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16th September 2026

Unlocking The Value of Real-world Data: Partner Case Study

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To the Question.....

What if the clinical data we've spent *decades* collecting could do *more* than retrospective audit ?

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My qualifications for giving this talk

We build registries – lots of them!

- UK & Ireland Society of Cardiothoracic Surgery
- UK Microsurgery Reconstruction Registry
- UK Immunotherapy Registry for Severe Allergy
- UK National Bone & Joint Infection Registry
- British Association of Endocrine & Thyroid Surgery
- British Obesity & Metabolic Surgery Registry
- SHOT – UK Serious Hazards of Transfusion Registry
- British National Elbow Replacement Registry
- UK National Acute Myeloid Leukaemia Registry
- UK National Castleman Registry

BAPRAS

BAJIS

NBSR National Bariatric Surgery Registry

BESS Excellence through knowledge

CDNUK Castleman Disease Network UK

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My qualifications for giving this talk

We build registries – lots of them!

- European EACTS LVAD Registry
- European ESOT Solid Organ Transplant Registries
- European ESVS Venous Stent Registry
- International Cardiac Rehabilitation Registry
- International Angiodynamics IRE Registry
- Global GARFIELD Atrial Fibrillation Registry
- Global Alkaptonuria Registry
- Global IFSO Bariatric & Metabolic Surgery Registry
- Global CoviDiab Registry
- Global EB Registry

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Introduction to Dendrite

- Health Informatics/Clinical Data Management
- Henley-on-Thames based International Company
- 30+ year trading history
- Clients in 60 countries around the world
- Database software utilised in hundreds of hospitals
- Software running in 18 major languages
- ~ 200+ National & International Registries delivered
- Fast growing portfolio of Rare Disease Registries

To the Question.....

Why registry data matters ?

Can it empower surgeons (and their professional societies) to improve outcomes for patients ?

.....Cardiac Surgery Example

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...dark days if you were a surgeon in the UK during the 1980s/1990s

The PAST

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...dark days if you were a surgeon in the UK during the 1980s/1990s

At one point, *one in five* UK heart surgeons were suspended from work !

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Profession under Criticism

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The Pavement Demonstration Outside the Hospital

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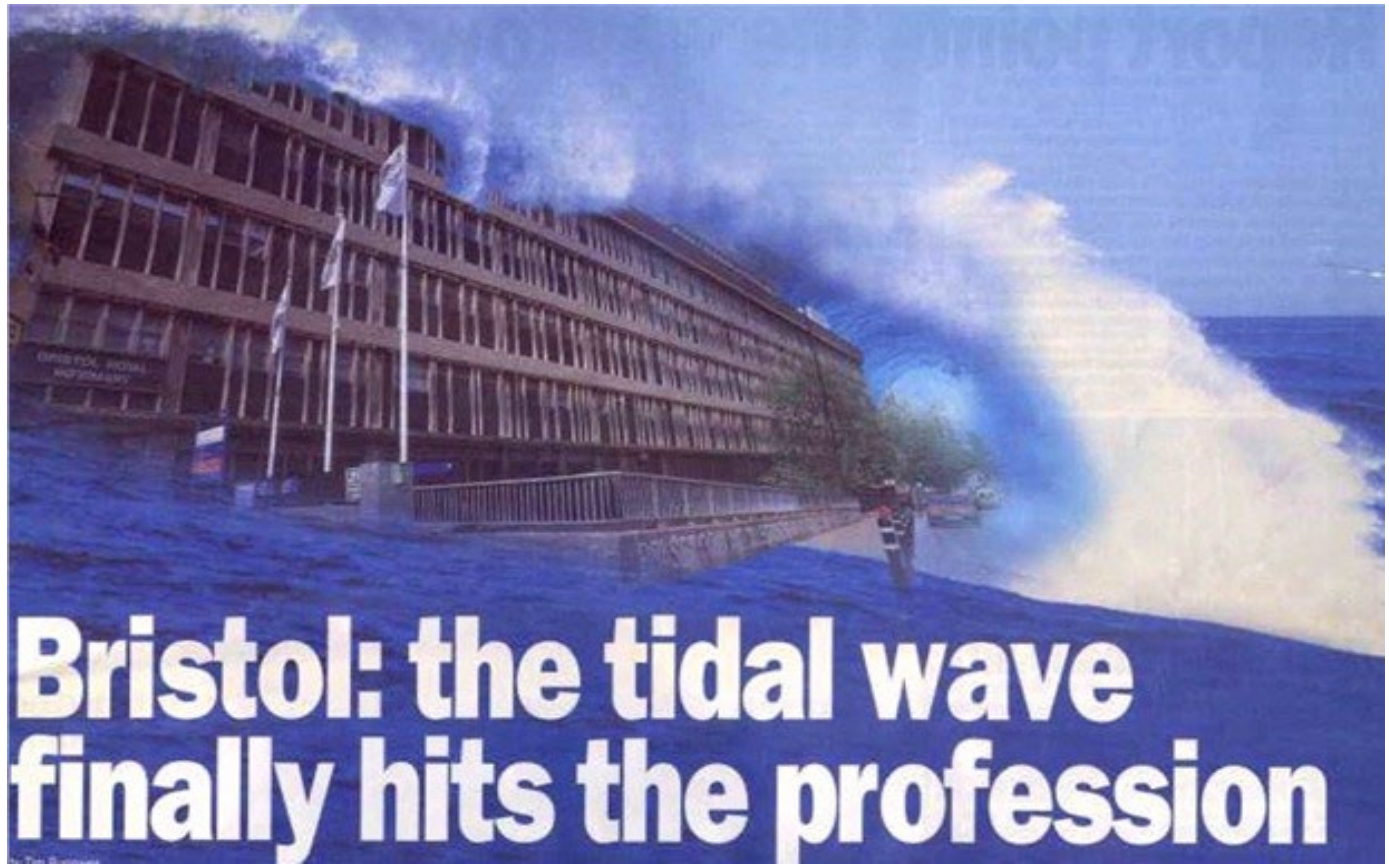
Profession under Criticism



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Pivotal discussion in 1995

Professor Ken Taylor
Cardiothoracic Surgery
Hammersmith Hospital

PW Question:

"*How about we run a data merge between 12 cardiac surgery centres to produce a pilot national registry report*?"

KT Answer:-

"*I'm not interested myself – go and talk to my senior registrar – he might like to run with the idea*"

Pivotal discussion in 1995

…and there in the small corner office on the 10th floor of the Post-Graduate Medical School with a nice view over HM Wormwood Scrubs prison and bent over his Macintosh computer….

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Pivotal discussion in 1995

…and there in the small corner office on the 10th floor of the Post-Graduate Medical School with a nice view over HM Wormwood Scrubs prison and bent over his Macintosh computer….

Prof. Sir Bruce Keogh

...and he said:

"***YES let's do it!*** "

This was the “Birth” of the “Blue Books”

The 1st Blue Book (actually white”) was published by Bruce Keogh & PW on behalf of the Society of Cardio-thoracic Surgeons in 1996

2nd Blue Book was published in 1998

- hospitals shown to be seeing patients with different demographic patterns of risk factors,
- all hospital data were completely anonymised

We were uniformly, nationally vilified, castigated and “demonised” even though mortality rates not published

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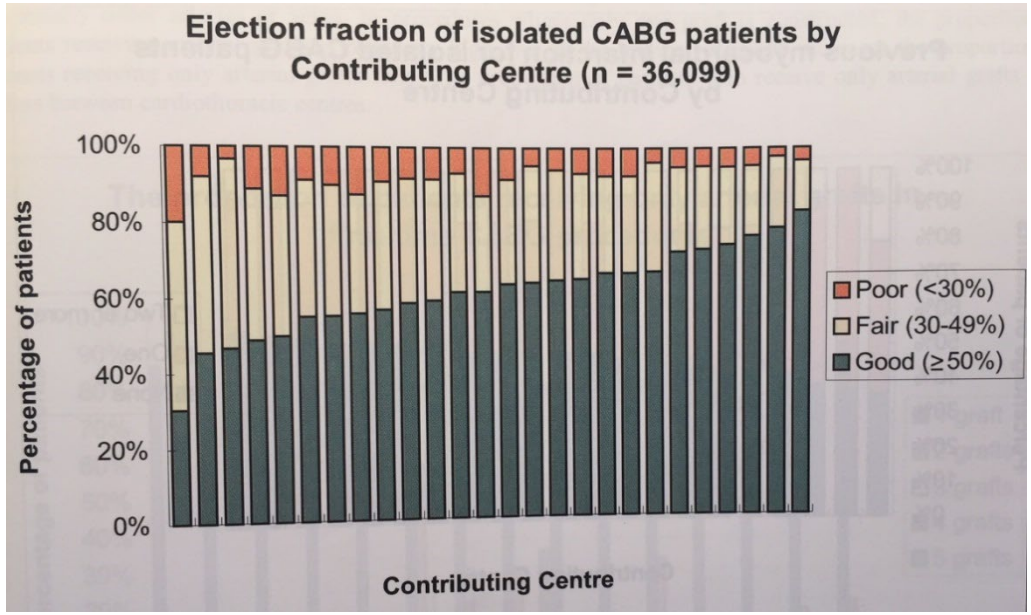
The First Real “Blue Book”



Example graph from the first “Blue Book”

The aim was simply to be able demonstrate that data could be merged and that there are patient population differences (and similarities) between UK cardiac surgery centres…and that these analyses would have value

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In 1999 The Society of Cardiothoracic Surgeons set out the Principles Behind Data Capture and the UK Cardiac Surgery Database Objectives were born

- Systematic Data Collection of an Agreed Minimum Dataset
- Aggregation and Validation of Data
- Analysis and Development of Risk Stratification Models
- Regular Feedback to Contributing Centres
- Continuous Evaluation of Performance
  and changing practice and the influence
  of clinical risk factors

….setting the “Rules of Engagement”

Strong Mandate for Data Collection

Desperate Need to **regain Public Confidence** in Heart Surgery and Heart Surgeons

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The Bristol Royal Infirmary Inquiry

Story – not of bad people but of bad "systems" and culture leading to unsatisfactory care

…data collection became mandatory by legislature

(Ian Kennedy Enquiry)

5th Adult Cardiac Surgical Database Report

Detailed results by Centre – named surgeons, hospital results by procedure + star ratings

Focus on Survival

Birmingham: Queen Elizabeth Hospital					**www.uhb.nhs.uk**
Chief Executive: Mr Mark Britnell			Hospital Telephone: 0121 472 1311		
Trust star rating 2003 / 2004	★★★ / ★★★		Networked data collection system		Yes
SCTS Quality accreditation	No		Dedicated surgical data manager		Yes
		Operations	**Mortality**		**Survival**
2001-2003	Isolated CABG	1,772	3.3%	(99% CI: 2.3-4.6%)	96.7%
	Isolated AVR	267	2.6%	(99% CI: 0.9-6.8%)	97.4%
2003	Isolated CABG	655	2.7%	(99% CI: 1.5-5.0%)	97.3%
	Isolated AVR	133	2.3%	(99% CI: 0.4-9.0%)	97.7%

Surgeons performing coronary surgery		**CABG per year**		**SCTS review of results**
Bonser	Adult cardiac	84		Meets SCTS standards (three years)
Graham	Adult cardiac	109		Meets SCTS standards (three years)
Keogh	Adult cardiac	80		Meets SCTS standards (three years)
Pagano	Adult cardiac	101		Meets SCTS standards (one year)
Rooney	Adult cardiac	130		Meets SCTS standards (two years)
Wilson	Adult cardiac	124		Meets SCTS standards (three years)

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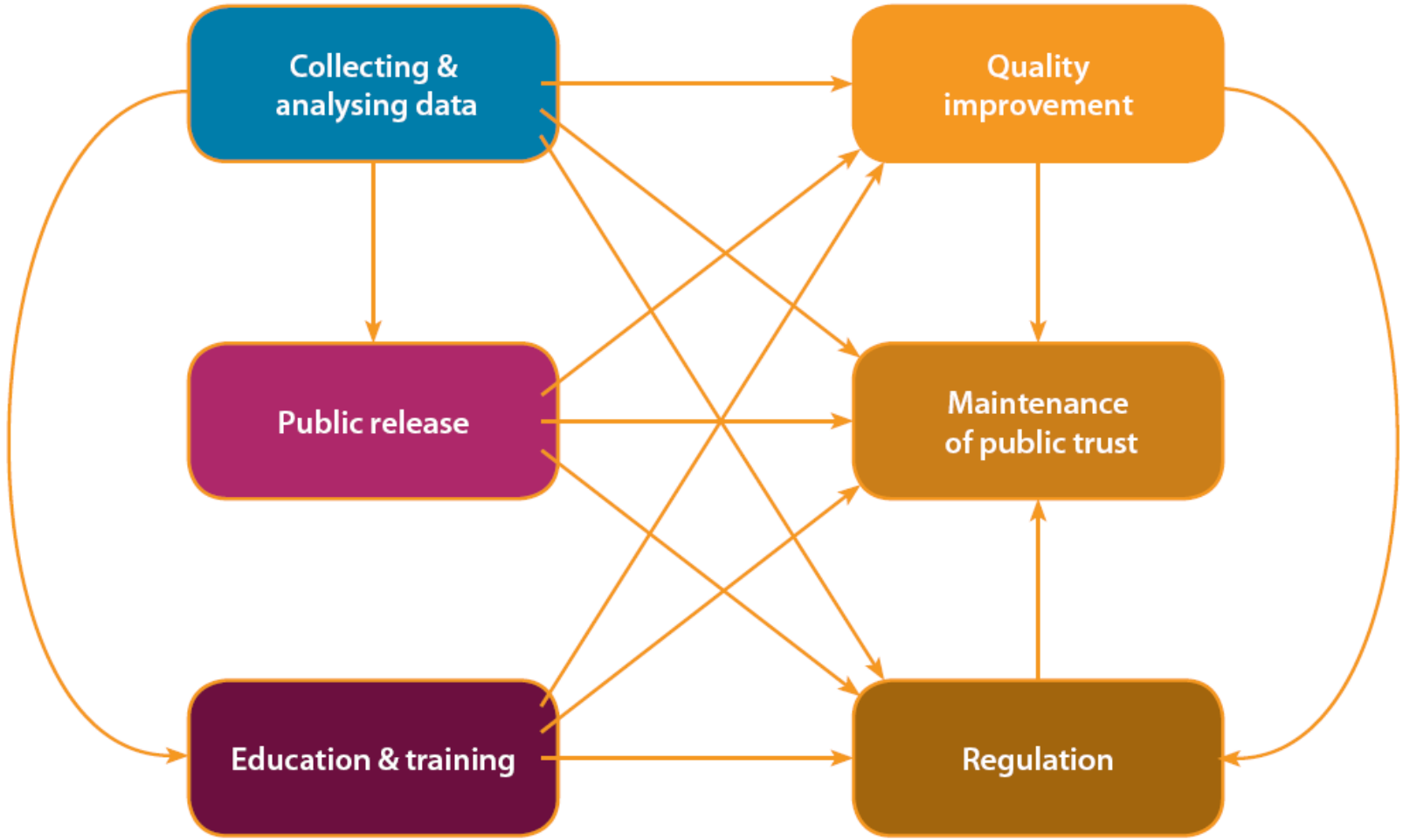
SCTSGBI New Commitment to Data



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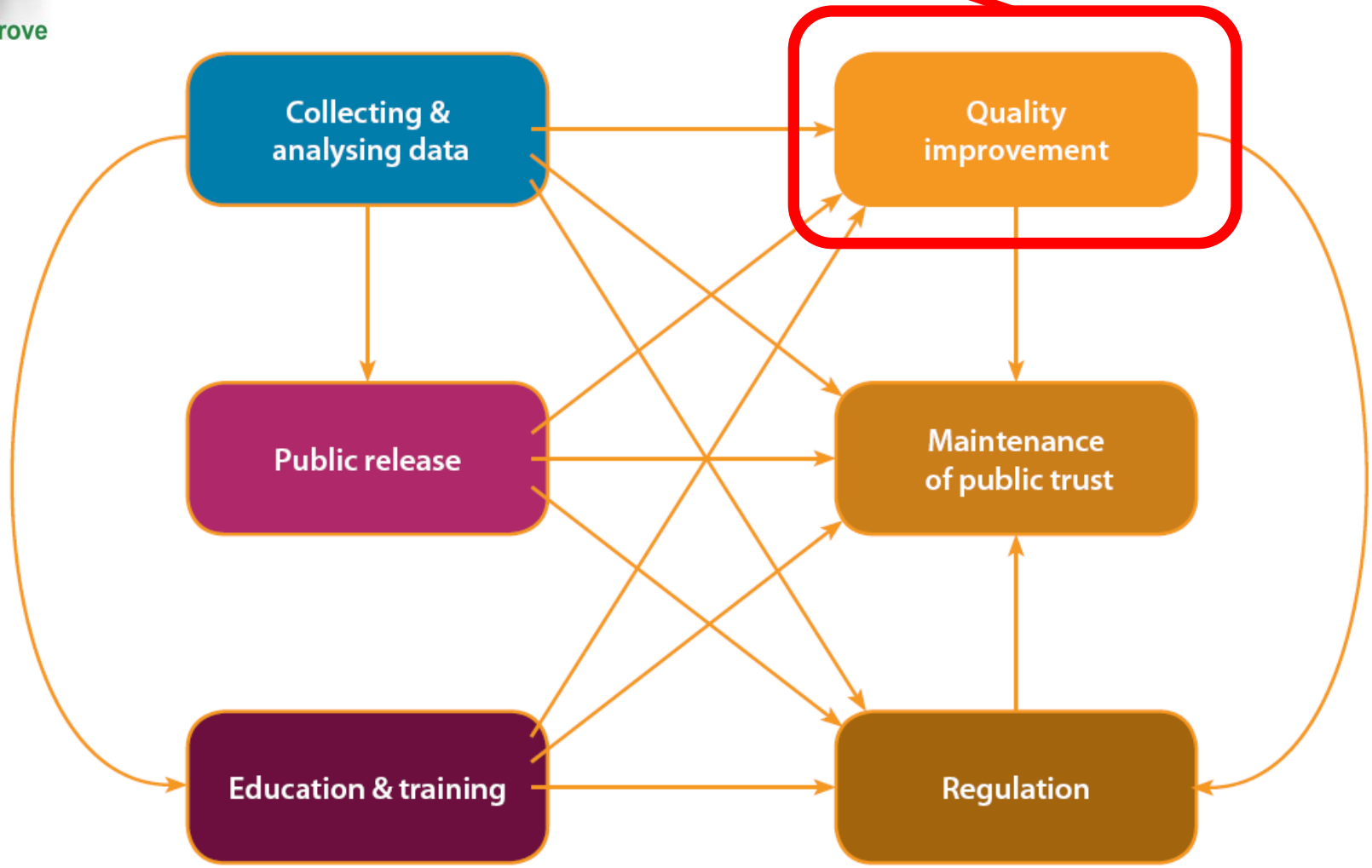
to get there……



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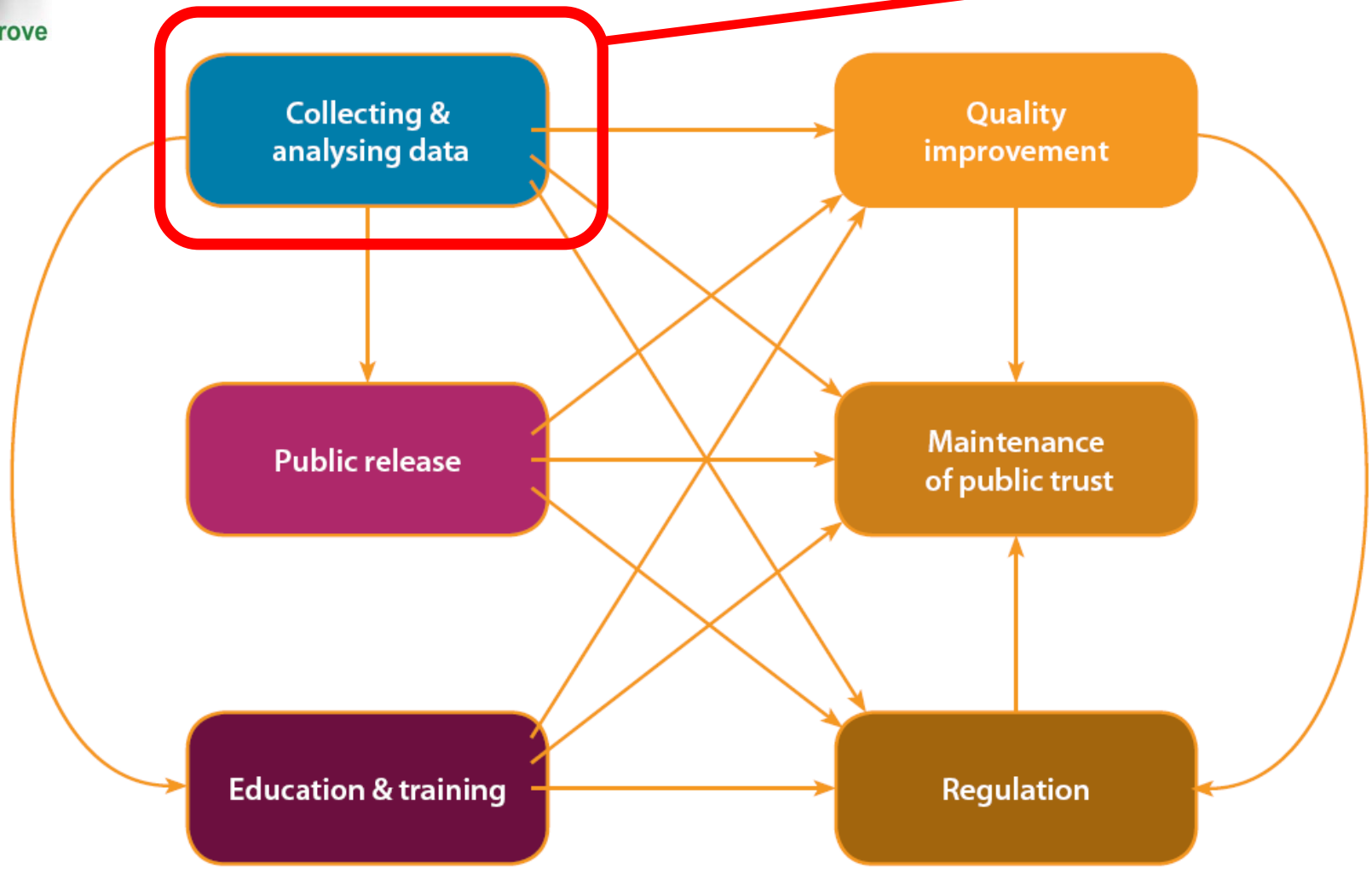
.....it all starts *HERE*



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The 6th UK Adult Cardiac Surgical Database Report – the "Blue Book"

* >500 Pages of detailed data analysis
* 100 % of National Health Service Hospitals
* Analysis on > 400,000 operations
* CABG & valve long term survival data
* 10 year data on risk factors
* 25 year trend data on activity & mortality and different types of operations
* Volume/outcome analysis by hospitals

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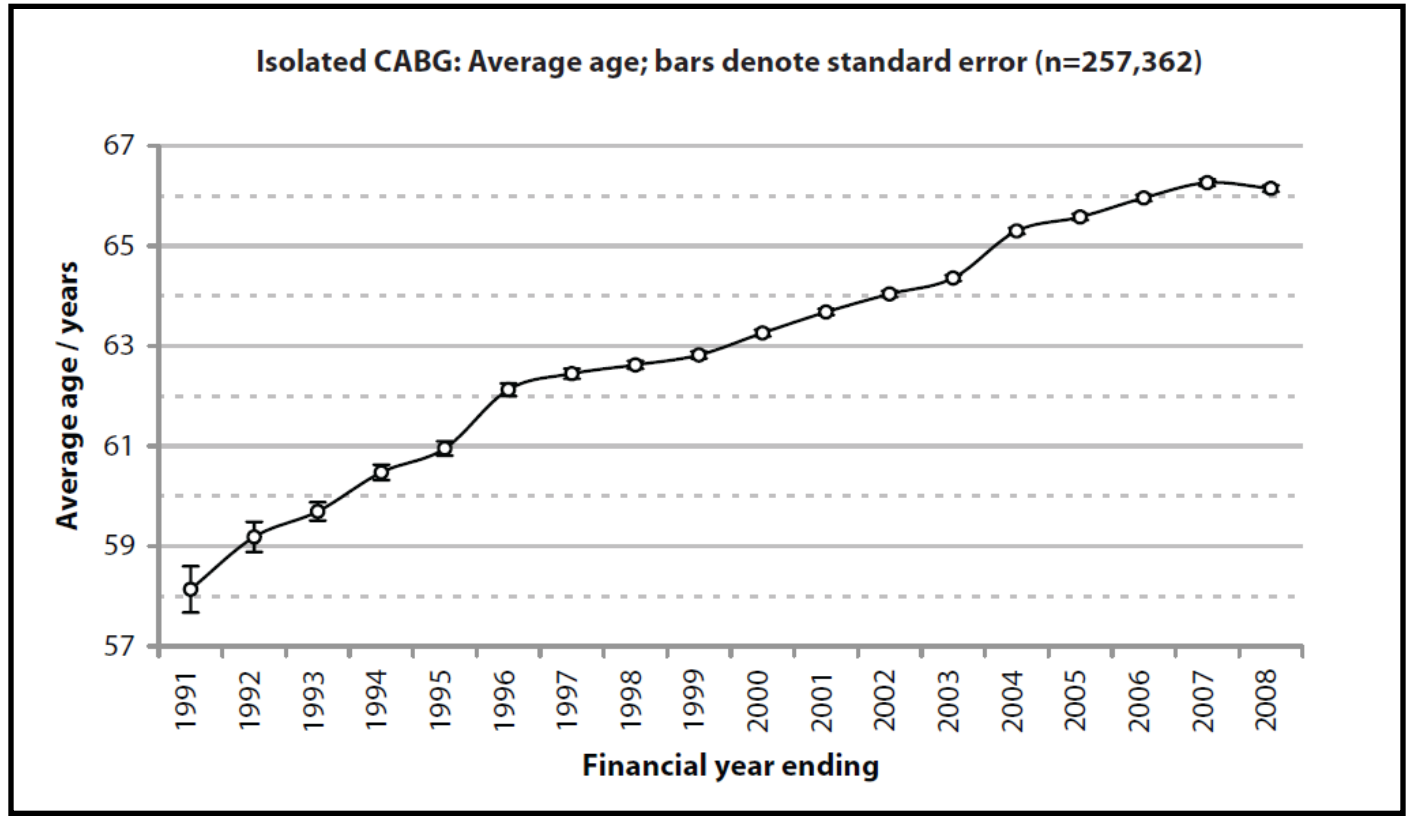
The Hawthorne Effect

Steady Increase in Average Age over Time



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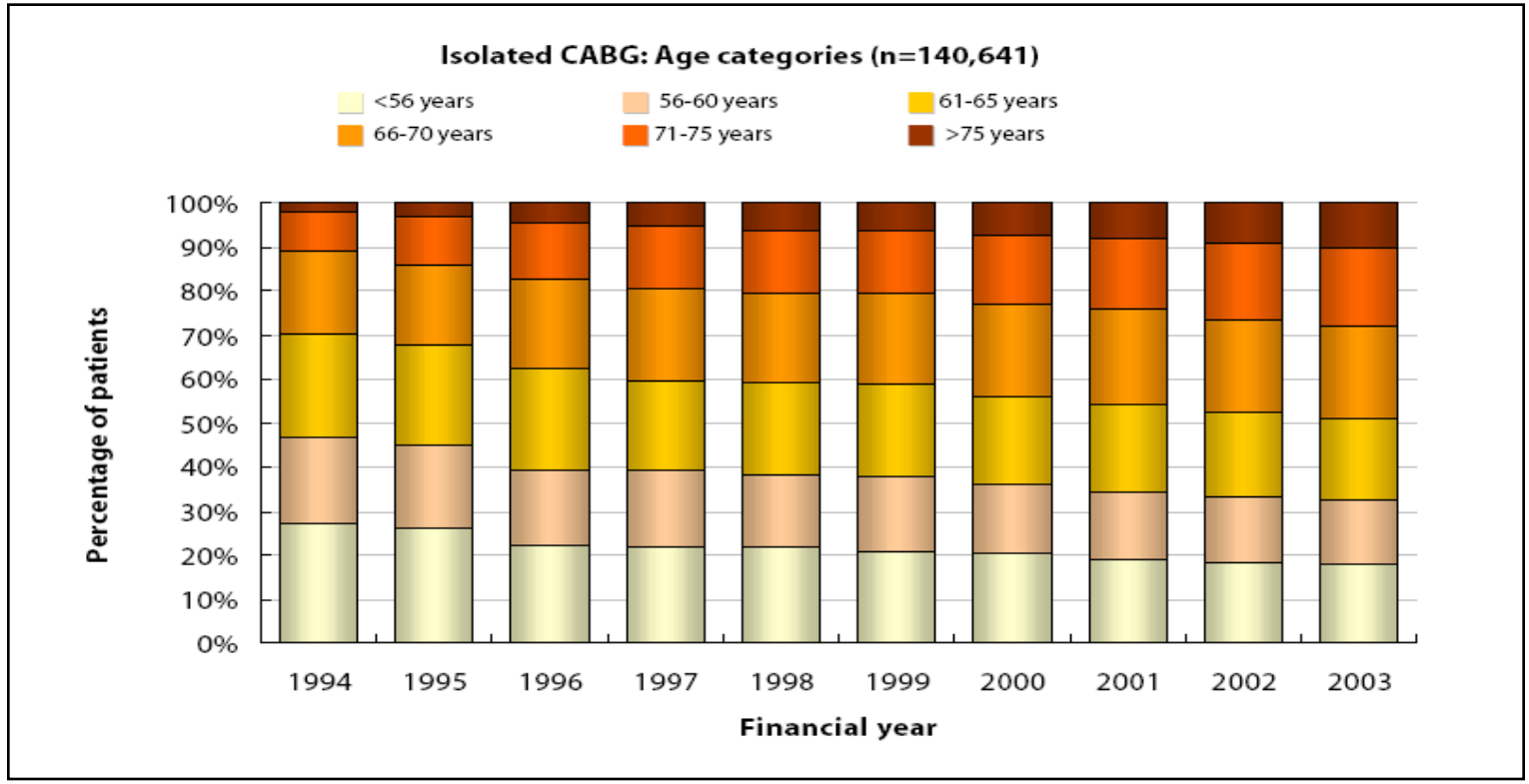
The Hawthorne Effect

Watch the increase in elderly patients



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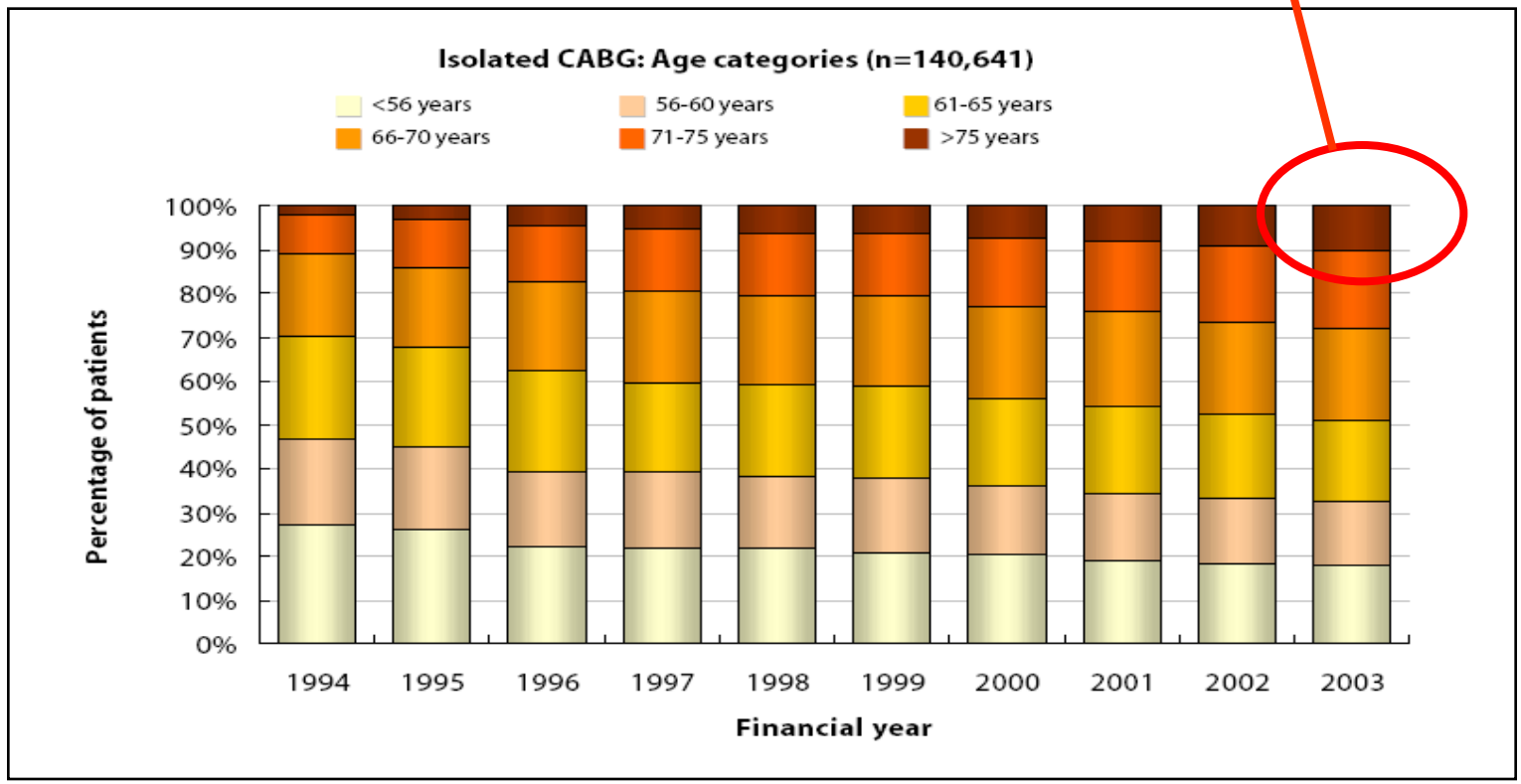
The Hawthorne Effect

A Fourfold increase in >75 yr olds in 8 years



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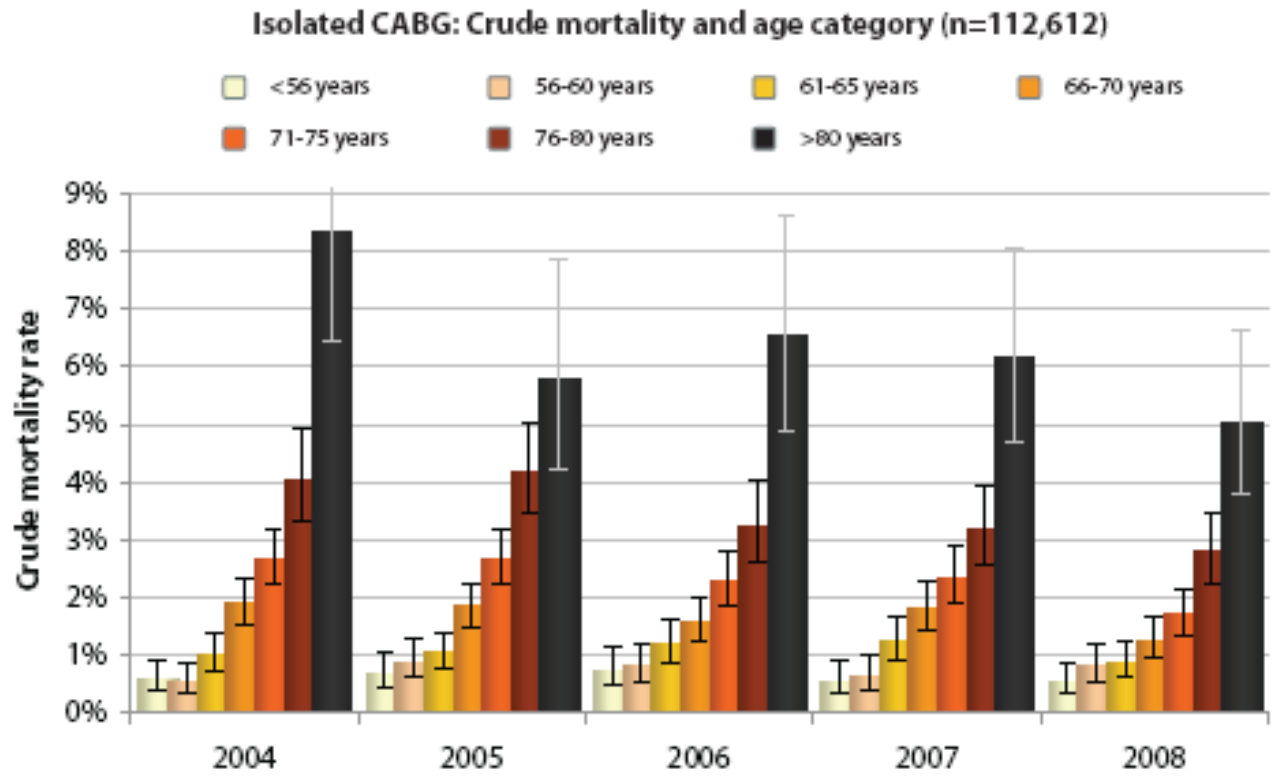
The Hawthorne Effect

And yet…year-on-year

Results have improved despite increasing risk profile of the patients under care



Probable Hawthorne Effect !!

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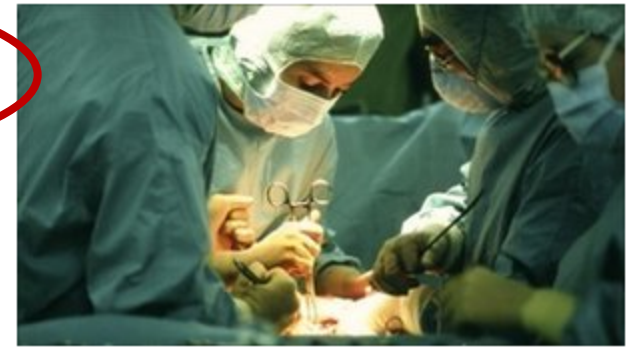
25 November 2010 Last updated at 00:35

Boost for UK over heart surgery performance

The UK is outperforming most of Europe when it comes to survival rates from heart bypass operations, according to an international audit.



Heart surgery survival rates are 25% better in England and Wales than the European average

Across Europe, 2.4% of patients on average die following a bypass.

This compared with 2.2% in Scotland, 1.8% in England and just 1.1% in Wales, the study found.

The European Association for Cardiothoracic Surgery looked at data from more than a million operations in 23 countries.

A leading heart surgeon said the decision to collect data on hospital performance had helped cut mortality by 50% in five years.

This is the first ever comparative study of heart operations across the continent, and the NHS was one of the most enthusiastic participants, contributing a large slice of the total data used.

Related stories

Heart surgery 'more successful'

Death data 'cuts risky surgery'

The Traditional Registry Model worked!

Time for Modernisation!

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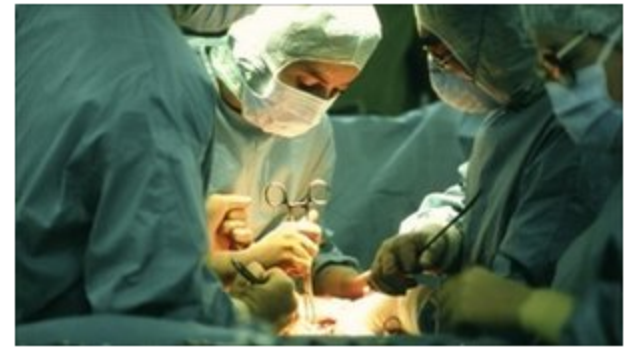

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Related stories

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Death data 'cuts risky surgery'

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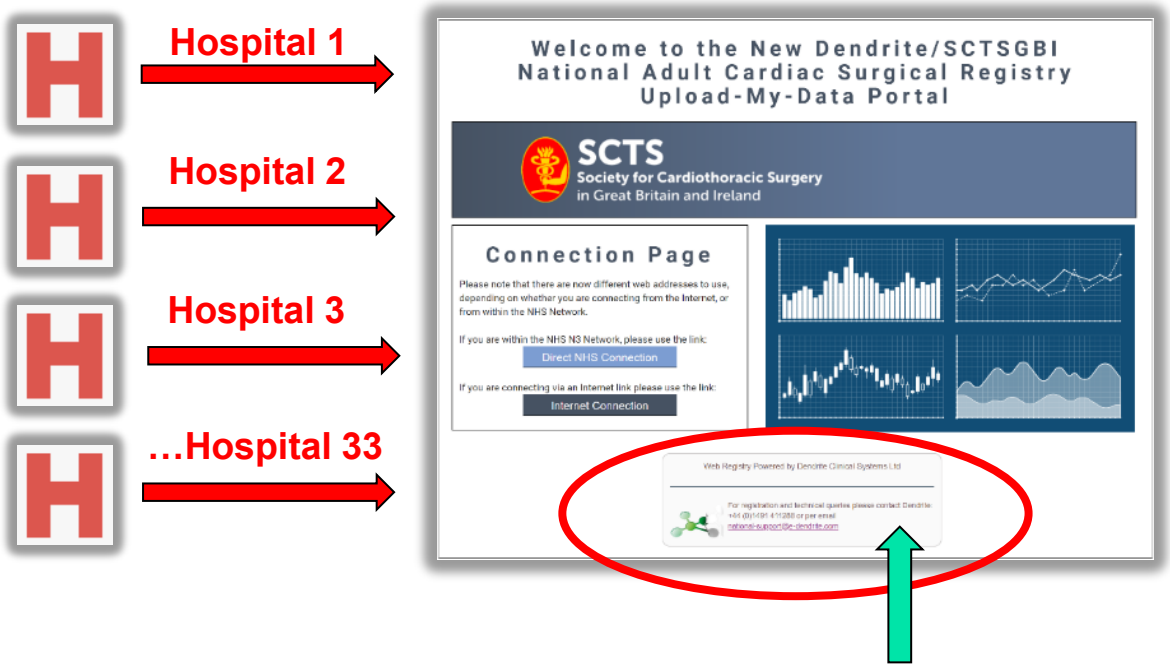
The PRESENT- On-line Benchmarking



Modernisation

Central Dendrite Registry powered by InterSystems Iris uploading data from multiple sources

……UK cardiothoracic centres hospitals upload their data to the central Dendrite/SCTS National Cardiac Surgical Web-Registry

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The Dendrite/SCTS UK National Registry *offers on-line Real-Time Benchmarking*

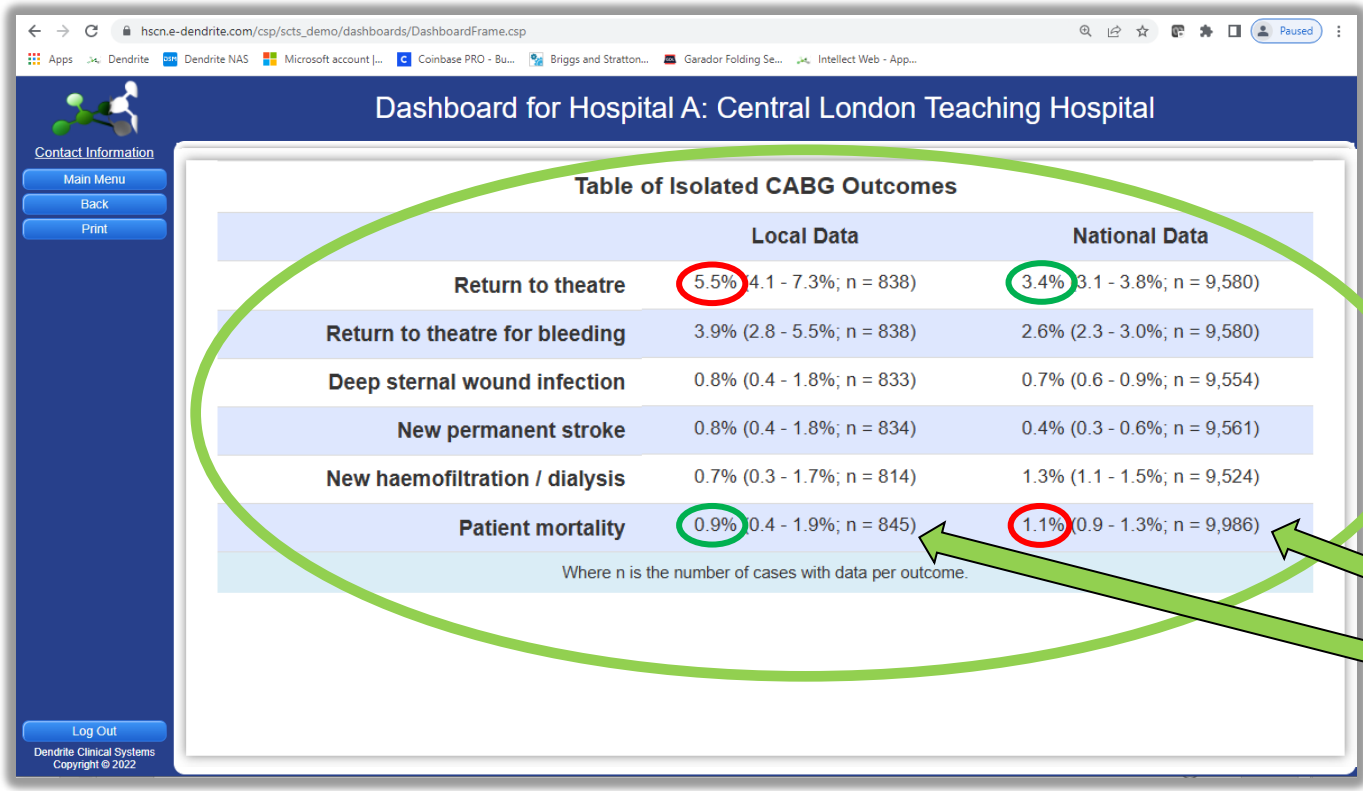

Table of Isolated CABG Outcomes

	Local Data	National Data
Return to theatre	5.5% (4.1 - 7.3%; n = 838)	3.4% (3.1 - 3.8%; n = 9,580)
Return to theatre for bleeding	3.9% (2.8 - 5.5%; n = 838)	2.6% (2.3 - 3.0%; n = 9,580)
Deep sternal wound infection	0.8% (0.4 - 1.8%; n = 833)	0.7% (0.6 - 0.9%; n = 9,554)
New permanent stroke	0.8% (0.4 - 1.8%; n = 834)	0.4% (0.3 - 0.6%; n = 9,561)
New haemofiltration / dialysis	0.7% (0.3 - 1.7%; n = 814)	1.3% (1.1 - 1.5%; n = 9,524)
Patient mortality	0.9% (0.4 - 1.9%; n = 845)	1.1% (0.9 - 1.3%; n = 9,986)

Where n is the number of cases with data per outcome.

and receive:

- ✓ **instant**
- ✓ **on-line**
- ✓ **real-time**
- ✓ **benchmarking of surgical outcomes**
- ✓ **compare local hospital results to national results**

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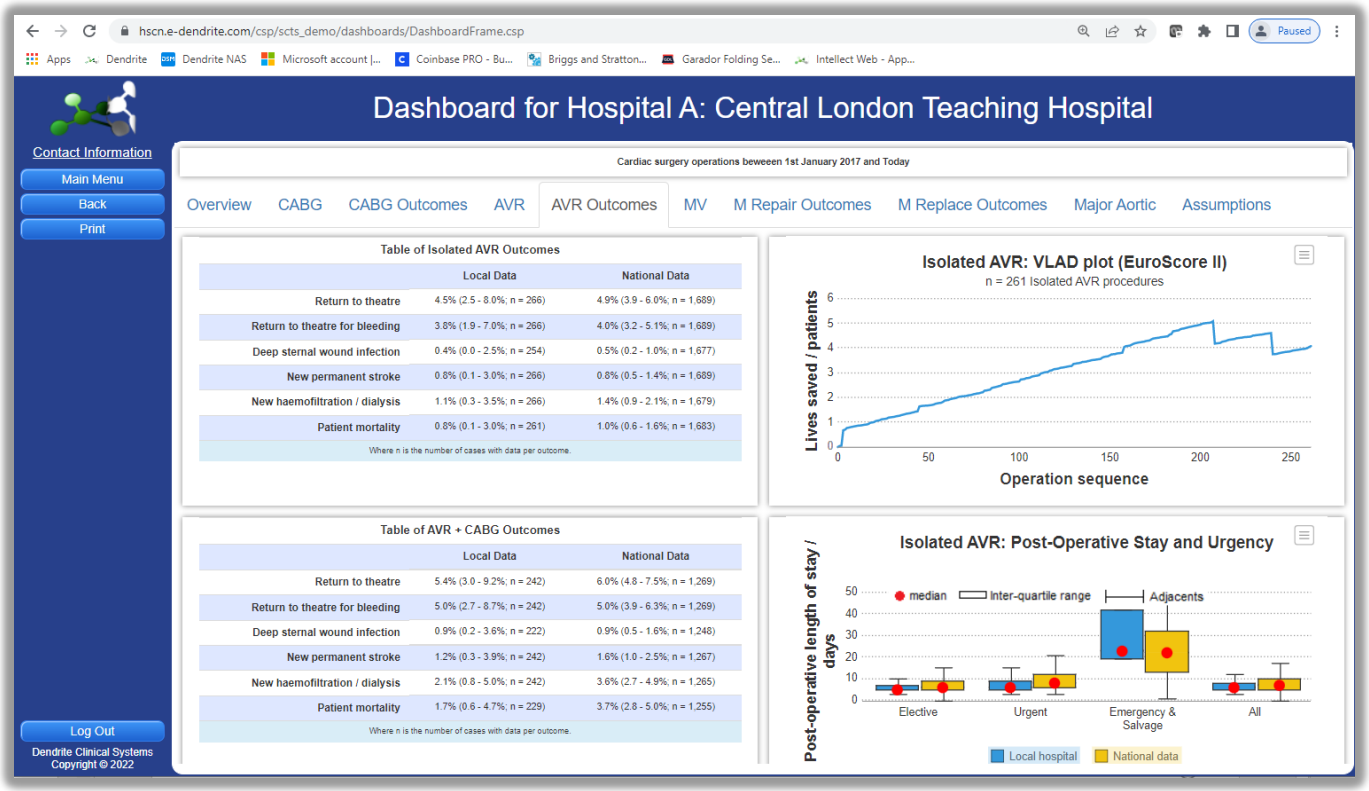
The Dendrite/SCTS UK National Registry *offers on-line Real-Time Benchmarking*



and receive:

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- ✓ **compared to national results**
- ✓ **risk-adjusted analyses**

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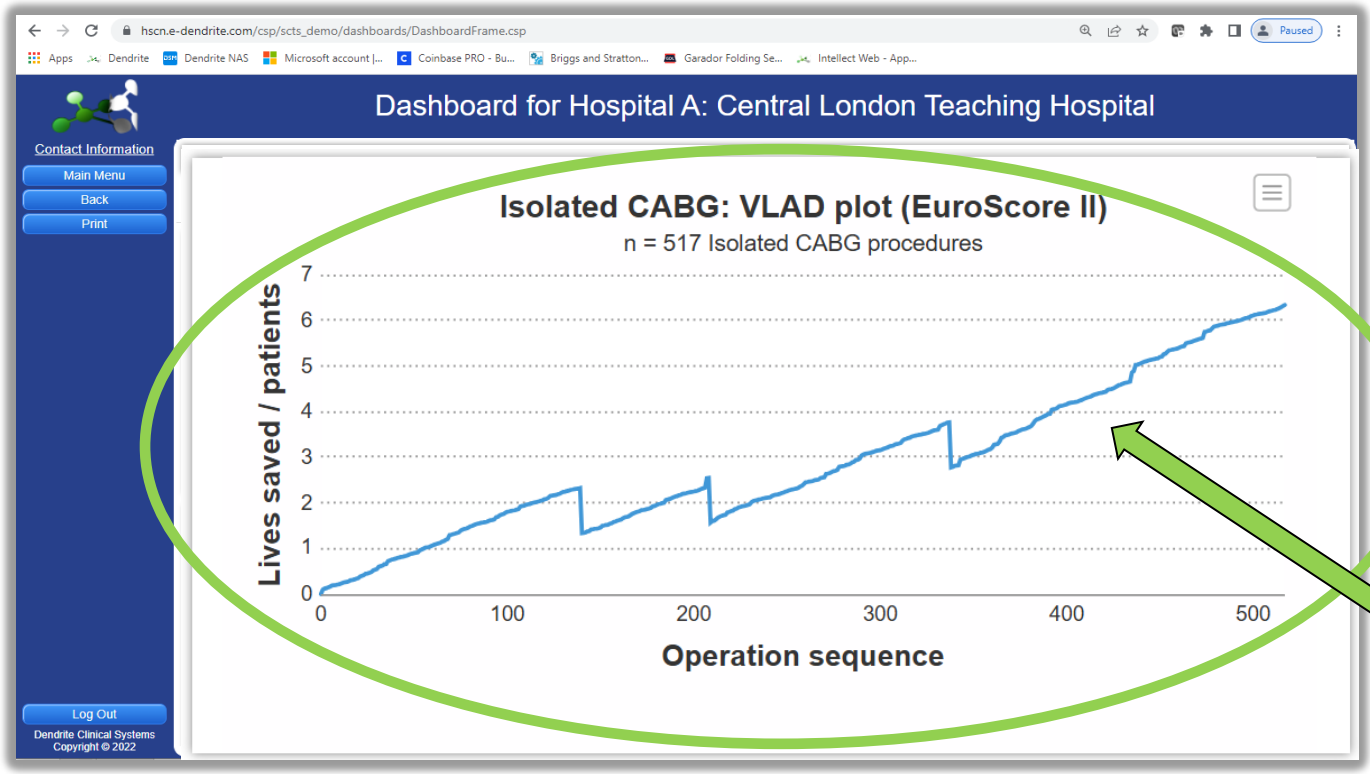
The Dendrite/SCTS UK National Registry *offers on-line Real-Time Benchmarking*



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- ✓ **compared to national results**
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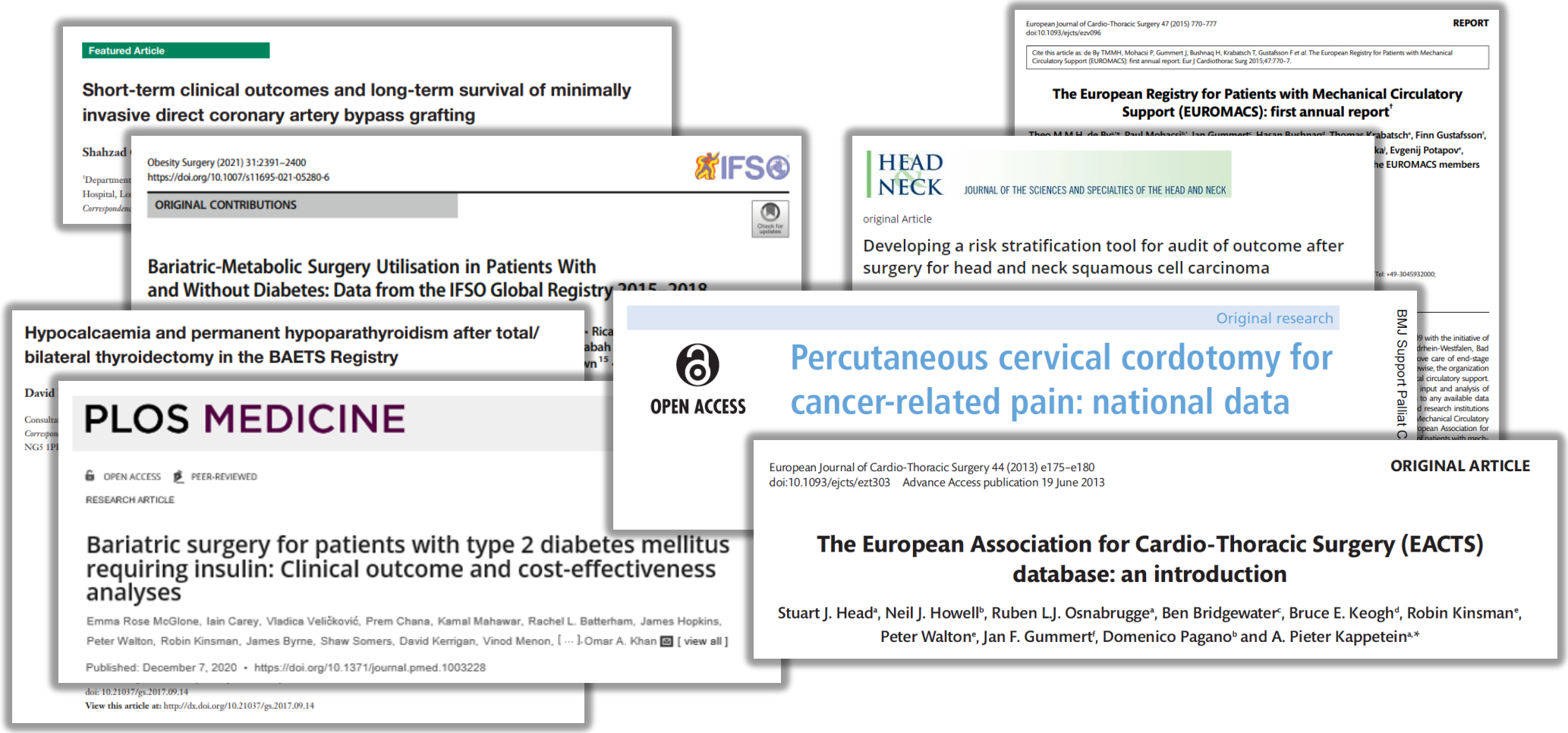
To date - Clinical Research Output from UK Web-Registries >> 3,000+ papers



To the Question.....

What if the clinical data we've spent *decades* collecting could do more than retrospective audit ?

Can registries now *empower* patients ?

...Cardiac & Bariatric surgery examples

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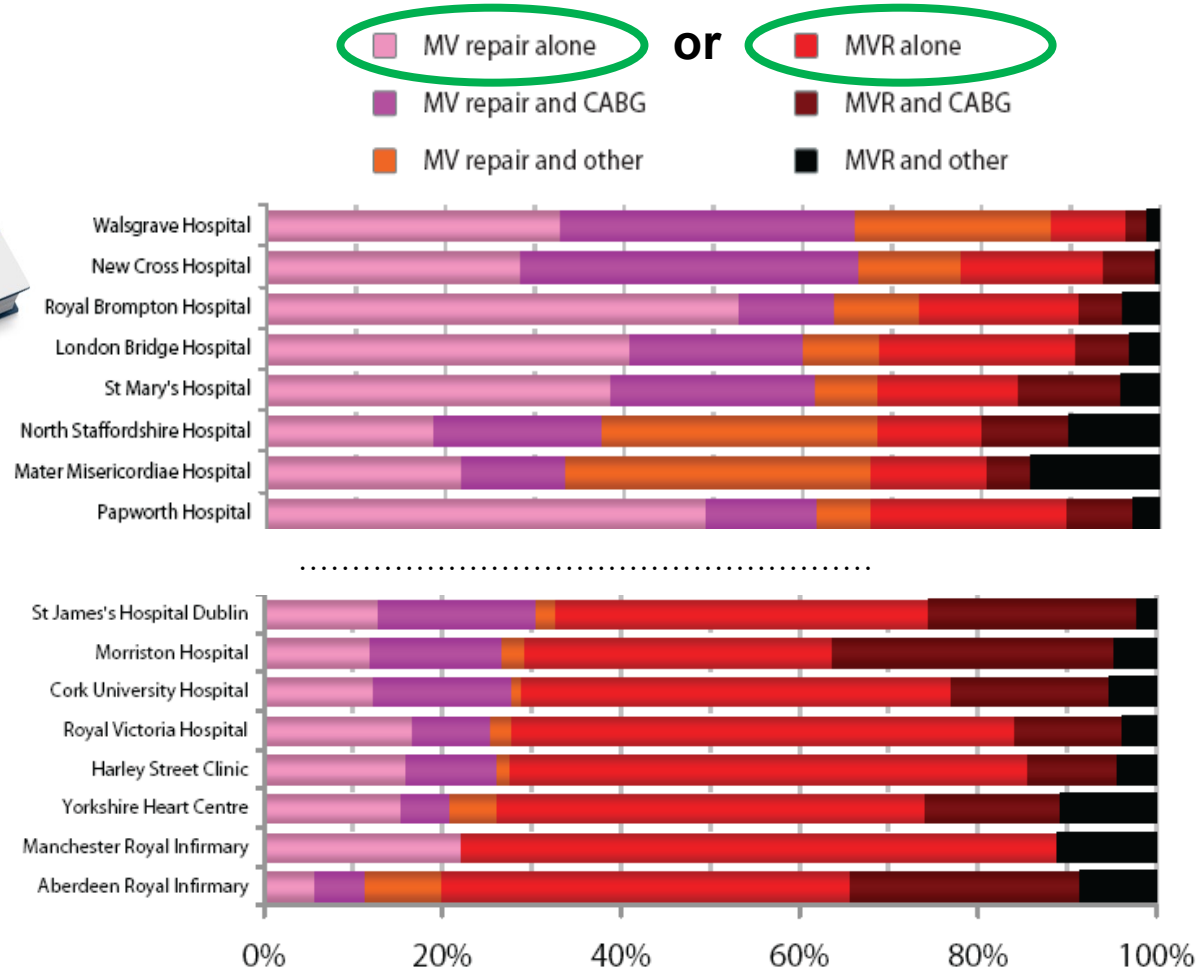
Registries can empower the patient

UK Blue Book

Huge differences in MV practice might warrant a question from the patient - which is the most suitable operation for me?



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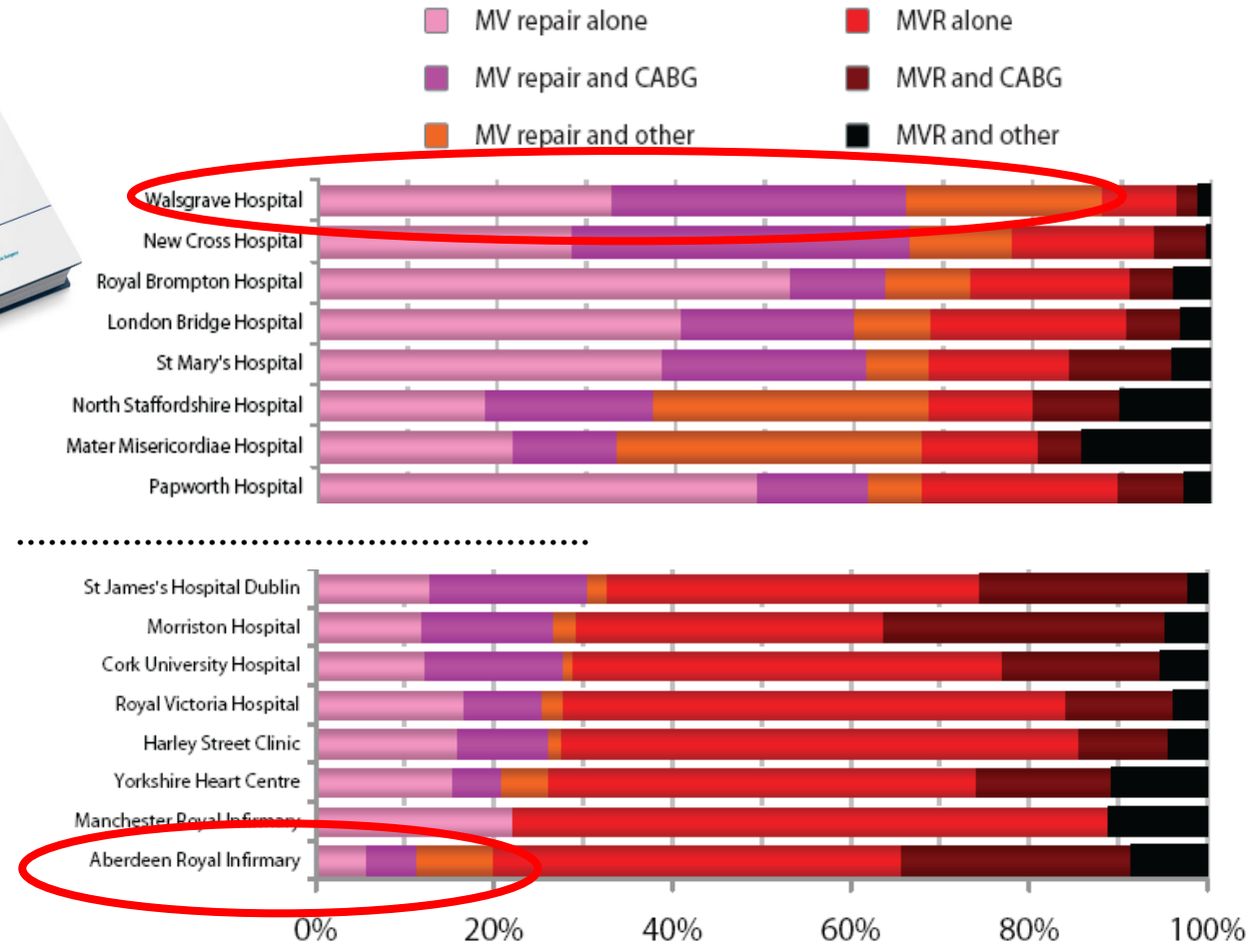
Registries can empower the patient

UK Blue Book

….. and why is there such a difference across the country & what is the impact on patient outcomes?



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Registry public portals for patients to access surgical outcome data....

Patients can View Hospital & Surgeon results

Endocrine Surgery

Bariatric Surgery

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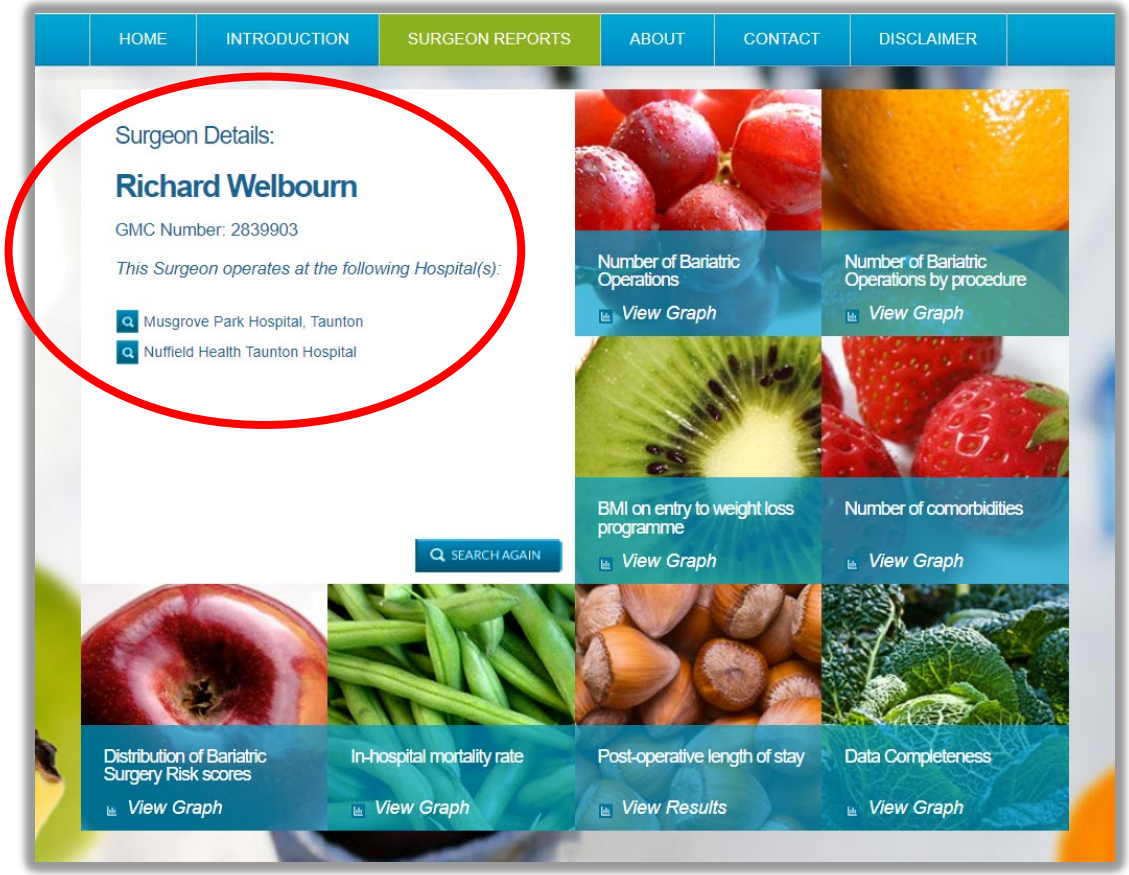
Registry public portals for patients to access surgical outcome data....



Patients can view either Hospital or Surgeon results

(Bariatric Surgery public portal example shown here)

Surgeon activity, patient demographics, surgical practice & mortality rates are all available to see

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Registry public portals for patients to access surgical outcome data....

Via the Public Portal Surgeon activity & pattern of practice (and outcomes) can be viewed versus national rates

(example here is for a UK Bariatric Surgeon)

Key Registry Stakeholders

- ✓ Doctors
- ✓ Professional Societies
- ✓ Patients

Who is next?

Governments & Commissioners of Care

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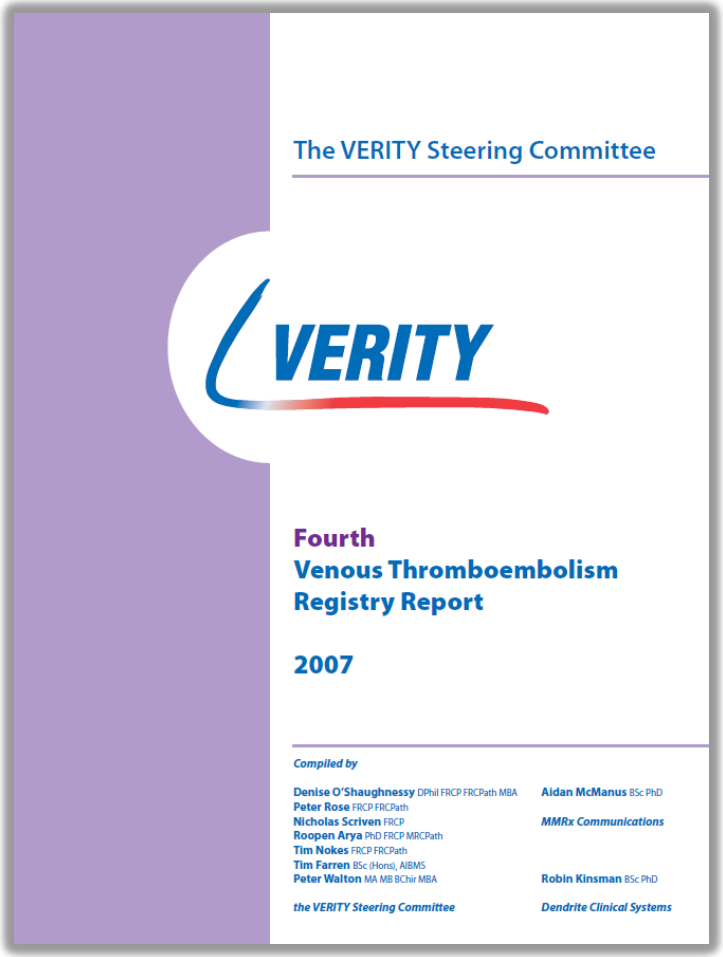
Example Dendrite Registry Influencing Protocols



The UK "Verity" Venous Thrombo-embolism Registry collected data on ~ 56,000 patients with a DVT and/or Pulmonary Embolus and published 4 National Registry Reports along with ~ 30 scientific papers and posters.

This registry was sponsored by Sanofi-Aventis, it ran successfully for 8 years and the registry data informed the UK Health Select Committee on its national strategy for prevention of thrombo-embolism in patients routinely admitted to UK hospitals.

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Example Dendrite Registry Influencing Protocols

House of Commons
Health Committee

The Prevention of Venous Thromboembolism in Hospitalised Patients

Second Report of Session 2004–05

Report, together with formal minutes, oral and written evidence

Ordered by The House of Commons to be printed 23 February 2005

VERITY

References

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7 Heit J. Venous thromboembolism epidemiology: implications for prevention and management. Semin Thromb Hemost 2002;28(2):3–13.

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Winds of Change – Push for more Transparency driven by Government, the Public and the Press

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Governments eventually “catch up” !

Establishing Operational Excellence

NHS England

Establishing Operational Excellence is a programme which is a key enabler in delivering the UK Government’s 10 Year Health Plan.

EOE includes six initiatives; platform modernisation, data flows transformation, **outcomes and registries**, Artificial Intelligence-enabled services, Mental Health Act digitisation and Strategic Transformation and Change Support and they are underpinned by the NHS Federated Data Platform (FDP).

The vision is a modern, resilient NHS infrastructure that delivers enhanced operational processes that are efficient, safe and resilient through streamlined data flows, Artificial Intelligence-enabled insights, trusted outcomes, and secure, future-proof platforms.

Tender released in 2026 to set up 300+ Registries

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Well it should now be all downhill !

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1. BIG Caveat with Gov. run registries

Who owns the data ?

Who can access the data ?

(NICOR example)

...how will it be used ?

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2. The Elephant in the room

GDPR !

- Assign Data Controller Role
- Assign Data Processor Role
- Ensure NHS IG Toolkit compliance
- Secure server – encrypted data
- Patient Consent for personal data
- Patient Consent for e-mail PROMS
- Tight user security controls
- Opt in/opt out processes ?? s251
- Privacy notices

- Keep all data safe and secure!

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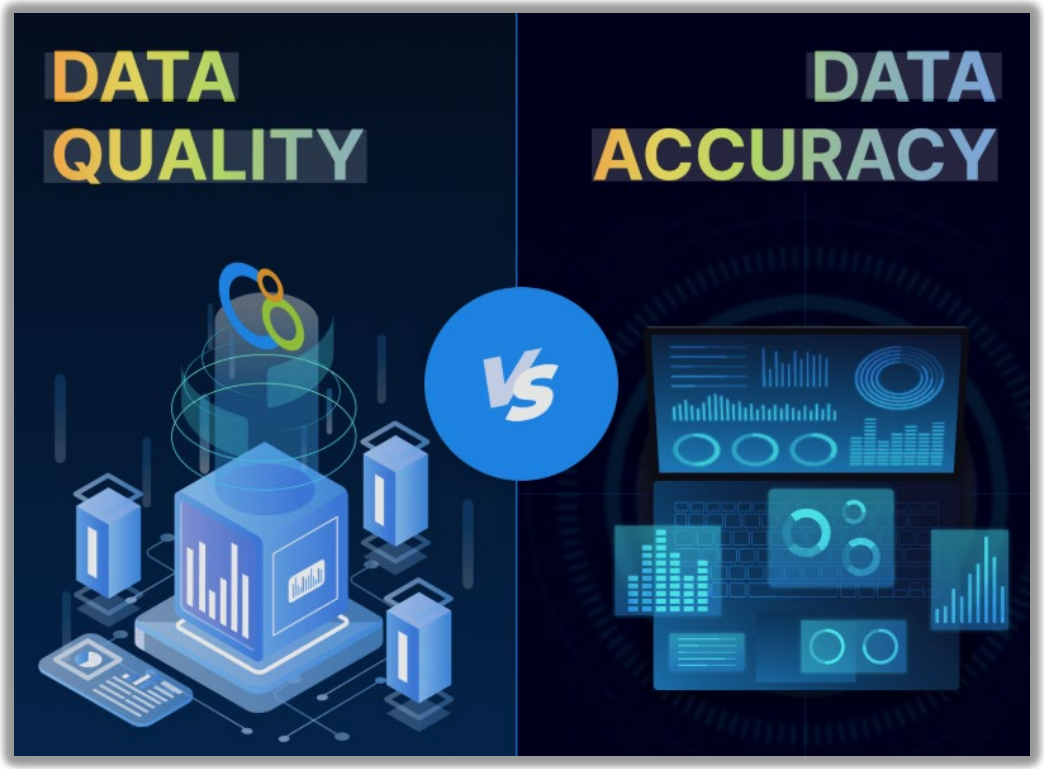
3. Quality of the Data Sources



Direct-Data-Entry (by whom?)

and/or

Electronic Upload

- from: existing registries
- from: EMRs/EHRs
- from: NHS systems
- from: Patient Apps
- from: Other sources

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4. Cyber Security Threat

Cyber attacks are a real and present danger to healthcare data

.....even more so with AI

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5. Statistical Knowledge

J Thorac Cardiovasc Surg 1994;107:914-924

SURGERY FOR CONGENITAL HEART DISEASE

Analysis of a cluster of surgical failures: Application to a series of neonatal arterial switch operations

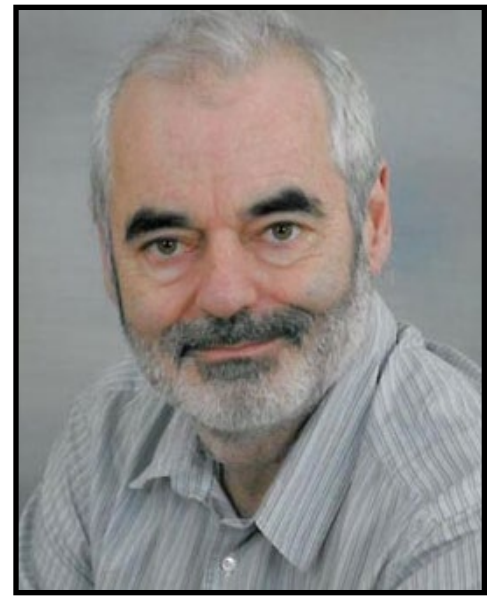
Marc R. de Leval, MD, FRCS, Katrien François, MD (by invitation), Catherine Bull, MRCP (by invitation), William Brawn, FRCS (by invitation), David Spiegelhalter, PhD (by invitation)

London, England

From the Cardiothoracic Unit, Hospital for Sick Children, Great Ormond Street, London, England.

Address for reprints: M.R. de Leval, MD, Cardiothoracic Unit, Hospital for Sick Children, Great Ormond Street, London WCIN3JH, England.

Sequential Outcome Analysis



Prof. Sir David Spiegelhalter
Winton Professor of the Public Understanding of Risk

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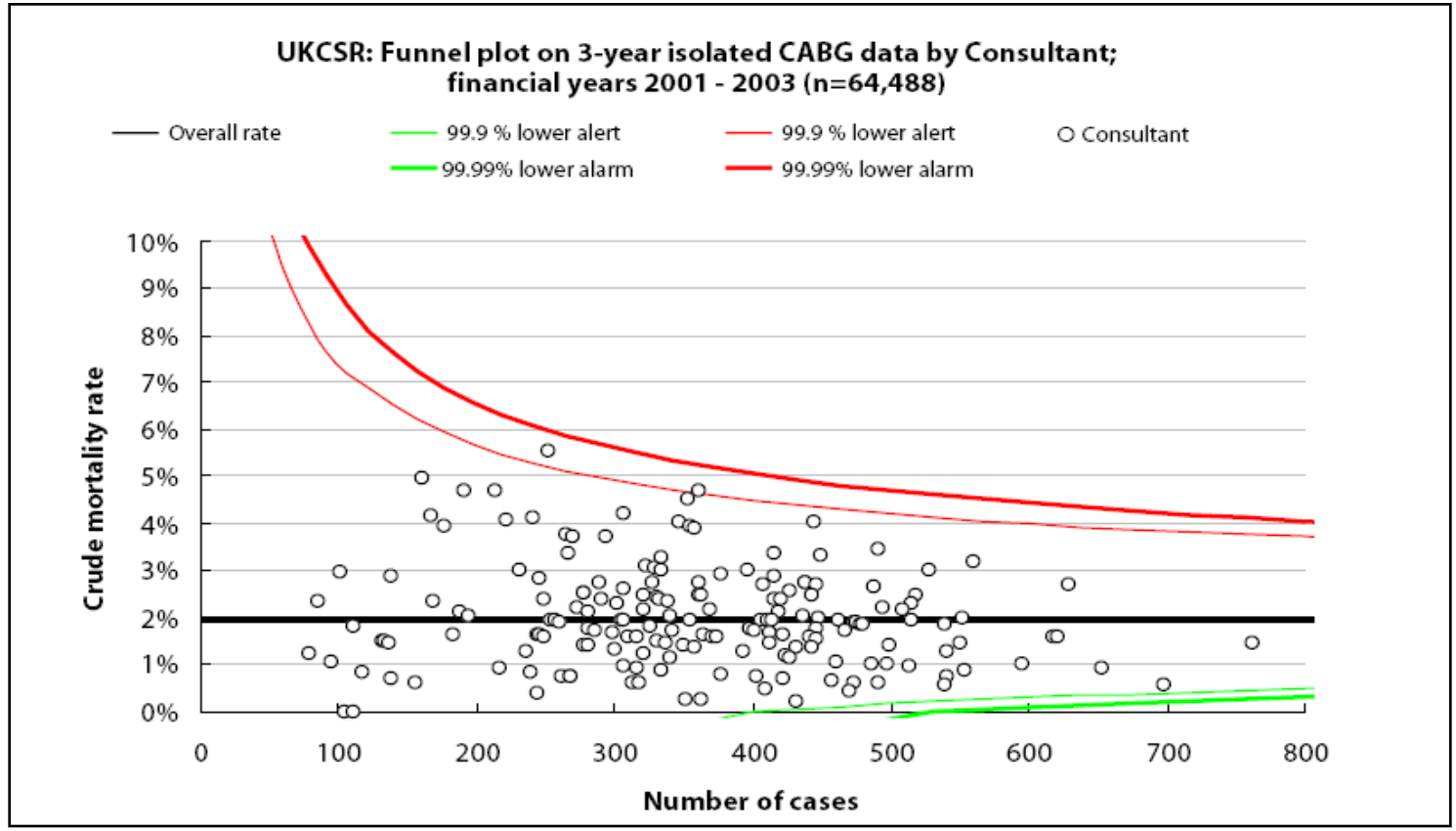
Get the Maths right!

Funnel plot demonstrates volume/outcome relationship on a surgeon-by-surgeon basis



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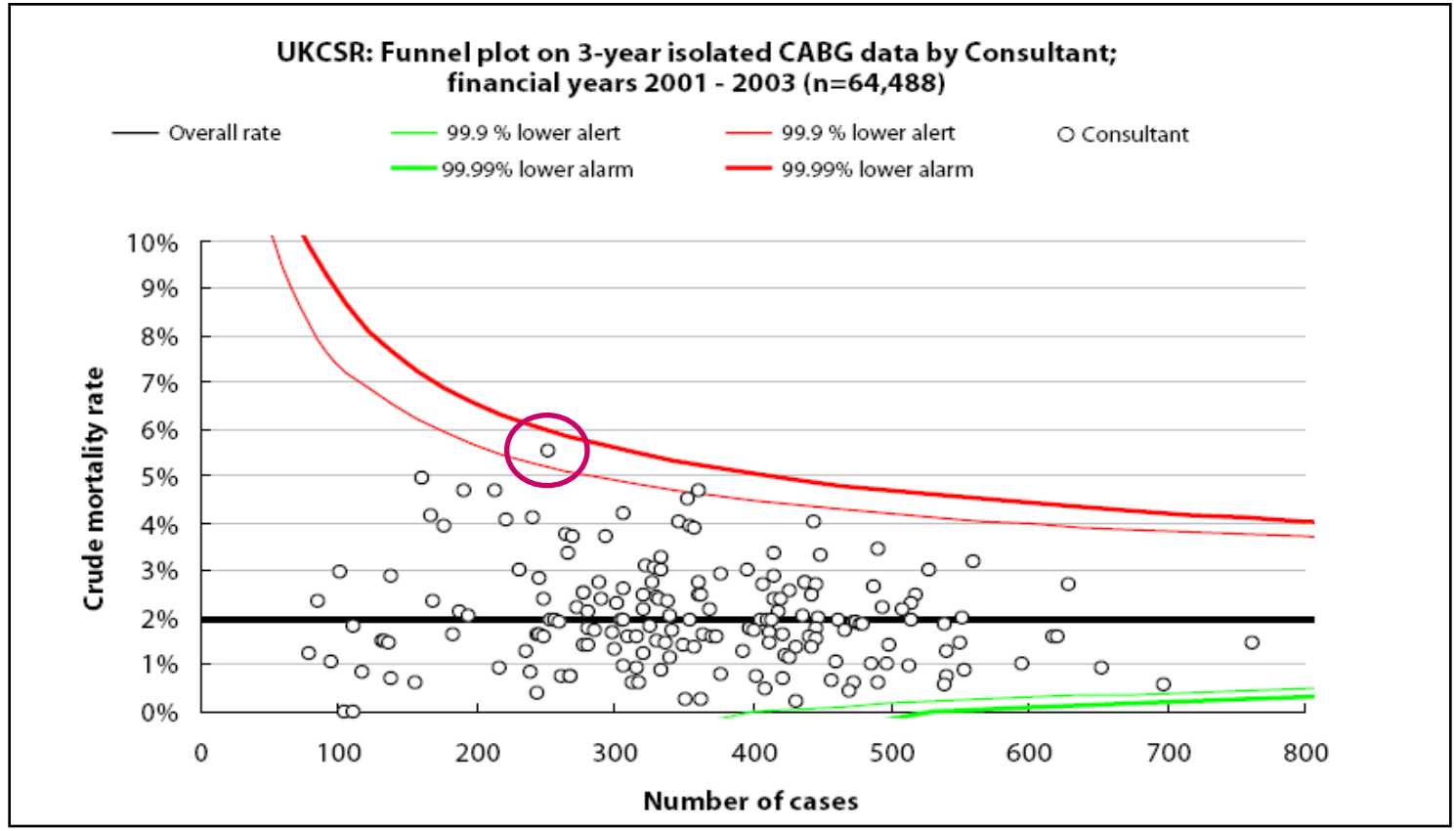
Get the Maths right!

Understand
What is an
“Outlier” ?



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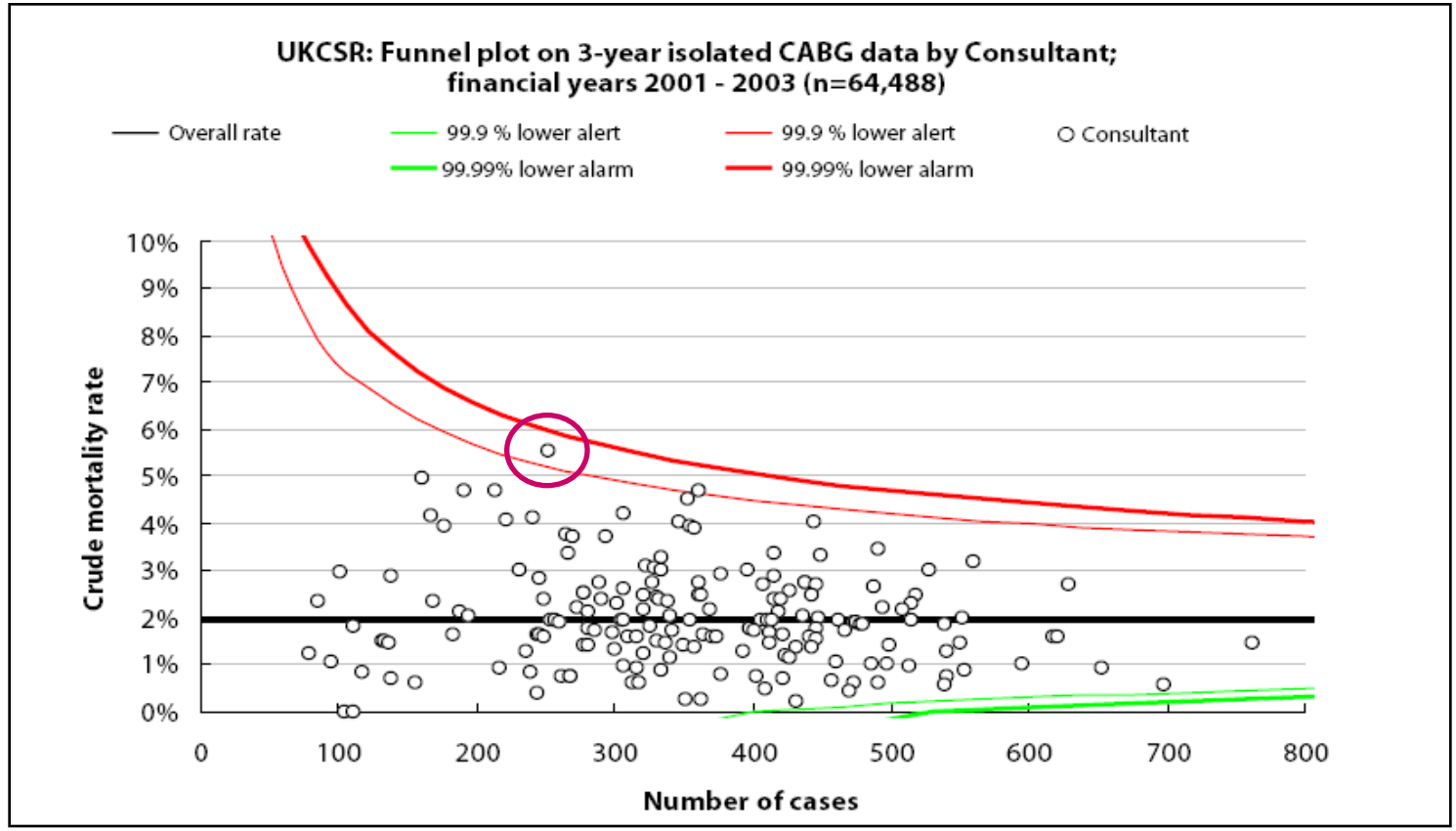
Get the Maths right!

Understand
What is an "Outlier"
…….and what it is NOT



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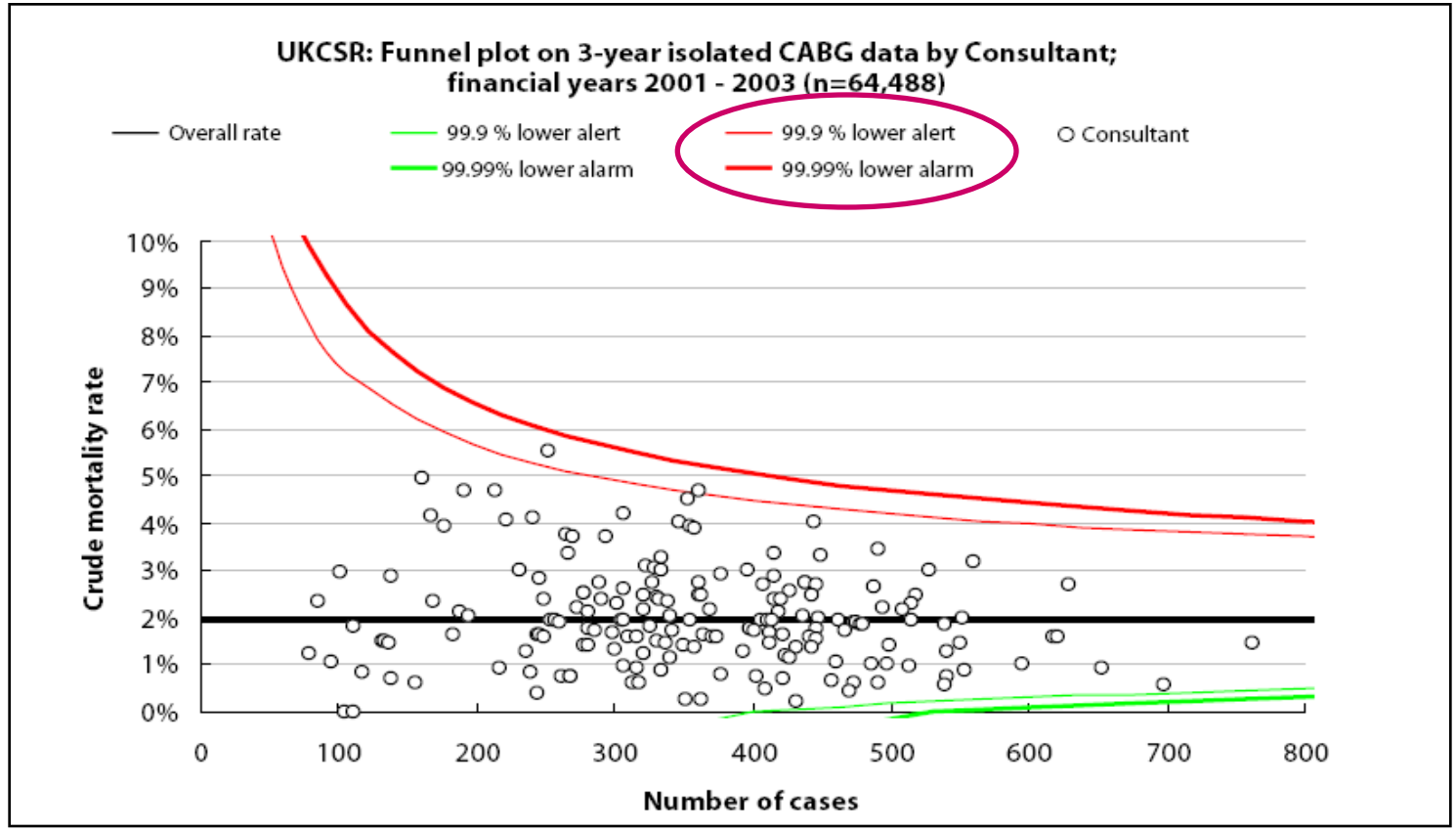
Get the Maths right!

If you are going to place outlier data in the public domain – make the control limits "understandable"



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Get the Maths right!

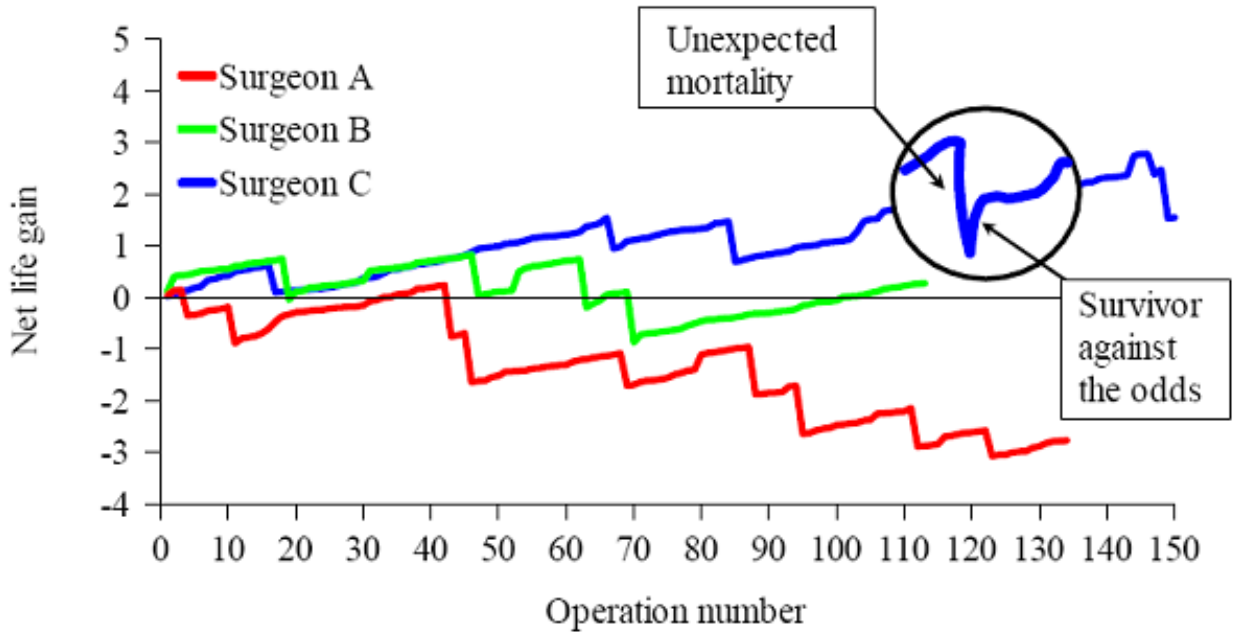

Figure 4. An illustration of VLAD plots for comparing peri-operative mortality rates for different (fictitious) surgeons

Progression in presentation by adjusting for risk
The VLAD Plot

Steve Gallivan
University College London

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The Power of a Registry to guide health service commissioning

Bariatric Surgery Suspended In Kuwait

MAY 15

According to Kuna.net's recent post, The Online Kuwait News Agency, Dr. Mohammad Al-Haifi, the Kuwaiti minister of health, has ordered a temporary suspension of bariatric surgery, also known as weight loss surgery, throughout the country. The suspension will run for a minimum period of 3 months during which time current medical protocols and regulations will be updated. The suspension is to take effect on the 1st of June 2013 and run till the 1st of September 2013. A temporary panel of doctors and surgeons, appointed by the minister of health, will be responsible in the creation of the new regulations and protocols in the safe provision of weight loss surgeries offered in the country. The panel will be chaired by Dr. Taleb Jumma, a surgeon and a consultant from the Amiri Hospital, a general hospital located in the Kuwait City with an estimated 400,000 patient visits per year.

The suspension will be applicable to all public and private hospitals throughout the whole country. The suspension will include both the gastric sleeve and gastric bypass weight loss surgeries.

Oil has brought great wealth to the Gulf, and to Kuwait, but has also brought a negative impact in their lifestyles too. The culture of fast cars and fast food have seen obesity and obesity-related illnesses rise every year. According to bbc.co.uk, obesity is a growing health problem in Kuwait with the 3rd highest rate of diabetes in the world. According to Forbes.com, Kuwait also ranked 8th on a 2007 list of fattest countries with a percentage of 74.2% of its citizens in the overweight category. Nauru, an island and a country in the south Pacific, tops the list with over 90% of its population overweight. In 2011 alone, the number of Kuwaitis undergoing weight loss procedures, including the gastric bypass weight loss surgery, was estimated to exceed 5,000 patients in that particular year.

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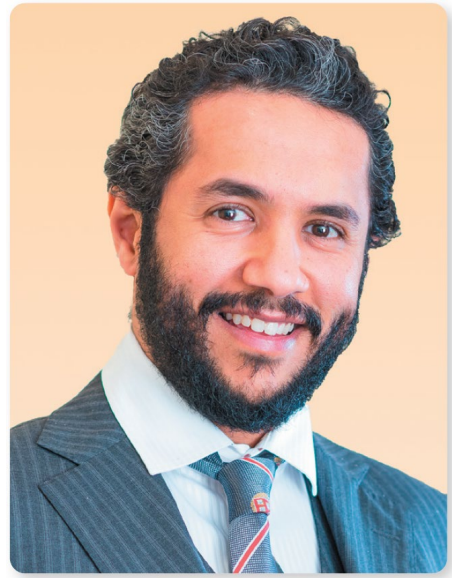
The Power of a Registry to guide health service commissioning



Sheikh Dr Salman Al Sabah

The State of Kuwait
Ministry of Health

MINISTRY OF HEALTH

شركة بدر سلطان وإخوانه ذ.م.م.
Bader Sultan & Brothers Company W.L.L.

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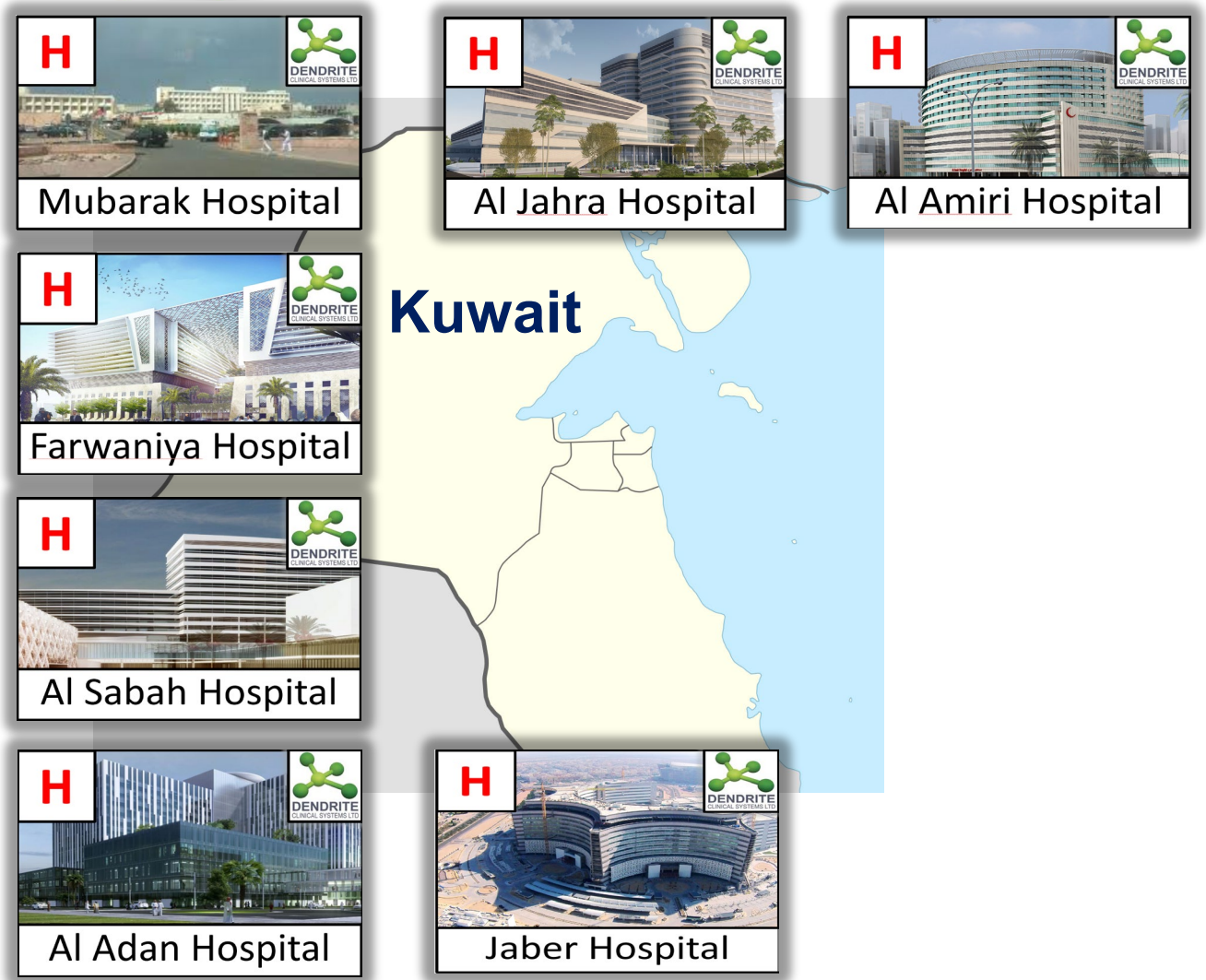
The Power of a Registry to guide health service commissioning



Dendrite installations in *each of 7* Kuwait Government Hospitals

MINISTRY OF HEALTH

The Power of a Registry to guide health service commissioning

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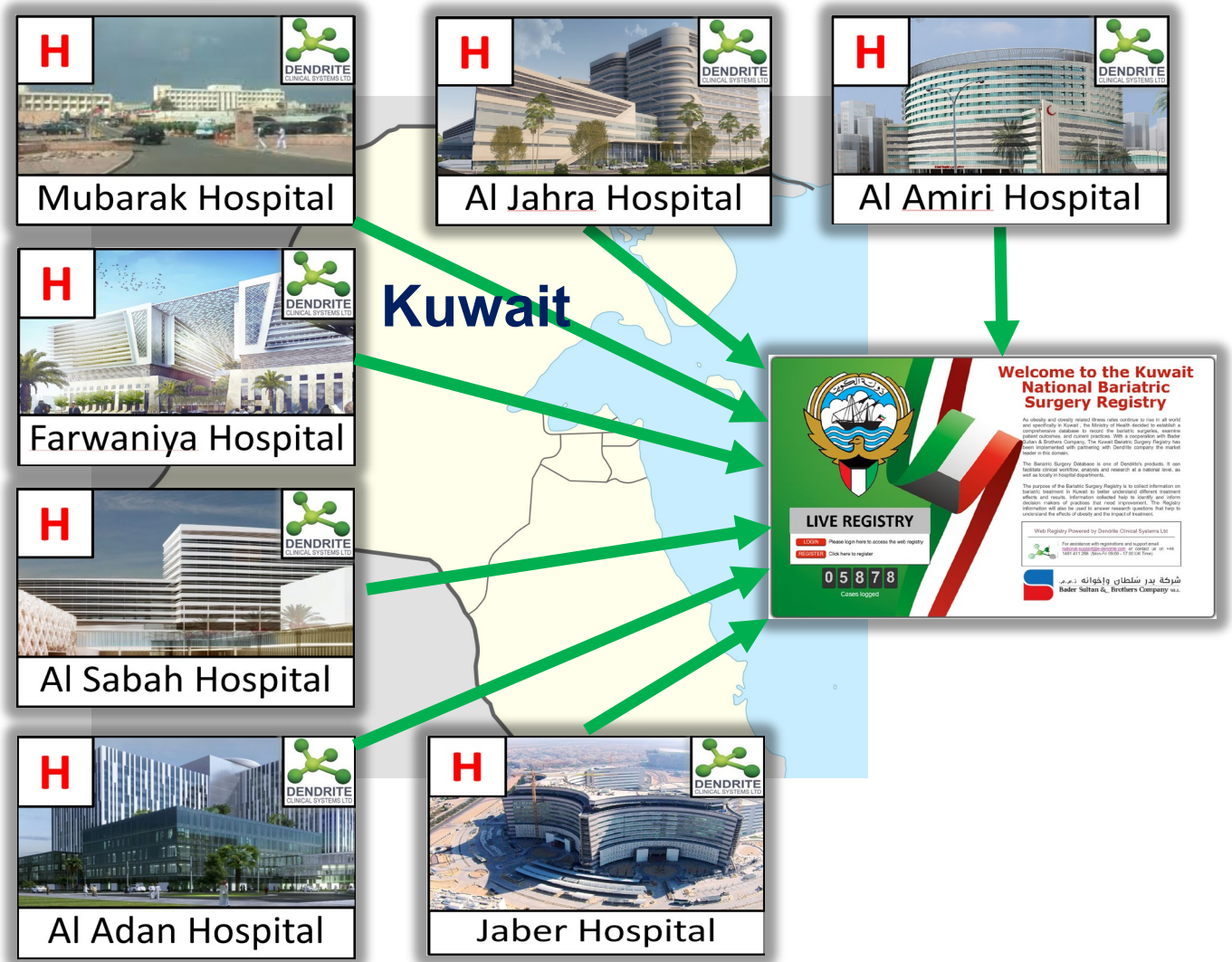

Dendrite installations in *each of* *7* **Kuwait Government Hospitals with daily streaming of data through to a single Dendrite National Registry platform inside Kuwait**

Dendrite Clinical Systems

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The Power of a Registry to guide health service commissioning

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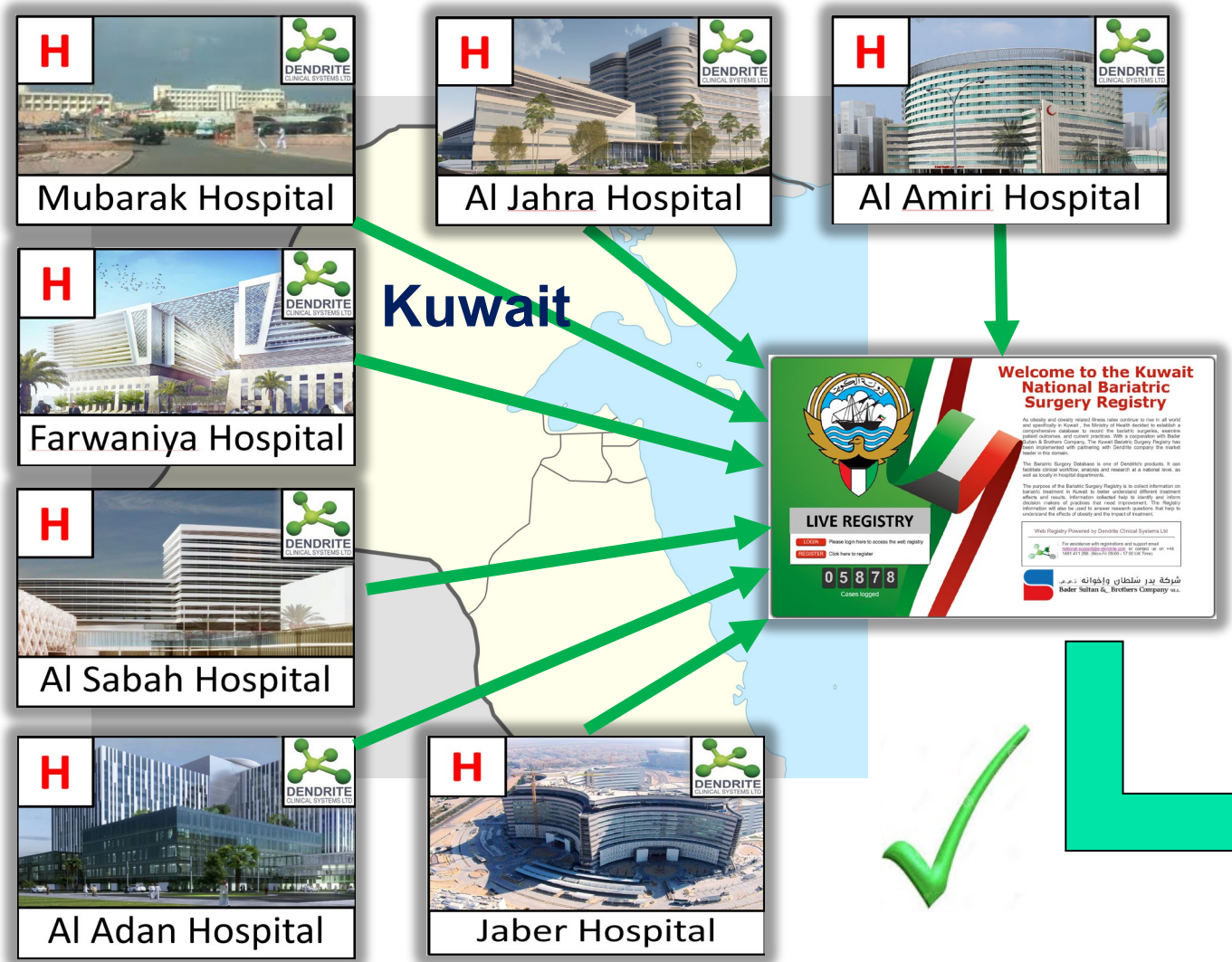

Dendrite installations in *each of* *7* **Kuwait Government Hospitals** with daily streaming of data through to a single Dendrite National Registry platform inside Kuwait **& onward to the Dendrite IFSO Global Registry**

Dendrite Clinical Systems
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reveal interpret improve

International Benchmarking Example

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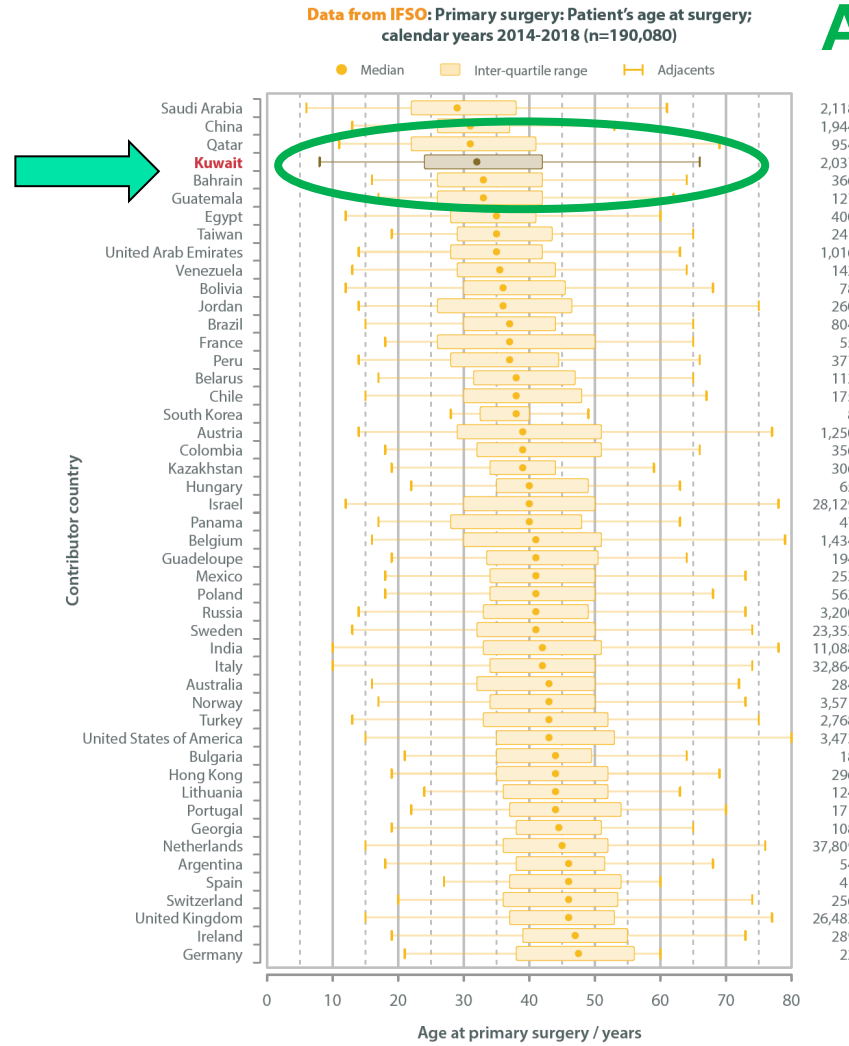
International Benchmarking Example

Age



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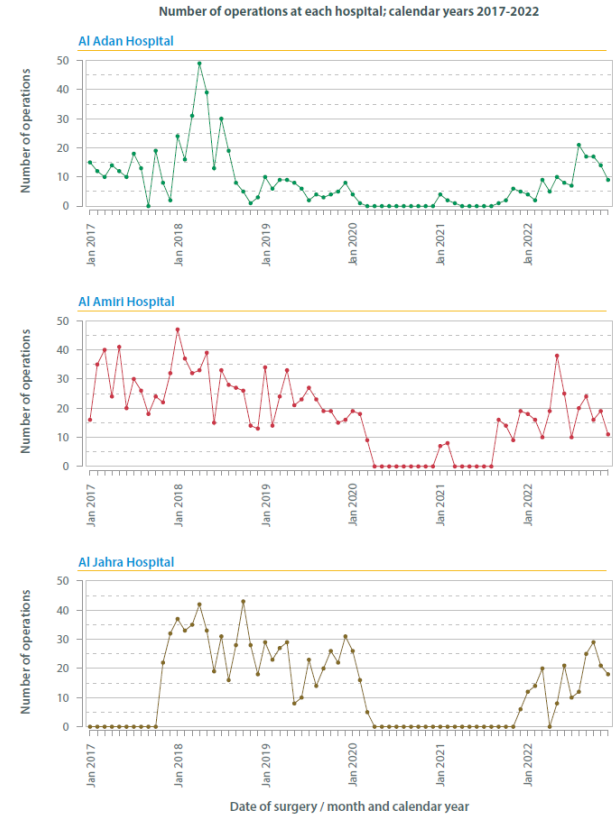
International Benchmarking Example

The Impact of a Pandemic



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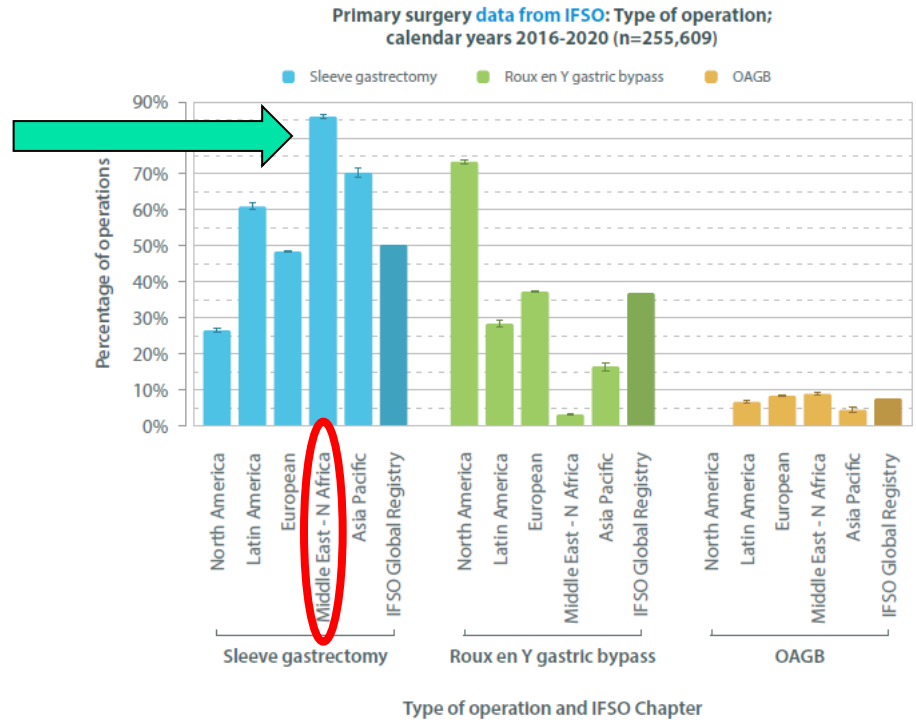
International Benchmarking Example

Differences in Operative Technique



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International Benchmarking Example

"We are VERY pleased to report that there have been no deaths from bariatric surgery since implementing the Dendrite Bariatric Surgery Web-Registry"

His Excellency Sheikh Dr Salman Al-Sabah
Chairman of the Kuwaiti Association of Surgeons

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Now.....and the Future !

MyeCare

The UK Prospective Real-World Registry

Generating Evidence to Improve Outcomes in Patients with AML Globally

ACT
ACCELERATING CLINICAL TRIALS FOR PATIENTS

DIDACT Foundation

UK Acute Myeloid Leukaemia Registry

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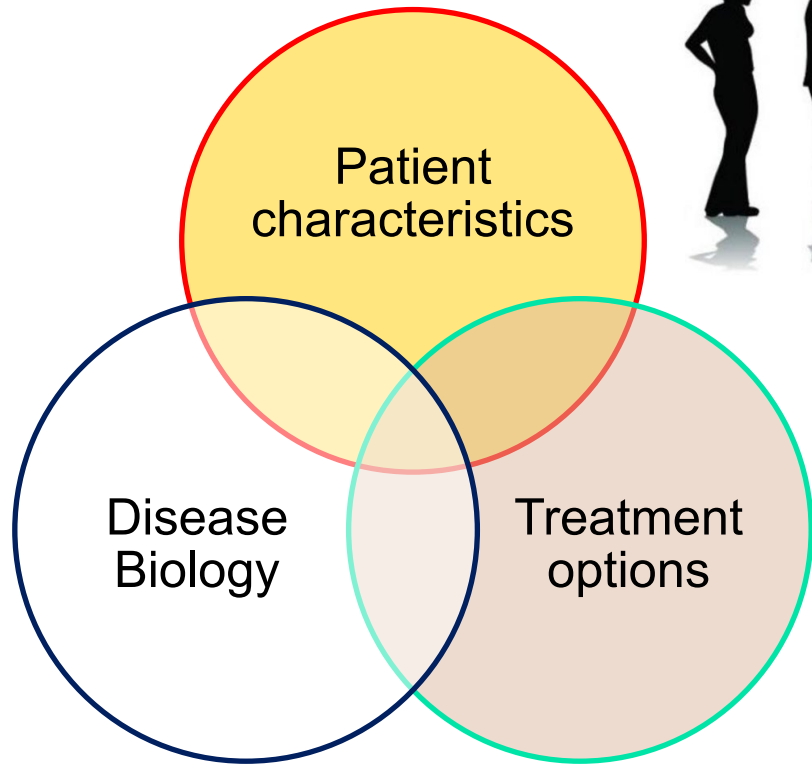
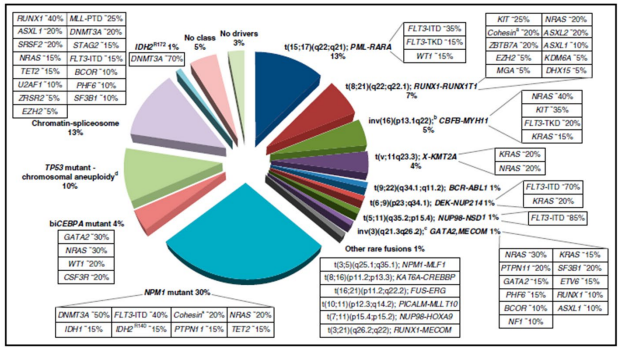
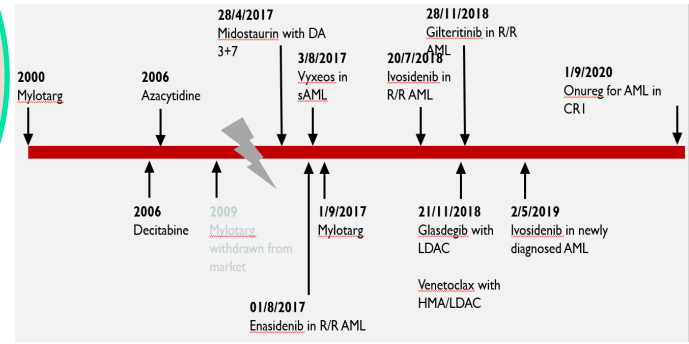
The Challenge: AML is a Heterogenous disease with complex treatment pathways

The aim of the registry is to focus on *real-world* outcome data on UK patients – especially in relation to clinical subgroups and patients of ethnic origins.







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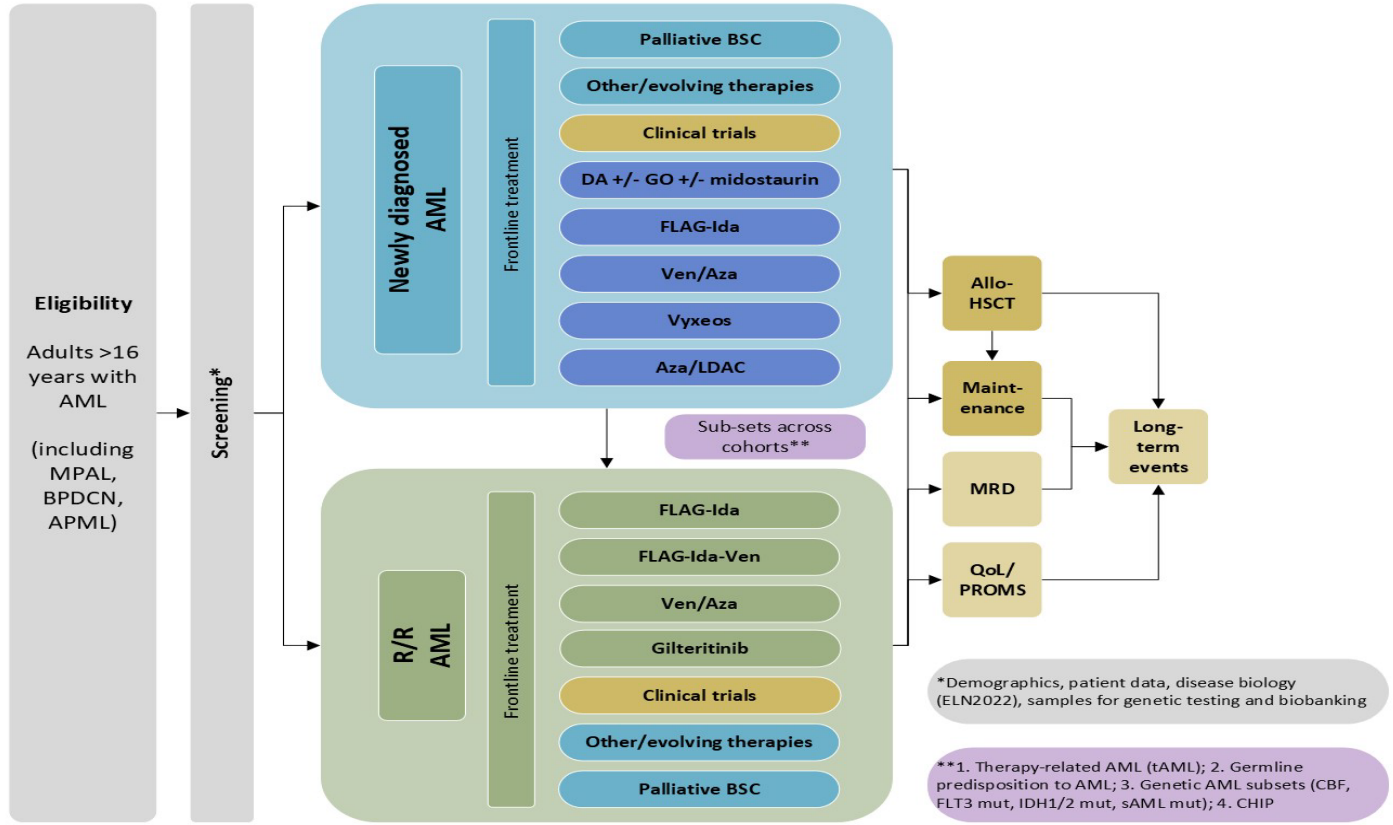
MyeCARE: Real World Evidence across all AML patient cohorts



Allo-HSCT = allogeneic haematopoietic stem cell transplantation; AML = acute myeloid leukaemia; APML = acute promyelocytic leukaemia; BPDCN = blastic plasmocytoid dendritic cell neoplasm; Aza = azacitidine; BSC = best supportive care; CBF = core binding factor; CHIP = clonal haematopoiesis of indeterminate potential; DA = daunorubicin & ara-C (cytarabine); FLAG-Ida = fludarabine, cytarabine, granulocyte-colony stimulating factor (G-CSF) and idarubicin; GO = gemtuzumab oxogamicin; LDAC = low-dose ara-C (cytarabine); QoL = Quality of Life; MPAL = mixed-phenotype acute leukaemia; MRD = measurable residual disease; mut = mutation; PROMS = patient-reported outcome measures; R/R = relapsed/refractory; sAML = secondary AML; Ven = venetoclax

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The Future !....is all about interoperability

Genomics England

Sample Sent

UK Acute Myeloid Leukaemia Registry

Uploading and returning data from Genomics England

Report Returned

...as a pdf report for attaching to the patient record

Based on the New Web-Registry Platform

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Today – interoperability in action !

my mhealth

3rd Party App
"myAsthma"

API

follow-up data automatically populates the Dendrite Severe Asthma Registry

Dendrite Clinical Systems

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Today – interoperability in action !

Fully automated
e-PROMs & e-PREMs
in action

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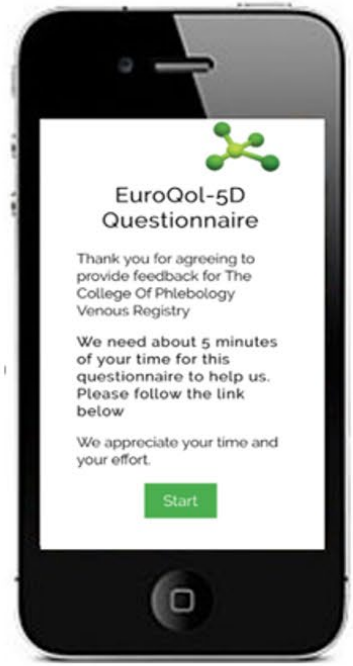
Today – interoperability in action !



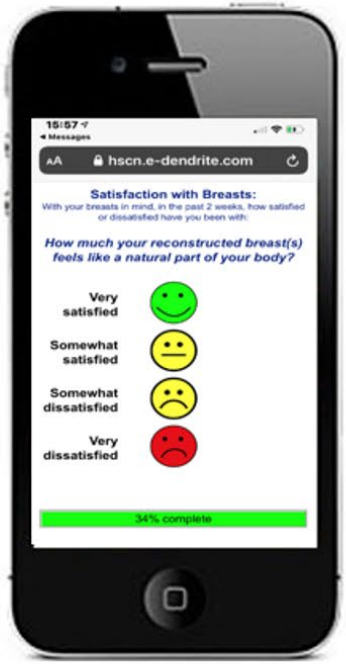
EuroQol-5D for:

NBSR NATIONAL BARIATRIC SURGERY REGISTRY

and…. THE COLLEGE OF PHLEBOLOGY™

HADS Anxiety & EORTC for:

The Rory Morrison Waldenström's Macroglobulinaemia UK Clinical Data Registry



Breast-Q and Enneking for:

BAPRAS

UK Flap Registry

Juniper and Allergy Quality of Life for:

bsaci improving allergy care through education, training and research

Key Registry Stakeholders

- ✓ Doctors
- ✓ Professional Societies
- ✓ Patients
- ✓ Governments & Commissioners of Care

Who is next?

Big Pharma & Medical Device Companies

The Future ! Useful Real-World-Data !

The UK's National Institute for Health and Care Excellence (NICE) and the Medicines and Healthcare products Regulatory Agency (MHRA) have **significantly intensified their alignment and expectations for Real-World Evidence (RWE)** to accelerate drug and medical device approvals. Rather than acting as a passive afterthought, RWE is now actively demanded to fill clinical trial gaps, ***particularly for rare diseases***, oncology, ***and complex medical devices***

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Example Global RWE Registry funded by Pharma

Global Anticoagulant Registry in the Field (**GARFIELD**) Study

Conducted by the Thrombosis Research Institute (London)

Target 55,000 patients

Enrolled 57,000+ patients

From 50 countries

96 scientific publications to date

Funded by: BAYER

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The Power of a Pharma Registry

Leads to Change in Client/Supplier Relationship

Pharma or MedTec Company

from Supplier

to trusted Collaborator

Medical Community

Providing True Disease Management Services where "Data is King"

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New Registry funded by Big Pharma

New Global TP53 Mutation Registry for Myeloid Tumours - 100% funding from Big Pharmaceutical companies wanting to just understand the disease epidemiological landscape & trajectory...there are no *current* drug therapies

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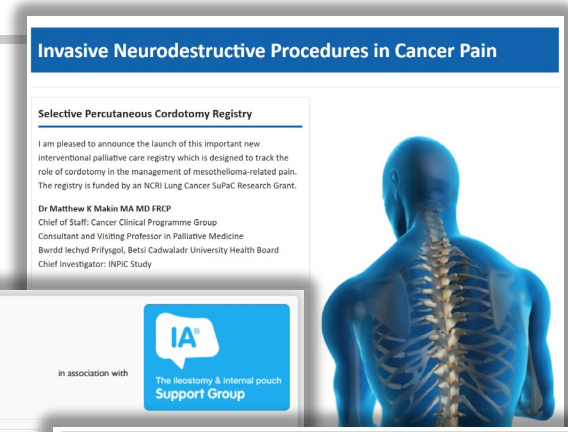
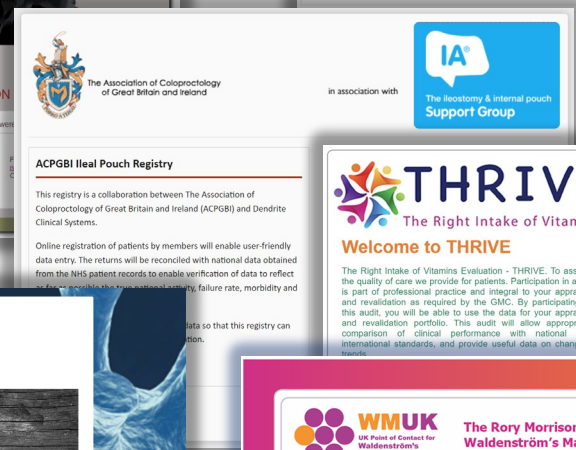
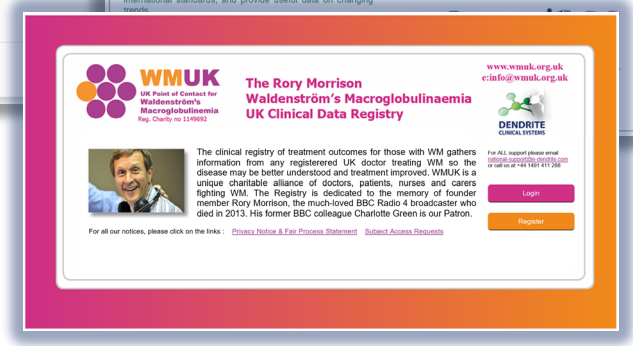
Examples of Dendrite Rare Disease & Rare Treatment Registries







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New Rare Disease Registry - example

debra Research
Treatments for EB

New Global Rare Disease Registry for Epidermolysis Bullosa (EB) commissioned in 2026 to link data from 50 Countries on 6 continents to track patient demographics, investigations & outcomes for a disabling disease with no current definitive treatment

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New Registry funded by Device Companies

reveal interpret improve

The Future ! ....working in partnership

We're currently very actively exploring using InterSystems AI LLM Agents to enhance Dendrite Registry Data Analysis & Reporting

....EXCITING early days – but as expected currently/definitely needs expert human scrutiny!

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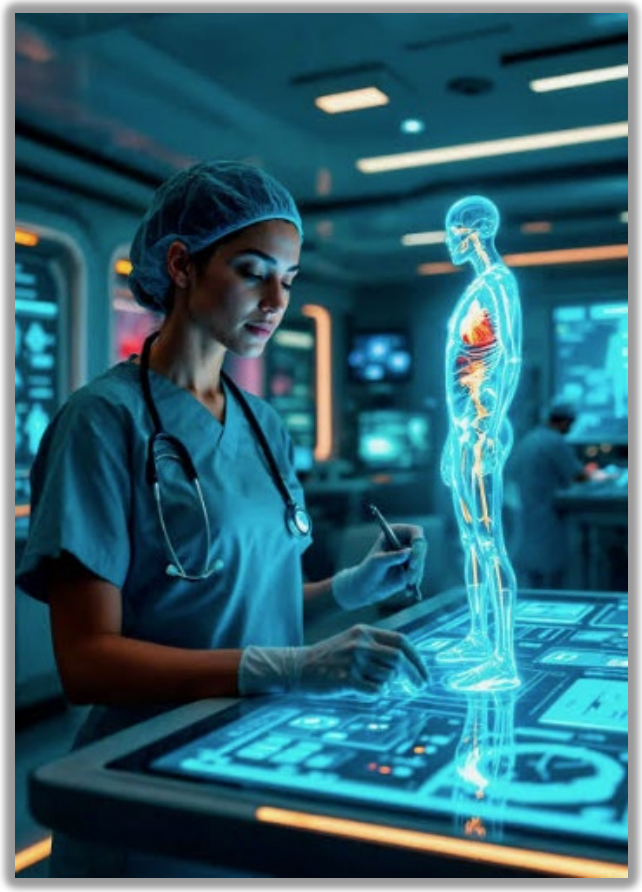
The Future !



Within the next 15-20 years *EVERY* medical & surgical investigation & treatment/procedure will be tracked on registries to *guide patients & doctors* to select the most appropriate disease management pathway *to get the right outcome for the right patient !*

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Thank you for your kind attention !

We're moving rapidly towards a new age of "Predictive Insight" in medicine and surgery using Real World Data from Registries to drive AI enabled clinical intelligence.....

peter.walton@e-dendrite.com