Public Health England

National Cancer Intelligence Network

Cancer Informatics in the ‘new NHS’: PHE and NCIN 18 months on….

Mick Peake
Clinical Lead, National Cancer Intelligence Network

The Health & Social Care Bill 2012: Two New Organisations from April 2013

- **NHS England**
  - "The purpose of NHS England is to use the £80bn commissioning budget to secure the best possible outcomes for patients"
  - To ensure the whole commissioning architecture is in place; will also commission some services directly
- **Public Health England (PHE)**
  - Information & Intelligence to support local PH and public making healthier choices
  - National Leadership to PH, supporting national policy
  - Development of PH workforce
  - A civil service function, not NHS

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Data Drivers

- Government
  - A spotlight on the role of data and transparency
- Commissioning
  - NHS Outcomes Framework
- Regulation
  - New regulation framework (CQC & Monitor)
- The ‘public’, patients and families
  - (e.g. ‘Friends and family test’)

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Providers of information in the new NHS

- Main sources/providers
  - Health & Social Care Information Centre (HSCIC)
  - National Audits
  - ONS
  - PHE (Civil Service)- Cancer Registries
  - NHS England Business Intelligence Teams (ATS/CSU)
- Information Intermediaries (e.g. CRUK, Dr Foster, MacMillan)

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Knowledge Directorate

- National Cancer Registration Service
- Analytical workforce from 8 registries moved into regional Knowledge and Intelligence Teams (KITs)
  - SSCRG Lead Area Work Programmes
  - Local contribution
- Health Intelligence Networks (HINs):
  - Mental Health, Maternal & Child Health, Cardiovascular & Diabetes, End of Life, **NCIN**

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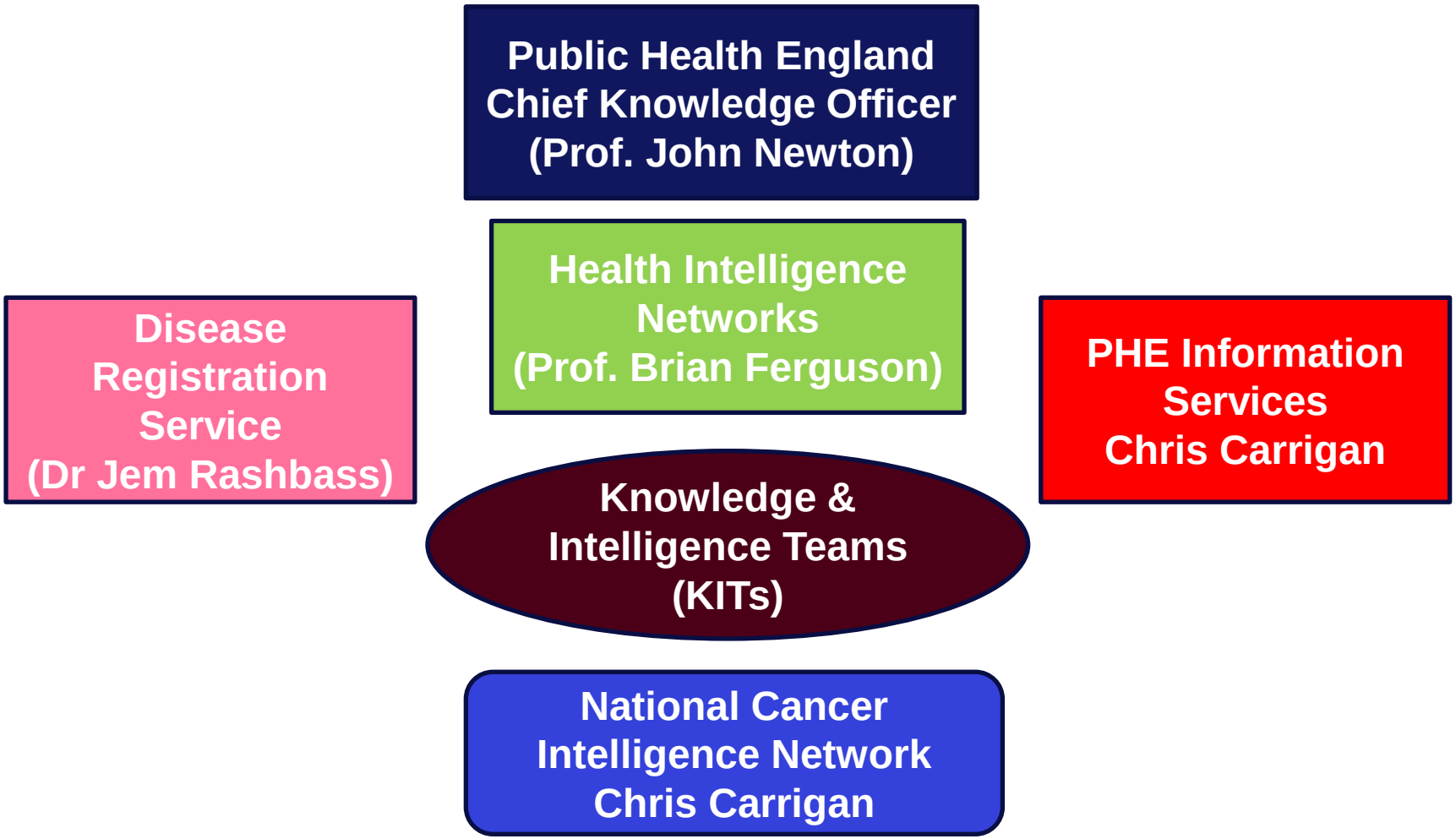
Emerging 'Intelligence' Structures



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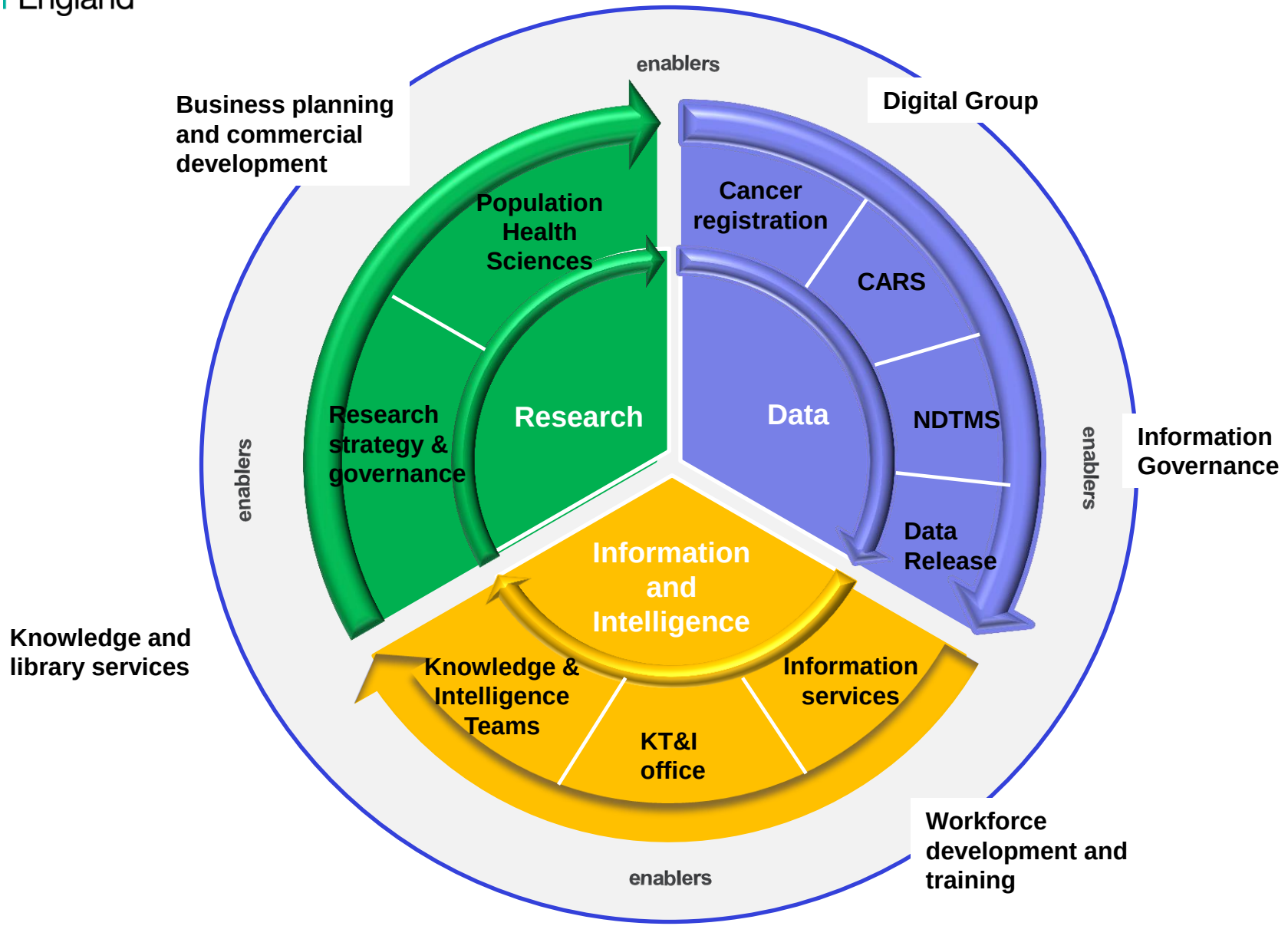
Chief Knowledge Office (CKO)



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The English National Cancer Registration System

- Comprehensive data collection and quality assurance over the entire cancer care pathway on all patients treated in England
- Single national system across England
- Routine electronic sources in registry practice
- Single integrated workforce – split off from the analytical work force
- Director of Disease Registration
- Evolving operational links with hospital leads
- Pan-England roll-out completed September 2013

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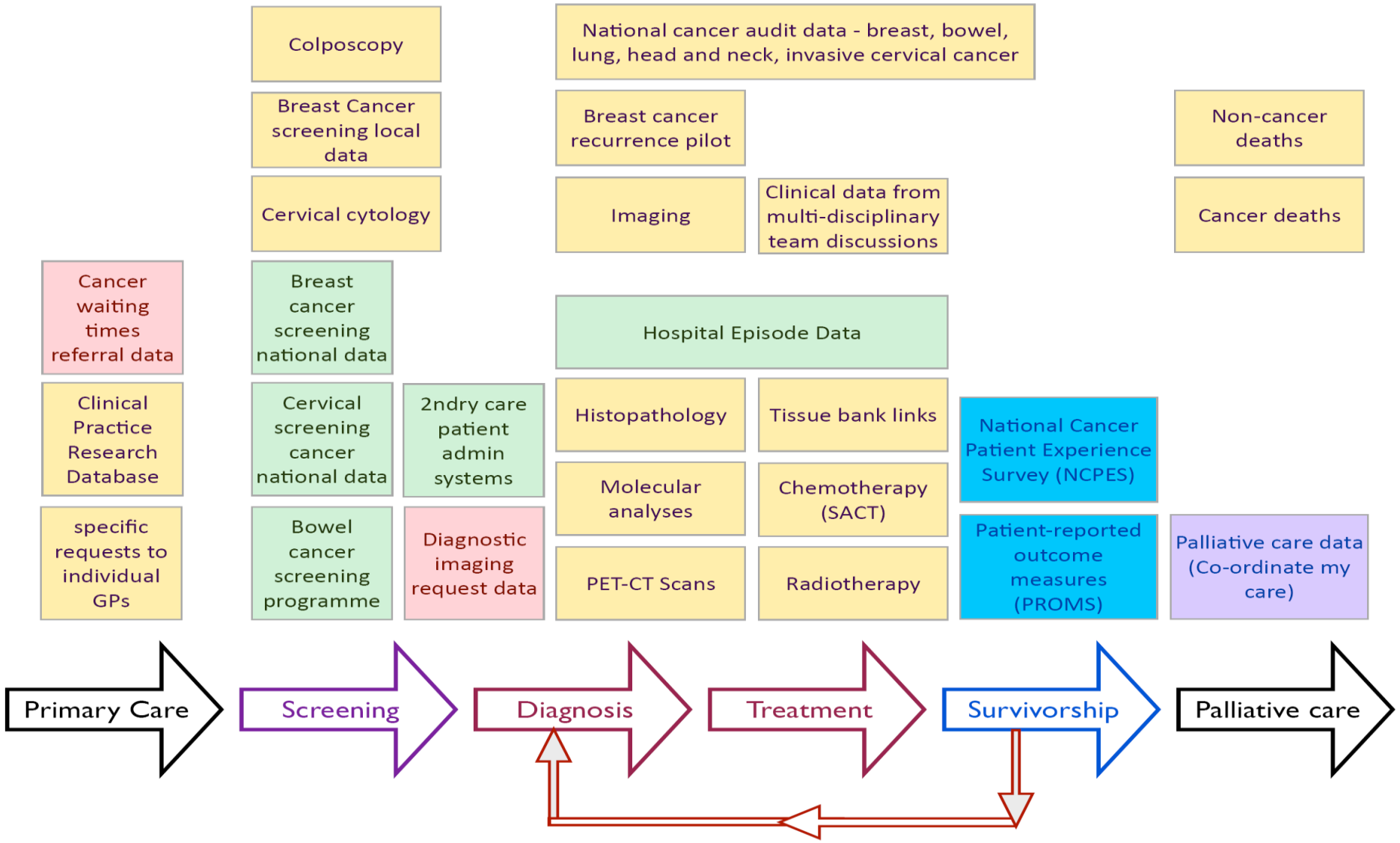
National Cancer Registration Service: Data Sources



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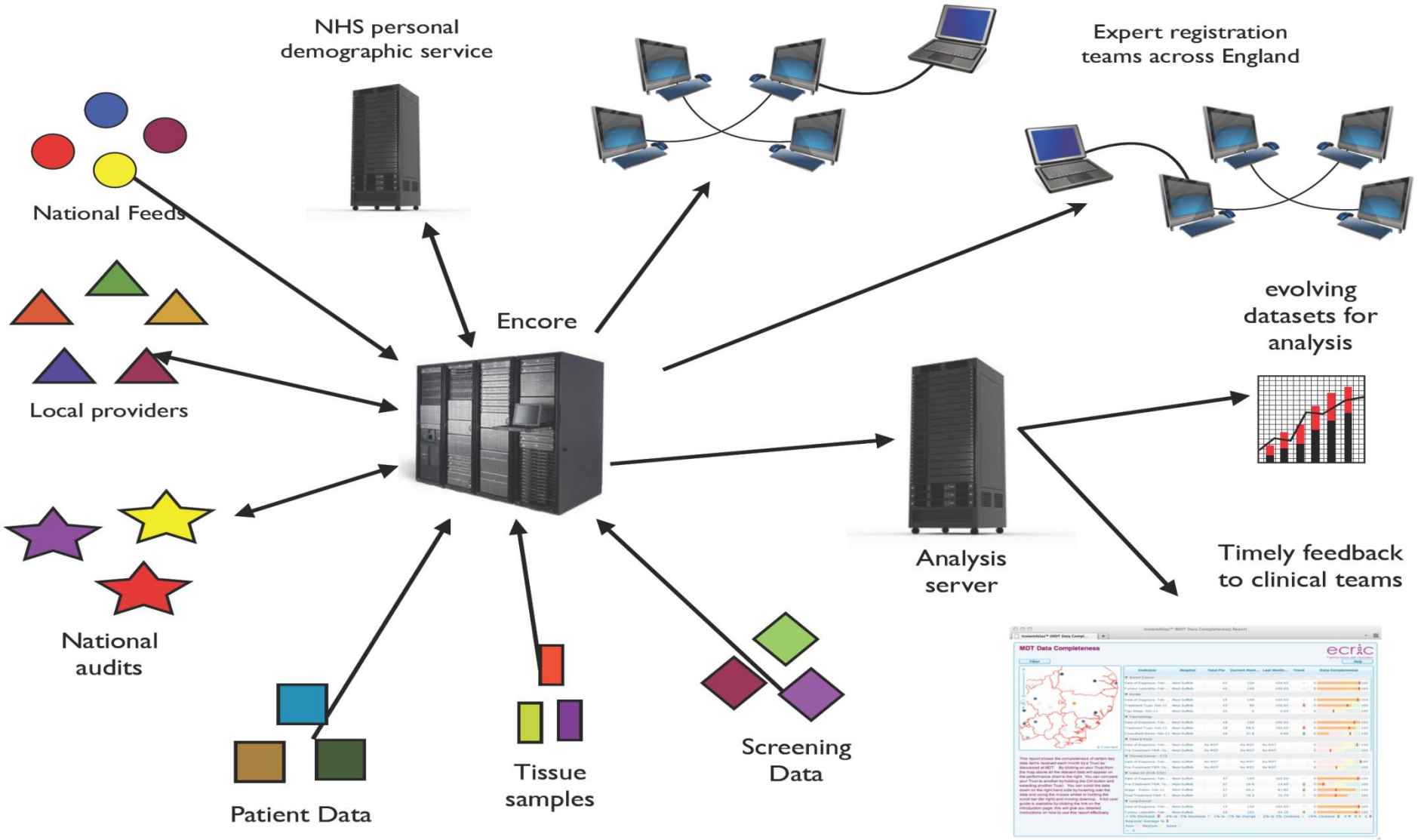
NCRS – ENCORE

(English National Cancer Online Registration Environment)



NHS England – current structures

- One national office in Leeds
- **4** regions, directly commission primary care & specialist services
- **10** specialised commissioning hubs within **27** Area Teams
- **12** clinical senates – clinical advice/leadership at strategic level to CCGs and HWBs
- **12** strategic Clinical Networks (up to 5 years)
- **12** Academic Health Science Networks
- **18** Commissioning Support Units – support to CCGs
- **27** Area Teams will support CCG development
- **211** Clinical Commissioning Groups (CCGs)
- **152** Health and Well Being Boards

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Specialist Commissioning

- **National Service Specifications** (e.g. radiotherapy, chemotherapy, mesothelioma, upper GI cancer, specialised urology, surgery….)
- **Clinical Reference Groups -** 12 relating to cancer (e.g. chemotherapy, radiotherapy, upper GI surgery, thoracic surgery…….)

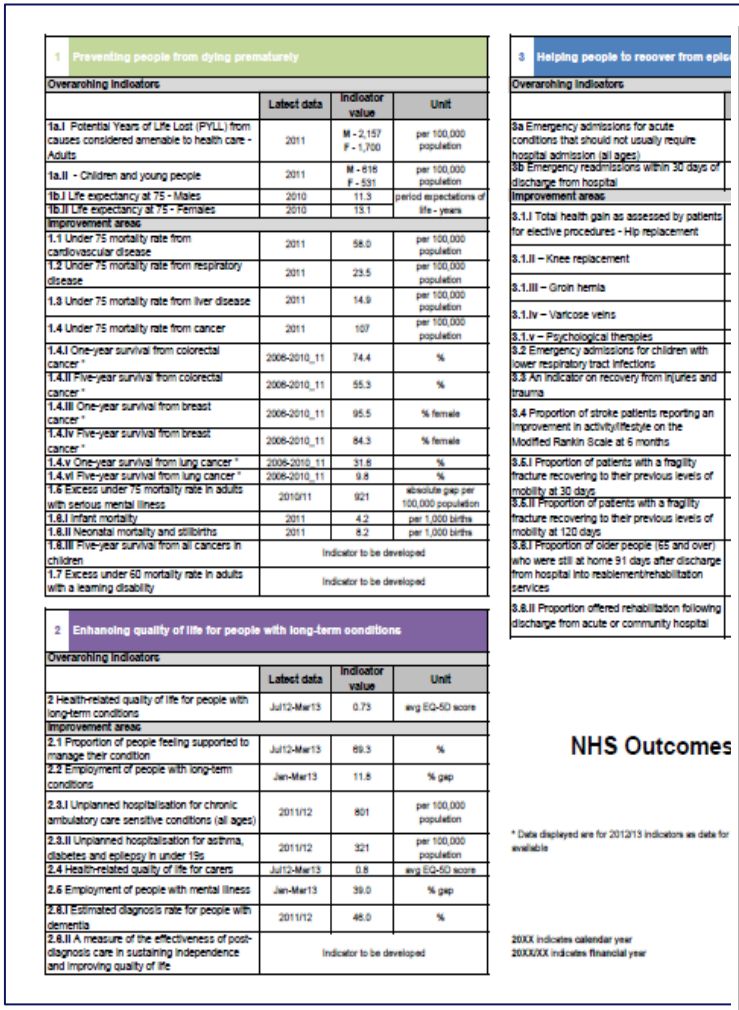
……..under review

- **New Lung CRG** (not directly analogous to the other CRGs)

Clinical Reference Groups - cancer

- Radiotherapy – *Peter Kirkbride and Adrian Crellin*
- PET-CT - *Wai Lup Wong*
- Specialised Cancer - *Sean Duffy*
- Blood and Marrow transplantation - *Antonio Pagliuca*
- Thoracic surgery - *Richard Page*
- Upper GI Surgery - *William Allum*
- Sarcoma - *Jeremy Whelan*
- CNS tumours - *Paul Grundy*
- Specialised urology - *Vijay Sangar*
- Chemotherapy - *Peter Clark*
- Complex Head & Neck - *Peter Thomson*
- Teenage and Young People Cancer - *Rachael Hough*

NHS Outcome Framework 2013/14 Dashboard



1 Preventing people from dying prematurely

Overarching indicators

	Latest data	Indicator value	Unit
1a.i Potential Years of Life Lost (PYLL) from causes considered amenable to health care - Adults	2011	M - 2,157 F - 1,700	per 100,000 population
1a.ii - Children and young people	2011	M - 616 F - 531	per 100,000 population
1b.i Life expectancy at 75 - Males	2010	11.3	period expectations of life - years
1b.ii Life expectancy at 75 - Females	2010	13.1	
Improvement areas			
1.1 Under 75 mortality rate from cardiovascular disease	2011	58.0	per 100,000 population
1.2 Under 75 mortality rate from respiratory disease	2011	23.5	per 100,000 population
1.3 Under 75 mortality rate from liver disease	2011	14.9	per 100,000 population
1.4 Under 75 mortality rate from cancer	2011	107	per 100,000 population
1.4.i One-year survival from colorectal cancer *	2006-2010_11	74.4	%
1.4.ii Five-year survival from colorectal cancer *	2006-2010_11	55.3	%
1.4.iii One-year survival from breast cancer *	2006-2010_11	95.5	% female
1.4.iv Five-year survival from breast cancer *	2006-2010_11	84.3	% female
1.4.v One-year survival from lung cancer *	2006-2010_11	31.8	%
1.4.vi Five-year survival from lung cancer *	2006-2010_11	9.8	%
1.5 Excess under 75 mortality rate in adults with serious mental illness	2010/11	921	absolute gap per 100,000 population
1.6.i Infant mortality	2011	4.2	per 1,000 births
1.6.ii Neonatal mortality and stillbirths	2011	8.2	per 1,000 births
1.6.iii Five-year survival from all cancers in children	Indicator to be developed		
1.7 Excess under 60 mortality rate in adults with a learning disability	Indicator to be developed		

2 Enhancing quality of life for people with long-term conditions

Overarching indicators

	Latest data	Indicator value	Unit
2 Health-related quality of life for people with long-term conditions	Jul12-Mar13	0.73	avg EQ-5D score
Improvement areas			
2.1 Proportion of people feeling supported to manage their condition	Jul12-Mar13	69.3	%
2.2 Employment of people with long-term conditions	Jan-Mar13	11.8	% gap
2.3.i Unplanned hospitalisation for chronic ambulatory care sensitive conditions (all ages)	2011/12	801	per 100,000 population
2.3.ii Unplanned hospitalisation for asthma, diabetes and epilepsy in under 19s	2011/12	321	per 100,000 population
2.4 Health-related quality of life for carers	Jul12-Mar13	0.8	avg EQ-5D score
2.6 Employment of people with mental illness	Jan-Mar13	39.0	% gap
2.8.i Estimated diagnosis rate for people with dementia	2011/12	46.0	%
2.8.ii A measure of the effectiveness of post-diagnosis care in sustaining independence and improving quality of life	Indicator to be developed		

3 Helping people to recover from epis

Overarching indicators

3a Emergency admissions for acute conditions that should not usually require hospital admission (all ages)
3b Emergency readmissions within 30 days of discharge from hospital
Improvement areas
3.1.i Total health gain as assessed by patients for elective procedures - Hip replacement
3.1.ii – Knee replacement
3.1.iii – Groin hernia
3.1.iv – Varicose veins
3.1.v – Psychological therapies
3.2 Emergency admissions for children with lower respiratory tract infections
3.3 An indicator on recovery from injuries and trauma
3.4 Proportion of stroke patients reporting an improvement in activity/lifestyle on the Modified Rankin Scale at 6 months
3.5.i Proportion of patients with a fragility fracture recovering to their previous levels of mobility at 30 days
3.5.ii Proportion of patients with a fragility fracture recovering to their previous levels of mobility at 120 days
3.8.i Proportion of older people (65 and over) who were still at home 91 days after discharge from hospital into reablement/rehabilitation services
3.8.ii Proportion offered rehabilitation following discharge from acute or community hospital

NHS Outcomes

* Data displayed are for 2012/13 indicators as data for available

20XX indicates calendar year
20XX/XX indicates financial year

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Clinical Commissioning Group Outcomes Indicator Set

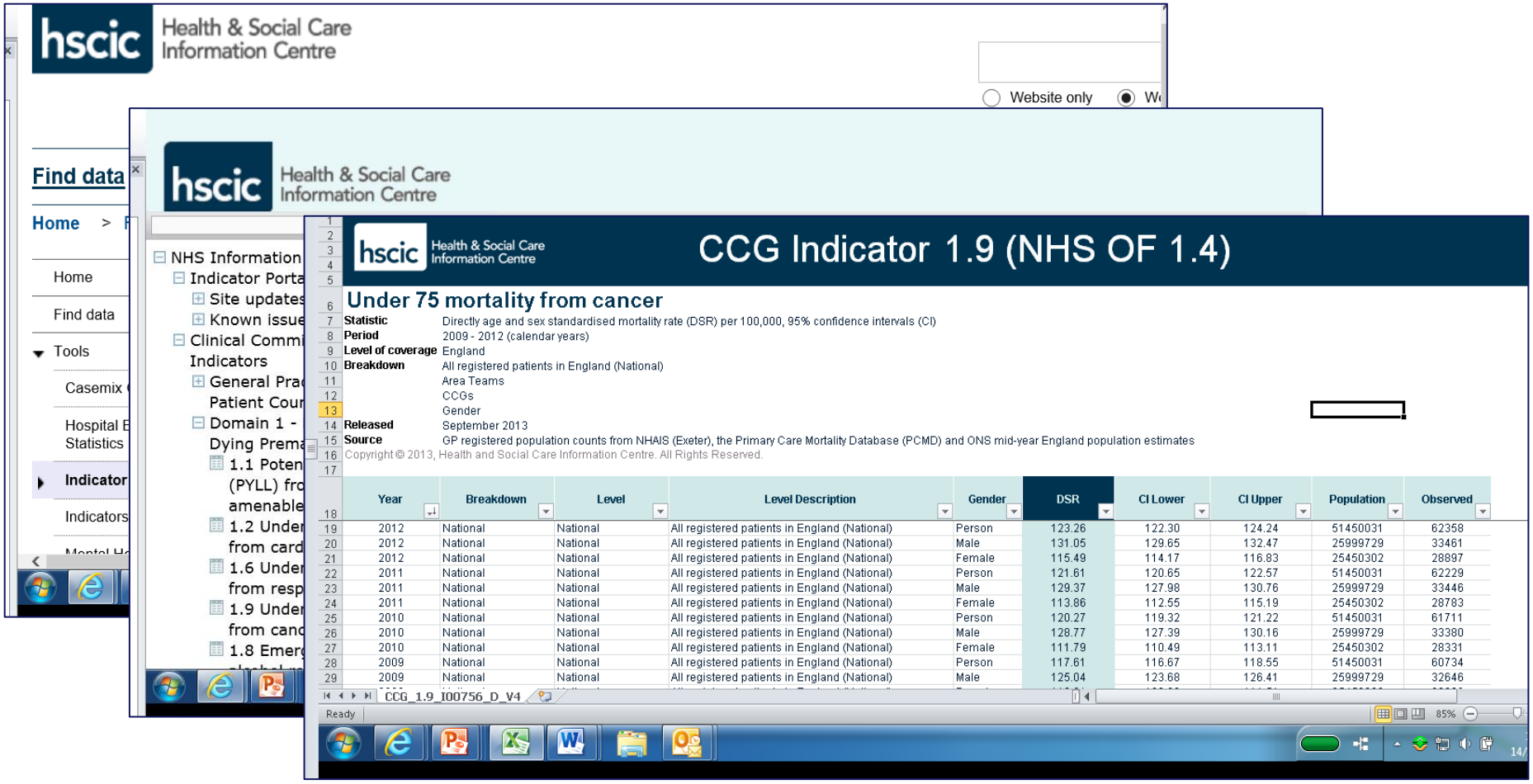
2013/14 under 75 mortality rate from cancer

- 1 and 5 year survival from all cancers
- 1 and 5 year survival from breast, lung & colorectal cancers

2014/15 additional indicators for cancer

- cancers diagnosed via emergency routes
- 5 year survival - children
- cancer stage at diagnosis
- cancers detected at stage 1 or 2
- 1 and 5 yr survival for lung, breast and colorectal cancers

HSCIC Indicator Portal



Datasets

- Radiotherapy Dataset (RTDS), 2009…..
- Diagnostic Imaging Dataset (DIDs), 2012..
- Systemic Anti-Cancer Therapy Dataset (SACT), 2012….
- Cancer Outcomes & Services Dataset (COSD), 2013…..

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Examples of the clinical value of new data

- Demonstration of variation
- Teasing out the causes of variation
- Demonstrating value of specialisation
- Building data into quality improvement
- Adding outcome data into Peer Review
- Providing robust evidence behind National Guidelines and Quality Standards (NICE)
- Supporting ‘intelligent commissioning’

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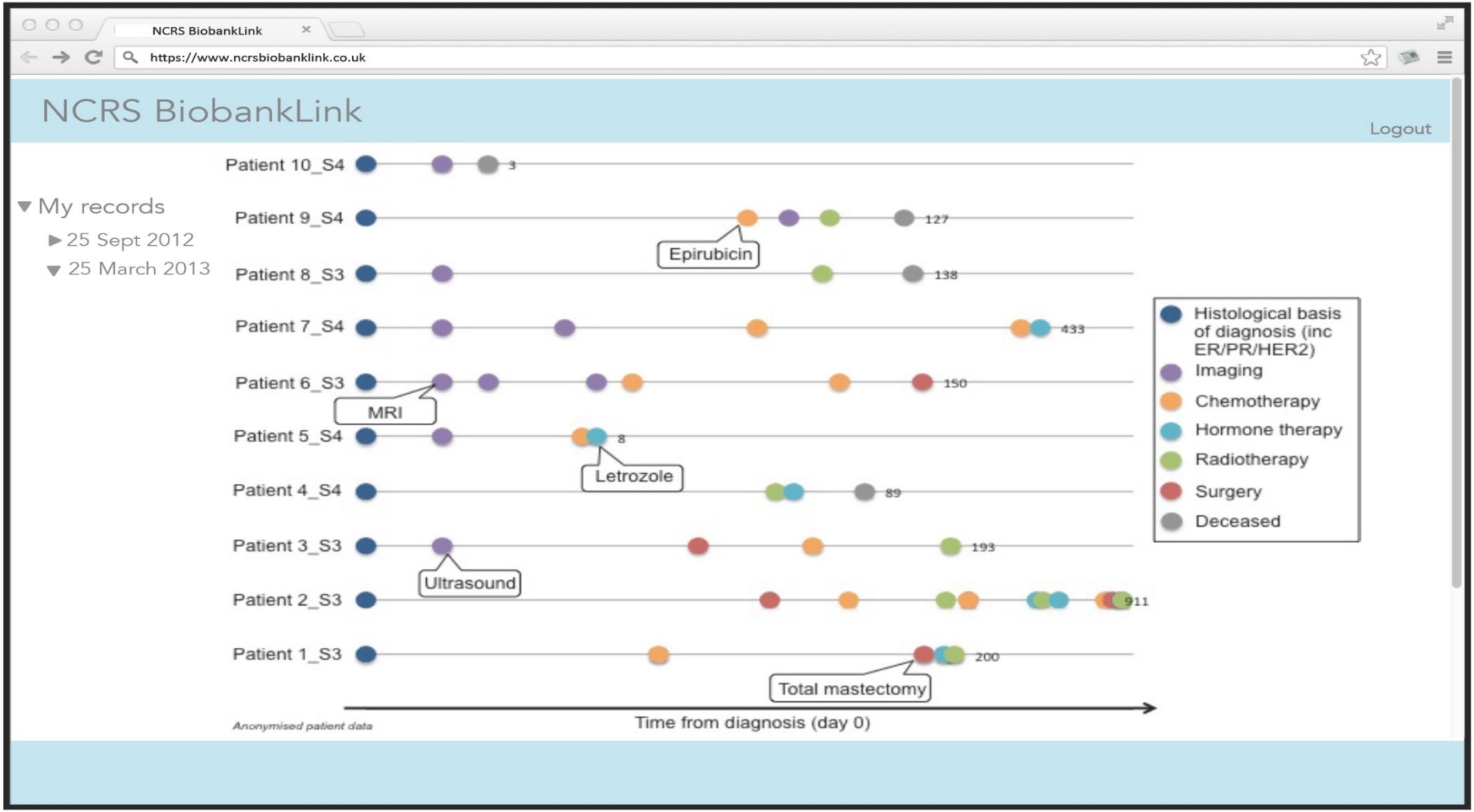
NCRS BiobankLink Service



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National Cancer Audits

- National Lung, Colo-rectal and Head & Neck Cancer Audits all have contracts that expire at the end of 2014
- Re-tendering process underway – smooth transition will be the main issue
- New Prostate Cancer Audit began 2014

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National Cancer Audits

NPCA
National Prostate Cancer Audit

RCS
ADVANCING SURGICAL STANDARDS

- New model for national cancer audits
  - Partnership between NCRS and professional bodies
- Information governance and data QA managed by NCRS
  - Near-real-time data collection from MDTs
  - Data set largely collected as part of routine flows
- Continuous feedback to clinicians and MDTs
- NCRS produces linked audit datasets for analysis

Feeding back: examples

Public Health England

- E Atlas
- Reports and data briefings
- Cancer Commissioning Toolkit
- *Service & GP Profiles – Sue Knights*

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Cancer e-Atlas

www.ncin.org.uk/cancer_information_tools/eatlas/network/atlas.html?select=Eav&indicator=i0

UK Cancer e-Atlas by cancer networks

Data being displayed: Prostate - Male Survival 5 Year

NCIN national cancer intelligence network

Guide | Print | Save | Select localities | Export data | Go to health boundary e-Atlas

Select cancer type below (use -/+ at bottom to expand the whole list)

Select cancer network	Rat
Essex	82.9 %
Greater Manchester and Cheshire	81.4 %
Greater Midlands	80.2 %
Humber and Yorkshire Coast	80.5 %
Kent and Medway	81.9 %
Lancashire and South Cumbria	85.4 %
Merseyside and Cheshire	82.0 %
Mount Vernon	78.9 %
North East London	81.5 %
North London	87.1 %
North Trent	74.4 %
North West London	86.4 %
North of England	79.9 %
North of Scotland	80.8 %
Northern Ireland	82.9 %
Pan Birmingham	86.5 %
Peninsula	79.2 %
Scotland	80.1 %
South East London	81.5 %
South East Scotland	82.2 %
South West London	87.8 %
Surrey, West Sussex and Hampshire	83.7 %
Sussex	82.8 %
Thames Valley	88.0 %
United Kingdom	82.2 %
Wales	76.6 %
West of Scotland	78.2 %
Yorkshire Cancer Network	82.0 %

Cancer type	Locality	No.Cases/Deaths	Rate/%	UK avge	Comparator to UK average rate
All cancers combined					
Bladder					
Brain					
Breast					
Cervix					
Colorectal (bowel)					
Kidney					
Leukaemia					
Lung including trachea and bronchus					
Malignant melanoma of skin					
Non-Hodgkin lymphoma					
Oesophagus					
Ovary					
Pancreas					
Prostate					
Male Incidence*	North of England	1,697	86.3 ■	100.5	0 — 150
Male Mortality*	North of England	538	24.7 ♦	24.0	0 — 80
Male Survival 1 Year	North of England	-	95.4 % ♦	95.0 %	0 — 100
Male Survival 3 Year	North of England	-	86.3 % ■	87.8 %	0 — 100
Male Survival 5 Year	North of England	-	79.9 % ■	82.2 %	0 — 100
Stomach					
Uterus					

■ North of England

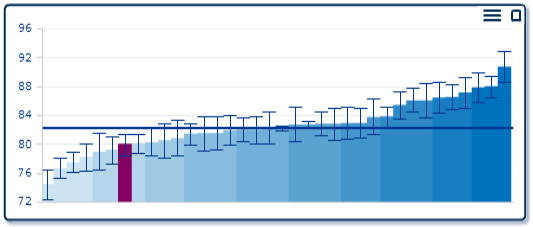
Significantly lower than UK average ■ Not significantly different than UK average ♦ Significantly higher than UK average ●

UK average | Data value ♦

Incidence | Mortality | Survival

* Age-standardised

Network rates



Information about the selected data item

Five-year relative survival estimate, males, ICD10 C61 : Prostate, 2000-2004

Relative survival is an estimate of the percentage of patients still alive five years on from their diagnosis with prostate cancer, taking into account the background mortality in the general population. It is therefore an estimate of the percentage of patients who survive their cancer for at least five years.

Data definitions:
Five-year relative survival estimate (%) based on people diagnosed during 2000-2004. Relative survival estimates shown above are not age-standardised.

Source: National Cancer Intelligence Network (NCIN), UK Cancer Information Service (UKCIS), accessed May 2011.
For more detailed information and definitions please see the Cancer e-Atlas Guide.

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National Cancer Intelligence Network

Cancer survival in England by stage

www.ncin.org.uk

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Figure 2, one-year survival, all stage, by year of diagnosis, not standardised by age

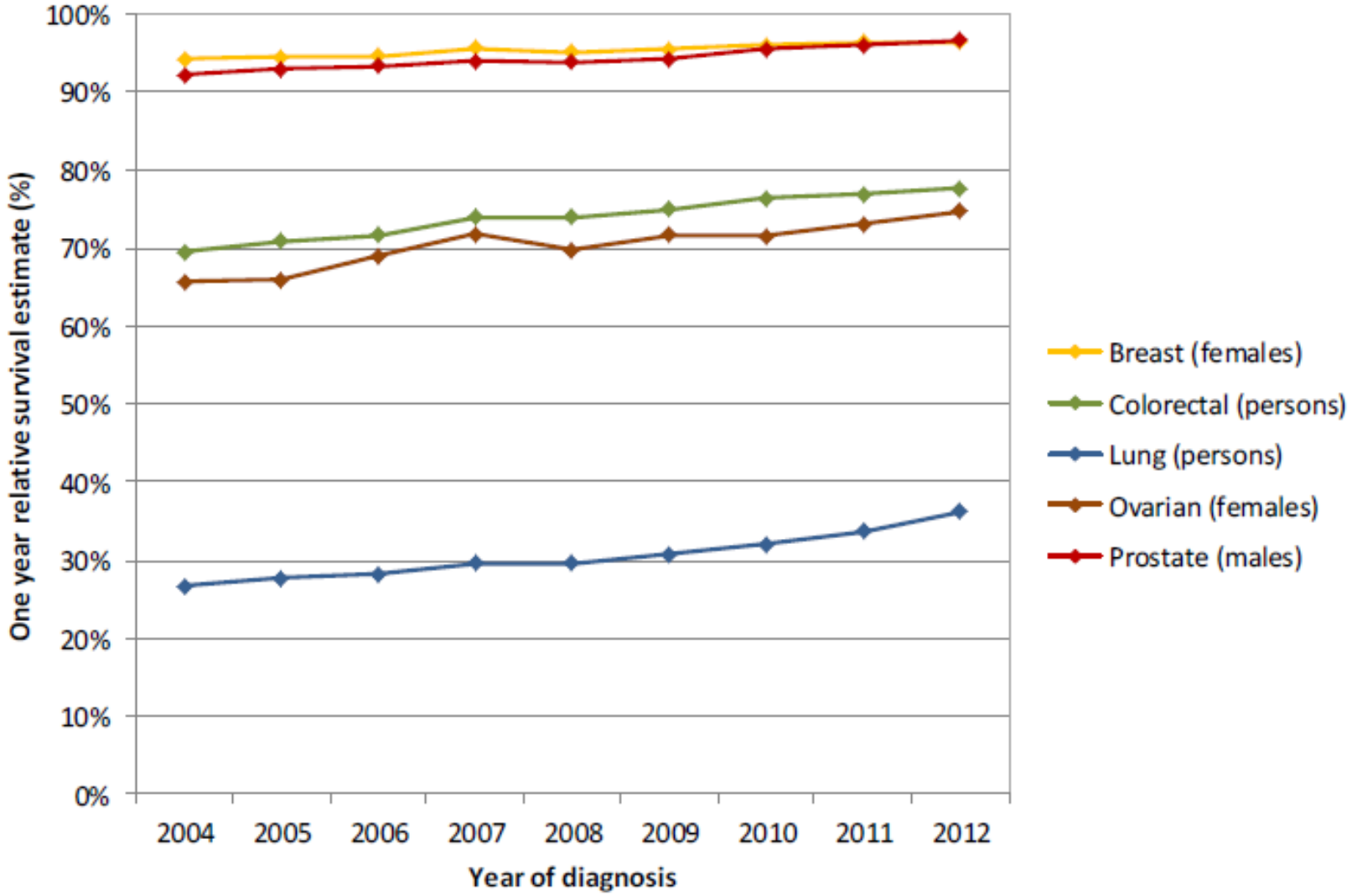

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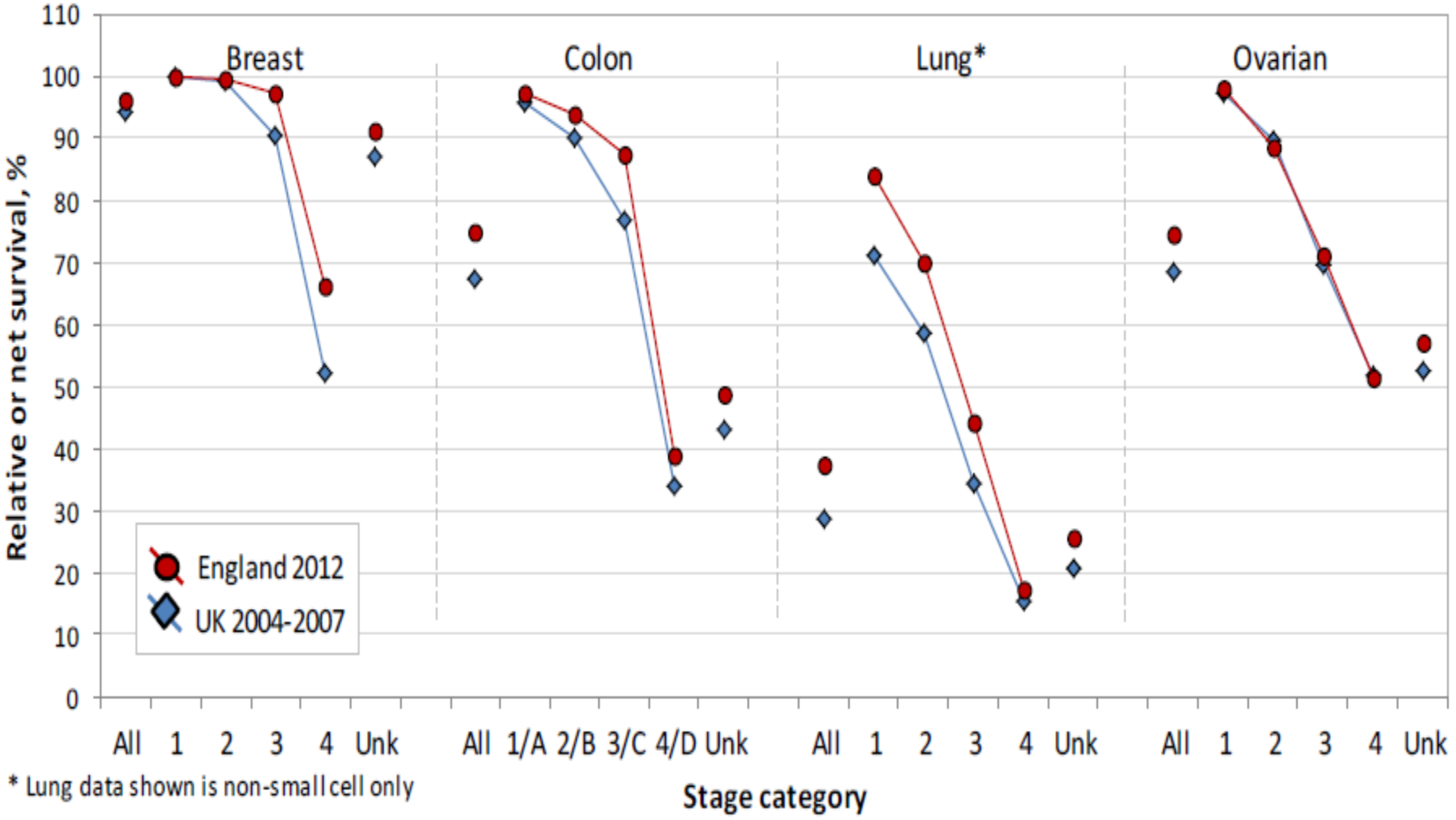
Figure 4 One-year relative/net survival, by stage, in the ICBP and England 2012 data



* Lung data shown is non-small cell only

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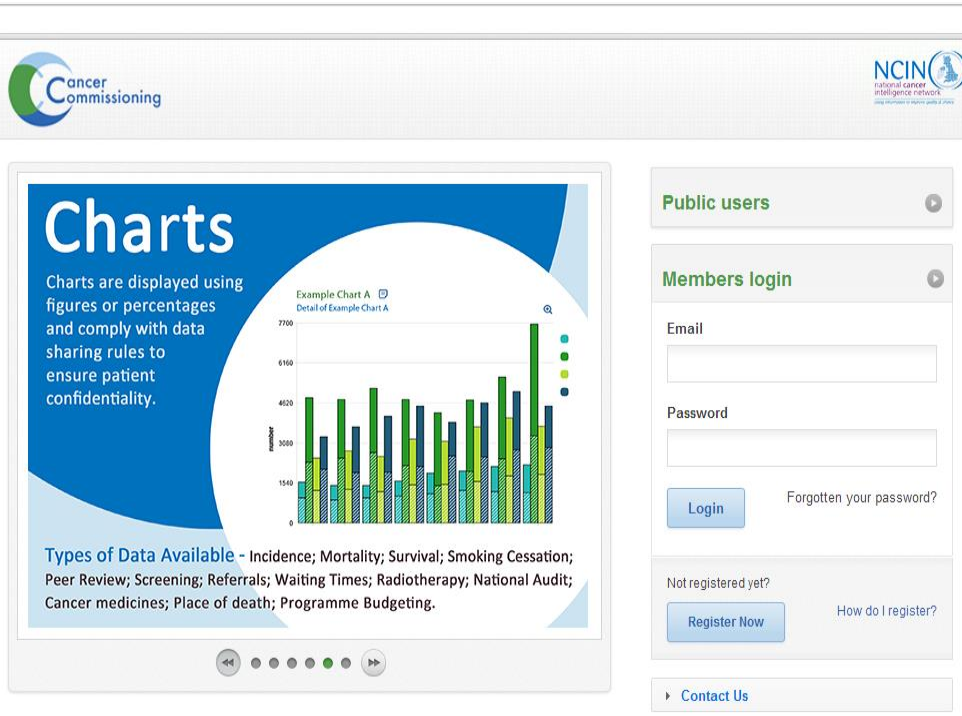
Cancer Commissioning Toolkit



www.ncin.org.uk

Created by concentra

1 year relative survival estimates benchmarked by Network

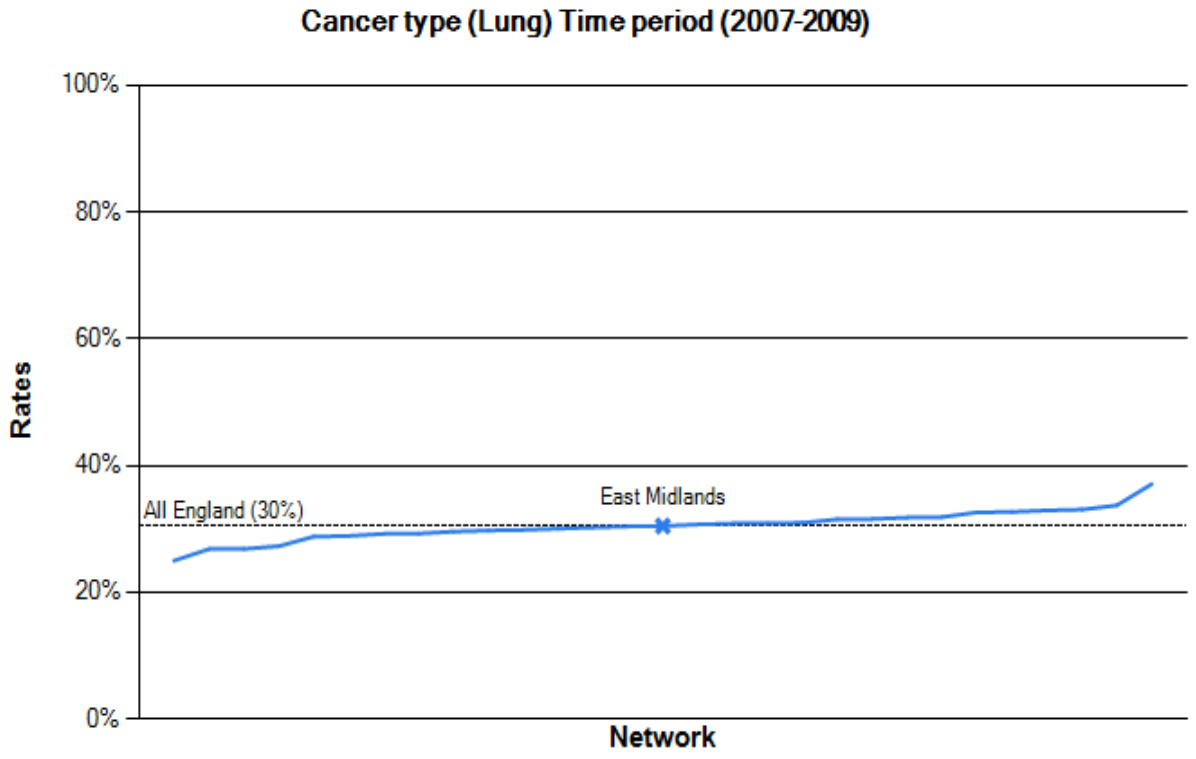


Chart by:
SHA Network PCT

Highlight:
East Midlands

Cancer type:
Lung

Time period:
2007-2009

Other charts within the module:
- 5 year relative survival estimates benchmarked
- Trend in survival

Links
- CCT- Website Terms and Conditions

Public Health England
NCIN national cancer intelligence network

1 year relative survival estimates benchmarked by PCT

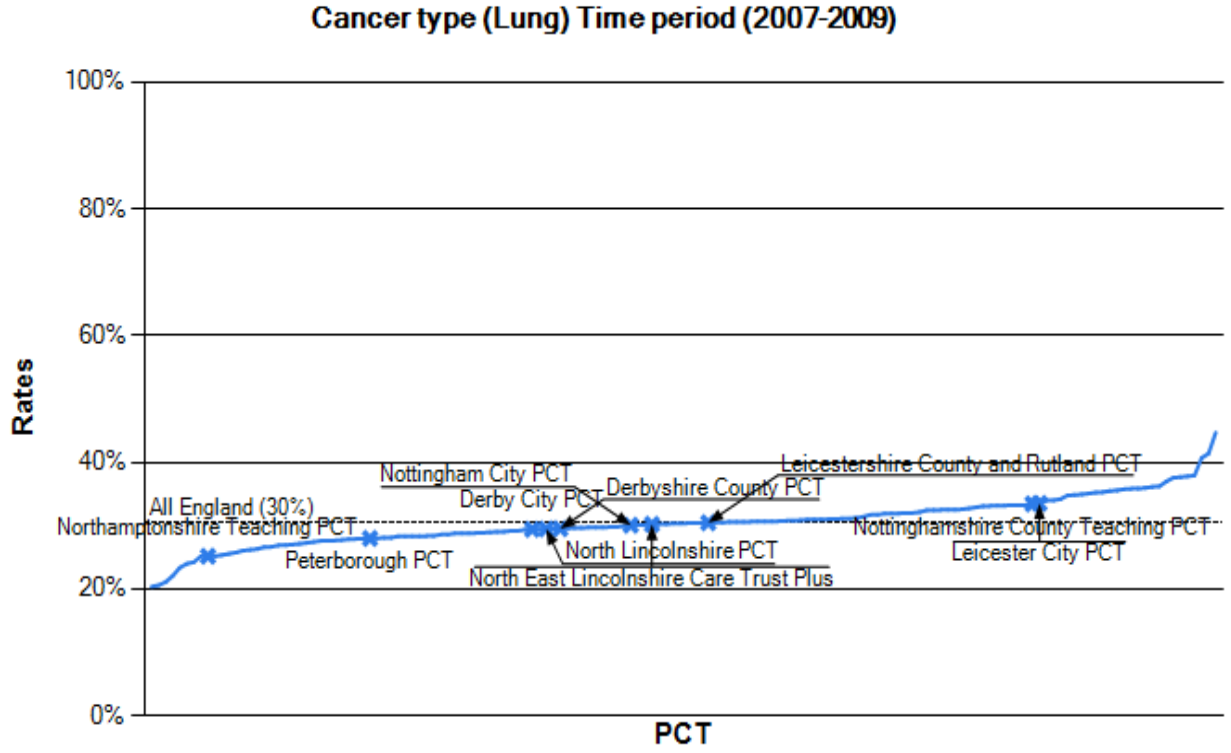


Chart by:
SHA Network PCT

Highlight:
* PCTs Selected

Cancer type:
Lung

Time period:
2007-2009

Other charts within the module:
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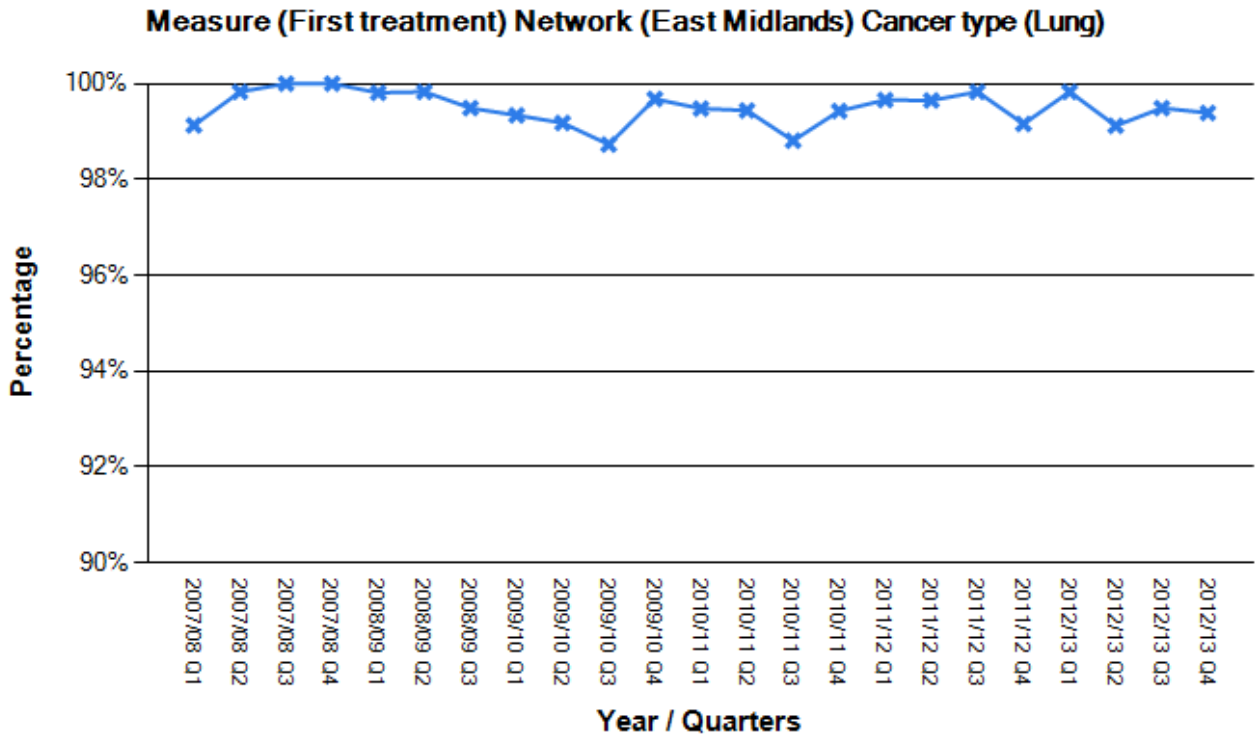
Public Health England
NCIN national cancer intelligence network

31 day standard performance time trend by SHA/PCT/Network



Measure:
First treatment
SHA:
No selection
Network:
East Midlands
PCT:
No selection
Cancer type:
Lung

Other charts within the module:

- 'Two Week Wait' performance
- 'Two Week Wait' Exhibited (non-cancer) breast symptoms performance
- TWR performance trend by PCTs/Networks
- TWR performance time series by Trust
- % TWR with cancer diagnosis
- Number of TWR with cancer diagnosis

Overview | **Filters**

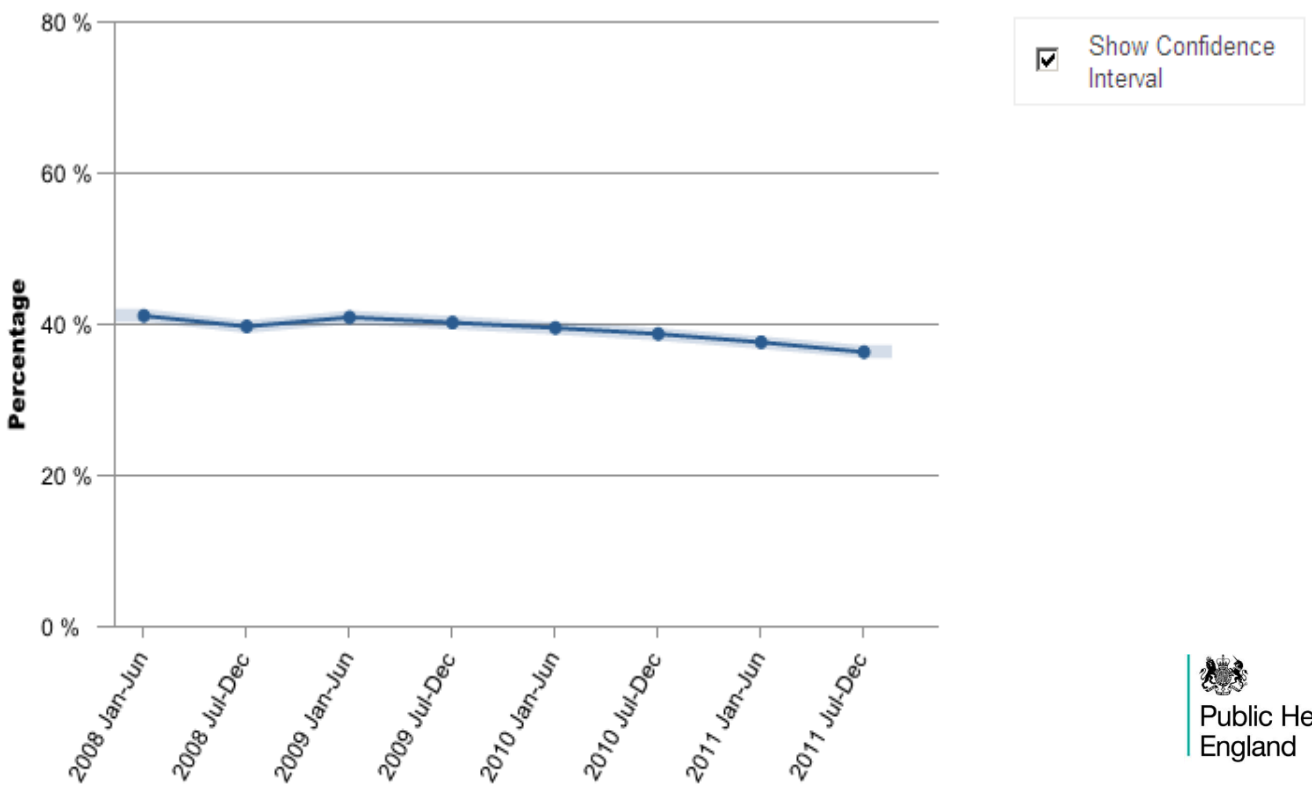
Cancer Type

1 Cancer Type(s) Selected

Filter

Proxy measure for emergency presentations for cancer

Proportion of newly identified tumours first presenting as an emergency calculated from Inpatient HES data



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Challenges

- Split of cancer registration and analytical services, with loss of experienced personnel
- Loss of links with NHS (Cancer Policy Team, National Cancer Action Team, NHS Improvement)
- Loss of old Cancer Network / PCT links
- Uncertainty around roles and responsibilities
- Loss of focus on cancer
- Current review of just about everything!

Conclusions

- The quality and range of clinically relevant data on cancer is increasing rapidly
- High quality population-based data can clearly drive clinical behavioural change
- We now have a large and expanding clinical community engaged with cancer data
- Feedback and ongoing interaction with clinicians is an essential part of the process – peer pressure is powerful
- There is a need to improve how information is used at a local level
- The collection and intelligent use of data are at the heart of good clinical practice and commissioning

International Consortium for Health Outcomes Measurement

ICHOM is a nonprofit dedicated to accelerating development, standardization and impact of outcomes measurement worldwide

ICHOM's three founders with the desire to unlock the potential of Value-Based Health Care:

INSTITUTE FOR STRATEGY AND COMPETITIVENESS

BCG
THE BOSTON CONSULTING GROUP

Karolinska Institutet

ICHOM

Our purpose:

*To define a **global standard set of outcome measures that really matter to patients** for the most relevant medical conditions…and drive adoption of these measures worldwide to unlock the potential of value-based health care*

Outcomes are the powerful lever to unlock a value-based healthcare system

Improve outcomes

Starting point is to measure and improve the health results that matter most for a patient's condition

Reduce costs

Streamline care delivery to only those services that improve outcomes

Increase value

Better outcomes at equal or lower cost leads to higher value

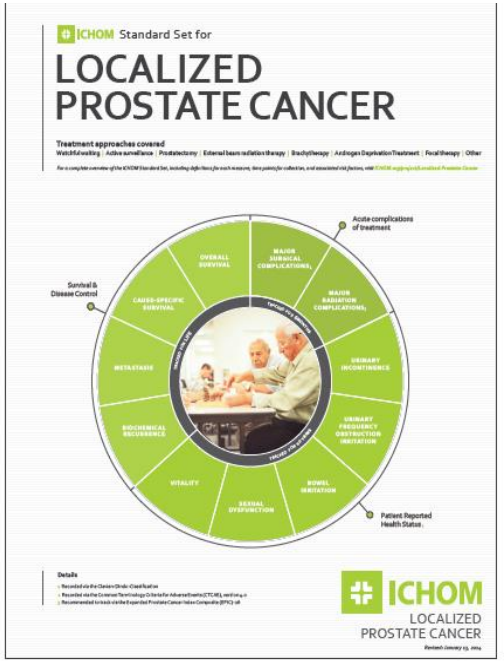
$$\text{Value} = \frac{\text{Patient health outcomes achieved}}{\text{Cost of delivering those outcomes}}$$

ICHOM organizes international Working Groups to define Standard Sets of outcomes we recommend all providers track

International Consortium for Health Outcomes Measurement (ICHOM) facilitates a process with international physician and registry leaders and patient representatives to develop a global Standard Set of outcomes that really matter to patients as well as standard risk factors for risk adjustment

Physician and registry leaders

Patient representatives



Next phase: implementation of standard set for lung cancer in institutions willing to participate

ICHOM is actively looking for pilot sites to demonstrate the value of measuring our Standard Sets

- By becoming an **ICHOM PILOT SITE,** you can improve outcomes at your own organization and capture valuable learning to help promote adoption and facilitate implementation globally

WHAT WE PROVIDE

SUPPORT throughout the implementation process

Expert **ICHOM CONSULTANT** to help:

- ensure buy-in from leadership
- conduct baseline assessment
- select the right tools for data collection
- develop reporting systems
- drive change

WHAT YOU PROVIDE

SPONSORSHIP for ICHOM, or assistance finding funding from third-party organizations

3-4 member **STEERING GROUP** to meet occasionally, take decisions, and review progress

PROJECT MANAGER (~0.2 FTE)

BENEFITS

OPPORTUNITY TO IMPROVE CARE and value for your patients by implementing your recommendations

OPPORTUNITY TO PUBLISH RESULTS in leading academic journals

RECOGNITION for your organization as an ICHOM sponsor/measuring partner/ pilot site

Want to know more? Contact implement@ichom.org

Public Health England

Requesting Access to Data

Through the Office of Data Release (ODR) which:

1. Has oversight of all ad-hoc data requests and releases
2. Ensures that all requests are logged and then tracked
3. Determines the appropriateness of data releases where the data is identifiable or potentially identifiable
4. Ensures that appropriate controls are placed on data recipients to maintain the security and confidentiality of PHE information

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Requesting Access to Data (2)

The ODR meets weekly to decide the outcome of data requests. Within 2 weeks of receiving your initial request, you will be informed of one of three outcomes:

- Request accepted
- Further information needed – request to be resubmitted
- Request declined