



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



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’)



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)



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**

Public Health England: Emerging 'Intelligence' Structures

**Public Health England
Chief Knowledge Officer
(Prof. John Newton)**

**Health Intelligence
Networks
(Prof. Brian Ferguson)**

**Disease
Registration
Service
(Dr Jem Rashbass)**

**PHE Information
Services
Chris Carrigan**

**Knowledge &
Intelligence Teams
(KITs)**

**National Cancer
Intelligence Network
Chris Carrigan**

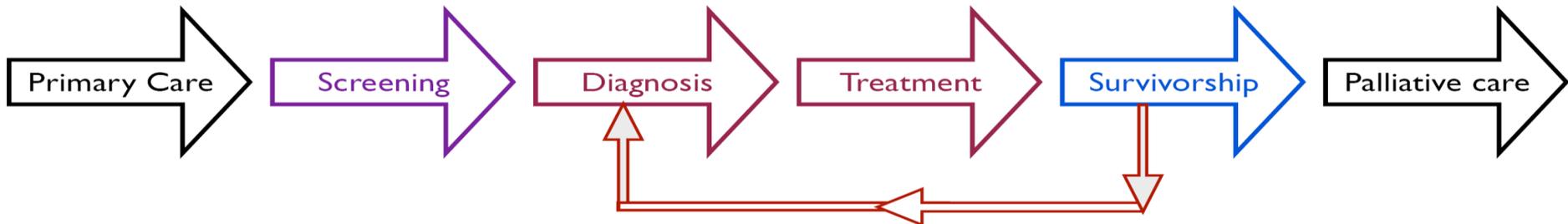
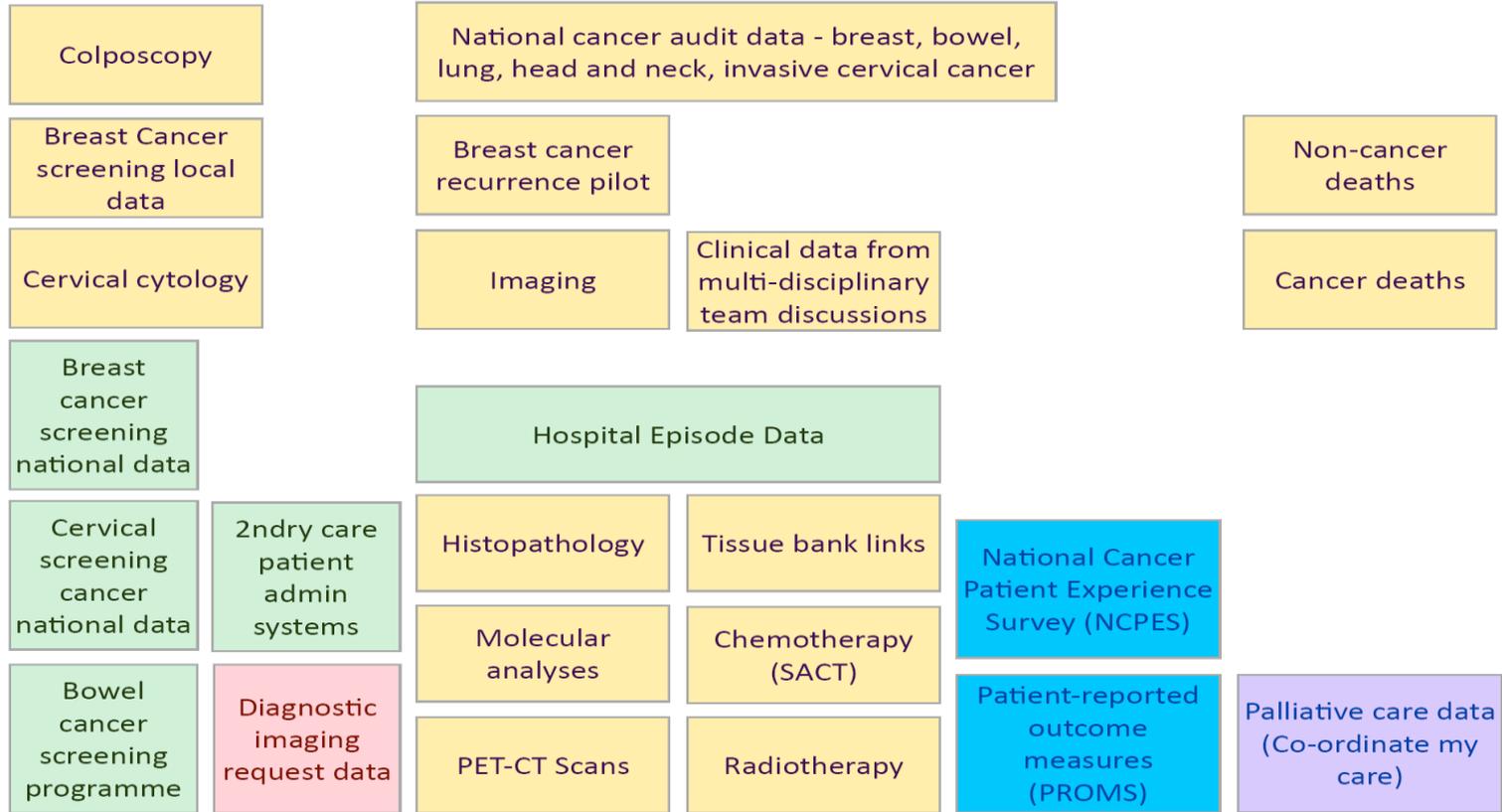


The English National Cancer Registration System

- 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



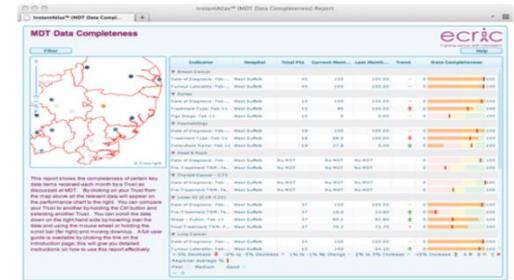
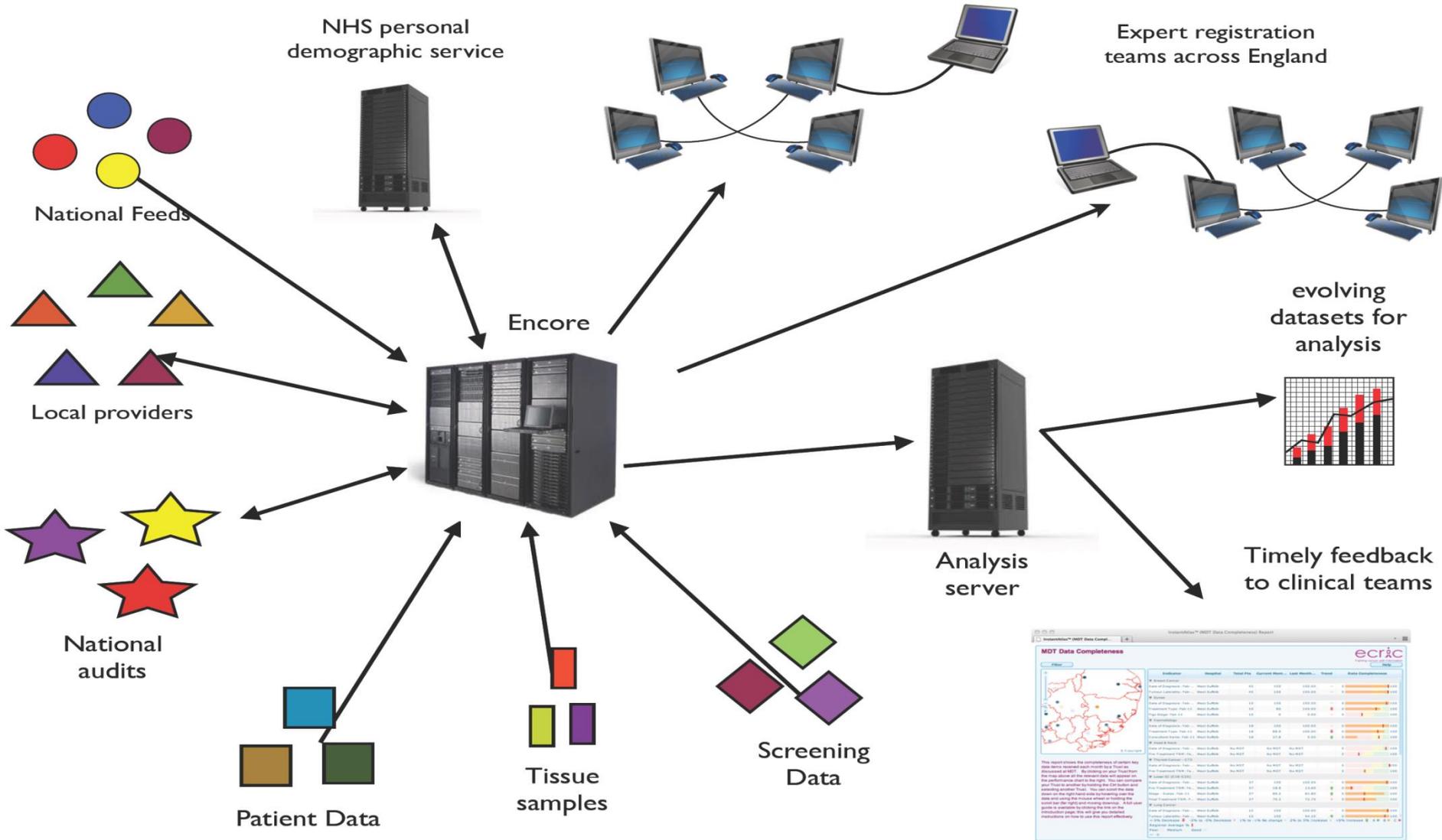
National Cancer Registration Service: Data Sources





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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



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

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*
- Complex gynaecological services - vacant
- 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				3 Helping people to recover from acute conditions			
Overarching indicators				Overarching indicators			
	Latest data	Indicator value	Unit		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	3a Emergency admissions for acute conditions that should not usually require hospital admission (all ages)			
1a.ii - Children and young people	2011	M - 616 F - 531	per 100,000 population	3b Emergency readmissions within 30 days of discharge from hospital			
1b.i Life expectancy at 75 - Males	2010	11.3	period expectations of life - years	Improvement areas			
1b.ii Life expectancy at 75 - Females	2010	13.1	period expectations of life - years	3.1.I Total health gain as assessed by patients for elective procedures - Hip replacement			
Improvement areas				3.1.II - Knee replacement			
1.1 Under 75 mortality rate from cardiovascular disease	2011	58.0	per 100,000 population	3.1.III - Groin hernia			
1.2 Under 75 mortality rate from respiratory disease	2011	23.5	per 100,000 population	3.1.IV - Varicose veins			
1.3 Under 75 mortality rate from liver disease	2011	14.9	per 100,000 population	3.1.V - Psychological therapies			
1.4 Under 75 mortality rate from cancer	2011	107	per 100,000 population	3.2 Emergency admissions for children with lower respiratory tract infections			
1.4.i One-year survival from colorectal cancer *	2006-2010_11	74.4	%	3.3 An indicator on recovery from injuries and trauma			
1.4.ii Five-year survival from colorectal cancer *	2006-2010_11	55.3	%	3.4 Proportion of stroke patients reporting an improvement in activity/lifestyle on the Modified Rankin Scale at 6 months			
1.4.iii One-year survival from breast cancer *	2006-2010_11	95.5	% female	3.5.I Proportion of patients with a fragility fracture recovering to their previous levels of mobility at 30 days			
1.4.iii Five-year survival from breast cancer *	2006-2010_11	84.3	% female	3.5.II Proportion of patients with a fragility fracture recovering to their previous levels of mobility at 120 days			
1.4.iv One-year survival from lung cancer *	2006-2010_11	31.6	%	3.5.III Proportion of older people (65 and over) who were still at home 91 days after discharge from hospital into reablement/rehabilitation services			
1.4.v Five-year survival from lung cancer *	2006-2010_11	9.8	%	3.5.IV Proportion offered rehabilitation following discharge from acute or community hospital			
1.6 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				1 Preventing people from dying prematurely			
Overarching indicators				Overarching indicators			
	Latest data	Indicator value	Unit		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	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
Improvement areas				1a.ii - Children and young people	2011	M - 616 F - 531	per 100,000 population
2.1 Proportion of people feeling supported to manage their condition	Jul12-Mar13	69.3	%	1b.i Life expectancy at 75 - Males	2010	11.3	period expectations of life - years
2.2 Employment of people with long-term conditions	Jan-Mar13	11.6	% gap	1b.ii Life expectancy at 75 - Females	2010	13.1	period expectations of life - years
2.3.I Unplanned hospitalisation for chronic ambulatory care sensitive conditions (all ages)	2011/12	801	per 100,000 population	Improvement areas			
2.3.II Unplanned hospitalisation for asthma, diabetes and epilepsy in under 19s	2011/12	321	per 100,000 population	1.1 Under 75 mortality rate from cardiovascular disease	2011	58.0	per 100,000 population
2.4 Health-related quality of life for carers	Jul12-Mar13	0.8	avg EQ-5D score	1.2 Under 75 mortality rate from respiratory disease	2011	23.5	per 100,000 population
2.6 Employment of people with mental illness	Jan-Mar13	39.0	% gap	1.3 Under 75 mortality rate from liver disease	2011	14.9	per 100,000 population
2.8.I Estimated diagnosis rate for people with dementia	2011/12	48.0	%	1.4 Under 75 mortality rate from cancer	2011	107	per 100,000 population
2.8.II A measure of the effectiveness of post-diagnosis care in sustaining independence and improving quality of life		Indicator to be developed		1.4.i One-year survival from colorectal cancer *	2006-2010_11	74.4	%

NHS Outcomes

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

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

1 Preventing people from dying prematurely			
Overarching indicators			
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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
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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	

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

hscic Health & Social Care Information Centre

hscic Health & Social Care Information Centre

CCG Indicator 1.9 (NHS OF 1.4)

Under 75 mortality from cancer

Statistic Directly age and sex standardised mortality rate (DSR) per 100,000, 95% confidence intervals (CI)

Period 2009 - 2012 (calendar years)

Level of coverage England

Breakdown All registered patients in England (National)
Area Teams
CCGs
Gender

Released September 2013

Source GP registered population counts from NHAIS (Exeter), the Primary Care Mortality Database (PCMD) and ONS mid-year England population estimates

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Year	Breakdown	Level	Level Description	Gender	DSR	CI Lower	CI Upper	Population	Observed
2012	National	National	All registered patients in England (National)	Person	123.26	122.30	124.24	51450031	62358
2012	National	National	All registered patients in England (National)	Male	131.05	129.65	132.47	25999729	33461
2012	National	National	All registered patients in England (National)	Female	115.49	114.17	116.83	25450302	28897
2011	National	National	All registered patients in England (National)	Person	121.61	120.65	122.57	51450031	62229
2011	National	National	All registered patients in England (National)	Male	129.37	127.98	130.76	25999729	33446
2011	National	National	All registered patients in England (National)	Female	113.86	112.55	115.19	25450302	28783
2010	National	National	All registered patients in England (National)	Person	120.27	119.32	121.22	51450031	61711
2010	National	National	All registered patients in England (National)	Male	128.77	127.39	130.16	25999729	33380
2010	National	National	All registered patients in England (National)	Female	111.79	110.49	113.11	25450302	28331
2009	National	National	All registered patients in England (National)	Person	117.61	116.67	118.55	51450031	60734
2009	National	National	All registered patients in England (National)	Male	125.04	123.68	126.41	25999729	32646

Datasets

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



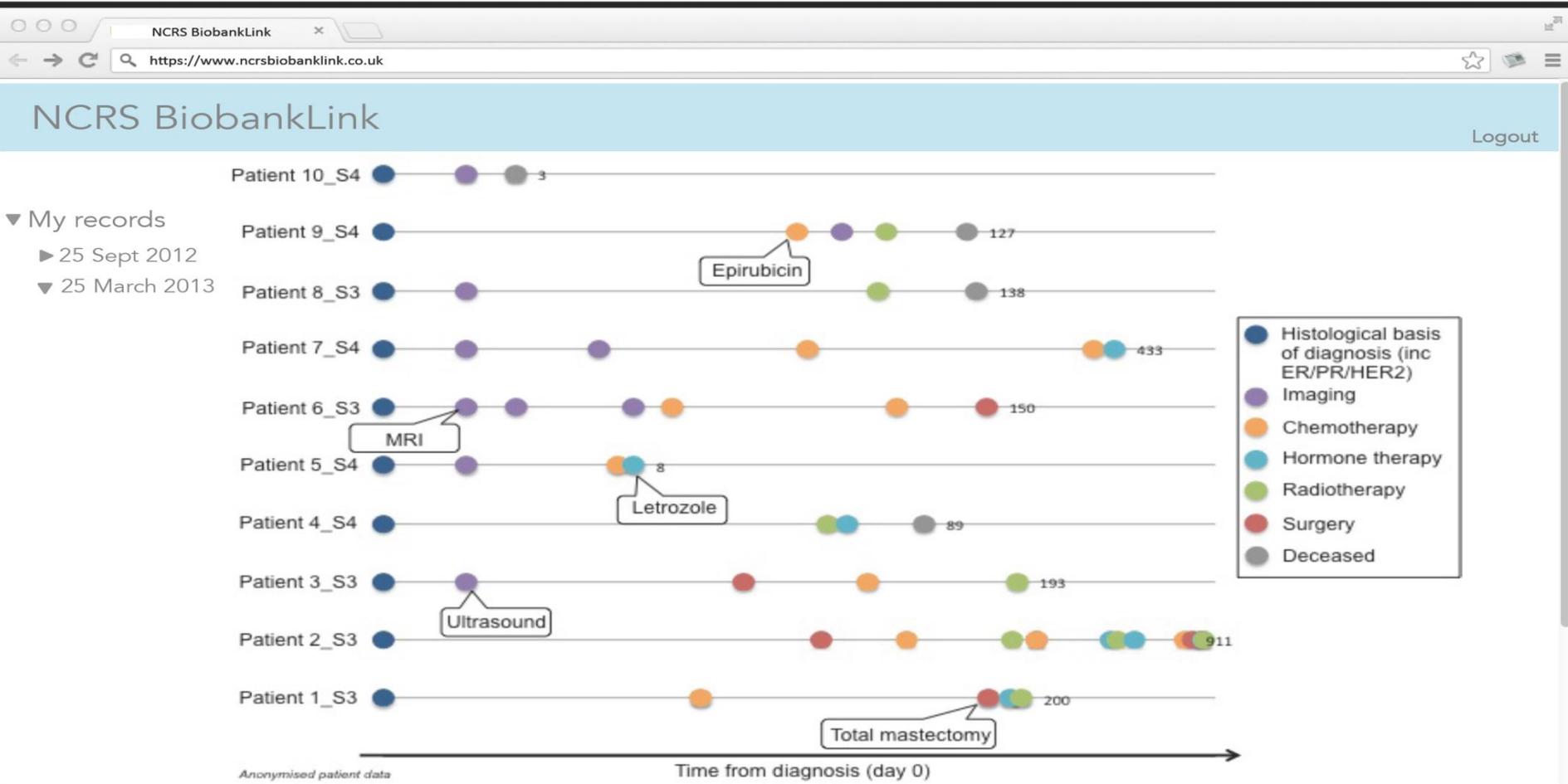
Examples of the clinical value of new data

- **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’**





NCRS BiobankLink Service





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
- Breast cancer audit likely to be commissioned in 2015



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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



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



UK Cancer e-Atlas by cancer networks

Data being displayed: Prostate - Male Survival 5 Year



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

Save | Export data

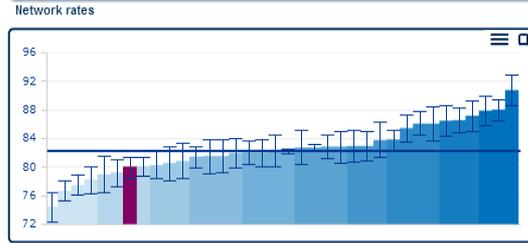
Go to health boundary e-Atlas

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

Select cancer network	Rate
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 ■
 - +



Information about the selected data item * Age-standardised

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



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

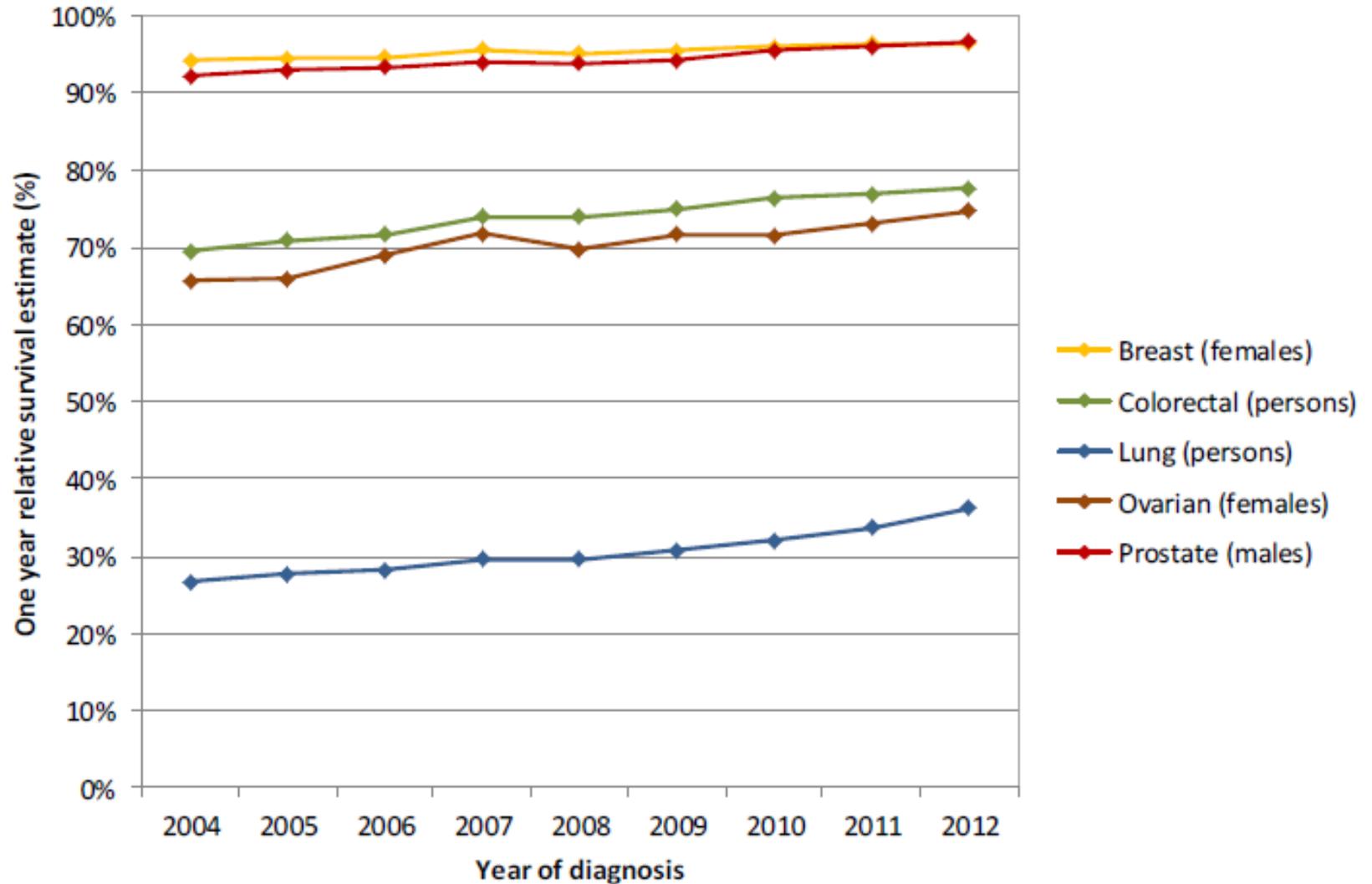
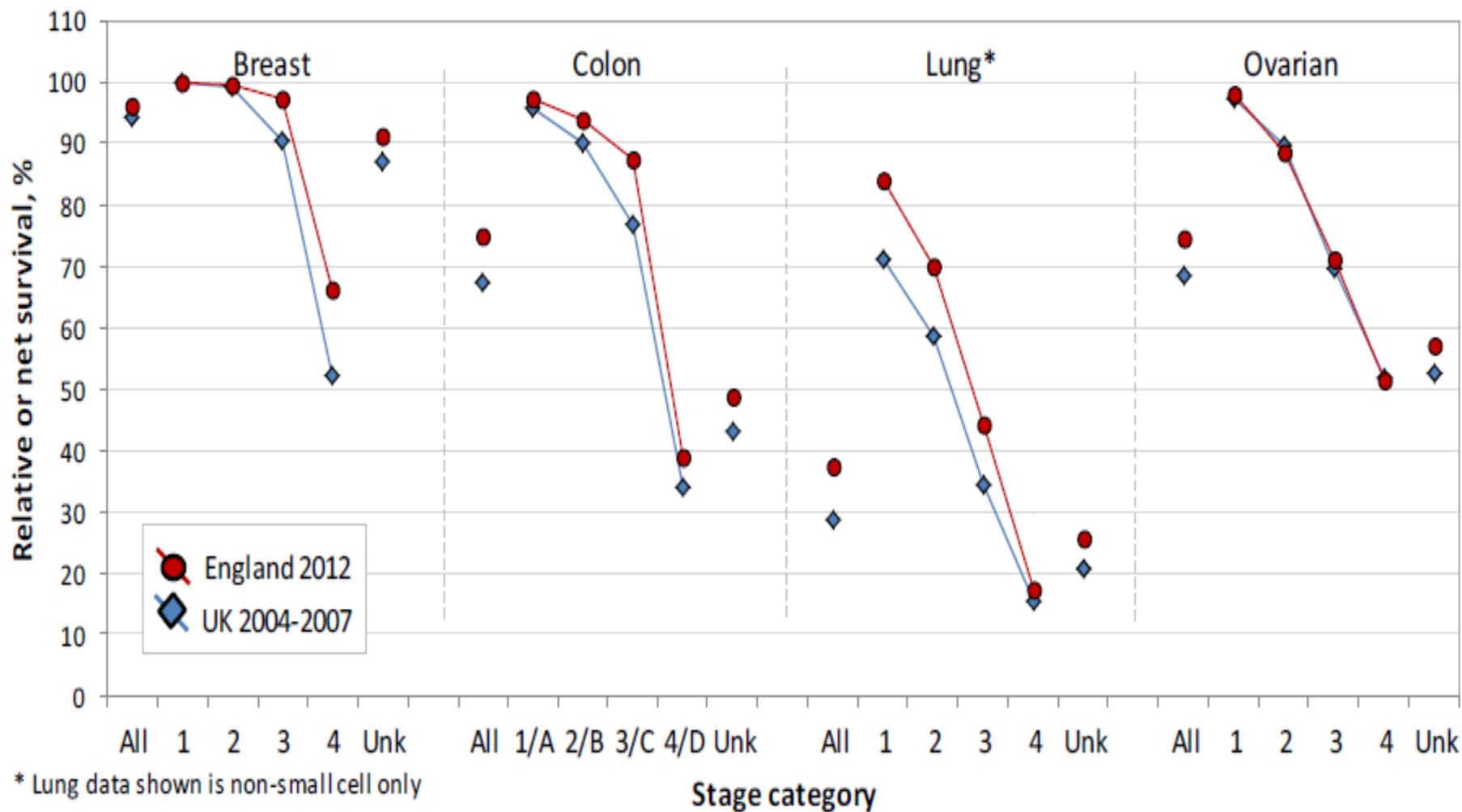




Figure 4 One-year relative/net survival, by stage, in the ICBP and England 2012 data





Cancer Commissioning Toolkit



Charts

Charts are displayed using figures or percentages and comply with data sharing rules to ensure patient confidentiality.

Types of Data Available - Incidence; Mortality; Survival; Smoking Cessation; Peer Review; Screening; Referrals; Waiting Times; Radiotherapy; National Audit; Cancer medicines; Place of death; Programme Budgeting.

Public users

Members login

Email

Password

[Login](#) [Forgotten your password?](#)

Not registered yet? [How do I register?](#)

[Register Now](#)

[Contact Us](#)

www.ncin.org.uk



Welcome Mick Peake

Log out



Chart by:
 SHA Network PCT

Highlight:
East Midlands

Cancer type:
Lung

Time period:
2007-2009

Other charts within the module:

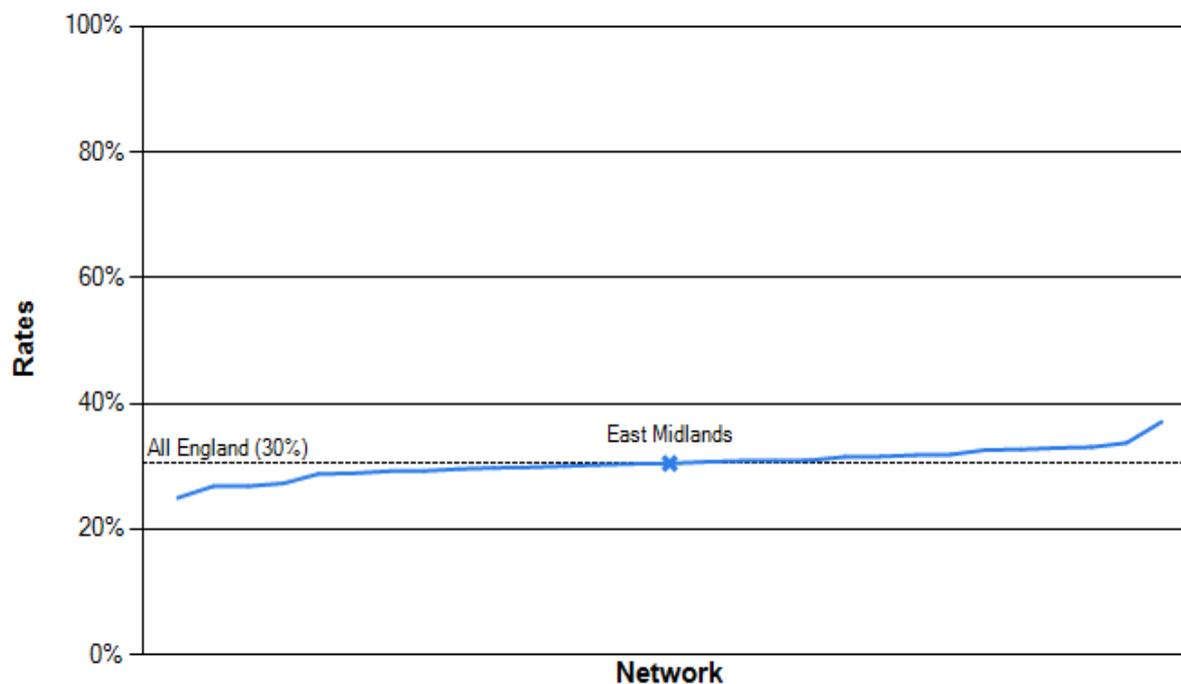
- > [5 year relative survival estimates benchmarked](#)
- > [Trend in survival](#)

Links
> [CCT- Website Terms and Conditions](#)



1 year relative survival estimates benchmarked by Network

Cancer type (Lung) Time period (2007-2009)



Overview

Filters

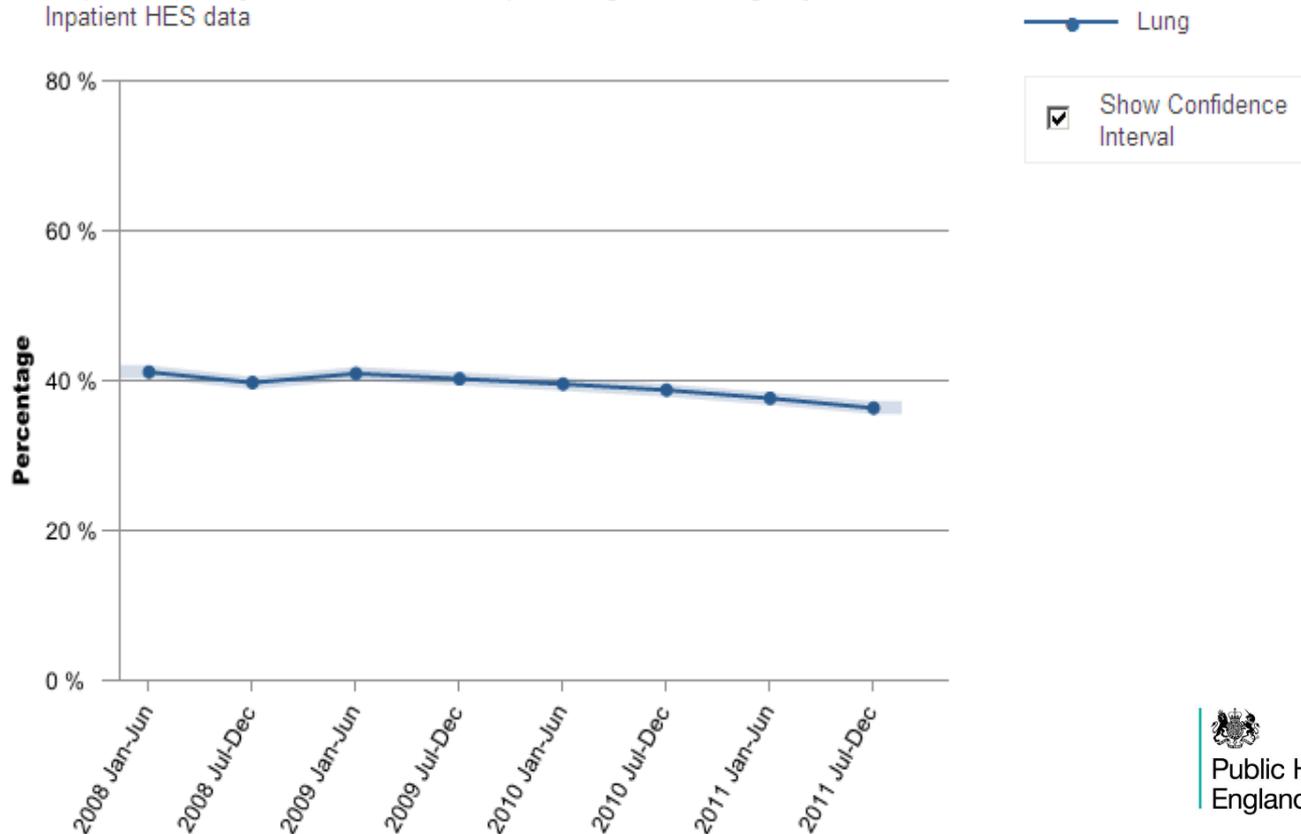
Cancer Type

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





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

