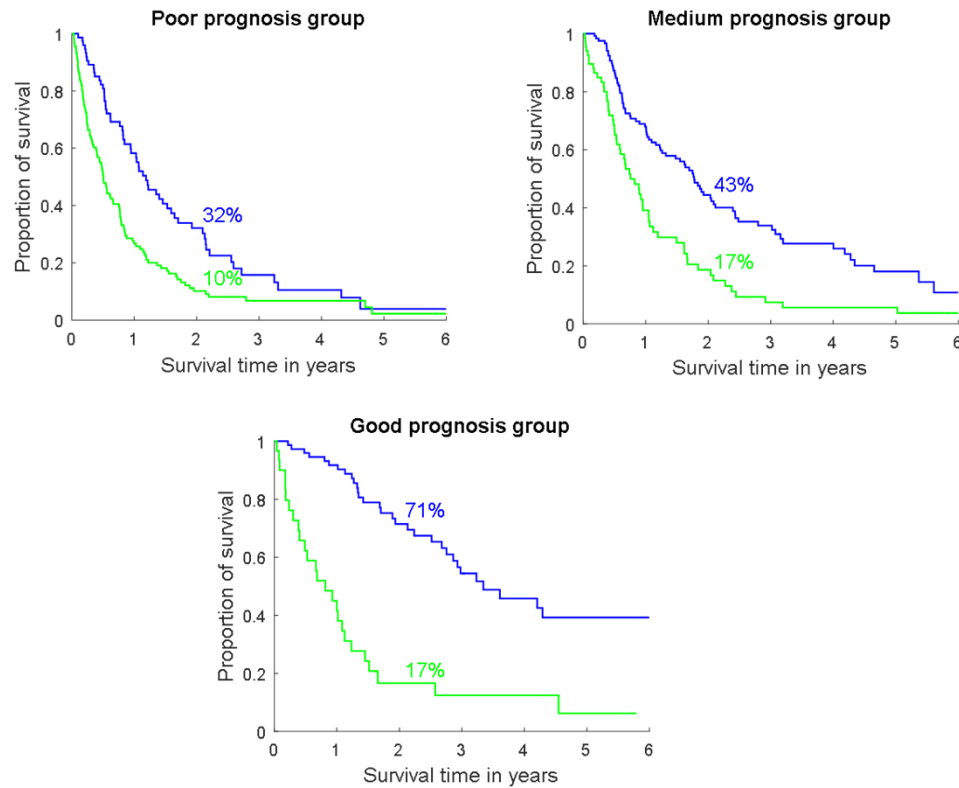
*SK Vinod, LC Holloway, M Field, MS Barakat, V  
Ahern, R Alvandi, M Carolan, E Hau, J Lehman, J  
Ludbrook, A Miller, J Sykes, M Bailey, T Lustberg, J  
Van Soest, S Walsh, A Dekker, D Thwaites*



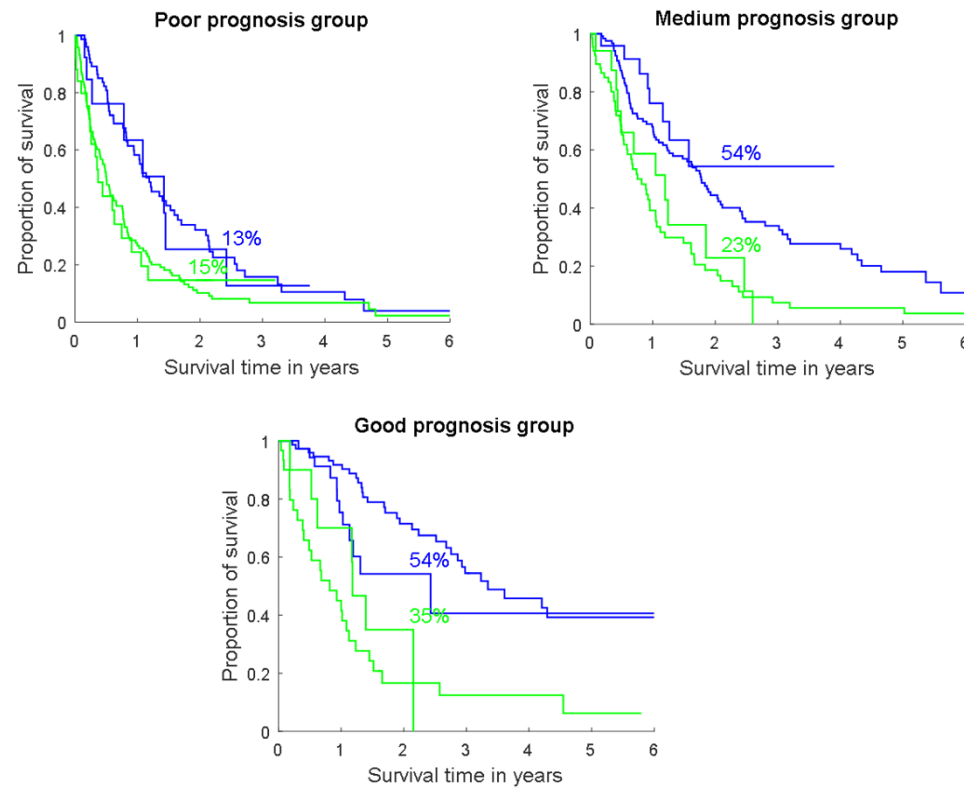
# Distributed Learning



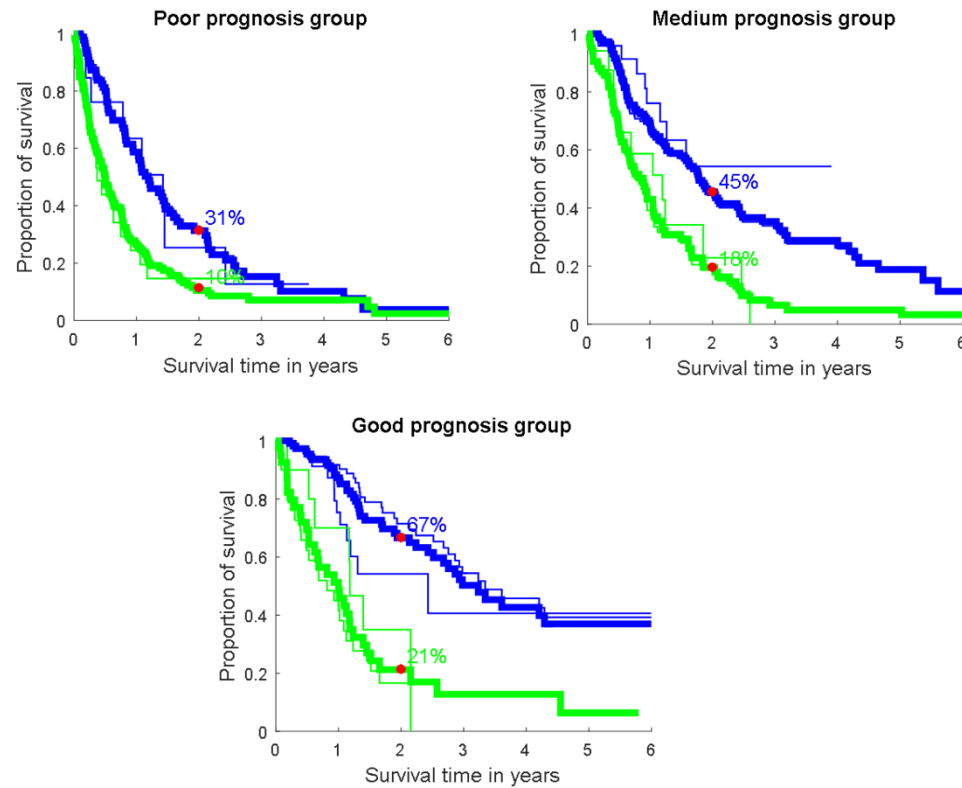
# NSCLC survival model



# NSCLC Survival Model



# NSCLC Survival Model



# **Data Linkage to Improve Cancer Care – A Case Study**

**PRESENTED BY PROF GEOFF DELANEY**

SOUTH WESTERN SYDNEY LOCAL HEALTH DISTRICT +  
INGHAM INSTITUTE OF APPLIED MEDICAL RESEARCH

# DATA LINKAGE TO IMPROVE CANCER CARE

DELANEY G., GABRIEL G., SHAFIQ J., YAP M., BARTON M.

STUDY FUNDED BY NSW CANCER INSTITUTE GRANT.



Prof Geoff Delaney  
SWSLHD



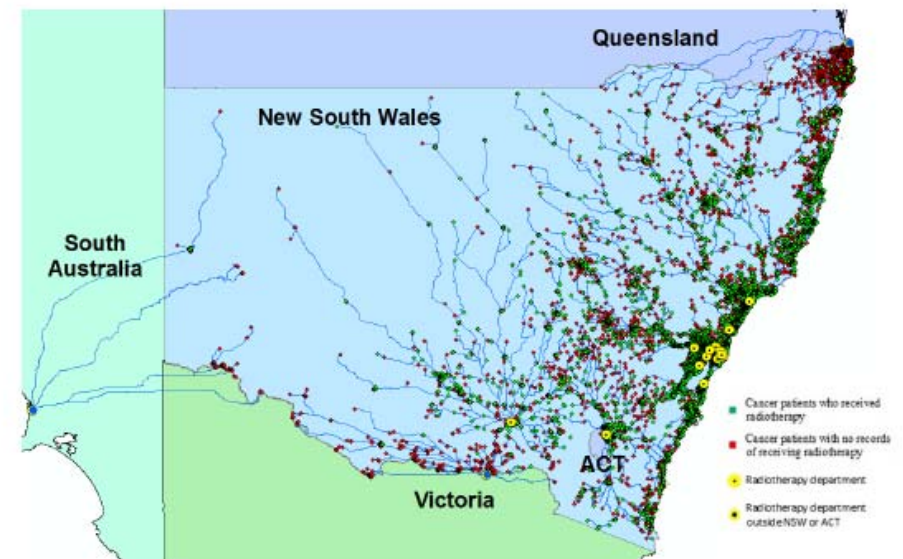


# USING EVIDENCE TO DRIVE TREATMENT

## FACTS

- Evidence-based guidelines and evidence-based decision trees exist
- Patients not treated necessarily always according to guidelines
- Some “reasonable” reasons for that
- However are all reasons appropriate or are patients “missing out”, “clinician roulette”?
- Would be good to understand where shortfall exists and why
- This proposed study uses data linkage to assess linked Cancer tumour data with stage and radiotherapy treatment

2004-2006





# DATA LINKAGE

- The data approval process remains slower than optimal. HOWEVER, IT HAS IMPROVED COMPARED WITH OUR EXPERIENCE 10 YEARS AGO
- Data linkage is potentially a powerful tool to examine actual care and compare it to other jurisdictions and to “optimal” models
- Data linkage is an excellent means to “efficiently” examine models of care over time, while protecting the privacy of individual patients
- However, the data need to be collected in “near real-time”
- To MAXIMISE BENEFIT - Systems could be developed to lower the level of bureaucracy of linkage studies by having an agreed, approved data pool of relevant linked, de-identified, DATA with data custodianship and approvals centralised or for the pooled data to be freely available (e.g. SEER data)

# **Data driven development of Youth Cancer Services in Queensland**

**PRESENTED BY ROSLYN HENNEY**  
QUEENSLAND YOUTH CANCER SERVICE



# Data driven development of Youth Cancer Services in Queensland

Natalie Bradford, Roslyn Henney,  
Danica Cossio and Shoni Philpot

Three overlapping, stylized hills in shades of green and teal, positioned at the bottom of the slide. The hills are semi-circular and overlap each other, with the largest one on the right and the smallest on the left.

# QYCS- Background and project aim

- Established 2013 to address unmet needs of AYA with cancer
- State-wide service
- Centrally coordinated by Multi-disciplinary team across 5 partner sites
- Collaboration with QCCAT to record, analyse and report data
  - Referral activity across five partner sites
  - Quality indicators
  - Benchmark set to achieve 75% of all indicators
- Project Aim: to measure performance and compare referrals against cancer registry data

# Methods and Results

- Two year activity data from 2015-2016 retrieved from QOOL
- Accessibility of the service by disease determined by comparing referrals with 3 years of cancer registry incidence data (2012-2014)

QYCS Indicators 2015-2016	N	%
New referrals to service	252	-
Received psychosocial care	252	100%
Presented and medical/surgical MDT	199	79%
Presented at psychosocial MDT	252	100%
Documented psychosocial care plan	219	87%
Provided with fertility preservation information	204	81%

Cancer registry 2012-14 data	N	Estimated QYCS referral %
Leukaemia	60	72%
Lymphoma	126	66%
Germ cell Tumour	98	56%
Bone sarcoma	31	55%
Brain cancer	56	27%
<b>All diagnosis</b>	<b>905</b>	<b>53%</b>

# Implications

- 30-40% treated in private sector
- Gaps identified across certain regional jurisdictions and for certain diagnosis
- Activity data and cancer registry data used to identify service strengths and opportunities for growth
- Understanding the cancer burden for AYA in QLD, location of where people live and access treatment is forming the basis of data driven service development







---

**Australian Government**  
**Department of Health**



**PROMPT-Care: An eHealth  
decision-support system  
linking cancer patient  
reported outcomes to service  
delivery and self-  
management**

**PRESENTED BY PROF AFAF GIRGIS**

INGHAM INSTITUTE FOR APPLIED MEDICAL RESEARCH,  
THE UNIVERSITY OF NSW



## **PROMPT-Care:** **An eHealth decision-support system linking cancer patient reported outcomes to service delivery and self-management**



**@Afaf\_Girgis**

### **Professor Afaf Girgis**

Director, Psycho-oncology Research Group  
Centre for Oncology Education and Research  
Translation (CONCERT)  
Ingham Institute for Applied Medical Research  
UNSW Sydney

Delaney G, Arnold A, Durcinoska I, Gerges M,  
Sandell T, Levesque JV, Kaadan N, Miller A,  
Masters K, Tran TT, Carolan M, Avery S, Ng W,  
Della-Fiorentina S



Ingham Institute  
Applied Medical Research



**Health**  
South Western Sydney  
Local Health District



**Health**  
Illawarra Shoalhaven  
Local Health District

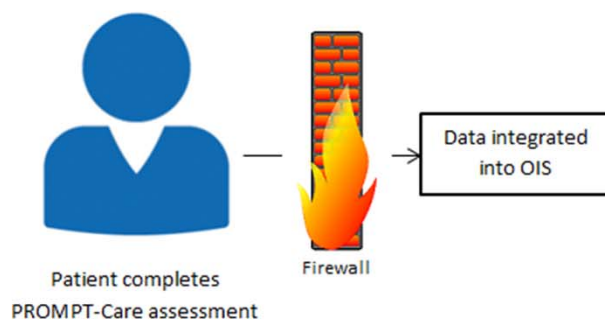


**cancer  
institute**  
NSW

# Overview of PROMPT-Care

**PROMPT-Care** is the first Australian integrated eHealth platform using systematically collected patient reported outcomes to inform cancer survivors' real-time clinical care and self-management.

**Funding:** Cancer Institute NSW & Bupa Health Foundation



# PROMPT-Care assessments

## PROs & measures (67 items)

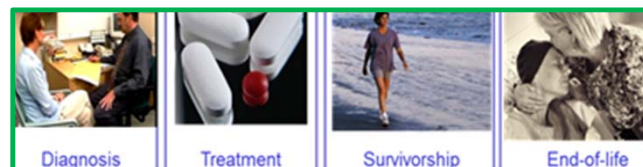
Symptoms: Edmonton Symptom Assessment Scale (ESAS)

Distress: Distress Thermometer & problem checklist

Unmet needs: Supportive Care Needs Survey-Screening Tool (SCNS-ST9)



**Frequency:** Approximately monthly; ongoing from start of treatment



**Location:** In clinic or from home

Survey: <https://e5gz8.enketo.islhd.health.nsw.gov.au/webform>

## Acceptability/feasibility:

Patients: 100% (n=35) found the time to complete assessments “about right” (mean 15 min); 96% found online assessment “easier/ same as” completing a paper copy; 79% willing to answer more questions

Clinicians: “gave greater granularity and specificity about .. needs”; potential to save time

**Implementation** (in progress): 300+ patients in 4 cancer centres; **1,363** assessments completed to date providing **91,321** data items

## System-level benefits

- PROs integrated with hospital's EMR
- Systematic data collection during & post-treatment
- Longitudinal and outcome data for all patients, not just research participants
- Patient-centred clinical care: automated PRO scoring; real-time clinician feedback; treatment and referral pathways; reports accessible by all team members
- Patient self-management and shared care with GPs – fulfilling patients' needs without necessarily using finite specialist resources
- In future: adapt for non-English speaking patients
- Potential for use with other chronic diseases

**Implementation of a  
surveillance protocol for  
individuals at high risk of  
melanoma in Australia: from  
a research study to the  
community**

**PRESENTED BY DR CAROLINE WATTS**

SYDNEY SCHOOL OF PUBLIC HEALTH,  
THE UNIVERSITY OF SYDNEY



# Implementation of a surveillance protocol for individuals at high risk of melanoma: from a research study to the community.

## **Presented by**

Dr Caroline Watts

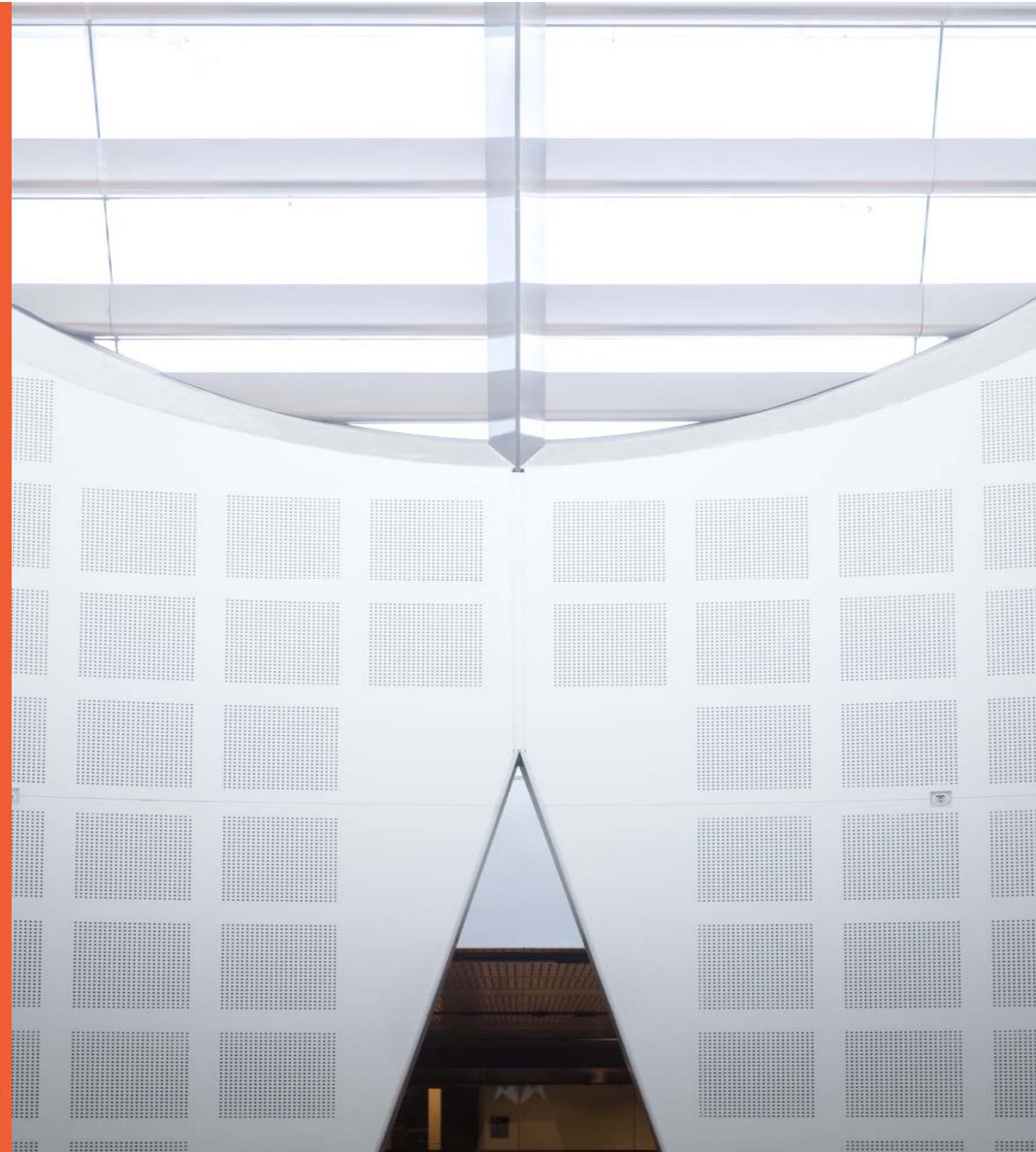
Cancer Epidemiology and Prevention  
Research Group, Sydney School of Public  
Health

## **Co-authors**

Rachael Morton, Sally Wortley, Sarah  
Norris, Scott Menzies, Pascale Guiterra,  
Lisa Askie, Graham Mann, Anne Cust



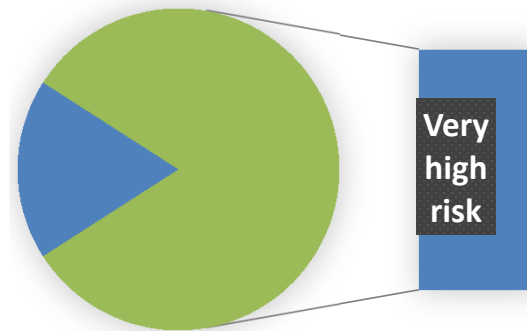
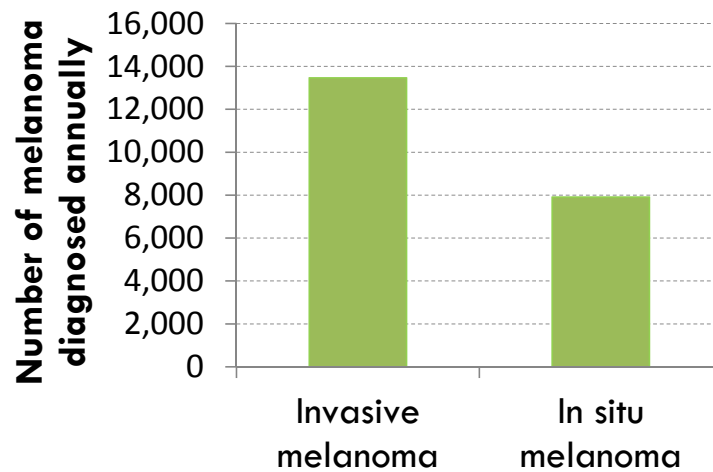
THE UNIVERSITY OF  
**SYDNEY**





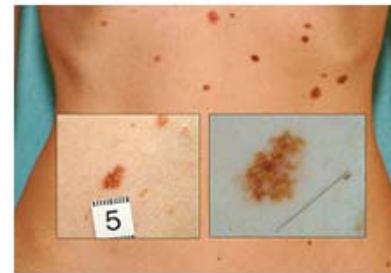
# Background

## Background



## Specialised surveillance

- 6 monthly appointments
- Full skin examination using dermoscopy
- Total body photography
- Sequential digital dermoscopy imaging



## Aims and Methods

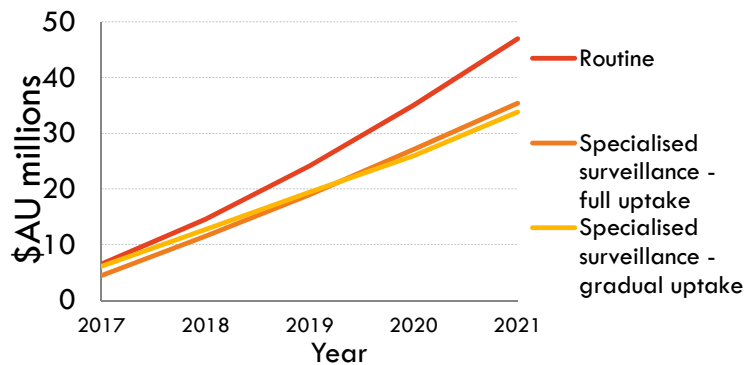
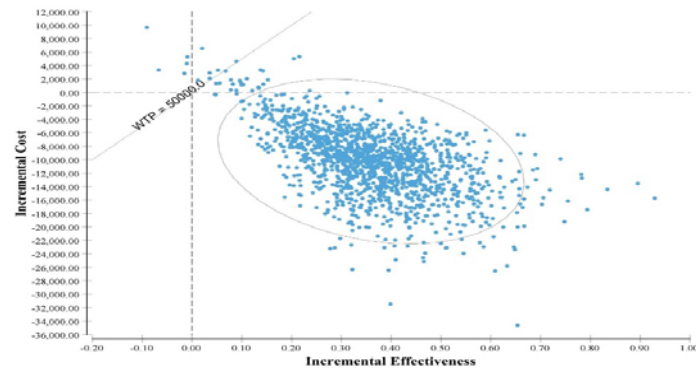
### Aims

Translation of specialised surveillance program for those at highest risk of melanoma into clinical practice

### Methods

- Micro-costing study
- Cost-effectiveness study
  
- Budget impact analysis
  - Estimate high risk population
  - Health system cost
  - Process to identify individuals at very high risk
  
- Examine the practicalities for transferability of the specialised surveillance model of care from a hospital clinic to clinical practice
  - Specialists
  - General practice

## Results and implications



### Implications

- Transferability of model of care
  - Dermatologists
  - General practitioners
- Compliance

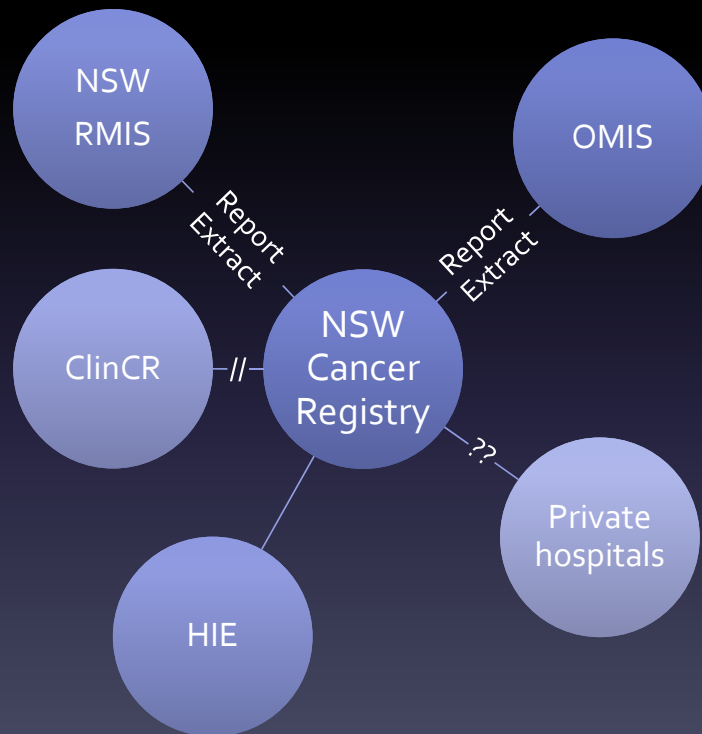
People diagnosed with melanoma in a year	Total
Total- invasive and in situ	21,373
Risk characteristic indicating very high risk of cutaneous melanoma and previous melanoma diagnosis	
Strong family history	100
Over 100 moles with multiple atypical nevi	3,206
Additional previous melanoma in the past 10 years	1,924
Risk characteristic without melanoma diagnosis	
Genetic mutation	43
TOTAL people at with one characteristic indicating very high risk	5,273
TOTAL people including individuals with > 1 risk characteristic	3,876

**Water, water everywhere:  
a protocol for comparison of  
clinician access to lung  
cancer data across  
Australian and international  
cancer care settings**

**PRESENTED BY DR EMILY STONE**

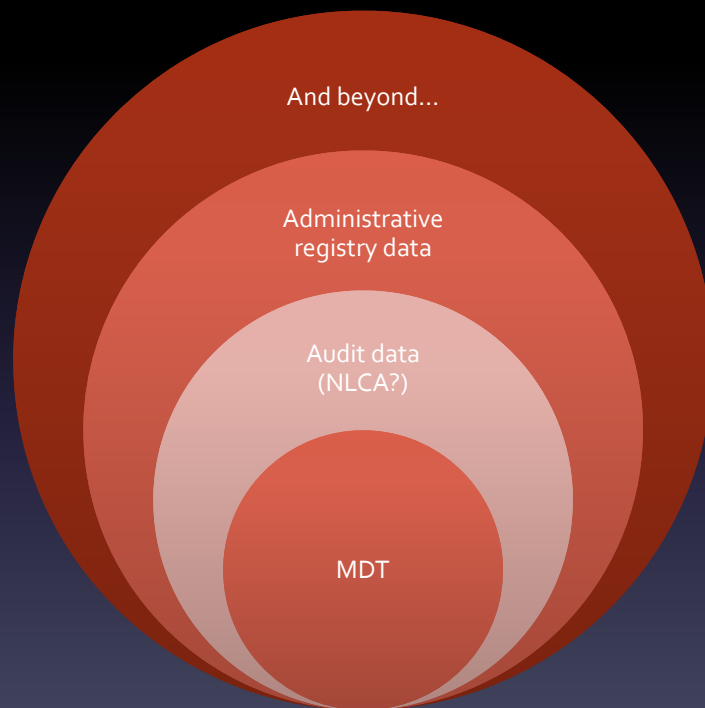
ST VINCENT'S HOSPITAL + KINGHORN CANCER CENTRE,  
SYDNEY CATALYST TCRC

# Background and Aims



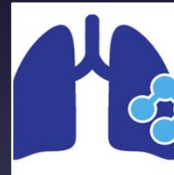
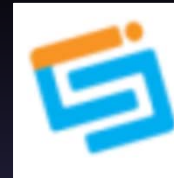
To develop a protocol to test data availability in a variety of lung cancer services.

# Methods and Results



Hospital  
databases

Cancer data  
online

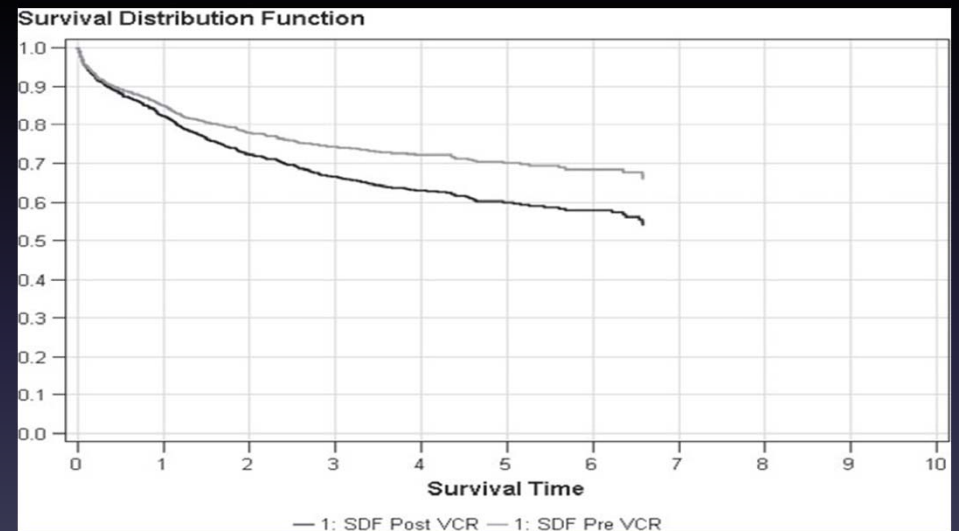
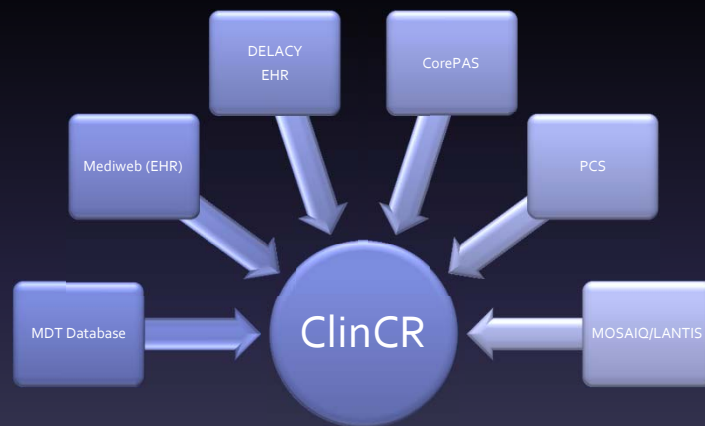


State-based  
registries

International  
models



# Implications



Field *et al.* Internal Medicine Journal 40 (2010) 566–573

# Acknowledgements

- Professor Tim Shaw
- Dr Nicole Rankin
- Professor Jane Phillips
- Professor Kwun Fong
- Professor David Currow



# Capturing change in lymphoedema

**PRESENTED BY ROBYN SIERLA**

UNIVERSITY OF SYDNEY +  
ROYAL PRINCE ALFRED HOSPITAL

# Capturing Change in Lymphoedema

## **Presented by**

Robyn Sierla

Doctoral student, Faculty of Health Sciences  
University of Sydney

## **Supervisory team**

Professor Sharon Kilbreath

Dr Elizabeth Dylke

Professor Tim Shaw

Associate Professor Simon Poon



# Establishing the breadth of outcomes used

## Qualitative Study

- 14 experienced therapists from public and private settings were observed assessing and treating patients with lymphoedema and then interviewed
- Wide range of assessments used by clinicians, determined by i) resources available; and ii) differences of opinion on assessment

## Systematic review

- 55 studies included
- Wide range of measurement tools used and outcomes reported
- Multiple outcomes reported for the *same* domain (rather than multiple outcomes for *different* domains of lymphoedema)
- 21 studies established a threshold for clinically significant change *a priori*; 20 of these thresholds differed

# Delphi study seeking consensus on minimum outcome set

- Breadth of outcomes offered in Delphi informed by SR and qualitative study
- Consensus = 70% agreement or 30% disagreement
- Clinicians and researchers from seven nations

Delphi round 1  
(48/70 – 69%)

Agreement to include these domains: size change, bio-impedance, palpation, visual change and symptom report

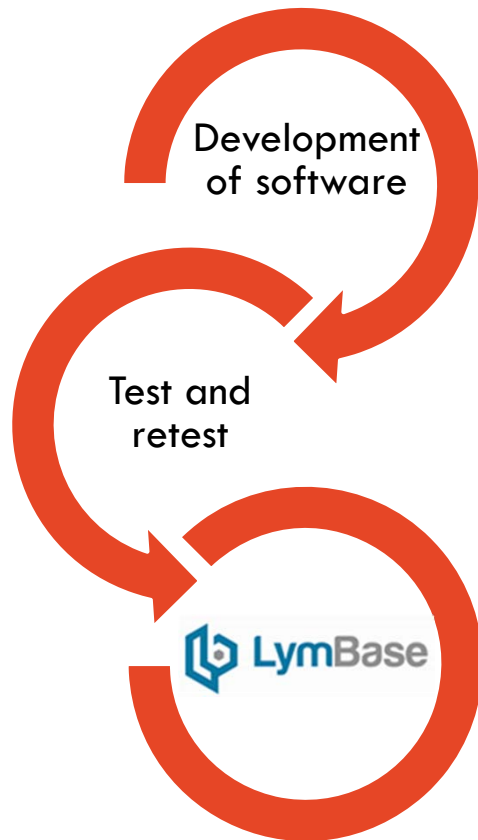
Questions remain: How should change be graphed? Which terms to describe changes observed and palpated

Delphi round 2  
(40/44 – 91%)

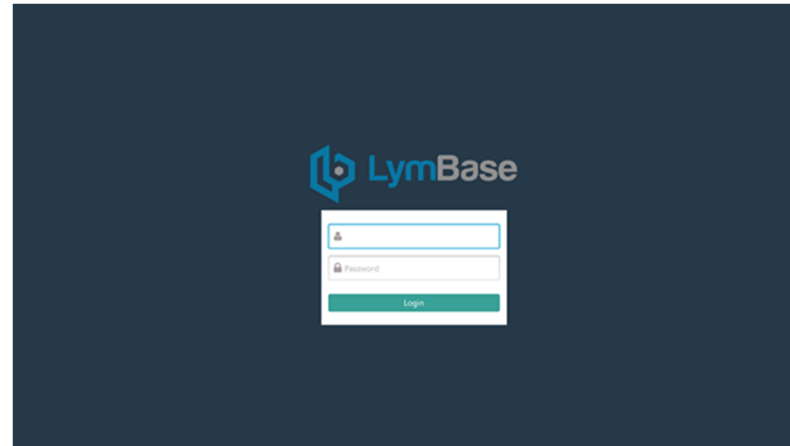
Agreement obtained on terms to describe changes observed and palpated

Although full agreement was not obtained for graphical representation of change, inter-limb difference as % was preferred

## Where to next?



## Outcome set defined to inform LymBase



Stores assessment data  
Simplifies data processing (e.g. cm to ml)  
Applies normative ranges and thresholds to patient's data  
Visually represents change over time  
Standardises outcomes used  
Facilitates use of data for research, and  
Enables review of data by patient, clinician and service

# **Closing the Gap - Promoting the transfer of clinical information by introducing an "Event Summary"**

**PRESENTED BY BRETT LY**

PRINCE OF WALES HOSPITAL,  
CANCER + HAEMATOLOGY SERVICES

# Closing the Gap:

## Promoting the Transfer of Clinical Information via an “Event Summary”

Prepared by **Brett Ly**

Clinical Lead - Clinical Information Systems

Cancer and Haematology Services, Prince of Wales Hospital

May 2017



**Health**  
South Eastern Sydney  
Local Health District

## Background, Aim

---

- MOSAIQ commenced roll-out at POWH in March 2011. Electronic prescribing and administration of chemotherapy and supportive medications using MOSAIQ continued in October 2011.
- POWH was in need of implementing an “Event Summary” document to assist with an integrated patient record across the LHD and as well as a business continuity strategy if MOSAIQ is unavailable.
- The aim of the Event Summary is to summarise key health information from MOSAIQ about significant healthcare events into a document, which can be interfaced into other eMR's, such as PowerChart.



**Health**  
South Eastern Sydney  
Local Health District



# Results

---

**The Event Summary summarises a set of data post a determined event and includes:**

Pre-entered data

- Care Plan or Protocol Data
- Medications Prescribed

Data entered on the Event Summary day

- Medications Administered
- Clinical Notes
- Event Summary sender information

**Following a simple trigger at the user's discretion, the process of generating the document and sending to PowerChart is completely automated.**



**Health**  
South Eastern Sydney  
Local Health District

# Screenshot and Implications

**Nelune Comprehensive Cancer Centre**  
Research led excellence in cancer care

**THE BRIGHT ALLIANCE** **UNSW**

Cancer and Haematology Services  
Prince of Wales Hospital  
Level 2, High Street  
Randwick NSW 2031  
Tel: 02 9382 2605 / 02 9382 2600  
Fax: 02 9382 3420

**EVENT SUMMARY**  
28 April 2017 Time Sent: 2:19 PM

Patient: Royal Isoft MRN:8045935 DOB:30/06/77 Gender: Female  
Address: 10 High Street Randwick, NSW, 2031, Australia Phone: 97504579

Attending Doctor: Dr Michael Friedlander

**Diagnoses/Interventions:**  
Diagnosis/Problem:

Dx Date	Description	Morphology Description	Laterality	T	N	M	Stage
02/03/2012	Malignant neoplasm of ovary	Scirrhous adenocarcinoma		T1c	N1	M1	IV

Protocol Name: Trial B6B-A317\_Study\_001 2 mg/kg q3w: Triple Washed Packed Cells 3 Unit  
Day: 21: 1 Intent: Curative (primary): Transfusion Cycle: 7: 1

**Adverse Reactions**  
Allergies:

ID Date	Allergy Type	Name	Reaction	Severity	Details	Status
16/09/2015	Misc. Allergy	MOSAIQ	Pain	Moderate		Active
16/09/2015	Misc. Allergy	MOSAIQ	Breathing Difficulties	Mild		Active
19/05/2016	Medication Allergy	Rituximab	Rash	Unknown		Active

*This document is generated to summarise the medication administered by Cancer and Haematology Services staff on the specified day only*

**Medications**  
Medications Ordered:

Date	Description	Condition	Dose Adjustment	Reason 1	Status
28/04/2017	B6B-A317 100 mg IV once	Do NOT shake, slowly swirl vial and allow up to 5 minutes for any bubbles to clear. Draw up the needed dose (10mg/mL) and make up with Sodium Chloride 0.9% to make a total volume of maximum 100mL. Infuse through a sterile, non-pyrogenic, low-protein binding 0.2 - 5	(Adjusted from 160 mg)		Approved

Date	Description	Condition	Dose Adjustment	Reason 1	Status
		micron in-line or add-on filter.			
28/04/2017	Triple Washed Packed Cells 1 International Units IVI once for 1 Time	Infuse at 250 mL/hr			Completed
28/04/2017	Triple Washed Packed Cells 1 International Units IVI once for 1 Time	Infuse at 250 mL/hr			Completed
28/04/2017	Triple Washed Packed Cells 1 International Units IVI once for 1 Time	Infuse at 250 mL/hr			Completed

Medications Administered:		
Start Date	Drug Name	Actual Dose
28/04/2017	Triple Washed Packed Cells	1 International Units
28/04/2017	Triple Washed Packed Cells	1 International Units
28/04/2017	Triple Washed Packed Cells	1 International Units

**Event Details**  
Progress Note: Ly. Brett 28/04/2017 Proglote Event Summary Testing, TWPC prescribed today as a training exercise, and administered by BL x 3. Event summary will be triggered using the "Event Summary transfer" assessment entry triggering the IQ engine to generate an eSCRIBE document in an Approved state. When the pdf interface has been configure to send this document type, this event summary document would be sent to eMR automatically.

Event Summary Sent By: Brett Ly  
Encounter Period: 28 April 2017

**Event Summary Transfer - MRN: 8045935 Isoft, Royal Hosp**

Info MAR Summary Note Status Print Unreviewed Reviewed Save Cancel

Record Date and Time: 08/05/2017 12:11:38 PM

Event Summary Sent By: Brett Ly

Event Summary Sent: ☒

Event Summary Transfer Will Be Added

Anyone who reviews the patient file in PowerChart will be able to see this document.



**Health**  
South Eastern Sydney  
Local Health District

# **Enabling near real-time clinical data capture for biobanks using electronic medical records**

**PRESENTED BY NICKI MEAGHER**

PRINCE OF WALES CLINICAL SCHOOL, UNSW



# Enabling near real-time clinical data capture for biobanks using electronic medical records

Nicki Meagher, Deborah Marsh, Susan Goode, Kevin Spring, Anna deFazio, Jitendra Jonnagaddala, David Goldsbury, Elena Shirley, Winston Liau, Peter Troke, Simon King, John Pimanda

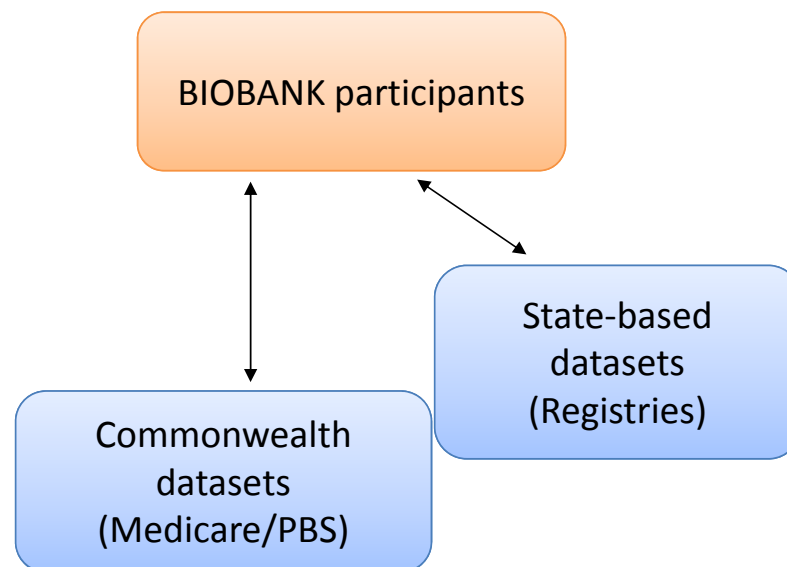


# Models of data collection

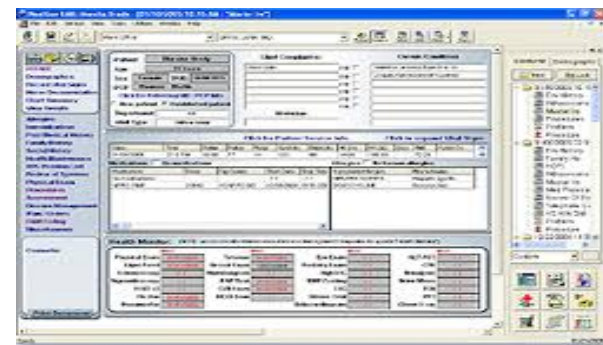
## MANUAL DATA MANAGEMENT



## DATA LINKAGE



## EMR EXTRACTION?



# Enabling near real-time clinical data capture for biobanks using electronic medical records

Year 1: Roadmap of essential data items across eMRs in 4 LHDs

Year 2: Framework for semi-automated extracts

Data categories	No. core items
Demographics	2
Tumour characteristics	9
Cancer treatment	12
Outcomes	5

Local Health District	Source systems		
	Pathology	Inpatient	Oncology
South-East	OmniLab	Powerchart	MOSAIQ/ARIA
South-West Sydney	PathNet/Powerchart	Powerchart	MOSAIQ
Hunter	AusLab	iPM/CAP	ARIA
Northern	AusLab	Powerchart	MOSAIQ/ARIA

# The data challenge

- Multiple systems within and across hospitals
- Data governance framework
- Completeness/quality
- Updates

## Importance of this project:

- Shed light on utility of eMR data for cancer research beyond biobanking
- Framework to be scalable and system-neutral

# Acknowledgements



- CINSW Biobanking Stakeholder Network
- Sarah Neilsen, Wayne Ng, Seven Gurney
- LHD/Cancer Services/Pathology IT teams
- Centre for Health Informatics/AIHI



# **Cancer Services Multidisciplinary Team Meeting Template**

**PRESENTED BY A/PROF PHILIP BEALE**

SYDNEY LOCAL HEALTH DISTRICT CANCER SERVICES

# Cancer MDT Templates in Cerner eMR : Real-time Data Analysis

*Flipping the record-using data to transform cancer care*

A/Professor Philip Beale

Director, Cancer Services and Palliative Care, SLHD

Director Concord Cancer Centre



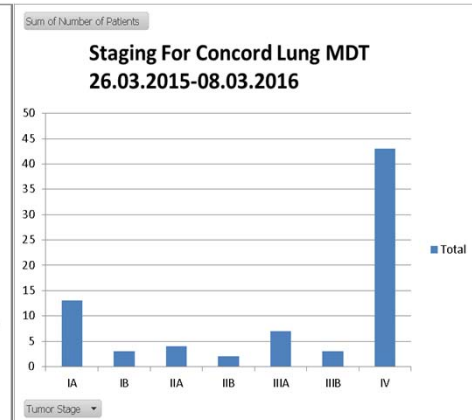
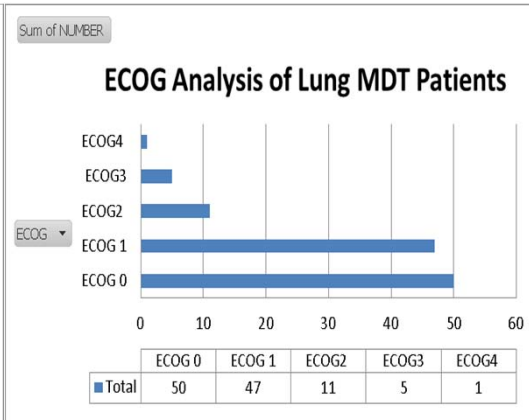
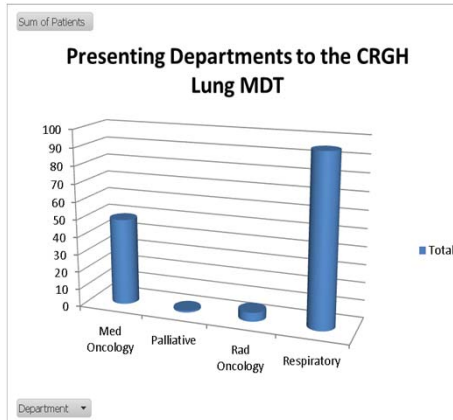
# Lung MDT Template

Lung MDT Form		TESTRPA, Test Royal - 123-14-57	
<b>Lung MDT Form</b>			
Patient: TESTRPA, Test Royal      MRN: 123-14-57			
Age: 23 years   Sex: Male   DOB: 12-12-1991			
Associated Diagnoses: None			
Author: Adeli, Javad			
<b>VISIT SUMMARY</b>			
Location: Admission/Attendance Date:		Attending M.O.: Medical Service:	
Pt Address:	12 Test Street CAMPERDOWN, NSW 2050	Indigenous Status:	Neither
Pt Phone:	02 9515 7983	Language spoken at home:	ENGLISH
		Interpreter Required:	NO
		Carer:	Testingcarer, test test (Friend-male)
General Practitioner:	Test, Dr		
GP Address:			
GP Phone:	00 9234 5678	GP Fax:	
Presenting Medical Officer: xxx			
Participants involved in discussion: xxx			
Relevant Medical History: xxx			
ECOG Performance Status (score): 2. Ambulatory and capable of all selfcare but unable to carry out any work activities. Up and about more than 50% of waking hours			
Tumour stage: xxx			
Diagnostic Tests: CT: Xxx			
Discussion: xxx			
Consensus/Treatment Plan: xxx			
GP follow-up:			
Printed by:	Adeli, Javad	Page 1 of 2	
Printed on:	12-02-2015 14:07	(Continued)	

Rankin NM, Collett GK, Brown CM, Shaw TJ, White KM, Beale PJ, Trevena LJ, Anderiesz C, Barnes DJ. Implementation of a lung cancer multidisciplinary team standardised template for reporting to general practitioners. Submitted to BMJ Open, June 2017.

## Analysis of the Lung MDT Data (Concord Repatriation General Hospital)

Age	Sex	Smoking Sta	Department	Presenting Clinician	Department	PET/Radiology	Histopat	Tumor Stagi	ECOG
84			Respiratory	Veitch	1	YES	YES	IIB	1
64	F	EX SMOKER	Respiratory	Brillante	1		YES		1
76	M	ASBESTOS	Respiratory	Makarie-Rofail	1		YES		0
64	F		respiratory	Brillante	1	YES		IA	0
84	M		Medical Oncology	Linton	0		YES		1
66	M	EX SMOKER	Medical Oncology	Linton	0			IV	



# Cancer MDT Templates in SLHD

## Results:

- Improved documentation of the MDT, attendance, discussion, data collection and extraction, and reporting to specialists and GPs in a timely manner.
- Explorer report can be generated from the reportable data fields, use for research and KPI reporting
- Live Templates: Lung and Upper GI (CRGH)
- Proposed Templates: Haematology (RPAH), Hepatocellular, Neuro-Oncology, Colorectal (CRGH)

## Implications:

- Positive step to contribute to the clinical data;
- Need a robust Terms of Reference
- Lengthy delays in the production of these templates

# **Linking data to practice and service delivery**

**PRESENTED BY JOSHUA HERDEN**

NSW HEALTH - HUNTER NEW ENGLAND LOCAL HEALTH  
DISTRICT - NORTH WEST CANCER CENTER



**Health**

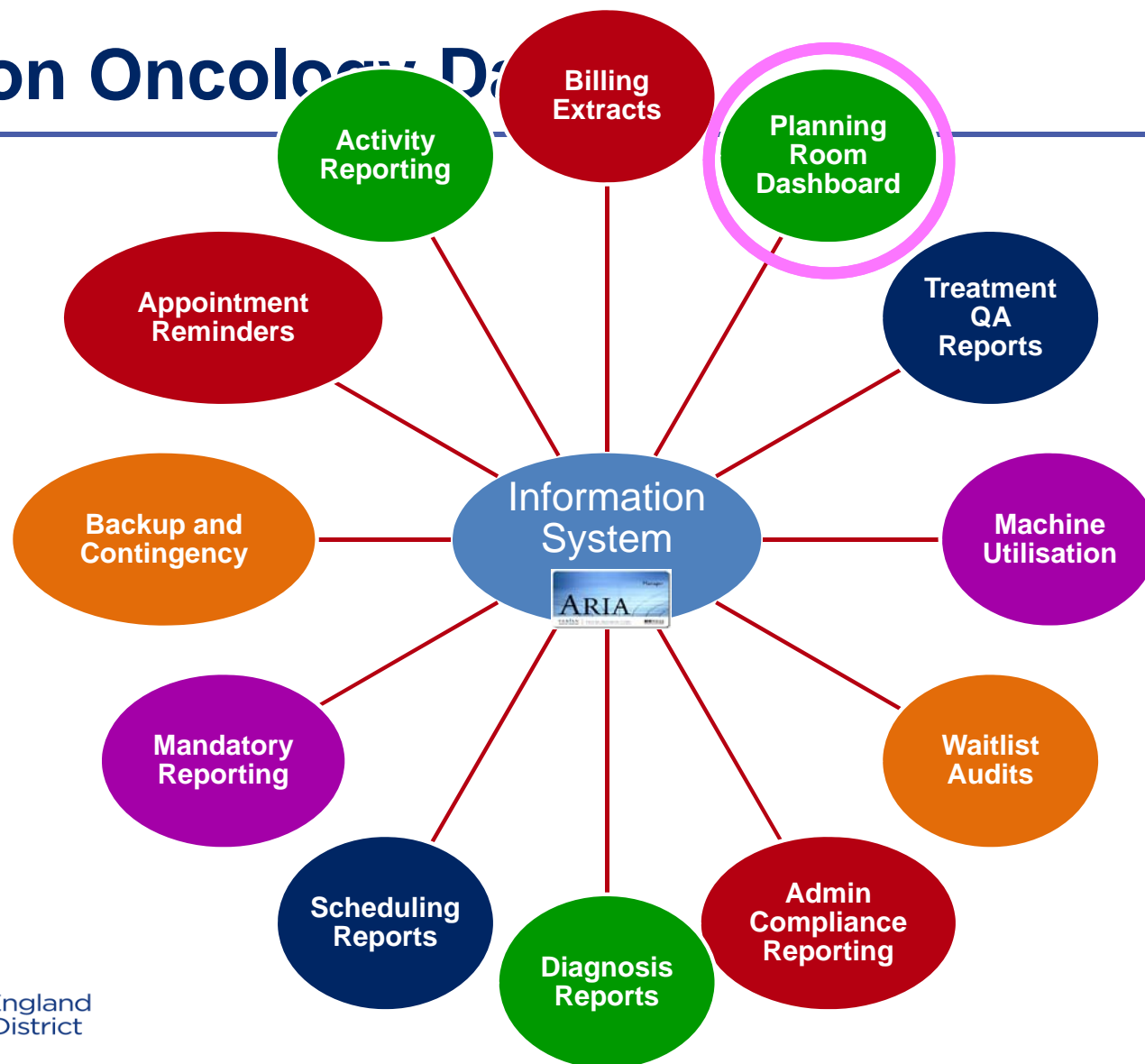
Hunter New England  
Local Health District

# Applying Business Intelligence to Radiation Oncology Workflows to Improve Care Coordination and Departmental Efficiency.

Joshua Herden  
Radiation Therapy Supervisor  
North West Cancer Centre



# Radiation Oncology Data



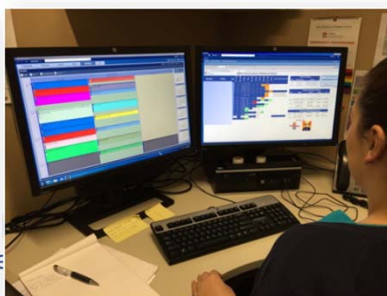
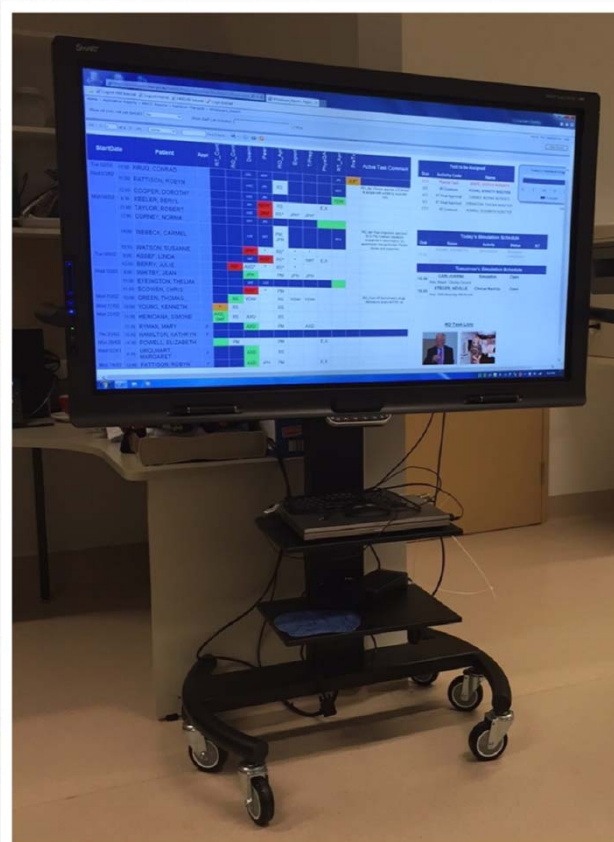


# Planning Room Dashboard



StartDate	Patient	Appt	RT_Cont	RO_Cont	Dosim	Peer	RO_Appt	Export	T/Prep	PhysQA	RT_Appt	PreTx	Active Task Comment
Tue 02/02					DRC	KEW					JPH	JLB*	
Wed 03/02					AXD	JPH	RS				KEW		RO_Appt Please approve 2 R Breast & update both scripts to read 6MV
					AXD	JPH					YDW		
Mon 08/02					JPH	KEW*	RS			E,X			
					AXD	JPH*	RS*	JPH*	JPH*				
					SMT	JPH							
					AJM	SMT	PM, JPH				KEW		RO_Appt by Dr P unapproved appreciably
					JPH*	*	RS*	*	*				
Tue 09/02					SMT	AXD*	RS*	*	SMT	E,X			
					RS*	AXD*	RS*	*					
Wed 10/02					JPH		PM	JPH	JPH				
					SMT	AXD							
					AXD*	*	PM						
Mon 15/02					RS	YDW	RS	YDW	YDW				RO_Cont mid set
Wed 17/02					*	RS		RS					
Mon 22/02					AXD, SMT	RS	AXD	RS					
					P		AXD	PM	AXD				
Thu 25/02					P								
Mon 29/02						PM		PM		E,X			
Wed 02/03					P		AXD	RS					
Mon 14/03					P		AXD	JPH	PM		E,X		

Task to be Assigned		
Due	Activity Code	Name
27/1	Planner Task	
2/2	RT Contours	
4/2	RT Final Approval	



# Outcomes



- Data quality improvement
- Operational visualisation
- Improved efficiency
- Unifying the pathway of care
- Linking data to service delivery



# **Quality improvement or research: Use of data for research purposes and informing practice**

**PRESENTED BY ALISON READ**

FACULTY OF HEALTH, UNIVERSITY  
OF TECHNOLOGY, SYDNEY

# Quality improvement or research: Use of data for research purposes and informing practice

FACULTY OF MEDICINE

## Stop Cancer PAIN Project

Funded by the National Breast Cancer Foundation

**Lead investigator:** Prof Melanie Lovell, Associate Clinical Professor  
USyd and Consultant Palliative Care Physician, HammondCare

**Chief investigators:** Prof Jane Phillips, Prof Meera Agar, Prof Fran Boyle, Prof Patricia Davidson, Dr Tim Lockett, Prof David Currow, Prof Lawrence Lam, Dr Nikki McCaffrey, Prof Tim Shaw,



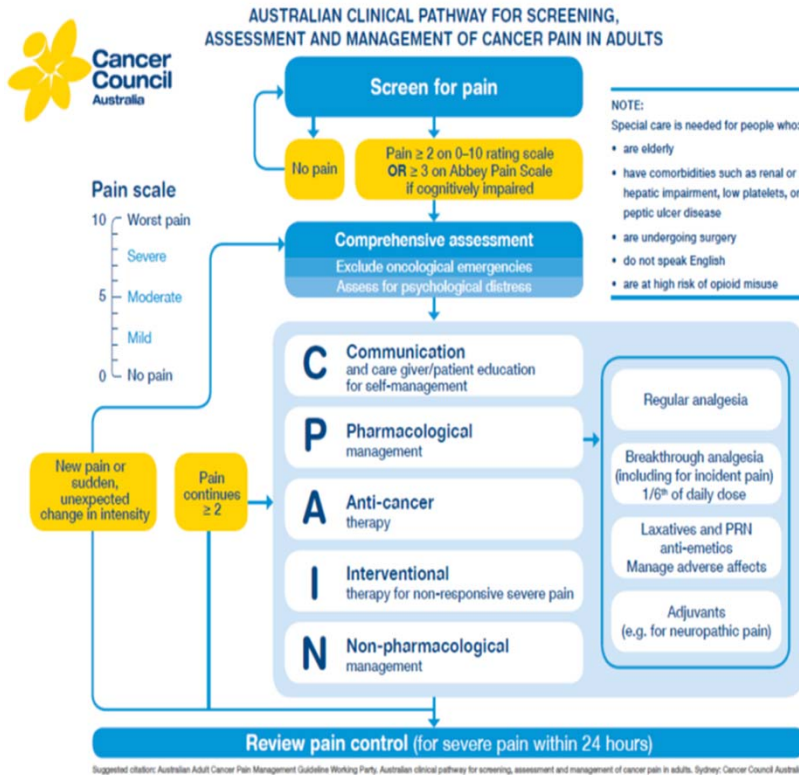
THE UNIVERSITY OF  
SYDNEY



UNIVERSITY OF  
TECHNOLOGY SYDNEY



Background: It is well documented that cancer pain management remains inadequate for a significant proportion of people with cancer in Australia



- To implement a national clinical practice guideline and clinical pathway (Cancer Council Australia Cancer Guideline Wiki) for screening, assessment and management of pain in adults with cancer
- Barriers to guideline implementation:
  - system level
  - provider level
  - patient level



# AIM: To highlight challenges & solutions in using data for both clinical & research purposes

Site LOGO

Attach patient details

## Date: Screening for Pain

Our service is currently working to improve how we recognise, assess and manage pain. The medical team would like to ask whether you have been experiencing pain and how severe it is. This information is important in helping us to provide you with the best possible care.

Please circle the number that best describes your worst pain in the last 24 hours

0 1 2 3 4 5 6 7 8 9 10

No  
pain

Worst pain you  
can imagine

Please circle the number that best describes your average pain in the last 24 hours

0 1 2 3 4 5 6 7 8 9 10

No  
pain

Worst pain you  
can imagine

To assist in evaluation of this service improvement, a member of the research team from the University of Technology Sydney may contact you, via telephone, to ask about your pain. You will be asked if you are interested in taking part in a phone based research project on pain management

If you do **NOT** want to be contacted, please tick the following box:

☐

For health professional's use only

Able to self-complete a 0-10 numerical rating scale for severity of worst and average pain in English

Chinese Italian Greek Vietnamese Arabic

Cancer Type

Cancer Status

Health Professional's initial:

# Research data

## Screening rates/month %

57

20

46

40

25

51

37

7

11

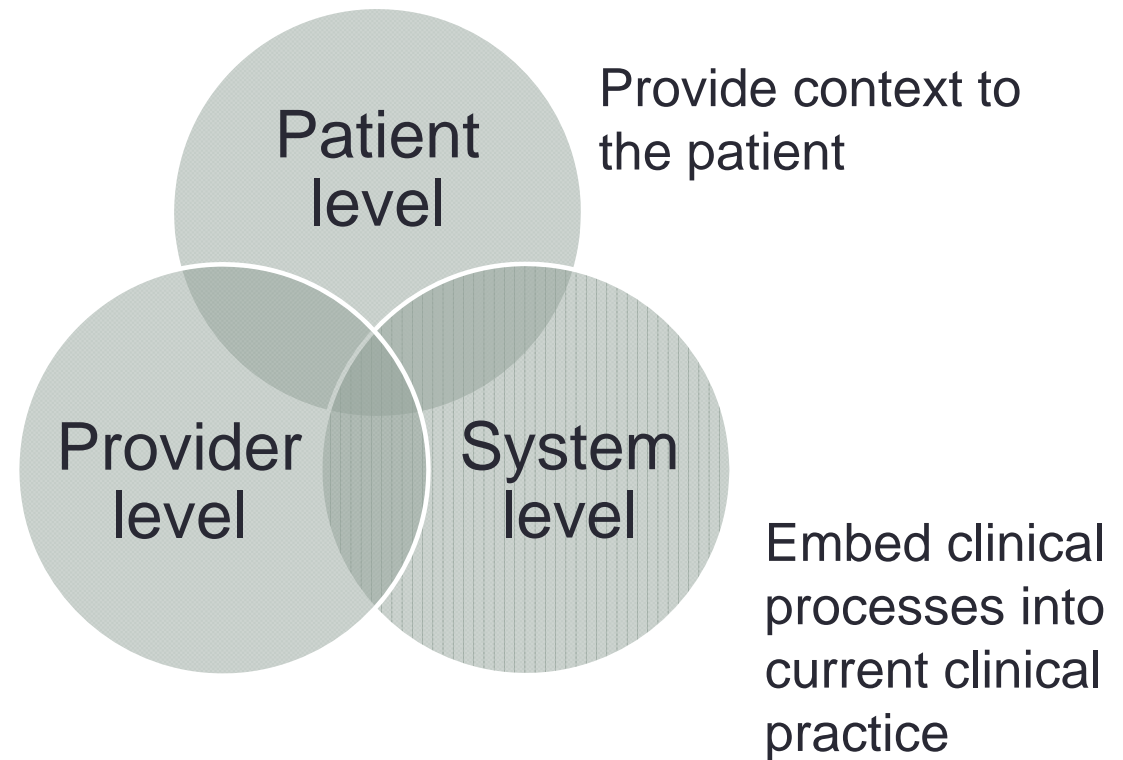
25

35



**IMPLICATIONS:** Studies with triple aim use of data for clinical and research purposes need to take a proactive approach overcome barriers

Proactive approach without assumption of background knowledge of implementation research





• 12:15 - 13:00 PM

**LUNCH**

**FLIPPING**

**the**

**RECORD**

#IMPSCI  
COMMUNITY  
OF PRACTICE



# CASE STUDY

---

## Clinical Quality Registries

by **A/ Professor Sue Evans**

---

ASSOCIATE DIRECTOR OF THE CENTRE OF  
RESEARCH EXCELLENCE IN PATIENT  
SAFETY (CRE-PS),  
HEAD OF THE CLINICAL REGISTRY UNIT  
MONASH UNIVERSITY



MONASH  
University

# Clinical Quality Registries

## NSW Oncology meeting-flipping the record: using clinical data to transform cancer care

Friday 21<sup>st</sup> July, 2017

Sue Evans PhD

Head, Prostate Cancer Outcome Registry-ANZ

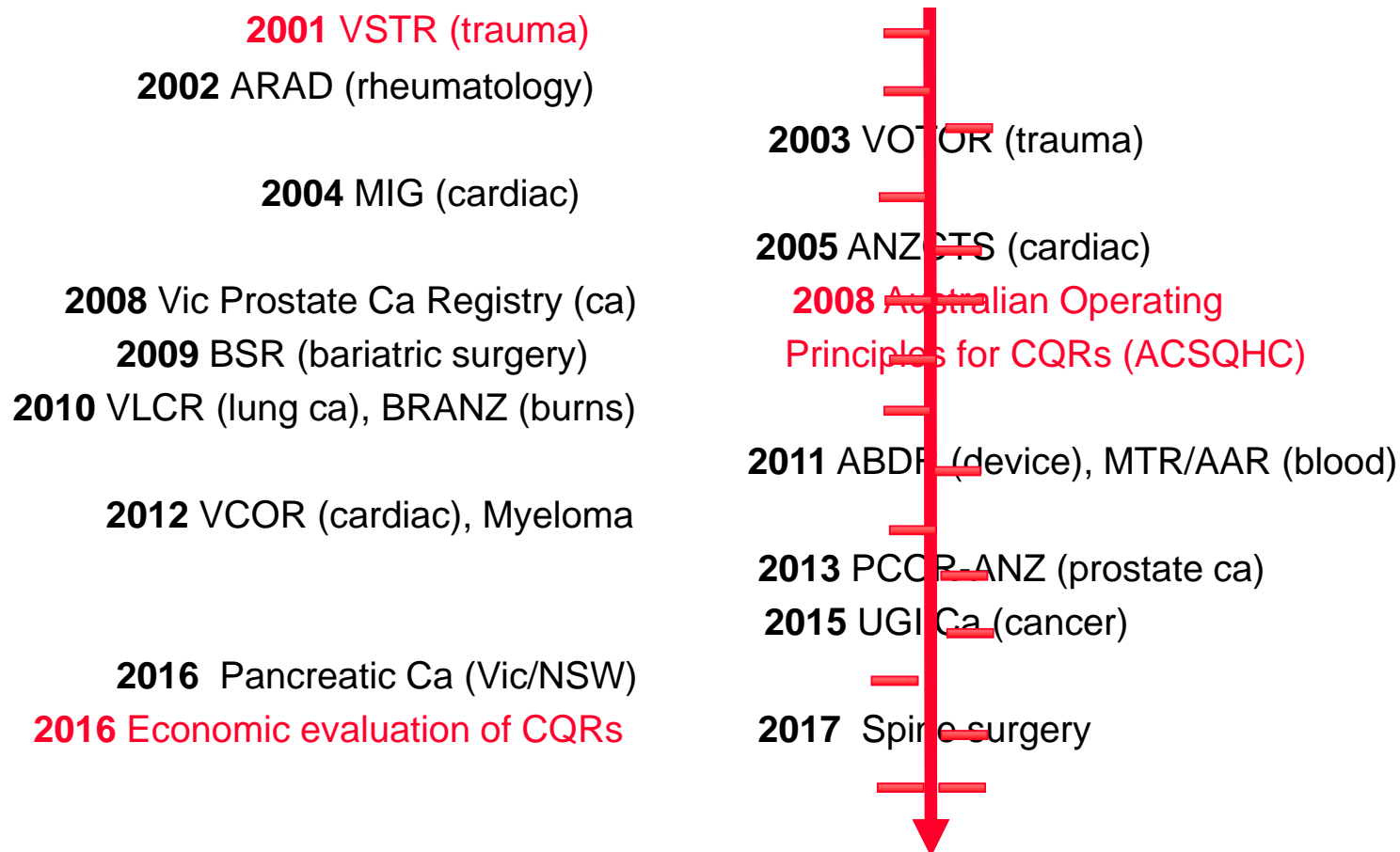
Co-lead, International Prostate Cancer Registry

PI, Pancreatic Cancer Clinical Quality Registry

Department of Epidemiology and Preventive Medicine



## Monash Clinical Registries - History

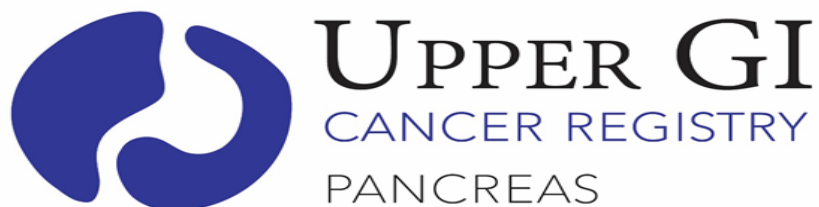


## Monash Clinical Quality Registries

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

**PROSTATE  
CANCER  
OUTCOMES**

REGISTRY  
AUSTRALIA &  
NEW ZEALAND

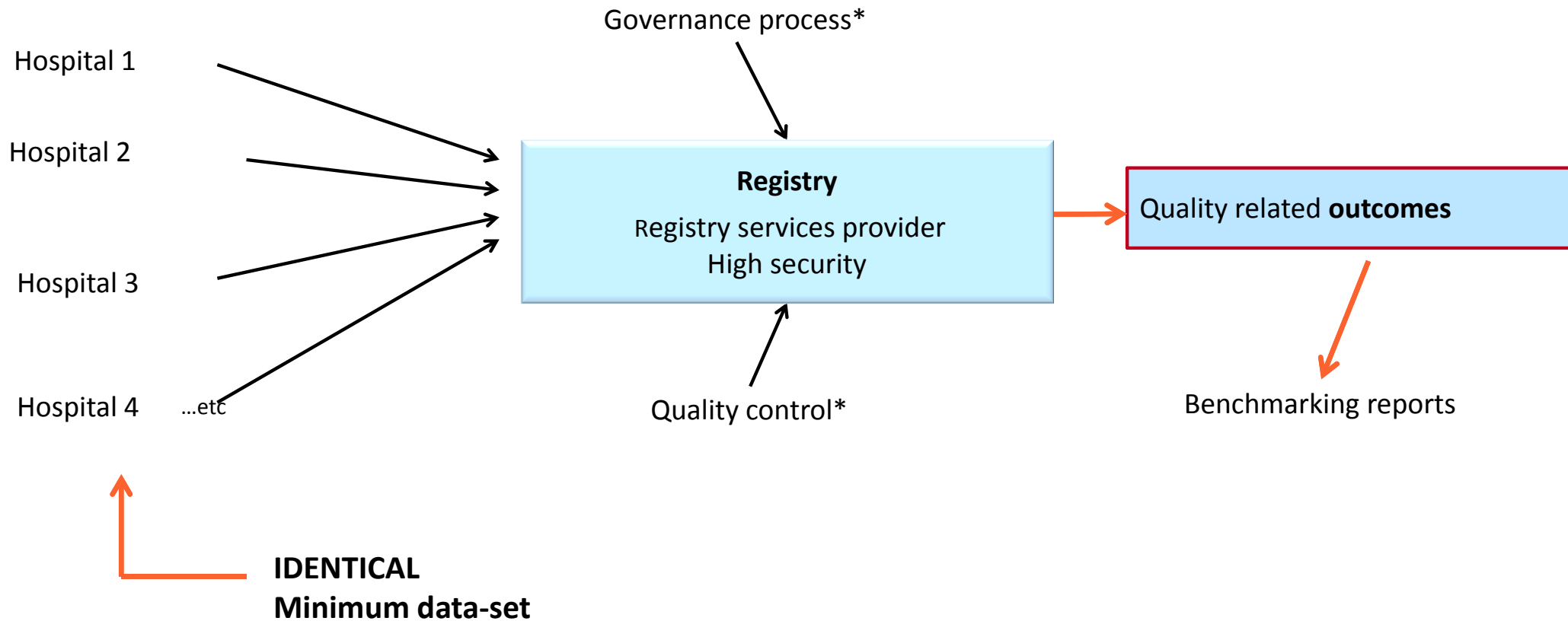


What are clinical registries?



- ❖ Provide information regarding *patterns of disease and care*
- ❖ Monitor and benchmark *quality of care*
- ❖ Provide a *platform for further research*

## Clinical Quality Registry Process Overview





# Clinical Quality Registry Development



Identification of a need to improve quality of care or understand gaps in knowledge

Funding

Stakeholder engagement-clinician and hospital

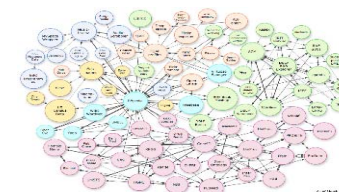
Development of recruitment and data collection methodology



Hospital research ethics and governance approvals required at each participating site before commence data collection



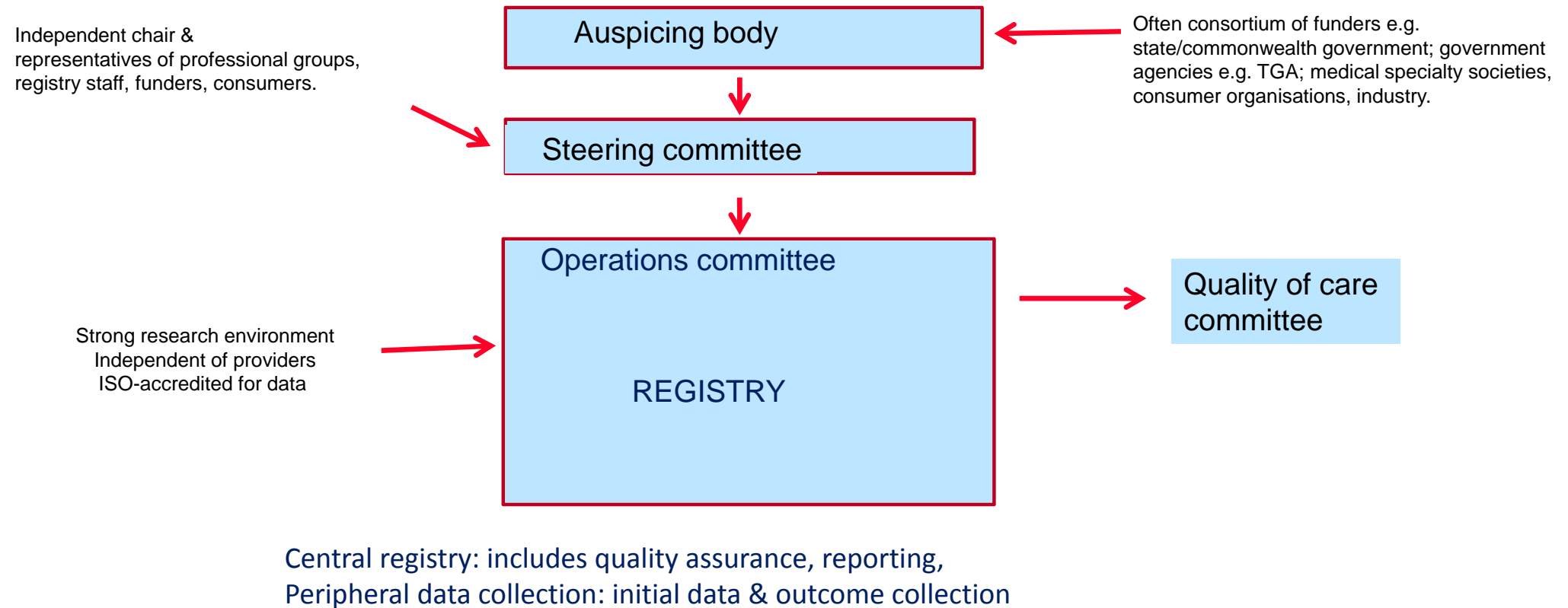
Registry Protocol, Policies and database development



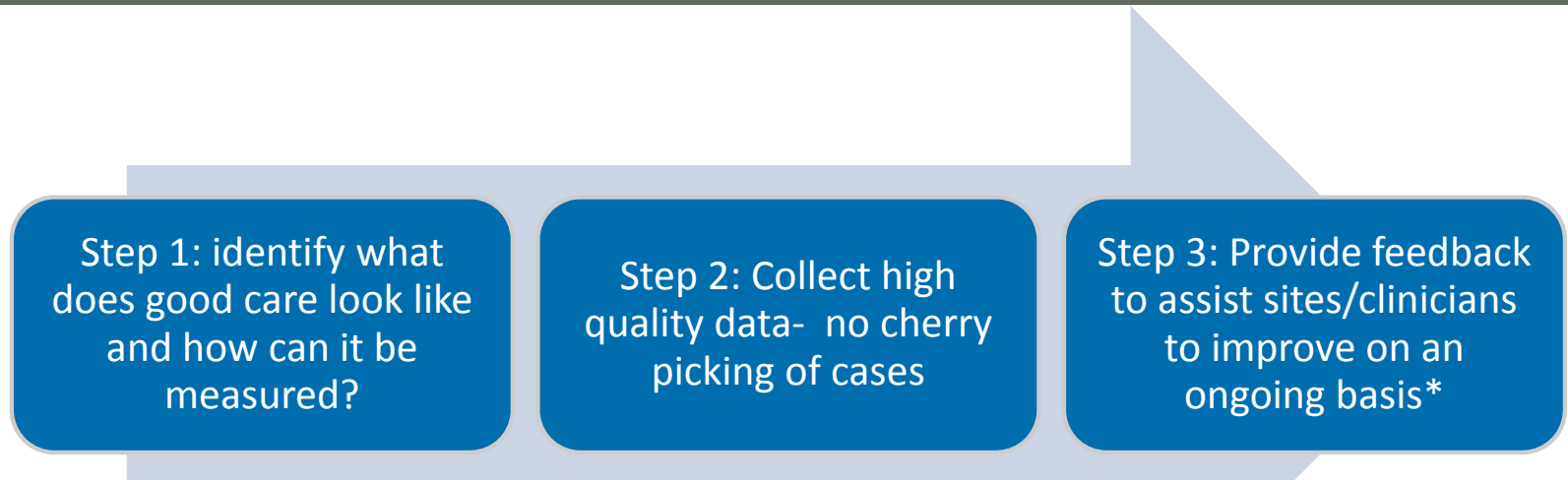
Development of minimum data set and clinical indicators



## Registry Governance and Funding



# How Registries work



\*Audit and feedback is most effective when baseline performance is low, the source of the feedback is a supervisor or colleague, it is provided more than once, it is delivered in both verbal and written formats and it includes targets<sup>4</sup>

Ivers N, Jamtvedt G, Flottorp S, et al. Audit and feedback: effects on professional practice and healthcare outcomes. The Cochrane database of systematic reviews 2012;6:CD000259. 10.1002/14651858.CD000259.pub3



# 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

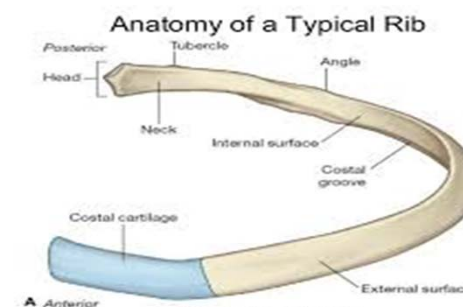


# Clinical Quality Registry Minimum Dataset



## DATA SPINE

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



DATA RIB may be time limited from interested centres typically requires funding



## Value of registries

### **Clinicians**

- Variation from norm
- Learn from best
- Early warning

### **Funders, insurers, administrators**

- Accountability, resource planning, policy development

### **Colleges**

- Credentialing

### **Researchers**

- Clinical trials
- Aetiology
- Prognosis

## Registry Outcomes- case study of prostate cancer registry



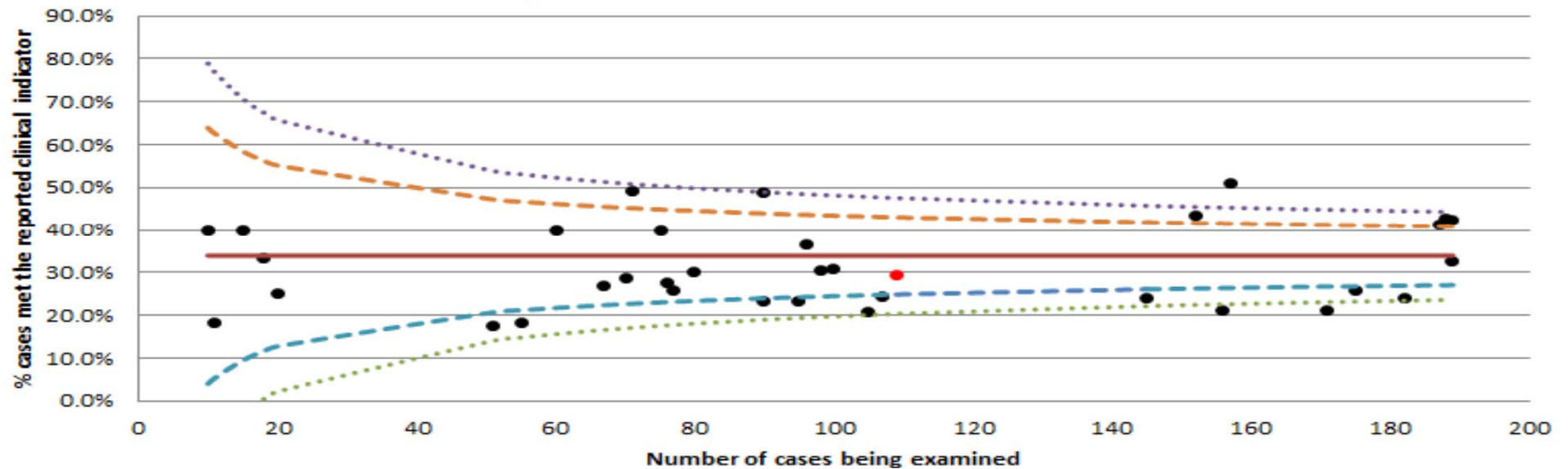
## Registries provides information on patterns of care

2008-2016

	Low risk disease (25%)	Intermediate risk (43%)	High risk (22%)	Very high risk/ mets (7%)
No active treatment	56%	15%	9%	2%
Prostatectomy	33%	59%	38%	10%
EBRT	3%	14%	29%	32%
EBRT + Prostatectomy	0.9%	4%	8%	4%
LDR	6%	6%	.	Chemo 7%
HDR+/- EBRT	.	0.4%	3%	
ADT only	0.4%	2%	13%	45%
TOTAL	100%	100%	100%	100%

## Registries monitor quality of care

Sample of Funnel Plot

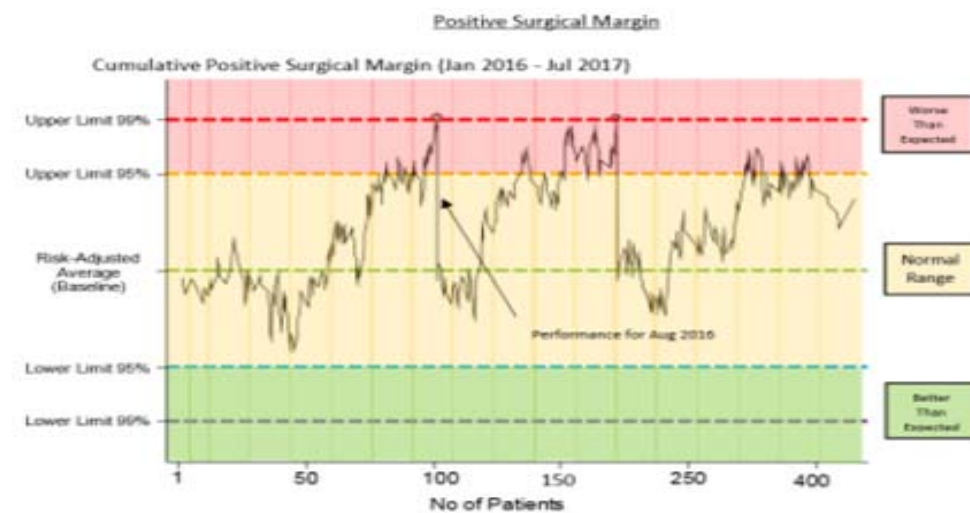
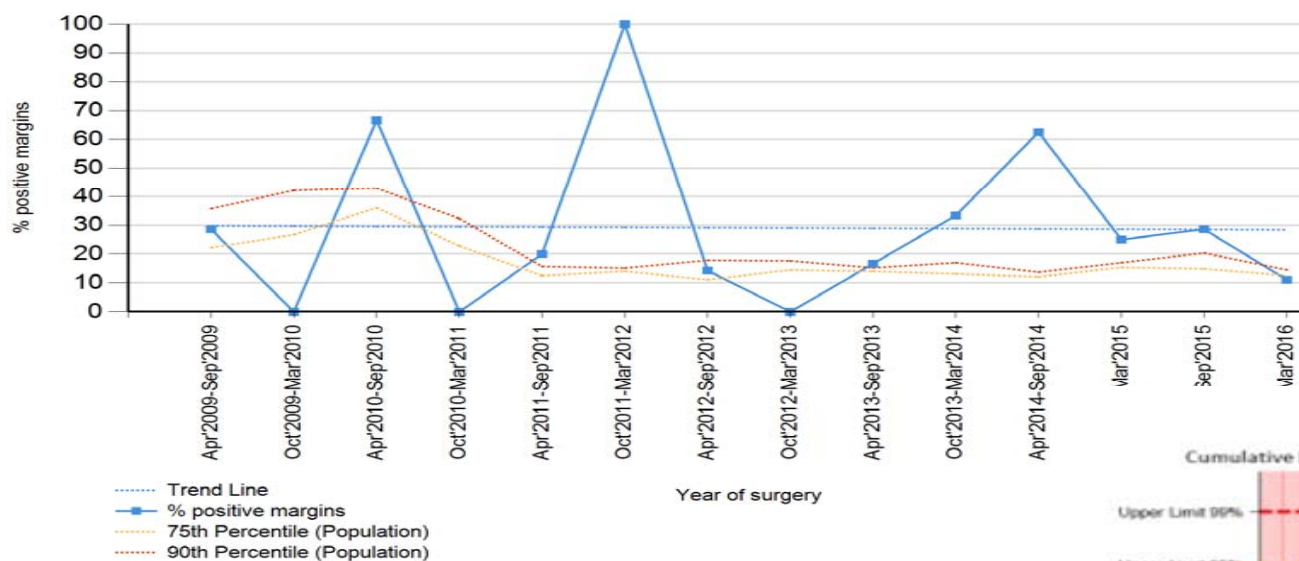


- % cases met the reported clinical indicator (by hospital/clinician)
- Pooled average % cases met the reported clinical indicator (for all hospitals/clinicians combined)
- ... Lower 99.8% Limit

- Lower 95% Limit
- Upper 95% Limit
- ... Upper 99.8% Limit



## Registries monitor quality of care



# Improving quality of care

PROSTATE  
CANCER  
OUTCOMES

REGISTRY  
AUSTRALIA &  
NEW ZEALAND



## Quality of Care Report for (10)

to 31/08/2016 (on men recruited to 31/08/2015)

Submission prepared by Associate Professor Sue Evans, Fanny Sampumo and Associate Professor Jeremy Millar on behalf of the Prostate Cancer Outcomes Registry Steering Committee

Department of Epidemiology and Preventive Medicine



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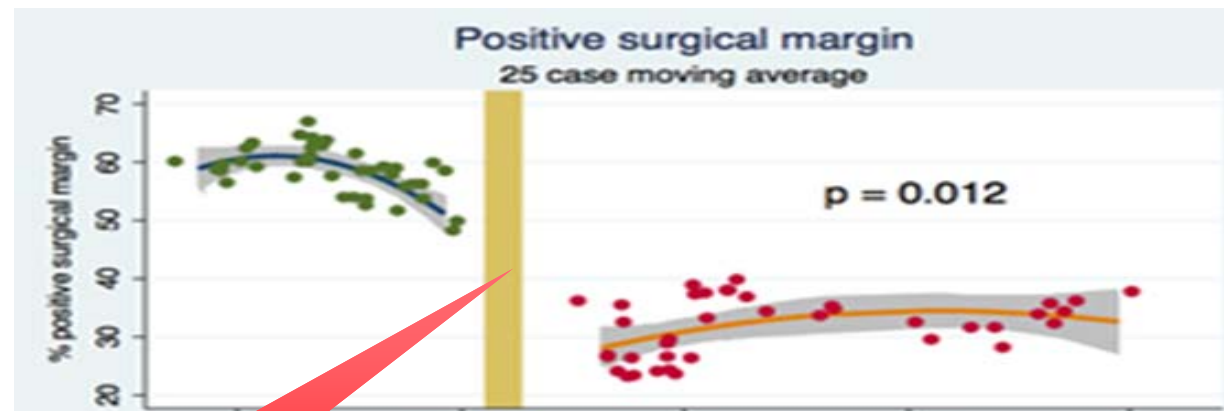
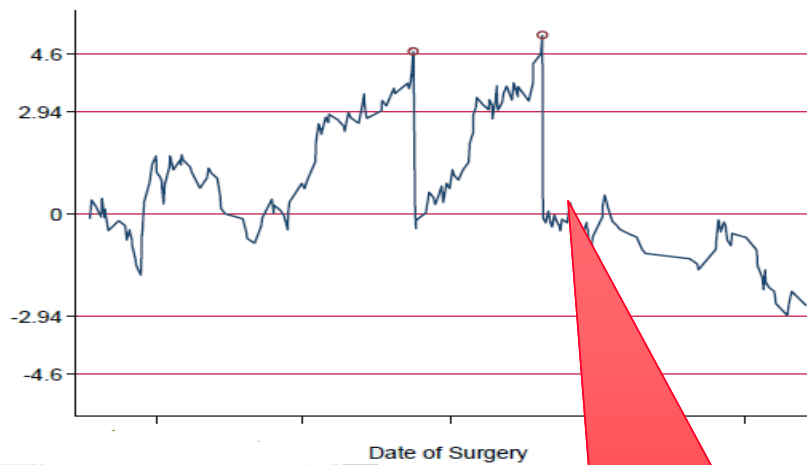
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Department of Epidemiology and Preventive Medicine



**MONASH University**  
Medicine, Nursing and Health Sciences

## Improving quality of care

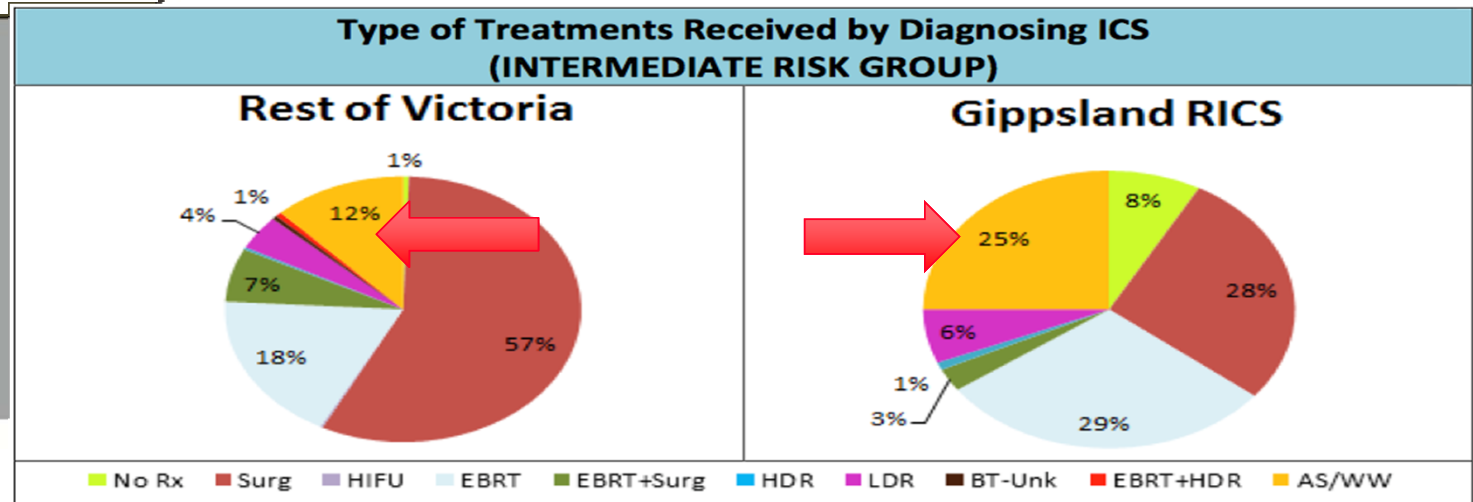
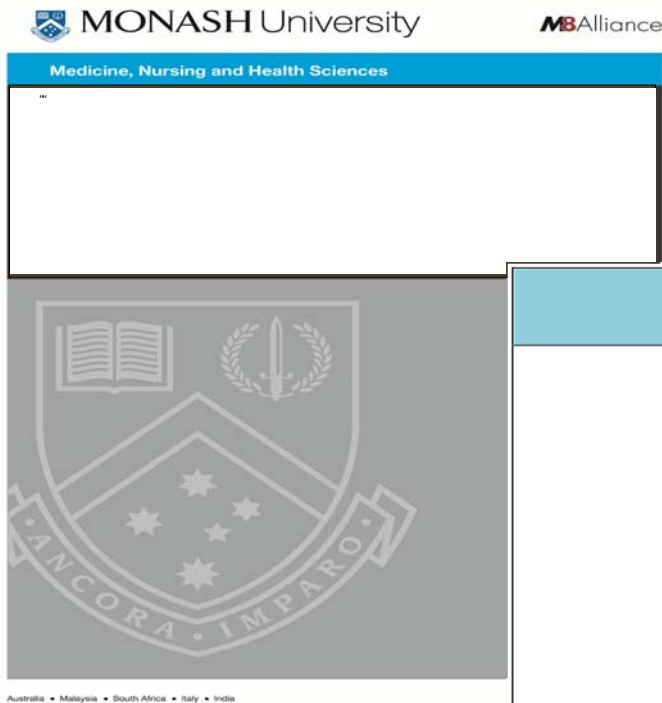


Excess positive surgical margins  
(adjusted NCCN, pT and surgery  
year)

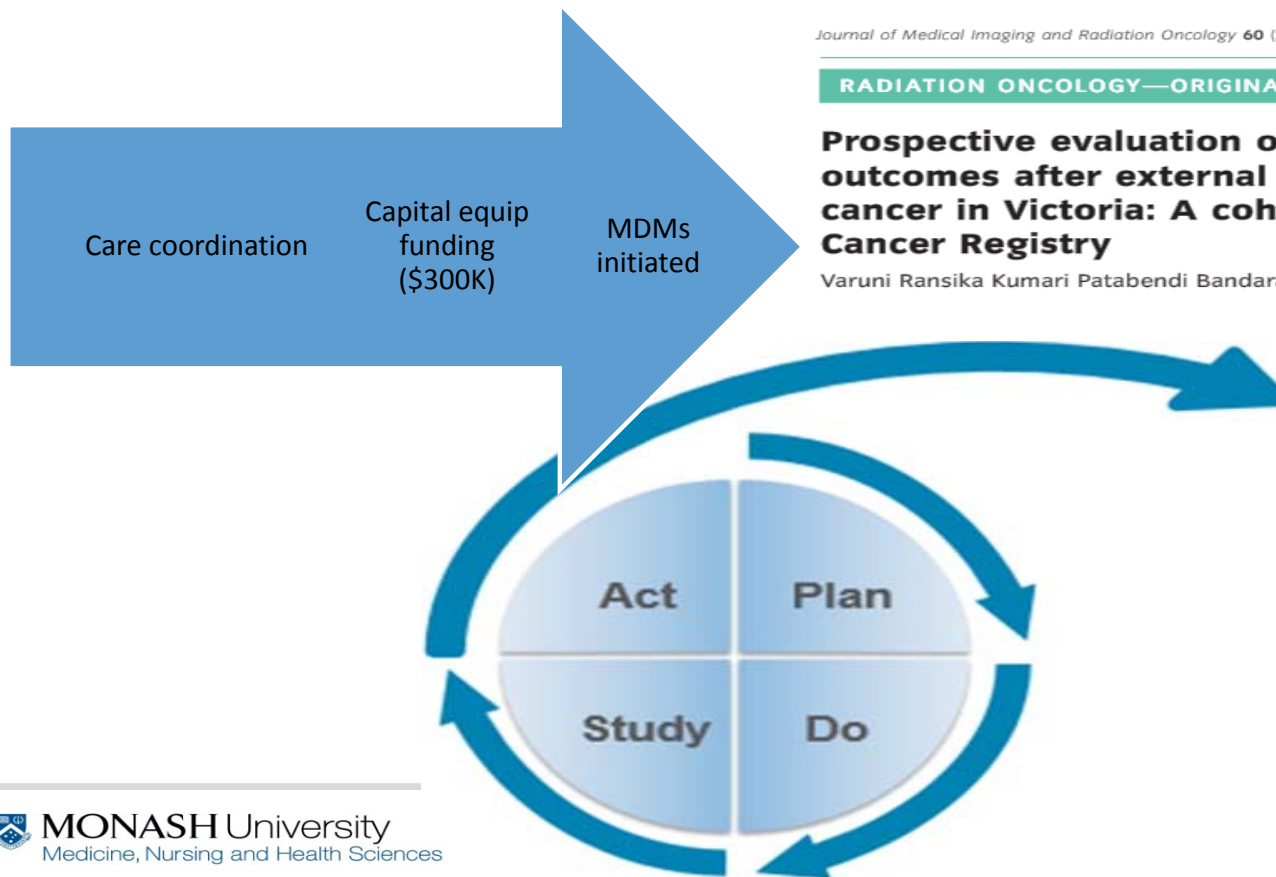


## Regional Variation - Gippsland project

- Presenting with more advanced disease at diagnosis
- More likely to present with symptomatic disease
- Having delayed (or no active) treatment
- Poorer quality of life, particularly bowel bother



## Improving quality of care



*Journal of Medical Imaging and Radiation Oncology* **60** (2016) 420–427

### RADIATION ONCOLOGY—ORIGINAL ARTICLE

#### **Prospective evaluation of patient-reported quality of life outcomes after external beam radiation treatment for prostate cancer in Victoria: A cohort study by the Victorian Prostate Cancer Registry**

Varuni Ransika Kumari Patabendi Bandarage,<sup>1</sup> Baki Billah,<sup>1</sup> Jeremy L Millar<sup>1,2</sup> and Sue Evans<sup>1</sup>

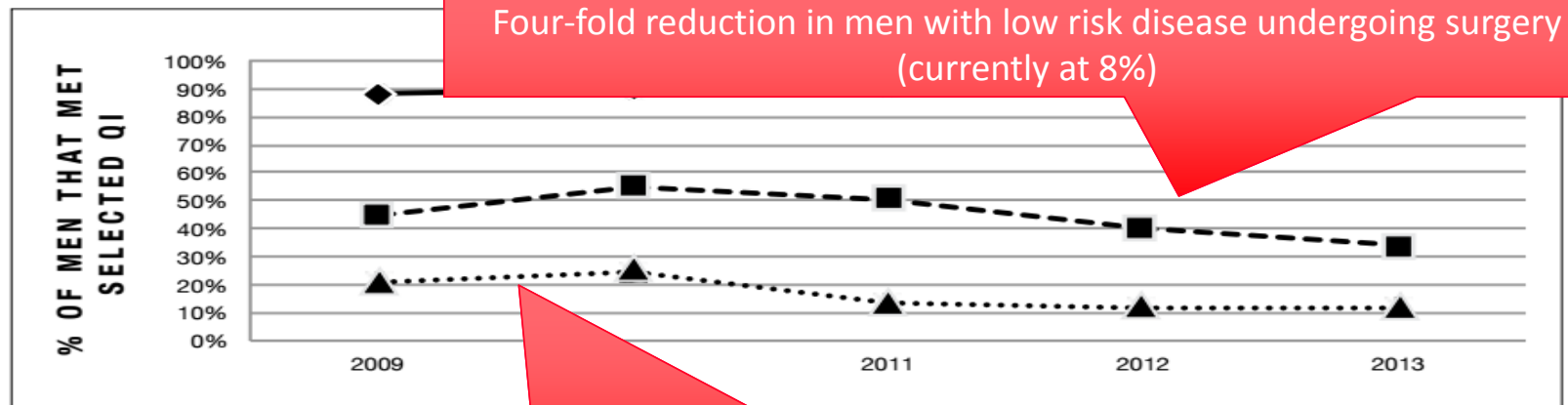


# Quality of care achievements of the Prostate Cancer Outcomes Registry–Victoria

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

---

Editorials

## Improving quality in prostate cancer

Paul S Craft

Med J Aust 2016; 204 (8): 290.

doi: 10.5694/mja16.00161

Measuring quality of cancer care enables **systematic improvement by health services and clinicians....**

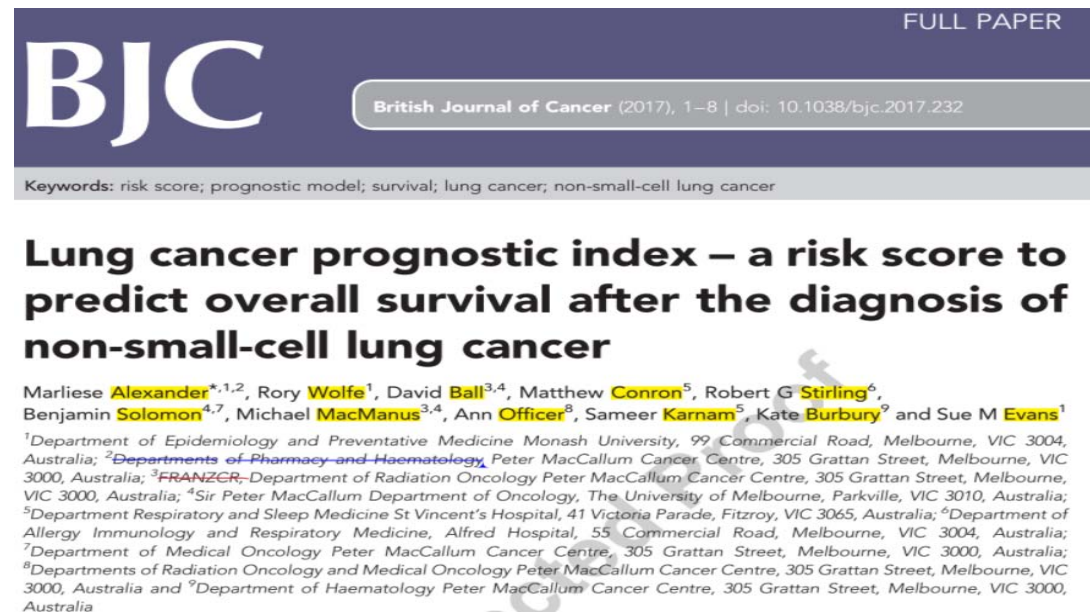
Quality indicators measured across the health system **enable facilities to benchmark their performance** against that of peers and assess change over time



Registries provide a platform for further research

## ACTIVE SURVEILLANCE- CURRENT STATE OF PLAY

**Conclusion** Management of almost three-quarters of men who appear to have curable prostate cancer suitable for AS in our community do not have follow-up investigations in a fashion consistent with defined AS protocols. The clinical consequences of this are unknown.





## Registries provide a platform for further research

### Potential to use registries for global studies

- global registry
- clinical trials



Country	Local Data Centre	Participating sites
Austria	1	1
Australia	4	12
Canada	4	7
Czech Republic	1	1
Germany	1	24
Ireland	1	6
Italy	3	3
Netherlands	1	8
New Zealand	1	9
Spain	1	22
England	2	6
USA	5	14
<b>TOTAL</b>	<b>25</b>	<b>113</b>

**The NEW ENGLAND JOURNAL of MEDICINE**

ESTABLISHED IN 1812      APRIL 14, 2016      VOL. 374 NO. 15

**A Randomized, Controlled Trial of Fusion Surgery for Lumbar Spinal Stenosis**

Peter Försth, M.D., Ph.D., Gylfi Ólafsson, M.Sc., Thomas Carlsson, M.D., Anders Frost, M.D., Ph.D., Fredrik Borgström, Ph.D., Peter Fritzell, M.D., Ph.D., Patrik Öhagen, Karl Michaëlsson, M.D., Ph.D., and Bengt Sandén, M.D., Ph.D.

**ABSTRACT**

**BACKGROUND**  
The efficacy of fusion surgery in addition to decompression surgery in patients who have lumbar spinal stenosis, with or without degenerative spondylolisthesis, has not been substantiated in controlled trials.

**METHODS**  
We randomly assigned 247 patients between 50 and 80 years of age who had lumbar spinal stenosis at one or two adjacent vertebral levels to undergo either decompression surgery plus fusion surgery (fusion group) or decompression surgery alone (decompression-alone group). Randomization was stratified according to the presence of preoperative degenerative spondylolisthesis (in 135 patients) or its absence. Outcomes were assessed with the use of patient-reported outcome measures, a 6-minute walk test, and a health economic evaluation. The primary outcome was the score on the Oswestry Disability Index (ODI), which ranges from 0 to 100, with higher scores indicating more severe disability 2 years after surgery. The primary analysis, which was a per-protocol analysis, did not include the 14 patients who did not receive the assigned treatment and the 5 who were lost to follow-up.

**RESULTS**  
There was no significant difference between the groups in the mean score on the ODI at 2 years (27 in the fusion group and 26 in the decompression-alone group,  $P=0.24$ ) or in the results of the 6-minute walk test (397 m in the fusion group and 405 m in the decompression-alone group,  $P=0.72$ ). Results were similar between patients with and those without spondylolisthesis. Among the patients who had 5 years of follow-up and were eligible for inclusion in the 5-year analysis, there were no significant differences between the groups in clinical outcomes at 5 years. The mean length of hospitalization was 7.4 days in the fusion group and 7.4 days in the decompression-alone group ( $P<0.001$ ). Operating time was longer in the fusion group, and surgical costs were higher in the fusion group than in the decompression-alone group. During a mean follow-up of 6.5 years, surgery was performed in 22% of the patients in the fusion group and in 14% of the patients in the decompression-alone group.

bar spinal stenosis, with or without degenerative spondylolisthesis plus fusion surgery did not result in better clinical outcomes at 2 years than did decompression surgery alone. (Funded by an Uppsala institutional research grant and the Swedish Spinal Stenosis Study Clinical Trials group.)

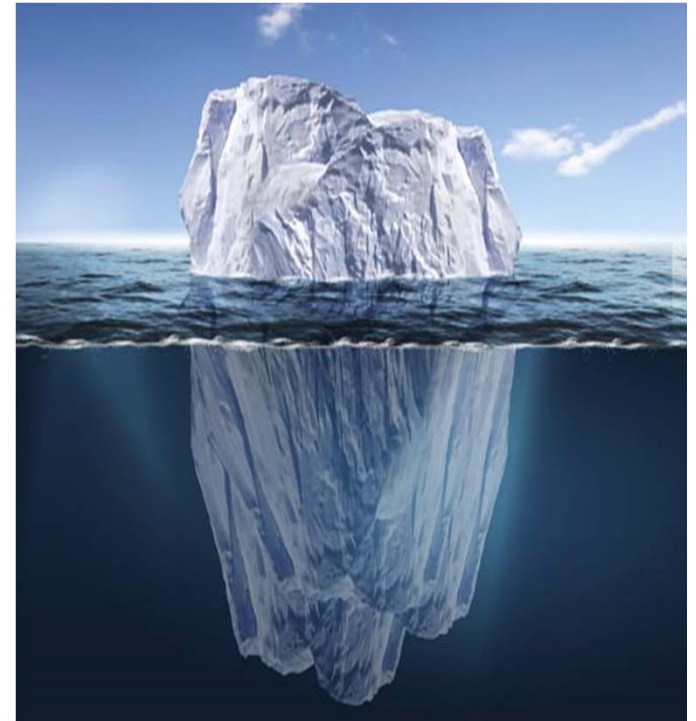
From the Department of Surgical Sciences, Division of Orthopedics (P. Försth, T.C., P. Fritzell, K.M., B.S.), and the Uppsala Clinical Research Center (P.O., K.M.), Uppsala University, Uppsala, Stockholm Spine Center (P. Försth, A.F.), the Department of Learning, Informatics, Management, and Ethics, Karolinska Institutet (G.O., F.B.), Stockholm, and Futurum—Academy for Health and Care, Neuro-orthopedic Center, Ryhov (P. Fritzell)—all in Sweden. Address reprint requests to Dr. Försth at the Department of Surgical Sciences, Uppsala University, SE-751 85 Uppsala, Sweden, or at peterforsth@surgeo.uu.se.

N Engl J Med 2016;374:1413-23.  
DOI: 10.1056/NEJMoa1511721  
Copyright © 2016 Massachusetts Medical Society.

1413

## Challenges

- **DATA BURDEN/COST**  
Currently largely voluntary participation  
Data linkage/ collection remains largely manual and difficult
- **ACCURACY**
  - Quality control
  - Risk adjustment
- **DATA SECURITY, REPORTING**
  - Real time data visualisation
- **GOVERNANCE**
  - Legal, ethical approvals
  - Reporting to whom?
- **ENGAGEMENT**
  - Funders
  - Clinicians
  - Researchers



# Thank you

[sue.evans@monash.edu](mailto:sue.evans@monash.edu)



by **Dr Richard Khor**

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RADIATION ONCOLOGIST,  
MEDICAL LEAD - RESEARCH DATA  
WAREHOUSE + ONCOLOGY  
INFORMATION SYSTEMS ROLLOUT  
AUSTIN HEALTH

# CASE STUDY

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Implementation of a data  
repository in research  
and practice in Victoria

# Implementing a research data warehouse: Challenges

Dr Richard Khor

Radiation Oncologist | Medical lead Research Data Warehouse

21/7/17



**Olivia  
Newton-John**  
Cancer Wellness & Research Centre



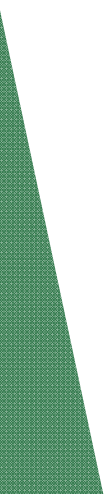
**Austin** Health



# Acknowledgements

- ▶ David Taylor and Rinaldo Bellomo (Austin Health)
- ▶ Vivek Krishnan (MKM Health)
- ▶ Ray Webster and Peter Carty (Business Intelligence Unit)
- ▶ Adrian Lio and James Burns (Clinical Intelligence Unit)
- ▶ Shane Lowe and the rest of the Data Warehouse project team
- ▶ I have no conflicts of interest to declare

Our research data warehouse has  
just launched



# Our research data warehouse has just launched

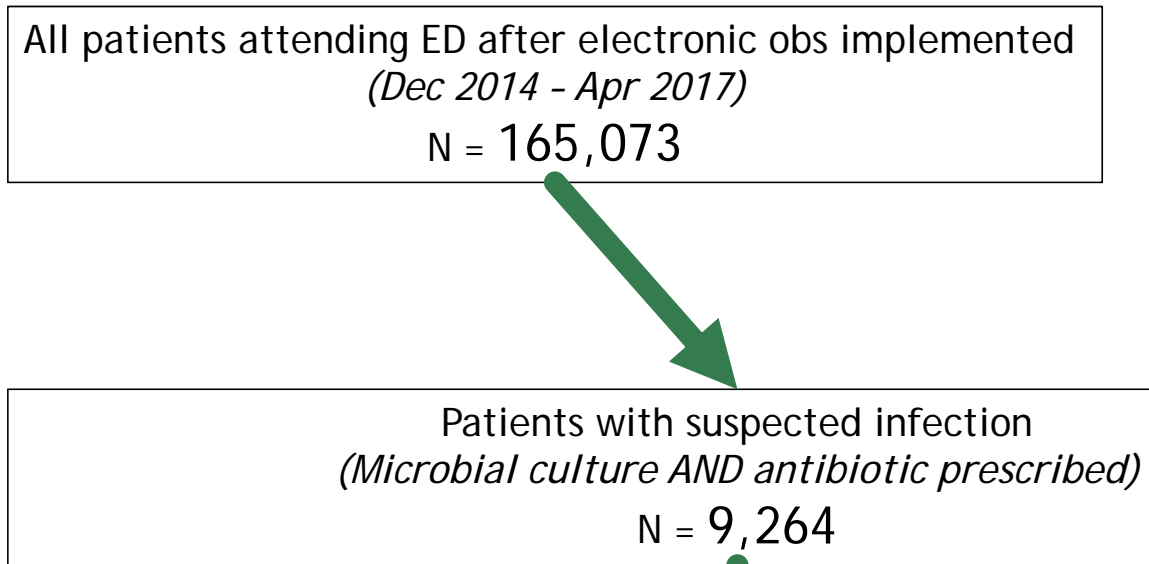
- ▶ Exemplar study: qSOFA sepsis prediction algorithm
- ▶ What is it?
- ▶ Challenges along the way



# Our pilot data: qSOFA validation project

- ▶ Quick Sepsis Organ Failure Assessment score
- ▶ In a patient with suspected infection
  - ▶ Systolic BP <100mmHg
  - ▶ Altered mental state (GCS)
  - ▶ Respiratory rate 22/min or more
- ▶ Predicts for increased mortality (~10% if 2 or more +ve)
- ▶ Recommended by Third International Sepsis Consensus Definitions Task Force (*doi:10.1001/jama.2016.0287*)

# Methods



All patients attending ED after electronic obs implemented  
(Dec 2014 - Apr 2017)

Attendances

N = 165,073

SPEED

SCALE

Patients with suspected infection  
(Microbial culture AND antibiotic prescribed)

Med orders/admin

N = 9,264

Pathology orders

COVERAGE

GRANULARITY

qSOFA positive patients  
(Two or more qSOFA criteria recorded in ED)

Observations

N = 1,560



# Preliminary Results

- ▶ Of the 1,560 qSOFA positive patients:
  - ▶ More qSOFA positive patient died or had ICU stay >3d
    - ▶ 6.6% vs 2.1% ( $p < 0.001$ )
- ▶ qSOFA positivity was associated with poorer outcomes
- ▶ Low absolute event rate limits its predictive usefulness
- ▶ 3 x 1 hour meetings  
(The researcher knew exactly what they wanted)

"Get some data for me"

**Consultant model**

"I want to try to access the data on my own with backup"

**Guided model**

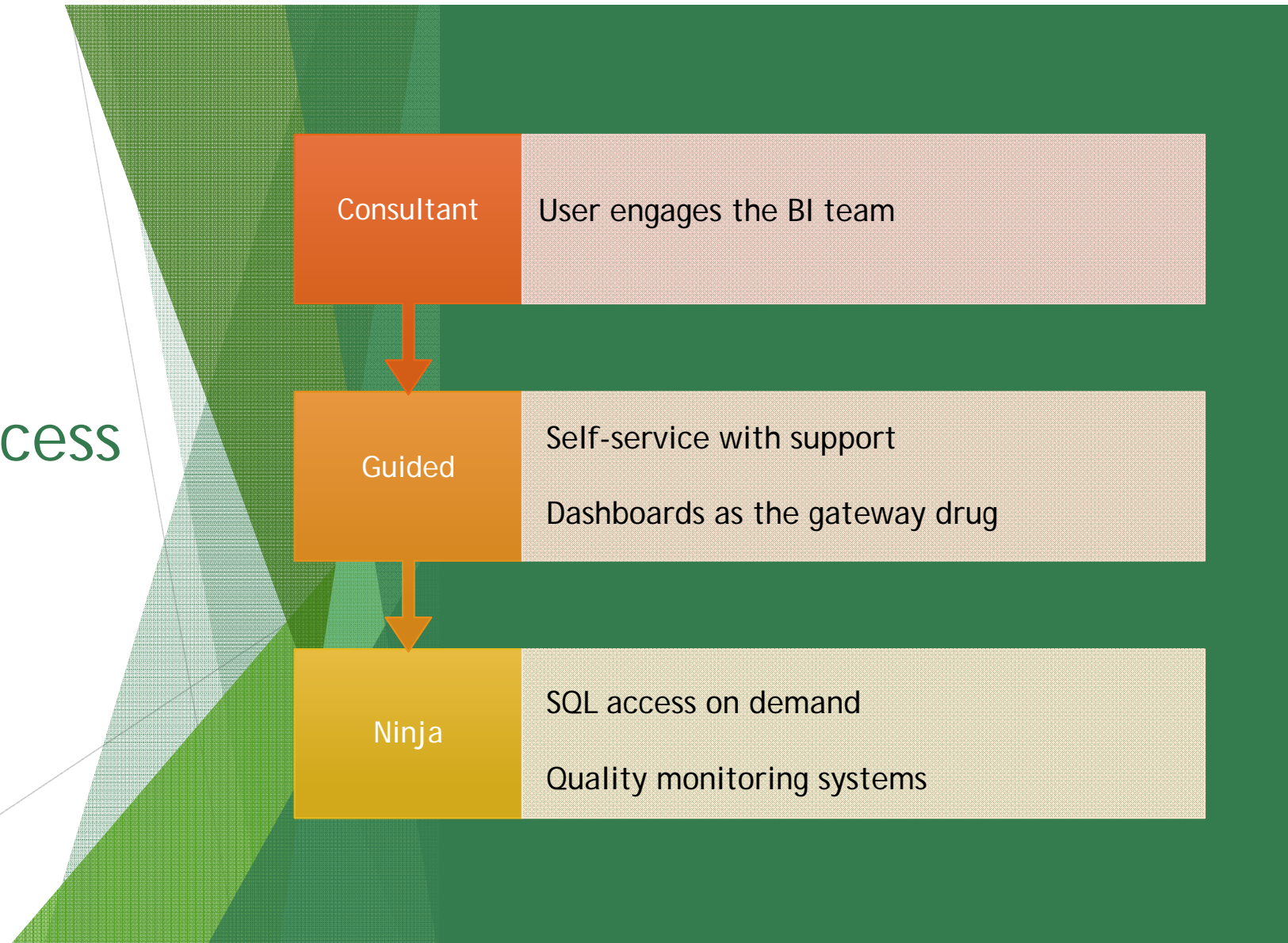
"I am a complete data ninja"

**Self-service model**

*"Can you please agree on what research you want to do?"*

Who is the target market?

## Tiered access model







A gateway to our data...



# What is in the data warehouse?

## CERNER

- Clinical notes
  - Discharge summaries
  - ED notes
- Observations
- Medication orders/admin
- Radiology orders/results
- Any other structured data
- (Fluid balance, etc)

## MERLIN

- Outpatient dispensing
- Inpatient dispensing\*

## TRAK

- Patient demographics
- Episode dates (clinic/ward)
- Coded discharge summaries
- Billing



# What is the data warehouse

## CERNER

- Clinical notes
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## MERLIN

- Outpatient dispensing
  - Inpatient dispensing
- PATIENT AND EPISODE LINK



## TRAK

- Patient demographics
- Episode dates (clinic/ward)
- Coded discharge summaries
- Billing

# Issues we have faced

TRAINING AND AWARENESS

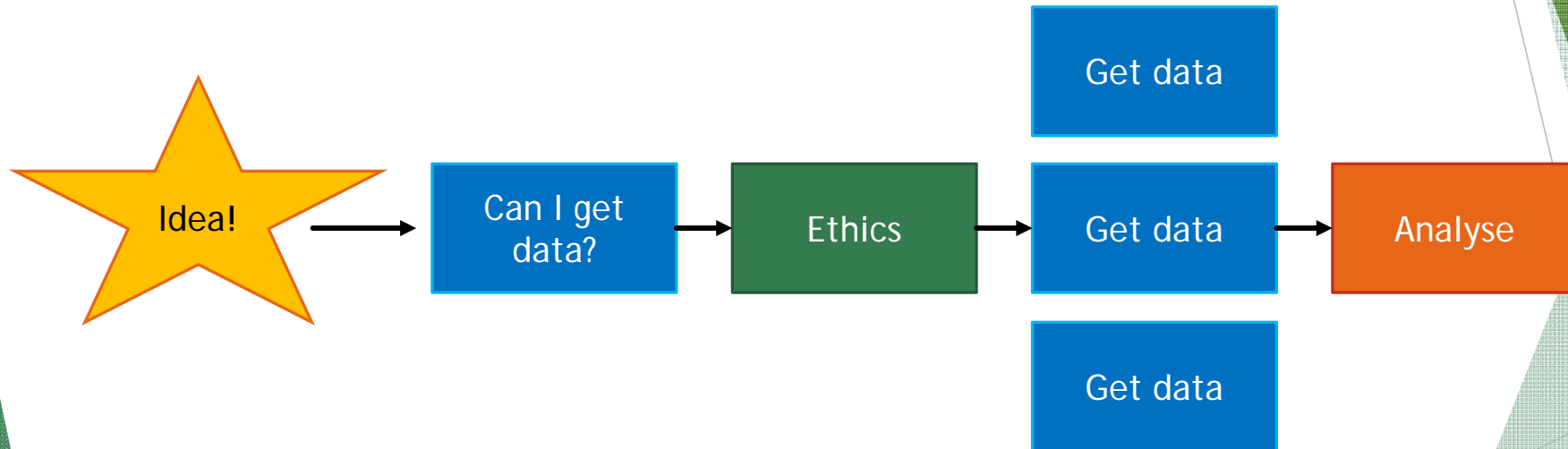
DATA SECURITY

ETHICAL / LEGAL GOVERNANCE / CONSUMER

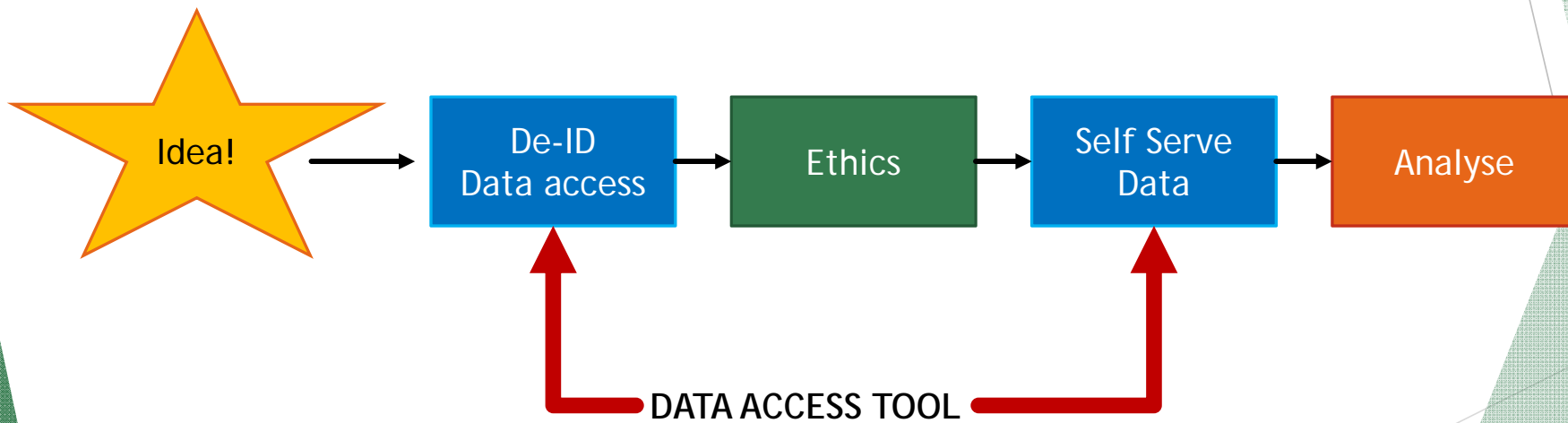


PATIENT AND EPISODE LINK

## Old model



# Data warehouse model





# Security and privacy risk

- ▶ Clinician-researchers play a critical role in new model
- ▶ Security is a joint responsibility
  - ▶ IT provides secure storage and account validation
  - ▶ User can competently retrieve the data\*\*
  - ▶ User understands their obligations/responsibilities

*\*\* New group of users we have created*

# Challenges

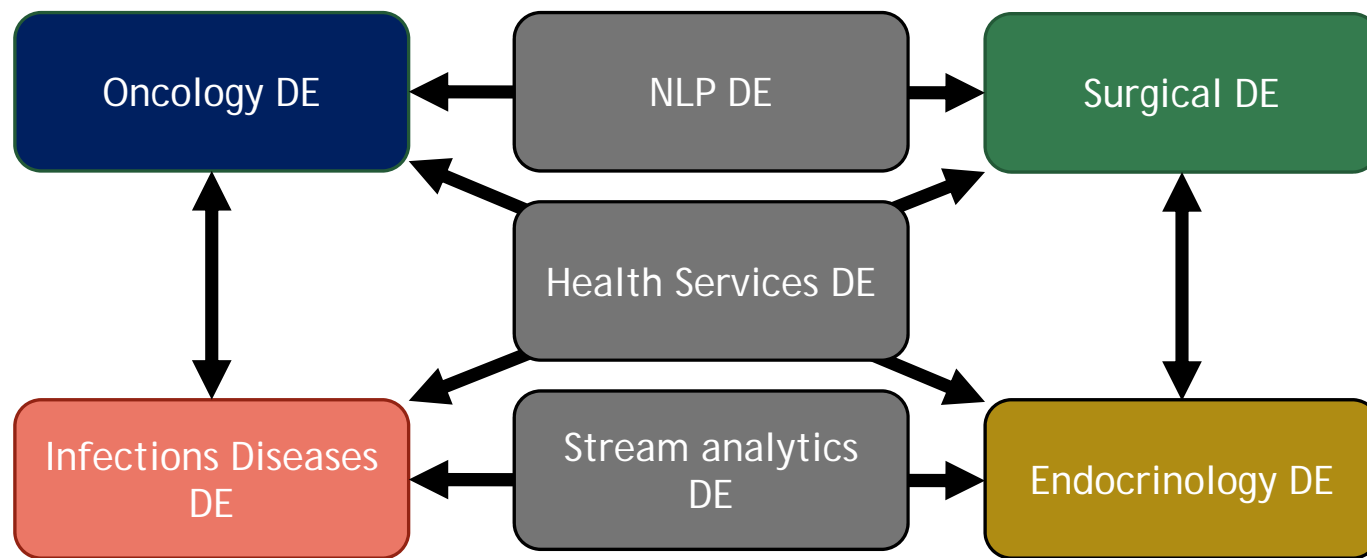
- ▶ What do you do if your super users cant use the data warehouse
- ▶ Overestimate of core competency
  - ▶ How data is coded
  - ▶ How data is linked
- ▶ Underestimate importance of User Experience/UI
  - ▶ Most user-friendly is Microsoft Power BI Desktop (Citrix)

# People are the answer?

- ▶ Domain Experts (DE)
  - ▶ Know what questions are relevant
  - ▶ Know what data events are clinically relevant
  - ▶ Know how the data are collected
  - ▶ May have an existing research base to bootstrap usage
  - ▶ May see value in mentoring younger colleagues
  - ▶ May be able to prioritise further developments

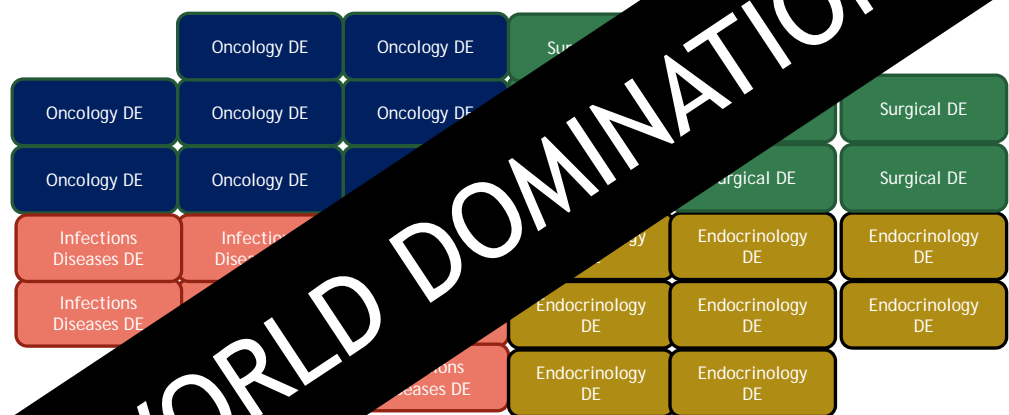


## Mentorship model





# Mentorship model



supported by robust credentialing and governance

# Next steps for the warehouse

*Continue to digitise hospital processes*

*e.g. blood bank*

*Increase number of data stores in warehouse*

*e.g. legacy scanned record and outpatient EMR*

*Sustainability - build a culture of health data centric research*

*Secure recurrent funding*

*Flattened datasets*



We need future doctors to be  
informaticists AND clinicians





# Summary

- ▶ The potential of a fully integrated RDW is clear
- ▶ Paradigm shifts in access model are required to realise full RDW potential
- ▶ The initial strategy for user engagement will need to evolve over time
- ▶ Any time data is exposed to researchers there is risk



by **Ms Shoni Philpot**

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**MANAGER**, QLD CANCER CONTROL  
ANALYSIS TEAM (QCCAT) + **HEALTH  
RESEARCH FELLOW**, QLD HEALTH

# CASE STUDY

---

QOOL - a multisided  
platform for sharing  
cancer information in  
Queensland

QOOL™

*- a multisided platform for sharing cancer  
information in Queensland*

Shoni Philpot – Manager  
QLD Cancer Control Analysis Team

21<sup>st</sup> July 2017

# The Partnership

## Qld Cancer Control Safety and Quality Partnership (The Partnership)

Was established in 2004

(under legislation in the Hospital and Health Boards Act 2011)

Is a Gazetted Quality Assurance Committee (QAC)

Promotes and supports clinician-led service improvement

(by providing tools that allow them to routinely share and compare cancer treatment and outcomes data)

Is supported by the Queensland Cancer Control Analysis Team (QCCAT)

(which, as part of The Partnership, is allowed to access identifiable information to better understand the safety and quality of the cancer care services delivered in Queensland)

Is Chaired by Professor David Theile AO

**\*Strict Privacy and Confidentiality provisions**

(cannot identify individual/facility data to another facility without its permission)

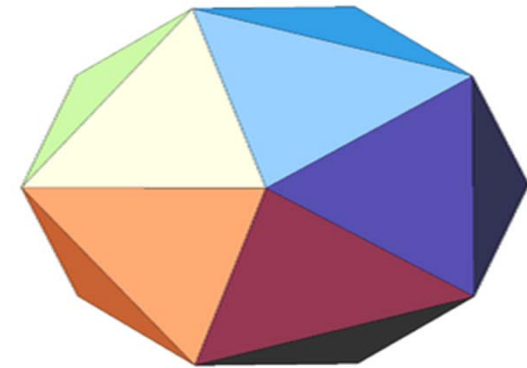
# Clinician led service improvement

Sub - Committee	Chair
Upper GI	Mark Smithers
Lung	Morgan Windsor
Breast	Colin Furnival
Colorectal	David Theile AO
Liver and Pancreas	Jon Fawcett/Nick O'Rourke
Youth cancer	-
Urology	Geoff Coughlin
Radiotherapy	Bryan Burmeister
Chemotherapy	Euan Walpole



# Multiple approaches to MSP

- Create a multisided platform (MSP) to facilitate interaction between parties
- Utilise existing electronic sources of data – leave the silos standing
- Bring together custodians, clinicians and health services around MSP
- Web application for collection of ‘missing’ clinical data eg stage - QOOL™
- Combined activities with ‘best practice’ multidisciplinary care
- MDM support – MDM coordinators
- Deliver clinically relevant information to clinicians & clinical teams
- Develop tools for analysis, reporting and feedback of cancer data:
  - QOOL™ - Analysis (MDT data – updated daily)
  - QOOL™ - OASys (Population incidence, mortality, survival 1982 – 2014)
  - QOOL™ - Projects

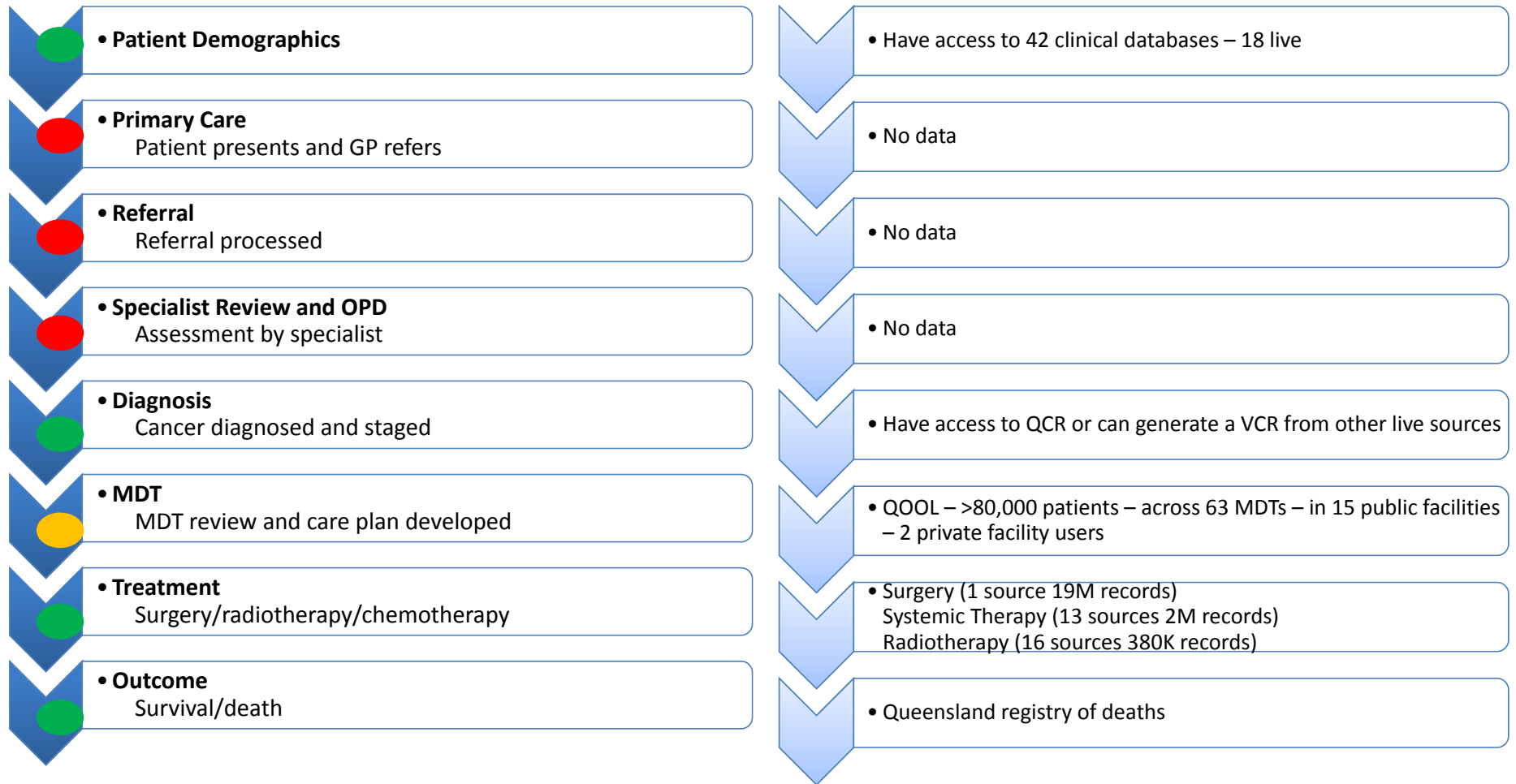


# Where does the data come from?

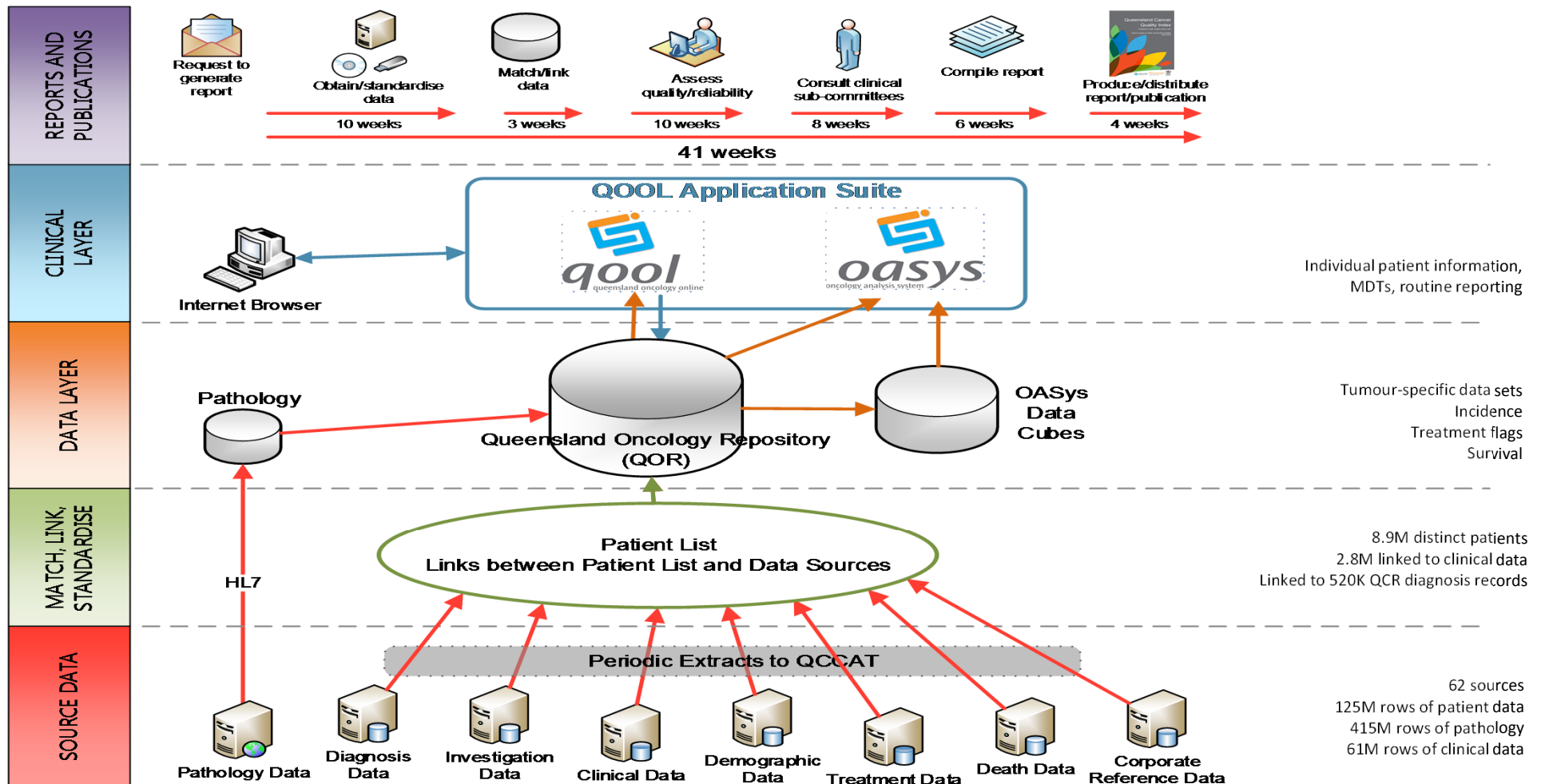
**Over 60 sources of data from the public and private sector across Queensland**

Demographic  
Diagnosis  
Staging  
QOOL  
Breastscreen  
Other clinical  
Surgery  
Chemotherapy  
Radiotherapy  
Pathology  
Death

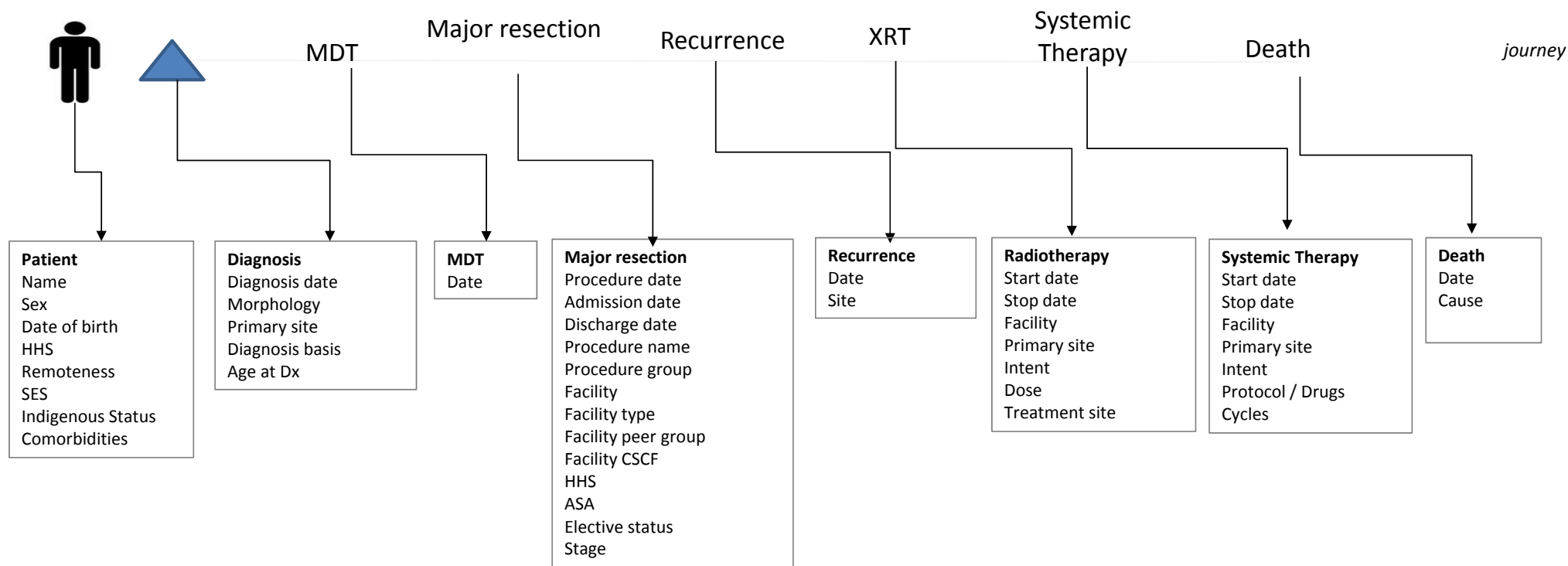
# Tracking the Patient's journey



# Multisided platform



## What does the data look like now?



# QOOL™

- Purpose built web-based tool to support multidisciplinary cancer care and data collection
- System agnostic drawing data from disparate sources
- Provides real time data from QOR and updates patients records as they receive health care (public and private facilities)
- Supports MDT and care co-ordination processes –
  - Online referrals, meeting agendas, letters/reporting,
  - Purpose built datasets
  - Facilitates information sharing – between teams and hospitals

CNS Profile

Pathology Report - Mozilla Firefox

<https://qccat.health.qld.gov.au/QOOL/Presentationlayer/ProtectedPages/PathologyResultPopUp?PresentationID=1163049&PathologyReportID=1163049>

UR No: RBWH 3096064

Lab No: 732073798

Source: Auslab

Patient: [REDACTED]

Doctor: [REDACTED]

Histo Biopsy

DOB: 03/02/1955

Collection Date: 12/12/2016

Sex: M

Print 8pt

Histopathology Report

RB16P49055

UR No: RB3096064

HISTORY

Tests requested: Histopathology.

Clinical notes: Re-do craniotomy for GBM.

MACROSCOPIC

One specimen is received labelled 'Right frontal tumour', and comprises numerous irregular fragments of tan soft tissue measuring 38 x 25 x 15mm in aggregate. On serial sectioning the tissue has a tan to grey appearance with a solid but friable cut surface. [1A-1C] largest pieces serially sectioned; [1D] remnant fragment wrapped and blocked in toto. Tissue blocked in toto. [Dr ]

MICROSCOPIC

Right frontal tumour: The sections show features of a glioblastoma with hypercellularity, nuclear atypia, frequent mitotic figures, endothelial vascular proliferation and necrosis including palisaded tumour necrosis.

SUMMARY

Right frontal tumour: Glioblastoma (WHO grade IV).

Pathologist: Dr [REDACTED]

Pathology Queensland

Royal Brisbane & Women's Hospital

Telephone: (07) 3646 0150

Date: 14 December 2016

Diagnosis CNS - Central Nervous System Grade

New

Site	Laterality	Result	Date	Notes
Frontal lobe	Right	+	20/01/2016	

Add New

New

New

Reports

Collection Date	Source	View	Selected
12/12/2016	Auslab		<input type="checkbox"/>
29/01/2016	Auslab		<input type="checkbox"/>
20/01/2016	Auslab		<input type="checkbox"/>
20/01/2016	Auslab		<input type="checkbox"/>

Genetics

+

-

NR

tion

ns

Validation) can not be based on these results alone and must only occur after review of the complete Pathology Results

Investigations – public and private labs

Diagnosis			Metastatic Sites at Diagnosis	
Diagnosis Basis*		Diagnosis Date		
Histology of Primary Tumour		20/01/2016	<input type="checkbox"/> Intraventricular <input type="checkbox"/> Subarachnoid space	
<a href="#">Add New</a>			<input type="checkbox"/> Other	
*QCR Basis of Diagnosis Codes 2008				
Primary Site			Recommended Treatment Plan	
<input checked="" type="radio"/> Central Nervous System		Frontal lobe	<b>Sequence</b> Surgery Radiotherapy   	
<input type="radio"/> Metastases to CNS <input type="radio"/> Unknown Primary <input type="radio"/> Benign Tumours <input type="radio"/> Other <input type="radio"/> Not determined			<b>Intent</b> <input type="radio"/> Curative <input checked="" type="radio"/> Extend Survival <input type="radio"/> Treat Symptoms <input type="radio"/> Not Determined	
Transformation			Treatment Refusal	
Transformed <input type="radio"/> Yes <input type="radio"/> No <input checked="" type="radio"/> NR Date: <input type="text"/> (dd/mm/yyyy) WHO Classification / Morphology Search morphology code or description			<a href="#">Add New</a> Comment	
WHO / Histopathological Grade			<b>Clinical Notes</b> NeuroOnc MDT 14/01/2016: 1/52 headache and confusion. Pronator drift. MRI & surgery. NeuroOnc MDT 21/01/2016: Large frontal lesion. Offer VERTU. Discuss next week with histo. Offer VERTU. NeuroOnc MDT 28/01/2016: NeuroOncology MDT RBWH 15/12/2016: Dx Jan right frontal GBM>screened VERTU> XRT (no temozolomide as pneumonia, and VERTU not methylated) on dendritic CMV trial private sector ( ) Plan – Dr Lwin to	
Synchronous Primary			Action Items	
<input type="radio"/> Yes <input type="checkbox"/> Unilateral <input type="checkbox"/> Bilateral <input type="radio"/> No <input checked="" type="radio"/> NR			<a href="#">Add New</a>	
Laterality	Tumour size			
<input type="radio"/> Right <input type="radio"/> Left <input type="radio"/> Bilateral <input type="radio"/> Midline <input checked="" type="radio"/> NR	L <input type="text"/> x W <input type="text"/> x H <input type="text"/> mm (max. diameter on imaging) <input type="radio"/> Cannot be assessed <input checked="" type="radio"/> NR			
WHO Classification/Morphology				

Diagnosis, staging & MDT decisions




CNS Profile

Name		Diagnosis	CNS - Central Nervous System
DOB	3/02/1955 (Age: 62)	Grade	
Sex	Male		

Diagnosis CNS - Central Nervous System  
Grade

Treatment Summary	
1	1
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88	88
89	89
90	90
91	91
92	92
93	93
94	94
95	95
96	96
97	97
98	98
99	99
100	100

Treatment Type	Facility	Date	Treatment Description	Source	Display 	
Surgery	The Sunshine Coast Private Hospital	07/10/2004	Ethmoidectomy, bilateral	Admitted Patient Data	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
Surgery	Caloundra Private Clinic	22/10/2004	Excision of lesion of skin and subcutaneous tissue of nose	Admitted Patient Data	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
Surgery	Caloundra Private Clinic	12/06/2012	Fibreoptic colonoscopy to caecum, with polypectomy	Admitted Patient Data	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
Surgery	Royal Brisbane & Women's Hospital	20/01/2016 20/01/2016	Intracranial stereotactic localisation Removal of lesion of cerebrum	Admitted Patient Data	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
Radiotherapy	Royal Brisbane & Women's Hospital	17/02/2016 - 01/04/2016	Dose: 60 Gy, Fractions: 30	ROIS	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
Surgery	Royal Brisbane & Women's Hospital	12/12/2016 12/12/2016	Intracranial stereotactic localisation Removal of lesion of cerebrum	Admitted Patient Data	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
Systemic Therapy	Royal Brisbane & Women's Hospital	04/05/2017 - 04/05/2017	Drugs: Temozolomide	iPharmacy System	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>

Add new Surgery Systemic Therapy Radiotherapy

Surgery

Systemic Therapy

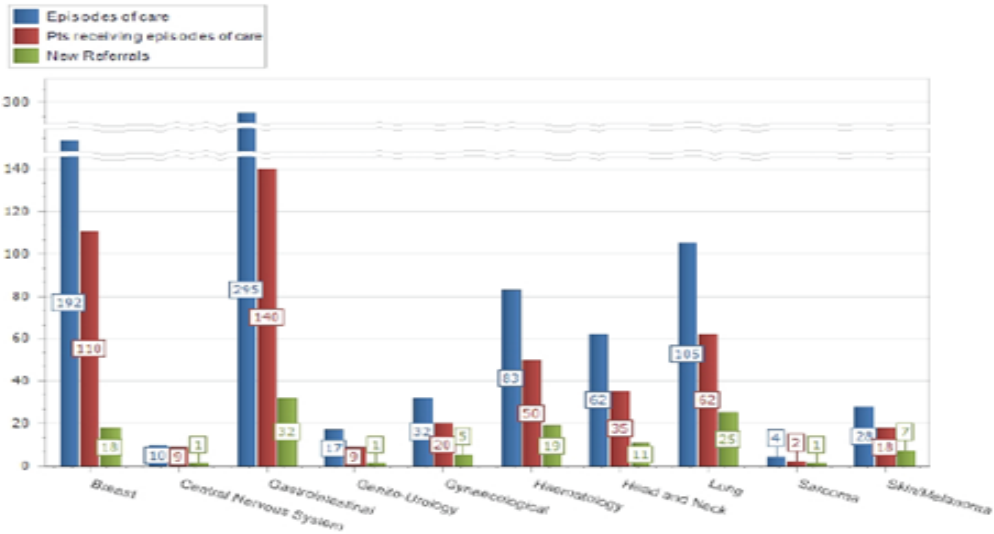
Radiotherapy

Treatment integrated from source systems – public and private facilities



## Facility Care Coordination Summary

Reporting Period: 01/01/2017 - 31/01/2017



Service Type	New Referrals	Episodes of care	Pts receiving episodes of care	Discharged	Total active patients
Breast	18	192	110	29	76
Central Nervous System	1	10	9	3	1
Gastrointestinal	32	295	140	29	109
Genito-Urology	1	17	9	0	18
Gynaecological	5	32	20	0	13
Haematology	19	83	50	10	34
Head and Neck	11	62	35	9	28
Lung	25	105	62	22	47
Sarcoma	1	4	2	1	1
Skin/Melanoma	7	28	18	1	0
<b>Total</b>	<b>120</b>	<b>828</b>	<b>455</b>	<b>104</b>	<b>327</b>

Routine Reporting – Activity

# QOOL™ - Analysis (OASys)

**Queensland Government**  
Oncology Analysis System

**Cancers in Queensland**  
Projections  
Statistics  
Incidence  
Mortality  
Survival Curve  
Relative Survival  
Prevalence  
Annual Percent Change  
Hospital Health Services  
Childhood & AYA  
More Information  
My Account  
Links  
Citation  
Logout

**oasys**  
oncology analysis system

**Welcome to OASys**, the most comprehensive on-line source of Queensland cancer statistics. OASys provides Queensland-specific cancer data - from age-standardised rates to prevalence and survival - most of which can be stratified by demographics and Hospital and Health Service.

**Where to begin?** Use the menu on the left to navigate through OASys. A Quick Tutorial and a [Glossary of Terms](#) is available, click on the links.

**With great data comes great responsibility.** The use and reporting of OASys data is governed by the OASys Data Access and Use Agreement. Logging into this website, indicates that you agree to the terms and conditions of this agreement.

OASys is an initiative of the Queensland Cancer Control Safety and Quality Partnership aimed at supporting safe quality cancer care. **Tell us what you think.** Send us your comments and suggestions by emailing [qccat@health.qld.gov.au](mailto:qccat@health.qld.gov.au).

**Incidence**

Prostate	3,876
Melanoma	2,976
Colorectal	2,869
Breast	2,784
Haematological	2,179
Lung	2,048
Urological	1,184
Gynaecological	862
Other Invasive Cancers	777

Web based analytics

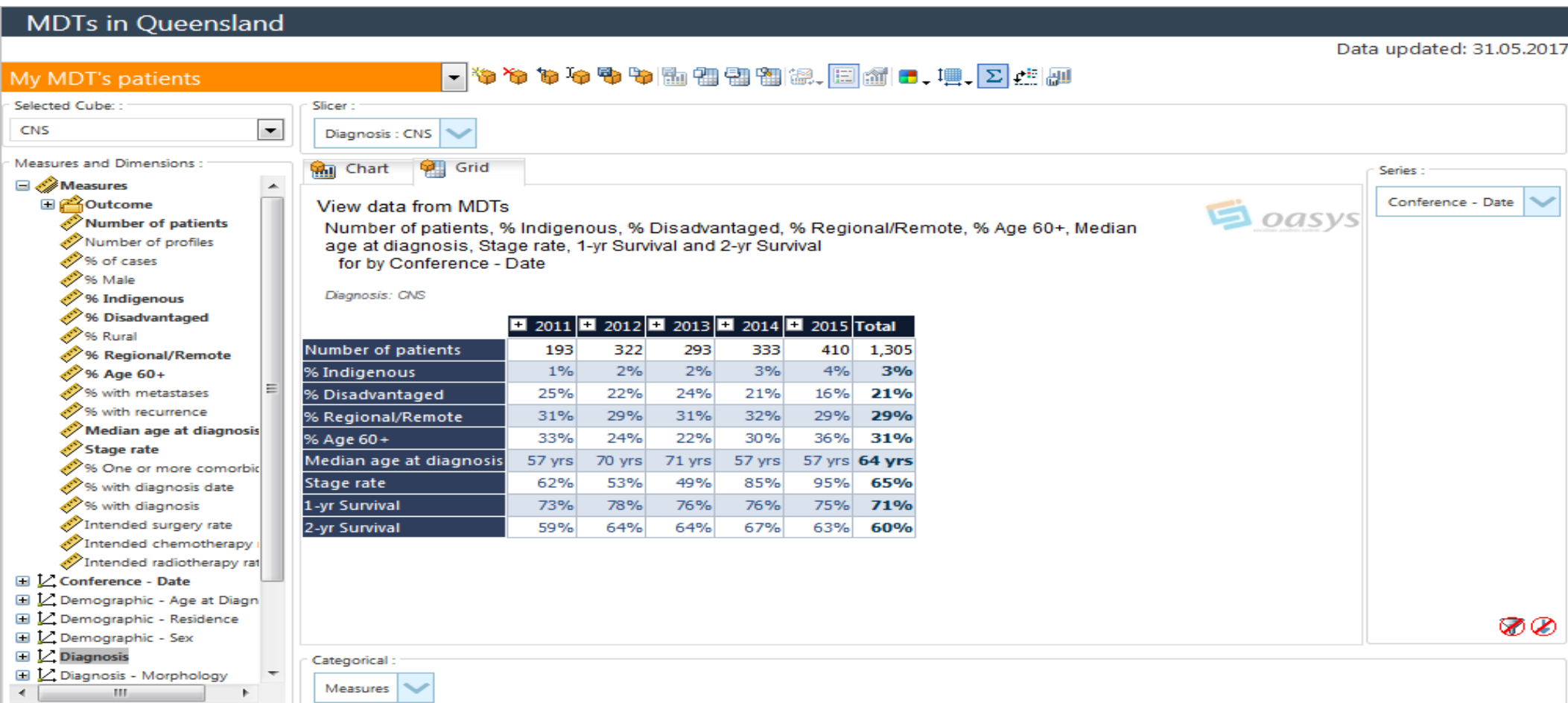
Data available at a statewide and Hospital and Health Service level

Compare demographic and diagnosis groups - age, sex, primary site, morphology, SES and more.....

Easy 'drag and drop' functionality

MDT module – updated daily

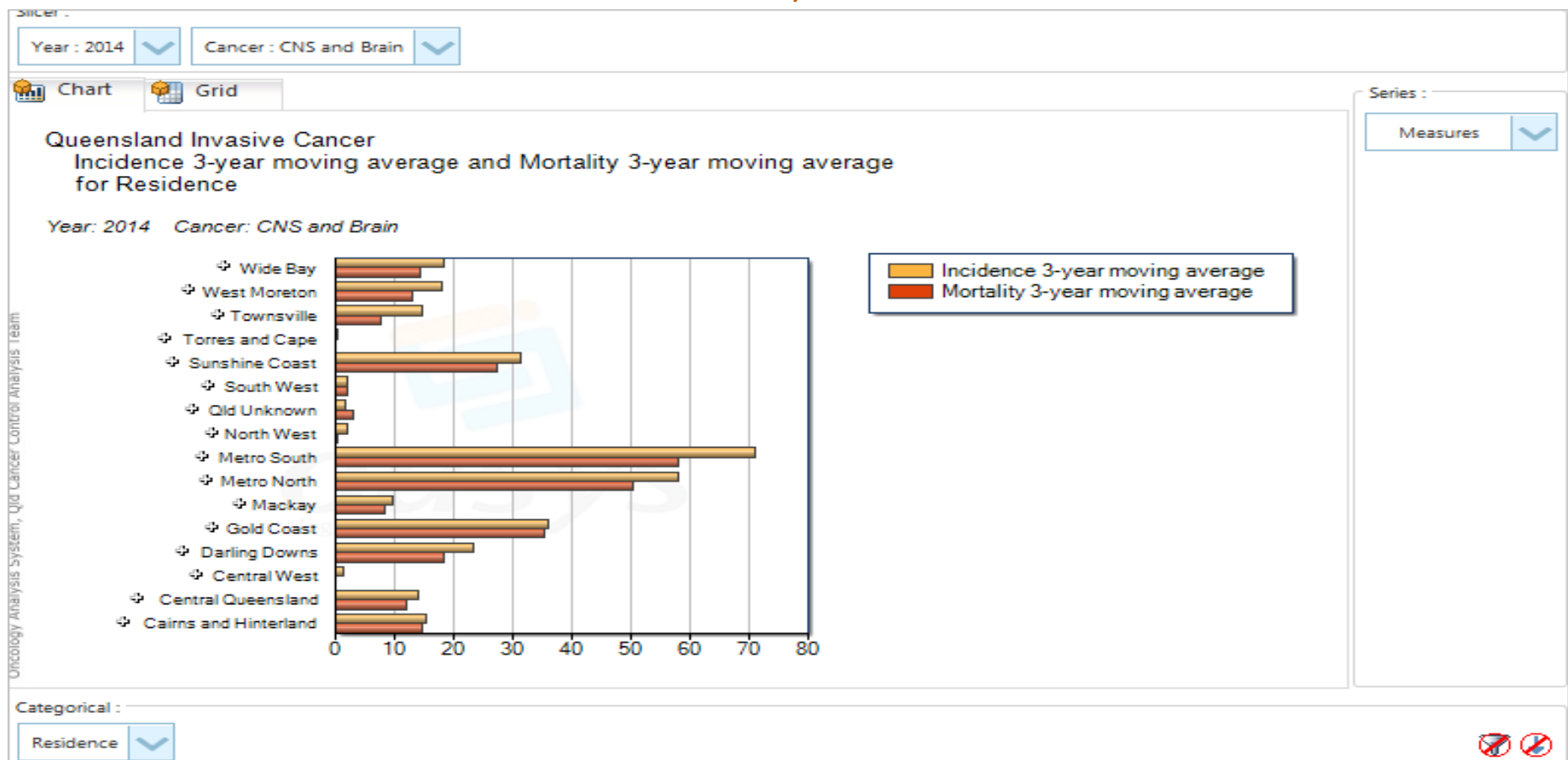
## My MD team data – updated daily

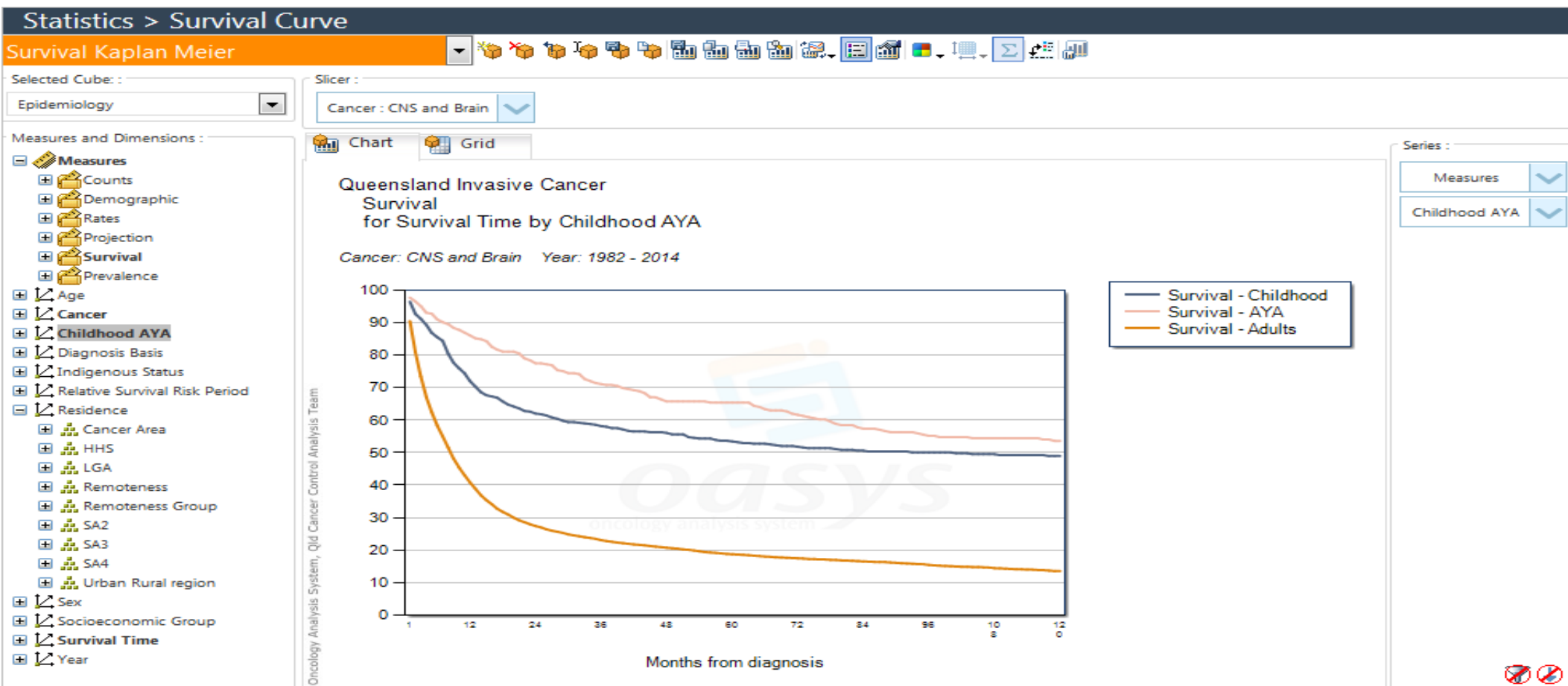


## Routine Reporting – Patient characteristics

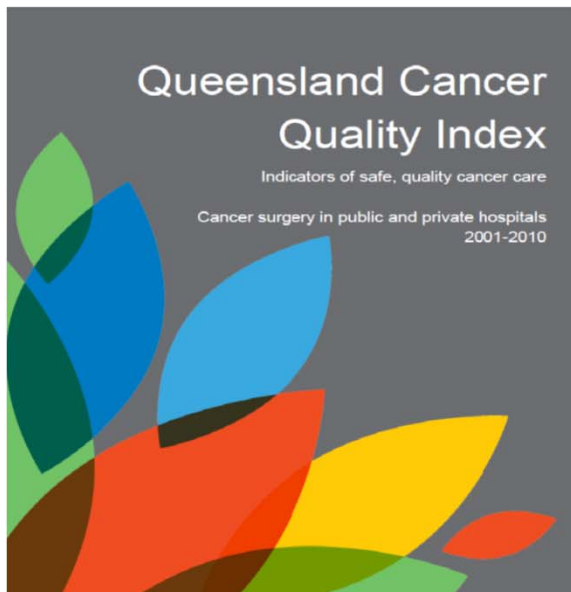
# Incidence & Mortality

Brain & CNS cancer by HHS of residence 2014





Routine Reporting for Qld – 1982 - 2014



*Queensland mortality rates after surgery are among the best in the world.*

*Overall there has been a decrease in mortality after cancer surgery.*

## 3.2 | 30 day mortality

**What percentage of patients die within 30 days of their cancer surgery?**

<b>30 day mortality</b> (% of patients who die $\leq$ 30 days following cancer surgery)		Queensland		Other Countries
Cancer	Surgery type	2001-2005 30 day mortality	2006-2010 30 day mortality	30 day mortality
Breast	Breast cancer surgery	<0.1%	<0.1%	US 0 - 0.24% <sup>1</sup>
Colon	Major resections	4.0%	3.0%	UK 2.9% <sup>2</sup>
Non-small cell lung	Major resections	2.5%	1.2%	US 2.8% <sup>3</sup>
Oesophagogastric	Gastrectomy	4.5%	3.5%	UK 2.3% <sup>4</sup>
	Oesophagectomy	1.5%	0.3%	UK 2.4% <sup>4</sup>
Pancreatic, biliary tract & duodenum	Pancreatico-duodenectomy	3.9%	1.7%	US 3.0% <sup>5</sup>
Rectal	Major resections	2.8%	2.0%	UK 2.9% <sup>2</sup>

*Rates have been adjusted for age and sex.*

<sup>1</sup> El-Tamer M, Ward M, Schiffner T, Neumayer L, Khuri S, Henderson W. Morbidity and Mortality Following Breast Cancer Surgery in Women, *National Benchmarks for Standards of Care*. *Annals of Surgery* 2007 May 245:5. Covers breast cancer surgery from 2001 to 2004.

<sup>2</sup> Health and Social Care Information Centre, *National Bowel Cancer Audit Annual Report 2013*. United Kingdom. Rates are for colon and rectal cancer and covers patients diagnosed between 1 April 2011 to 31 March 2012.

<sup>3</sup> Pezzi CM, Mallin K, Mendez AS, Greer Gay E, Putnam JB. Ninety-day mortality after resection for lung cancer is nearly double 30-day mortality. *J Thorac Cardiovasc Surg*. 2014; Aug 4. Covers major resections from 2007 to 2011.

<sup>4</sup> Health and Social Care Information Centre, *National Oesophago-Gastric Cancer Audit Annual Report 2014*. United Kingdom. Covers patients diagnosed between 1 April 2011 to 31 March 2013.

<sup>5</sup> Annamalai A, Kakarla VR, Nandipati K. Predictors of mortality following pancreaticoduodenectomy for periampullary cancer. *OA Surgery* 2014 Jan 18;2(1):2. Covers pancreaticoduodenectomies from 2005 to 2008.



## The Index

- 10 years, 2005 – 2014
- Expanded to include
  - Additional cancers
  - RT & CT utilisation
  - Time to first treatment
  - Variation between public & private sector
- Coming soon - August 2017





## 4.1 | Timeliness

What percentage of public compared to private patients received their first cancer treatment within 30 days of diagnosis?

Time to first cancer treatment		Queensland					
		2005-2009			2010-2014		
		Time to first cancer treatment			Time to first cancer treatment		
		(% patients whose time from diagnosis to first cancer treatment is ≤30 days)					
Cancer group	Cancer	All	Public	Private	All	Public	Private
Breast	Breast	73%	54%	87%	65%	45%	81%
Colorectal	Colon	77%	70%	83%	72%	62%	82%
	Rectal	58%	45%	69%	54%	38%	69%
Gynaecological	Cervical	39%	32%	53%	30%	21%	50%
	Ovarian	84%	77%	90%	84%	79%	88%
	Uterine	62%	33%	88%	58%	31%	84%
	Vulva	44%	28%	62%	39%	22%	63%
Hepatobiliary	Pancreatic, biliary tract & duodenal	65%	51%	77%	62%	49%	73%
Lung	Non-small cell lung	52%	43%	68%	46%	37%	61%
Upper GI	Oesophagogastric	47%	36%	62%	44%	32%	60%
Urological	Bladder	40%	36%	45%	39%	34%	44%
	Testicular	98%	98%	97%	97%	97%	98%

Rates have been adjusted for age and sex.

*Cancer treatment requires careful planning.*

*The time between diagnosis and first cancer treatment is influenced by the number and complexity of tests required to develop the treatment plan.*

#### 4.2.2 | Time to first treatment ≤ 30 days

What percentage of rural and remote patients received their first cancer treatment within 30 days of diagnosis?

Rural and remote time to first cancer treatment		Queensland					
		2005-2009			2010-2014		
		Time to first cancer treatment			Time to first cancer treatment		
		Rural & Remote	Regional	Metropolitan	Rural & Remote	Regional	Metropolitan
Breast	Breast	68%	70%	75%	59%	59%	68%
Colorectal	Colon	79%	77%	77%	69%	71%	74%
	Rectal	56%	58%	58%	49%	51%	57%
Gynaecological	Cervical	36%	37%	41%	30%	30%	30%
	Ovarian	82%	83%	84%	83%	81%	84%
	Uterine	55%	58%	65%	55%	58%	59%
	Vulva	37%	40%	47%	41%	32%	41%
Hepatobiliary	Pancreatic, biliary tract & duodenal	57%	62%	67%	64%	60%	63%
Lung	Non-small cell lung	53%	53%	51%	53%	48%	43%
Upper GI	Oesophagogastric	37%	47%	50%	40%	40%	46%
Urological	Bladder	44%	37%	41%	36%	42%	39%
	Testicular	97%	98%	98%	96%	99%	97%

*Rates have been adjusted for age and sex.*

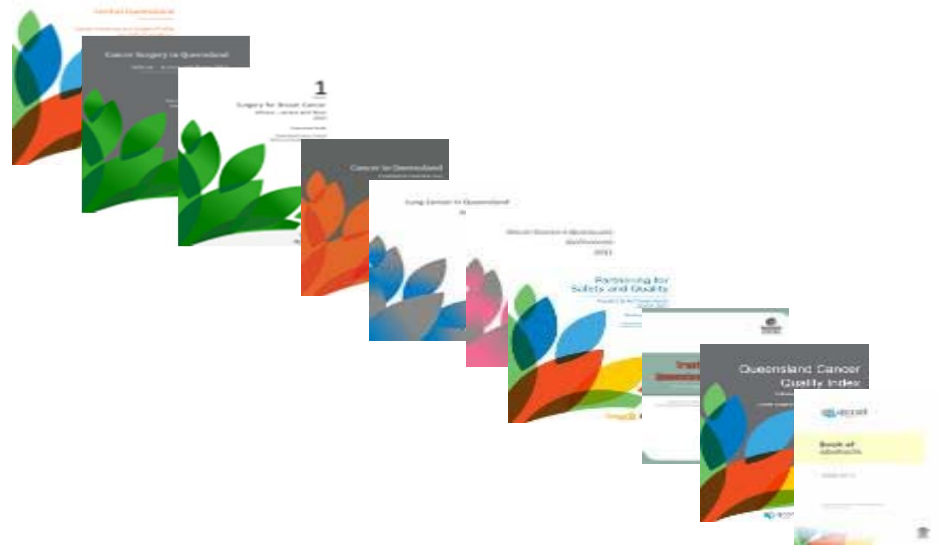
*Some cancers require specialised management in metropolitan areas.*

*There is little difference in the time to first cancer treatment between patients living in rural and remote, regional and metropolitan areas.*

# Routine Reporting

Since 2012 over 1500 reports generated which are now routinely provided to hospitals, MDTs, HHS & public

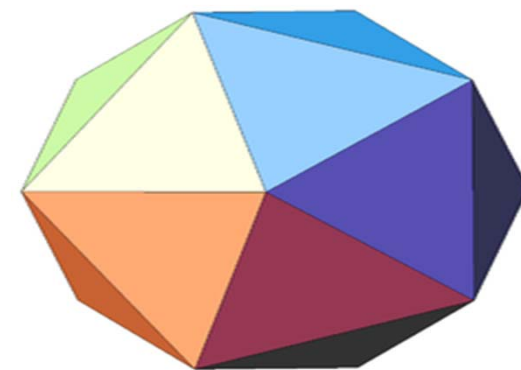
- The Queensland Cancer Index
- Cancer in Queensland
- Cancer surgery in QLD
- Cancer incidence and surgery profiles by HHS
- Impacts and Achievements
- Treating cancer in Qld public hospitals
- MDT activity in Qld hospitals
- Hospital indicators for breast, colon, rectal, lung, upper GI, pancreatic cancers
- OASys cancer facts




# MSP in action in Queensland

- Facilitate interaction between parties
- Exchange information between data custodians and clinicians, across hospitals, between health services, across diverse IT platforms
- Create relevant, clinically meaningful information out of data stores
- Routinely provide real time information and analysis
- Bring clinicians together around 'tricky' clinical issues

And practice is changing



# Where can you find us?

**Queensland Government**

Contact Us | Help

**Queensland Health**

 **Queensland Cancer Control Analysis Team**

Home Program of work Data access Toolbox Library Projects About

**Who We Are**

- The Partnership
- QCCAT
- Breast Sub-Committee
- Upper GI Sub-Committee
- Colorectal Sub-Committee
- Our focus
- Contact us
- Partnership Membership

[QCCAT Home](#) > [About](#) > [Contact us](#)  
**Contact Us**  
**Address**  
**Street & Postal Address**  
QLD Cancer Control Analysis Team  
Level 5 - R Wing  
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199 Ipswich Road  
Woolloongabba Qld 4102  
Australia  
  
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+61 7 3176 4400  
GOOL/OASys Support  
0407 746 420  
**Email**  
General Enquiries  
[qccat@health.qld.gov.au](mailto:qccat@health.qld.gov.au)  
OASys Support  
[oasysupport@health.qld.gov.au](mailto:oasysupport@health.qld.gov.au)  
GOOL Support  
[gool-support@health.qld.gov.au](mailto:gool-support@health.qld.gov.au)  
Last updated: Nov 13, 2015

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Queensland Government

<https://qccat.health.qld.gov.au>



by **A/ Professor Alexander Engel**

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**SPECIALIST COLORECTAL SURGEON,**  
ROYAL NORTH SHORE HOSPITAL +  
**DIRECTOR,** SYDNEY VITAL  
TRANSLATIONAL CANCER RESEARCH  
CENTRE

# CASE STUDY

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Using registry data to  
improve outcomes in  
colorectal cancer -  
the Dutch experience

# The Dutch Colorectal Audit Effect On Outcome

Alexander Engel

Director Sydney Vital

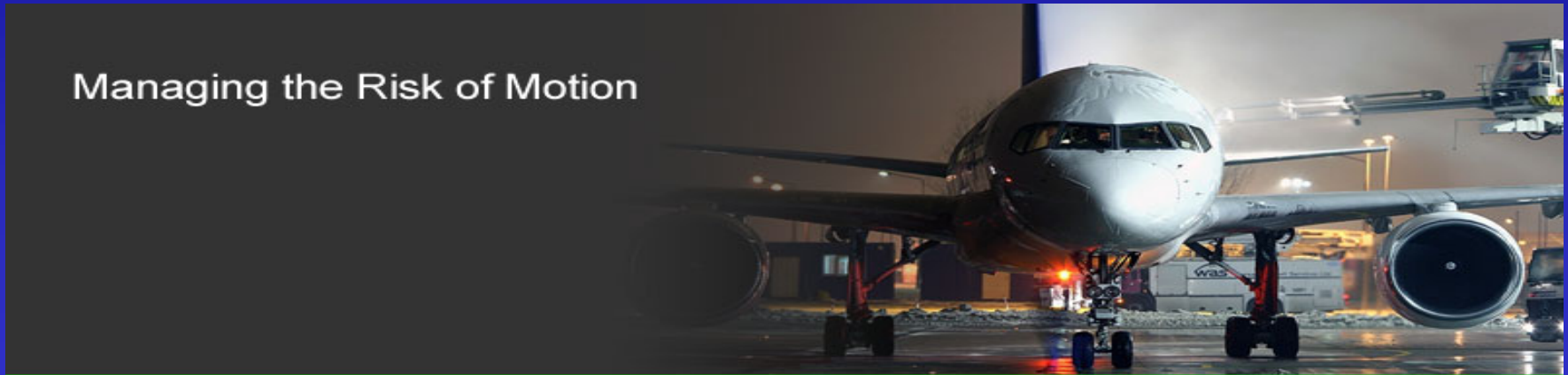
Head of Colorectal Department, RNSH





# Kudos To The Aviation Industry

Managing the Risk of Motion



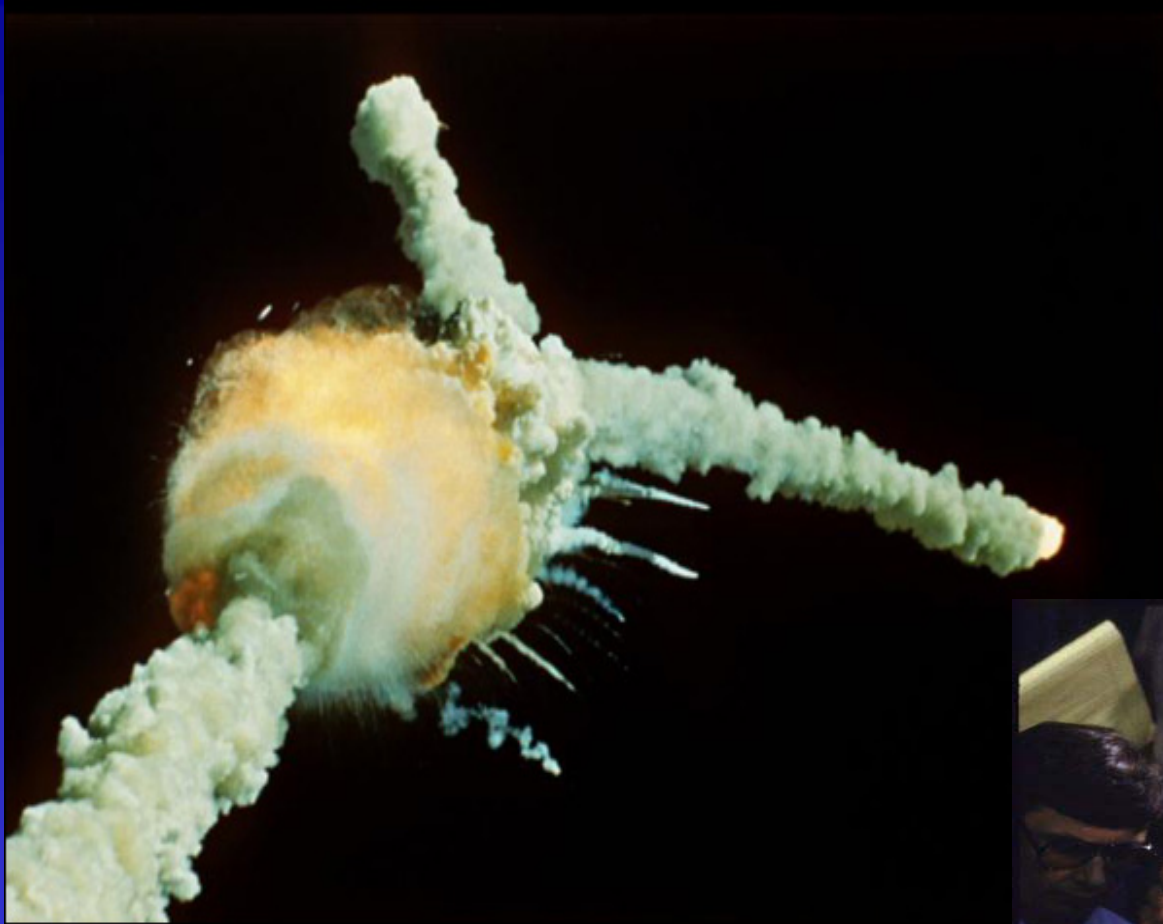




# RELIABLE DATA







..simple rubber O-ring  
did not expand at  $32^{\circ}\text{F}$   
to seal the rocket booster..



## Early Adapter



...actual mortality in hospitals is very much higher than the mortality of the same class of diseases treated out of hospital...

Florence Nightingale 1863

## Slide 274

---

- e1 improved sanitation, less crowding and distant from urban areas  
engela, 9/17/2010

**Numerology is the easiest, and consequently the most dangerous, method for finding patterns. It is easy because anybody with a *spreadsheet* can do it and dangerous for the same reason**

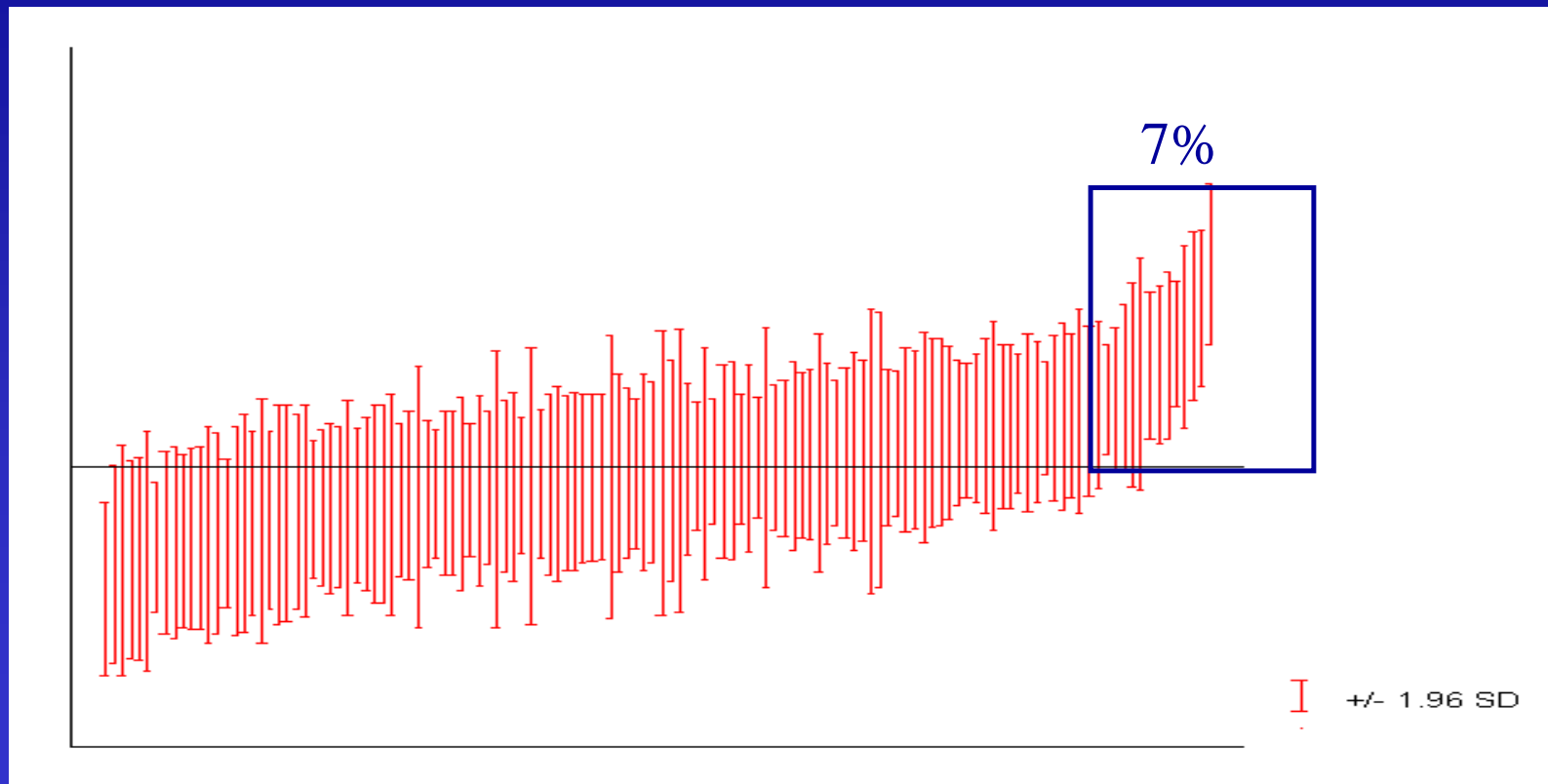


Ian Stewart, *Nature's Numbers*  
1995



# Hierarchical, Multilevel, Model of Mortality After Colorectal Surgery The Netherlands 1994- 1999

0 effect



Hospitals

# USE OF AUDIT DATA

- Proper provider comparison may lead to improvement
  - Effectiveness of care
  - Cost containment
  - Implementation studies
  - Patient education
- 
- *Guide personalized treatment-planning ???*

# DUTCH SURGICAL COLORECTAL AUDIT DSCA

- Initiated by the Dutch working party for colorectal surgery
- 2009 First audit year
- 2012 Integrated in compulsory national hospital KPIs
- 2014 Participation and data entry by 80 hospitals, non excluded, providing Colorectal cancer care



**MAKE  
CARE  
COUNT** **DICA**  
DUTCH  
INSTITUTE  
FOR CLINICAL  
AUDITING

partners  
in quality

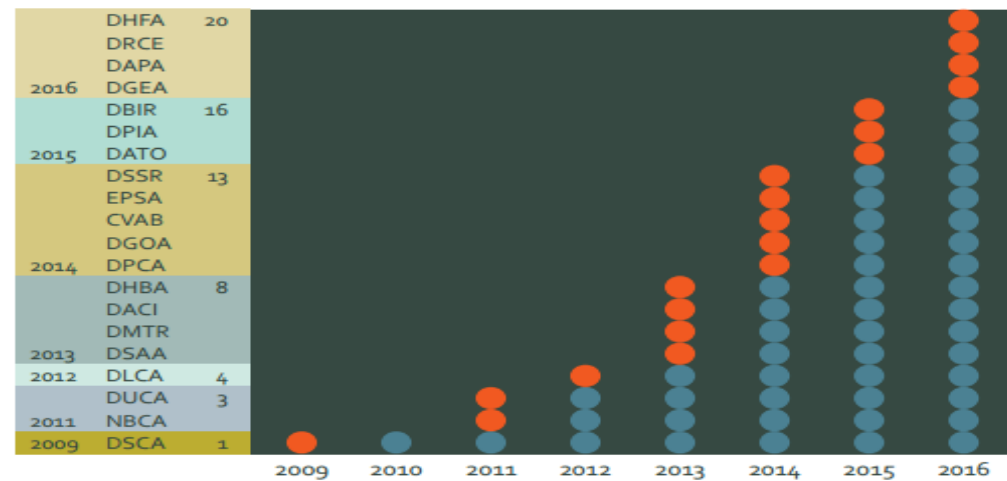
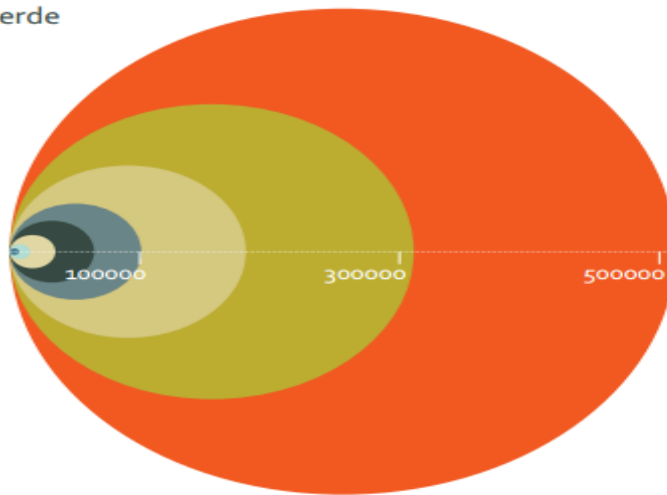
JAARRAPPORTAGE 2016

# DICA PARTNERS

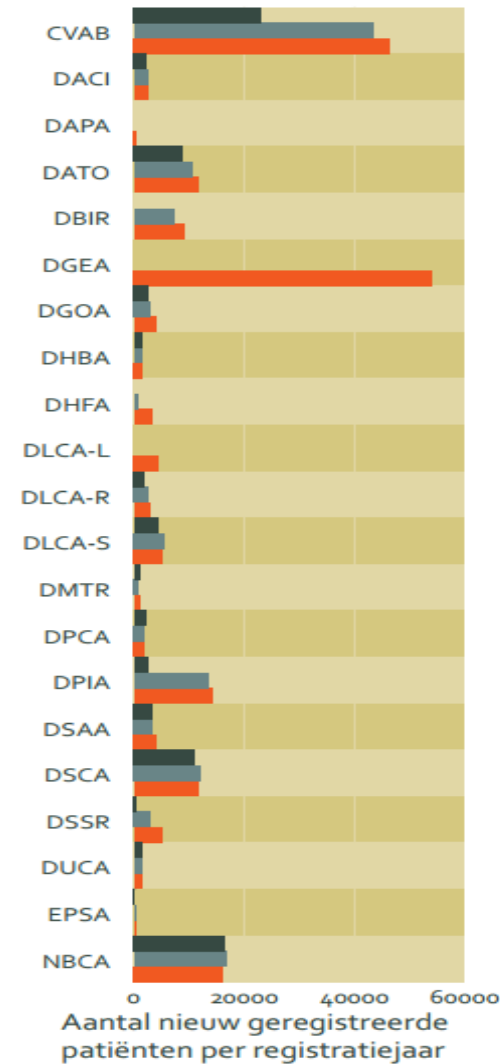
- Political parties
- Government /Health inspection
- Hospital organisations
- Patient representation groups
- Professional bodies
- Insurance companies
- Scientific organisations and Academia
  
- Media/Industry

## Totaal aantal geregistreerde patiënten (2009-2016)

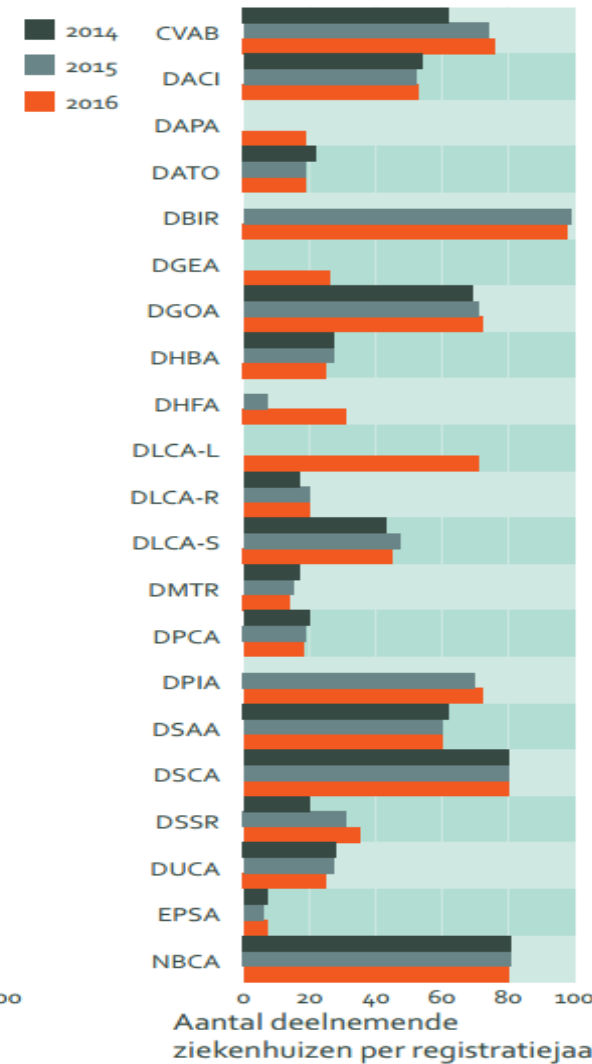
2009	7232
2010	15821
2011	35090
2012	64971
2013	101285
2014	181818
2015	311008
2016	512386



Aantal DICA-registraties per jaar



Aantal nieuw geregistreerde patiënten per registratiejaar



Aantal deelnemende ziekenhuizen per registratiejaar

Annual registries

New patients

Hospitals

DICA

DUTCH  
INSTITUTE  
FOR CLINICAL  
AUDITING



# PARTNERS IN QUALITY

8 EN 9 JUNI 2017

BEURS VAN BERLAGE AMSTERDAM

# DSCA REGISTRY DATA

- Age, Sex,ASA
- Patient discussed at MDT and timeline
- Acute/Elective
- Neoadjuvant/adjuvant management
- Open/Laparoscopic
- Type and consequence of local rectal resection
- Tumor location, procedure, stage and radicality of resection, harvested lymphnodes
- Postop complications, ICU, RTT, mortality, LOS
- **Failure to rescue**



# DSCA

## *PROCESS and STRUCTURE*

		2013	2014	2015	2016
PARTICIPATING HOSPITALS		71	80 (100%)	80 (100%)	80 (100%)
COLON RESECTION		6525	7588	8242	8170
RECTUM RESECTION		2681	3037	3341	3220

# DSCA

## *PROCESS and STRUCTURE*

		2013	2014	2015	2016
PARTICIPATING HOSPITALS		71	80 (100%)	80 (100%)	80 (100%)
COLON RESECTION		6525	7588	8242	8170
RECTUM RESECTION		2681	3037	3341	3220
					140 primary resections per hospital

# DSCA

## *PROCESS and STRUCTURE*

		2013	2014	2015	2016
COLON RESECTION		6525	7588	8242	8110
RECTUM RESECTION		2681	3037	3341	3220
<5 WEEKS TO FIRST TREATMENT COLON		70%	70.2%	70.6%	71.2%
<5 WEEKS TO FIRST TREATMENT RECTUM		48.6%	53.5%	55%	55.8%

# DSCA

## *PROCESS and STRUCTURE*

		2013	2014	2015	2016
COLON RESECTION		6525	7588	8242	8110
RECTUM RESECTION		2681	3037	3341	3220
<5 WEEKS TO FIRST TREATMENT COLON		70%	70.2%	70.6%	71,2%
<5 WEEKS TO FIRST TREATMENT RECTUM		48.6%	53.5%	55%	55.8%
ELECTIVE/ACUTE		80/20	82/18	86/14	89/11

# DSCA *OUTCOME*

[illegible]

# DSCA *OUTCOME*

		2013	2014	2015	2016
R1 RESECTION	cT4 COLON	86.6%	89.5%	92.6%	93.3%
R1 RESECTION	cT1-3 RECTUM	5.2%	4.4%	4.0%	3.6%
ABDOMINO-PERINEAL RESECTION		32.3%	29%	25.4.%	22.1%

# DSCA *OUTCOME*

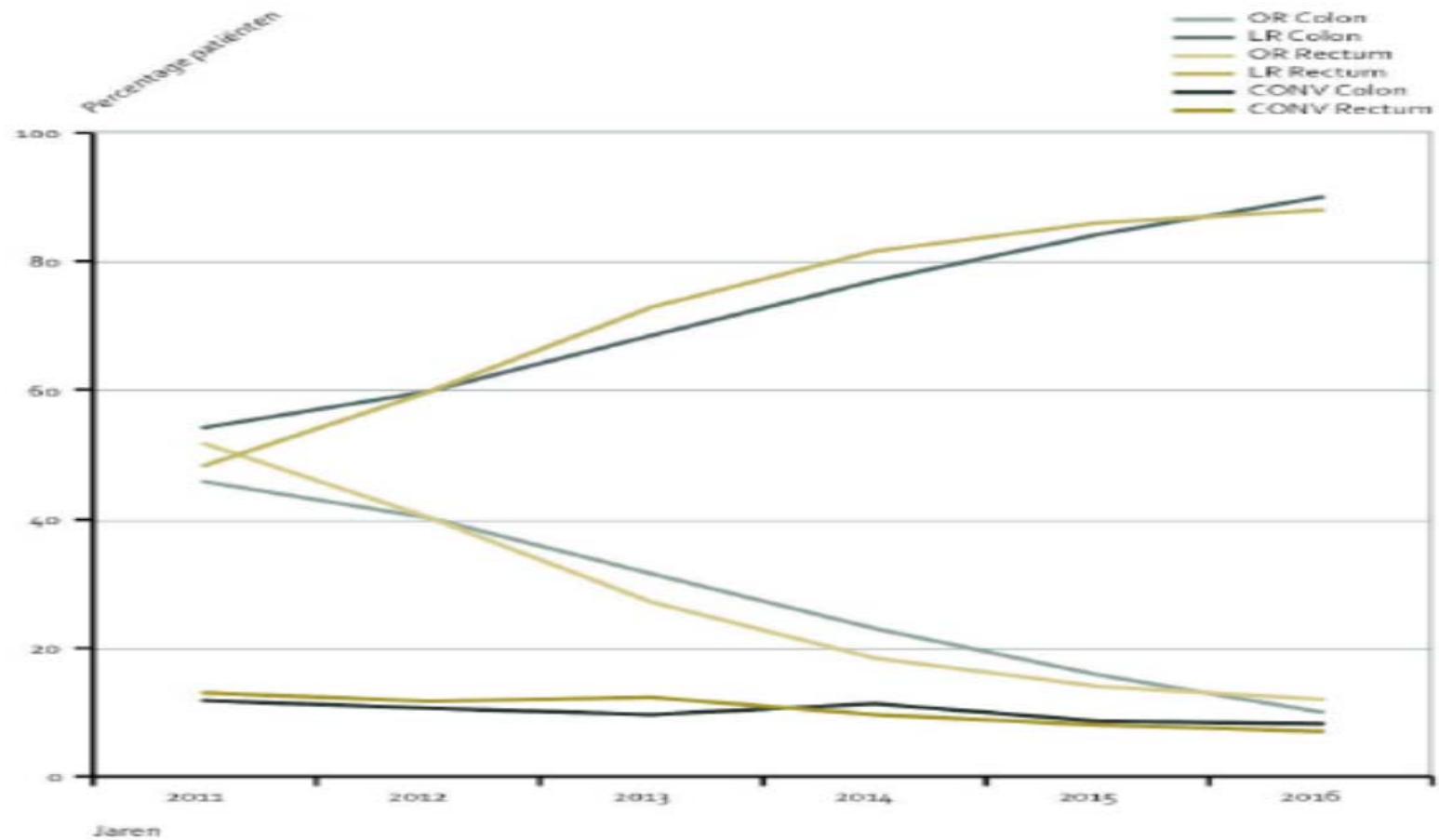
		2013	2014	2015	2016
R1 RESECTION	cT4 COLON	86.6%	89.5%	92.6%	93.3%
R1 RESECTION	cT1-3 RECTUM	5.2%	4.4%	4.0%	3.6%
ABDOMINO-PERINEAL RESECTION		32.3%	29%	25.4.9%	22.1%
MAJOR COMPLICATIONS COLON		17.6%	16.8%	15.2%	14.2%
MAJOR COMPLICATIONS RECTUM		21%	20.5%	20%	19.3%

# DSCA *OUTCOME*

		2013	2014	2015	2016
R1 RESECTION	cT4 COLON	86.6%	89.5%	92.6%	93.3%
R1 RESECTION	cT1-3 RECTUM	5.2%	4.4%	4.0%	3.6%
ABDOMINO-PERINEAL RESECTION		32.3%	29%	25.4.9%	22.1%
MAJOR COMPLICATIONS	COLON	17.6%	16.8%	15.2%	14.2%
MAJOR COMPLICATIONS	RECTUM	21%	20.5%	20%	19.3%
<b>30-DAY MORTALITY</b>		<b>3.6%</b>	<b>3.2%</b>	<b>2.7%</b>	<b>2.4%</b>
<b>FAILURE TO RESCUE</b>		<b>12.1%</b>	<b>10.2%</b>	<b>9.4%</b>	<b>9.0%</b>



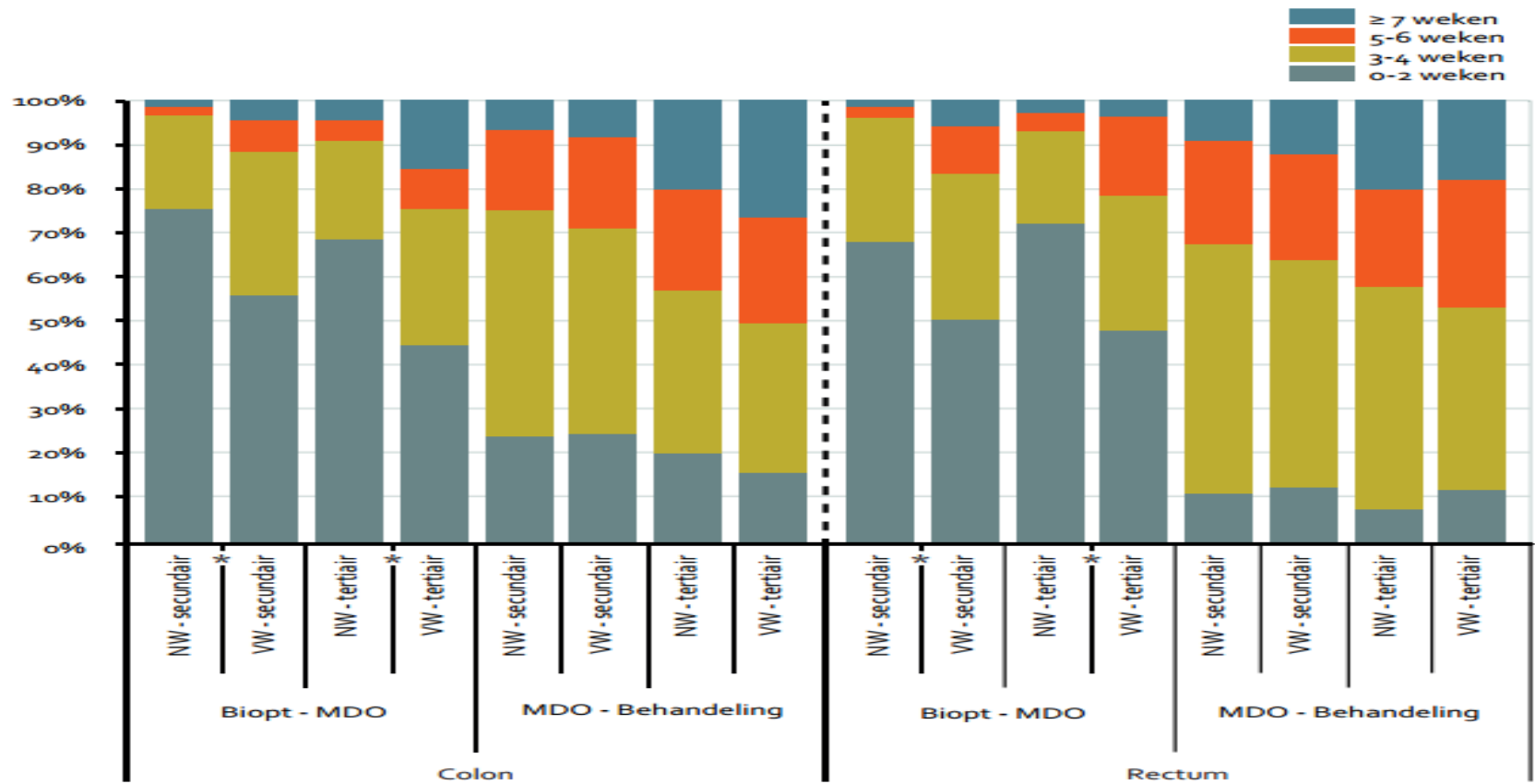
## MINIMAL INVASIVE APPROACH COLORECTAL CANCER



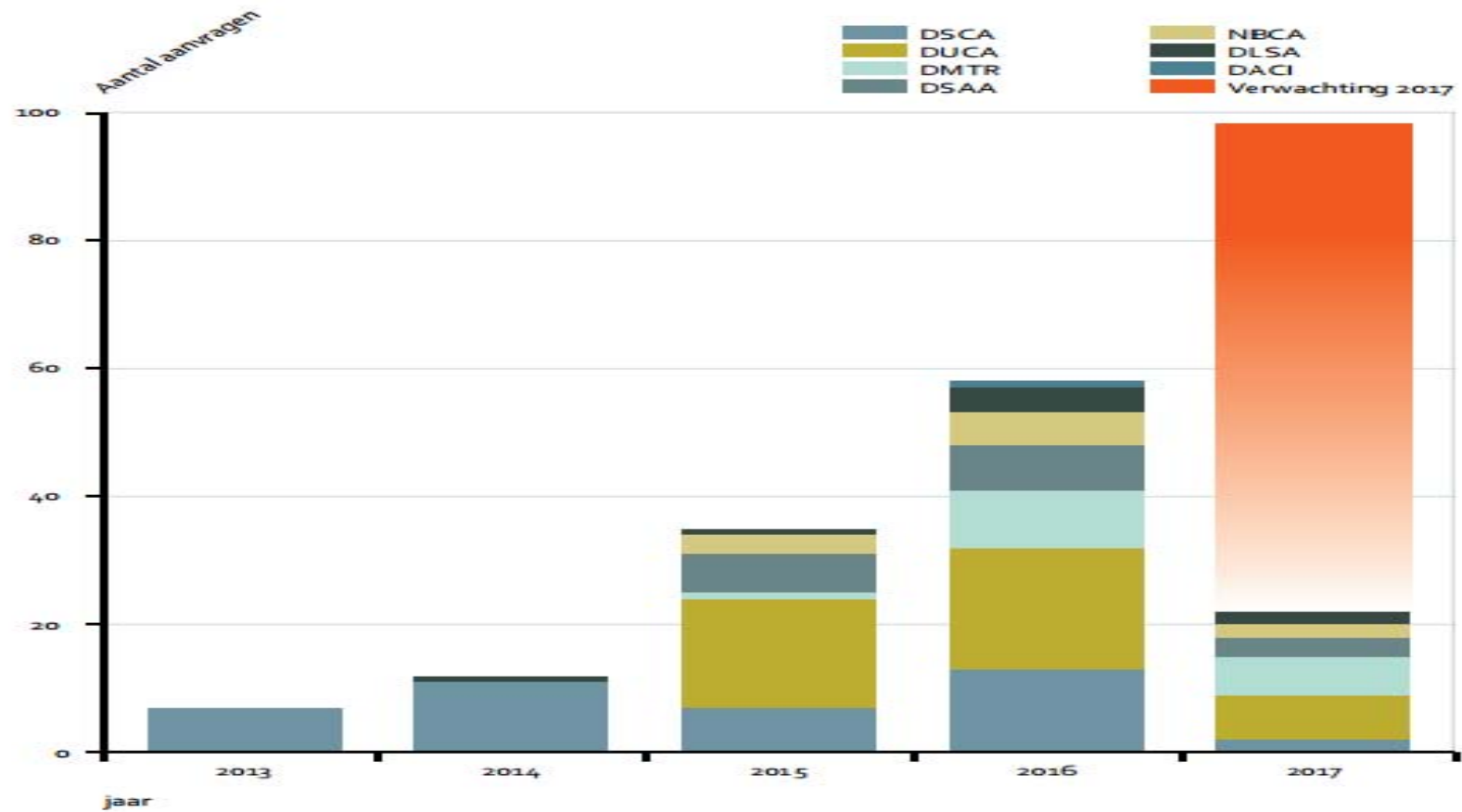


# THE HAWTHORNE EFFECT

# TIME to MDT and TIME to FIRST TREATMENT



# RESEARCH REQUESTS FOR AUDIT DATA



For every complex problem there is a simple  
solution.....

*And it is invariably wrong*

HL Mencken

• 14:00 - 14:15 PM

**AFTERNOON  
TEA**

**FLIPPING**

**the**

**RECORD**

#IMPSCI  
COMMUNITY  
OF PRACTICE

# WHAT DOES SUCCESS LOOK LIKE?

Consumers

Clinical Teams

Researchers

Organisations/  
Systems

# WHAT ARE THE KEY BARRIERS AND ENABLERS?

Consumers

Clinical Teams

Researchers

Organisations/  
Systems



# EVALUATION SURVEY

<https://tinyurl.com/FlippingTheRecord>

THANK YOU VERY MUCH  
FOR YOUR TIME

#IMPSCI  
COMMUNITY  
OF PRACTICE

**FLIPPING**

**the**

**RECORD**

• 16:30 - 18:00 PM

**DRINKS +  
NETWORKING**

#IMPSCI  
COMMUNITY  
OF PRACTICE