



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')



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**



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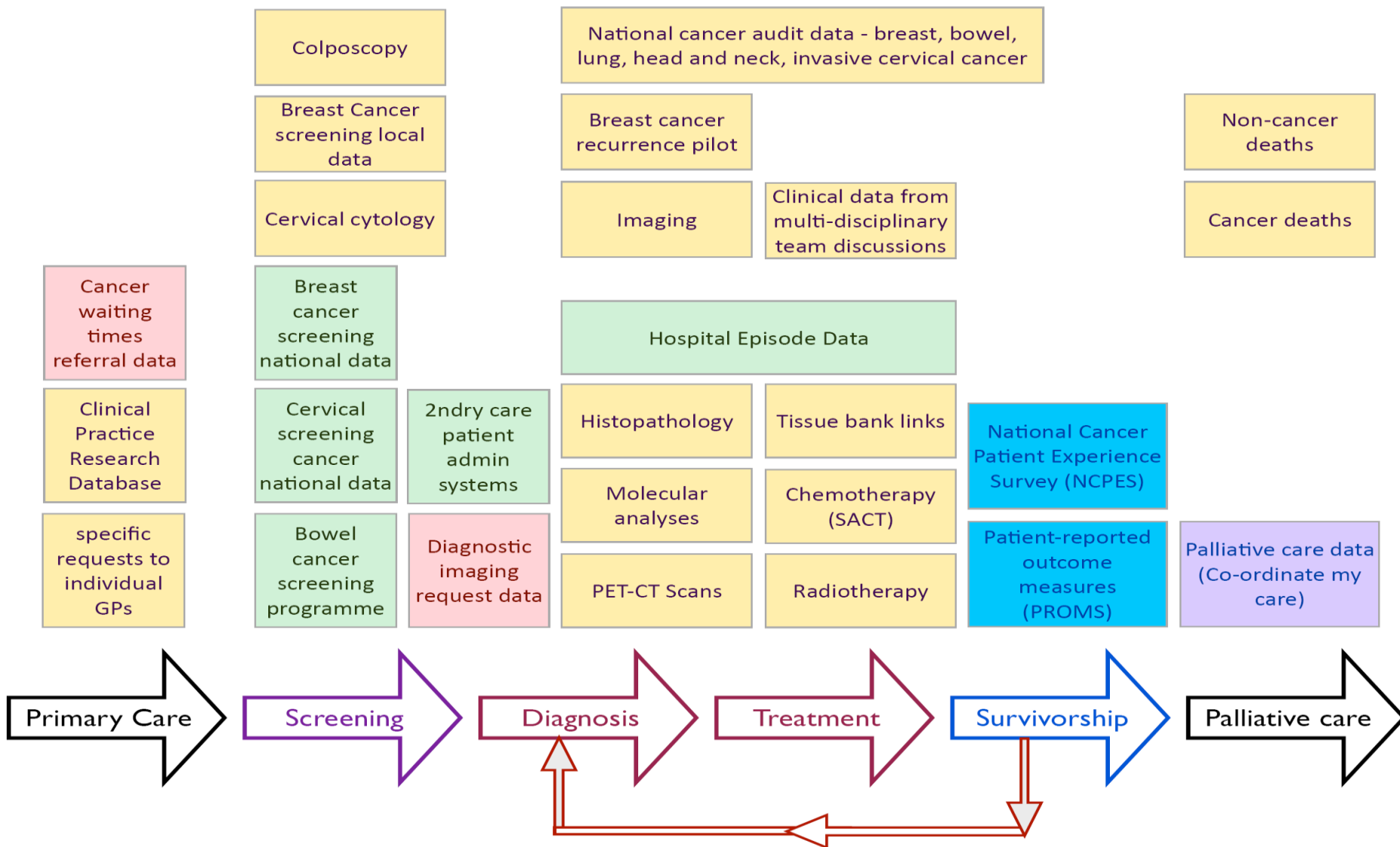
The English National Cancer Registration System

- 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

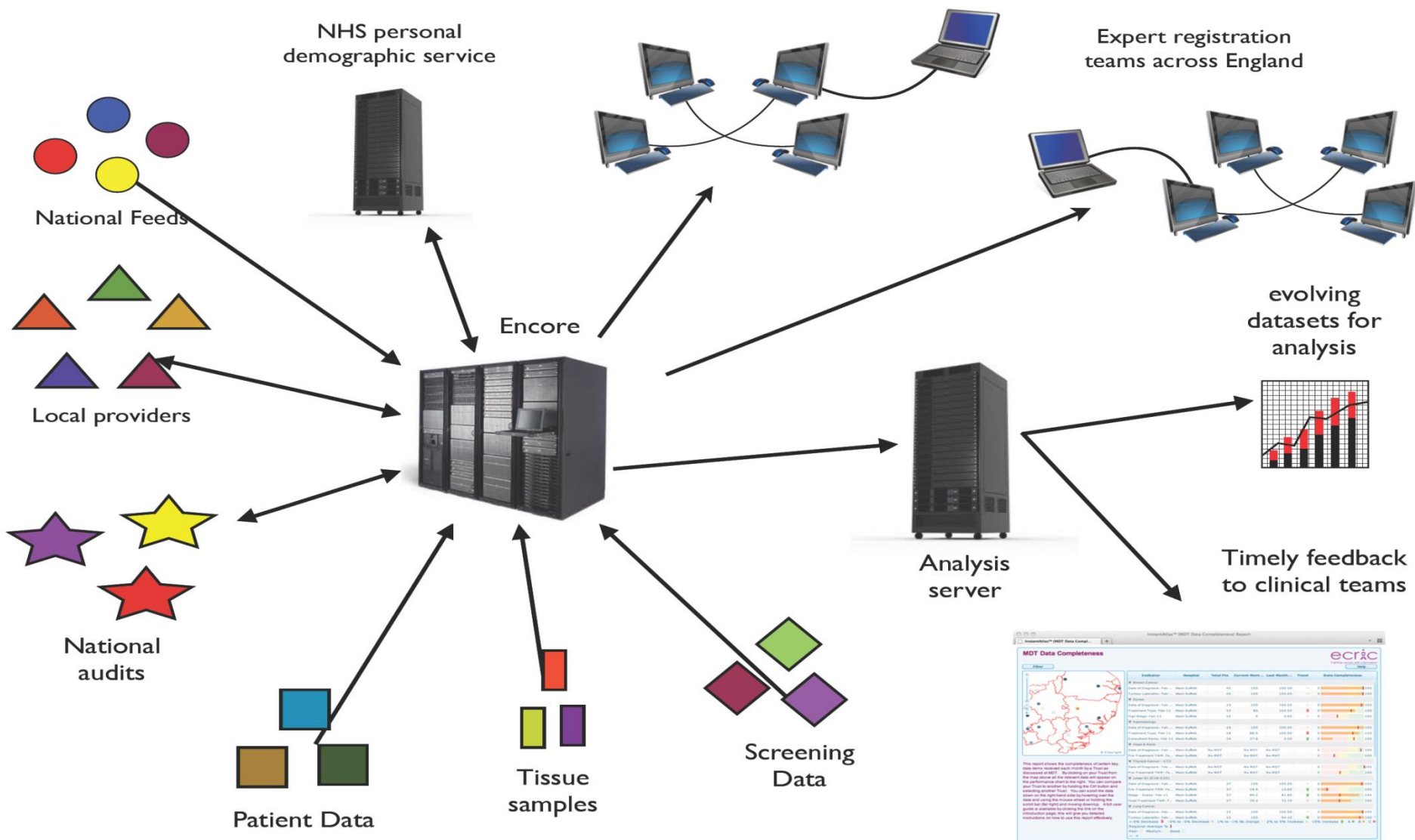




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NCRS – ENCORE

(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



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

| 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 | period expectations of life - years |
| 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 | 31.6 | % |
| 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 | 11.6 | % 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 |
| 2.5 Employment of people with mental illness | Jan-Mar13 | 39.0 | % gap |
| 2.6.i Estimated diagnosis rate for people with dementia | 2011/12 | 48.0 | % |
| 2.6.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 episodic conditions

| Overarching indicators | Latest data | Indicator value | Unit |
|--|-------------|-----------------|------------------------|
| 3a Emergency admissions for acute conditions that should not usually require hospital admission (all ages) | 2011 | 11.3 | per 100,000 population |
| 3b Emergency readmissions within 30 days of discharge from hospital | 2011 | 11.3 | per 100,000 population |
| Improvement areas | | | |
| 3.1.i Total health gain as assessed by patients for elective procedures - Hip replacement | 2011 | 58.0 | per 100,000 population |
| 3.1.ii - Knee replacement | 2011 | 23.5 | per 100,000 population |
| 3.1.iii - Groin hernia | 2011 | 14.9 | per 100,000 population |
| 3.1.iv - Varicose veins | 2011 | 107 | per 100,000 population |
| 3.1.v - Psychological therapies | 2011 | 107 | per 100,000 population |
| 3.2 Emergency admissions for children with lower respiratory tract infections | 2011 | 107 | per 100,000 population |
| 3.3 An indicator on recovery from injuries and trauma | 2011 | 107 | per 100,000 population |
| 3.4 Proportion of stroke patients reporting an improvement in activity/lifestyle on the Modified Rankin Scale at 6 months | 2011 | 107 | per 100,000 population |
| 3.5.i Proportion of patients with a fragility fracture recovering to their previous levels of mobility at 30 days | 2011 | 107 | per 100,000 population |
| 3.5.ii Proportion of patients with a fragility fracture recovering to their previous levels of mobility at 120 days | 2011 | 107 | per 100,000 population |
| 3.6.i Proportion of older people (65 and over) who were still at home 31 days after discharge from hospital into rehabilitation services | 2011 | 107 | per 100,000 population |
| 3.6.ii Proportion offered rehabilitation following discharge from acute or community hospital | 2011 | 107 | per 100,000 population |

NHS Outcomes

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

200X indicates calendar year
200X/XX indicates financial year

1 Preventing people from dying prematurely

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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

The screenshot displays the HSCIC Indicator Portal interface. The top header shows the HSCIC logo and 'Health & Social Care Information Centre'. A search bar is present on the right. The left sidebar contains navigation links: 'Find data', 'Home', 'Tools', 'Casemix', 'Hospital Statistics', 'Indicator', and 'Indicators'. The main content area is titled 'CCG Indicator 1.9 (NHS OF 1.4)' and 'Under 75 mortality from cancer'. It provides a detailed breakdown of the indicator, including the statistic, period, level of coverage, and source. A table below shows the data for the years 2009 and 2010, broken down by gender and population.

hscic Health & Social Care Information Centre

Find data

Home

Tools

Casemix

Hospital Statistics

Indicator

Indicators

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)

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

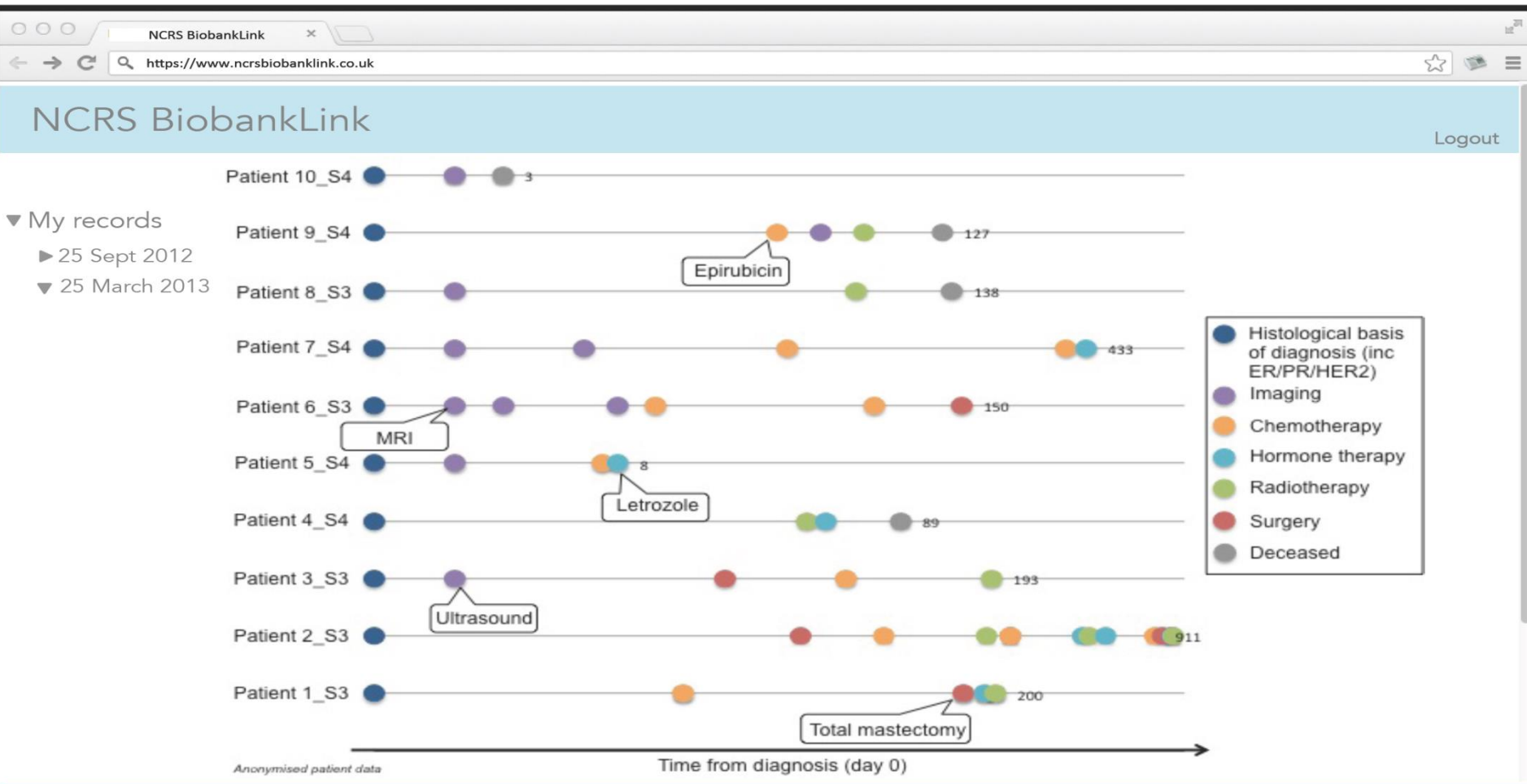
- **Demonstration of variation**
- **Teasing out the causes of variation**
- **Demonstrating value of specialisation**
- **Building data into quality improvement**
- **Adding outcome data into Peer Review**
- **Providing robust evidence behind National Guidelines and Quality Standards (NICE)**
- **Supporting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





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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
- 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*



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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

Guide

Print

Select localities

Go to health boundary e-Atlas

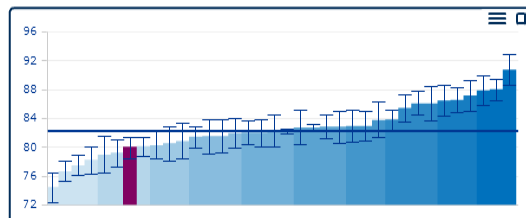
Save

Export data



| 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 % |

Network rates



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

| 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

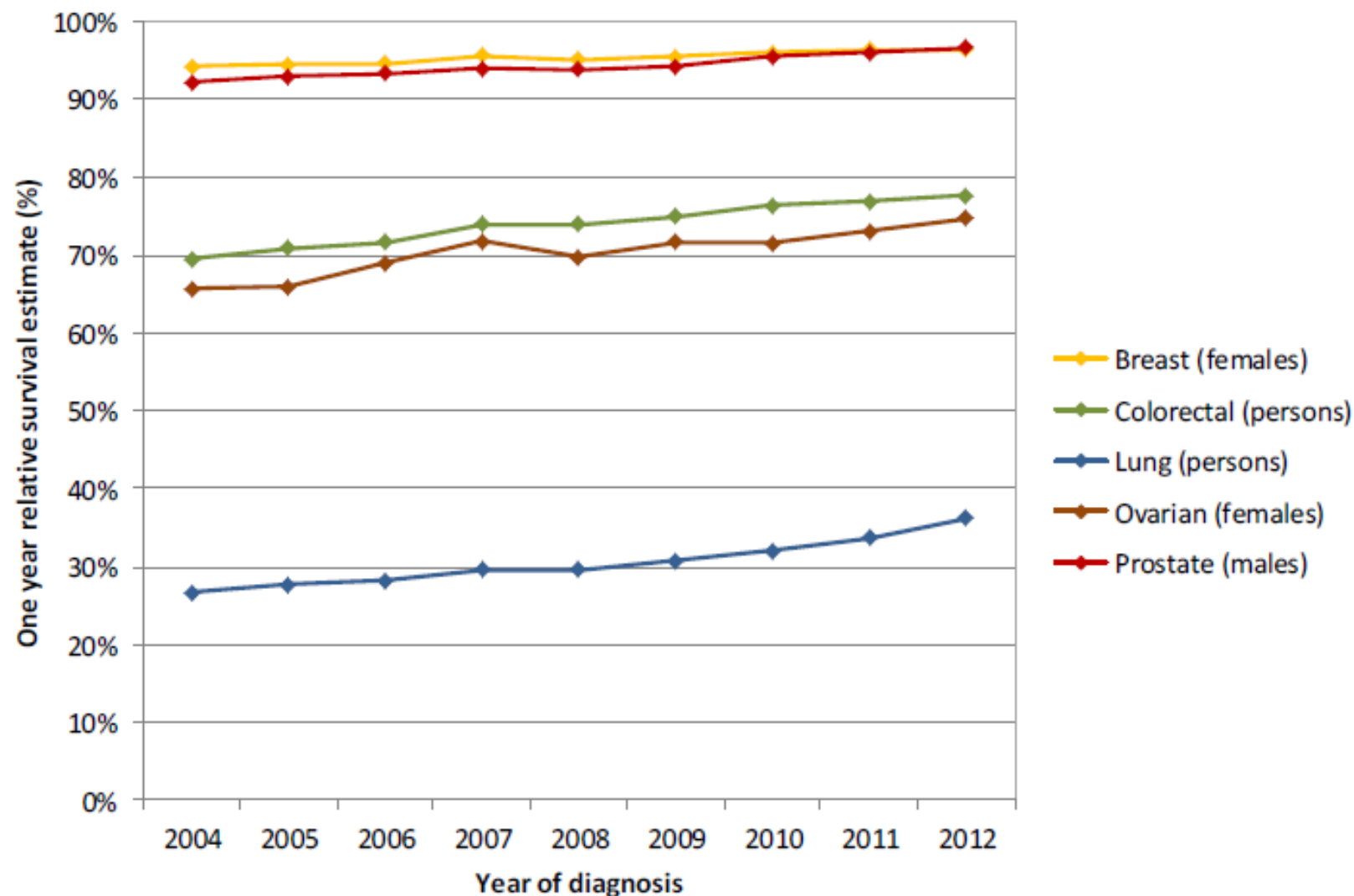
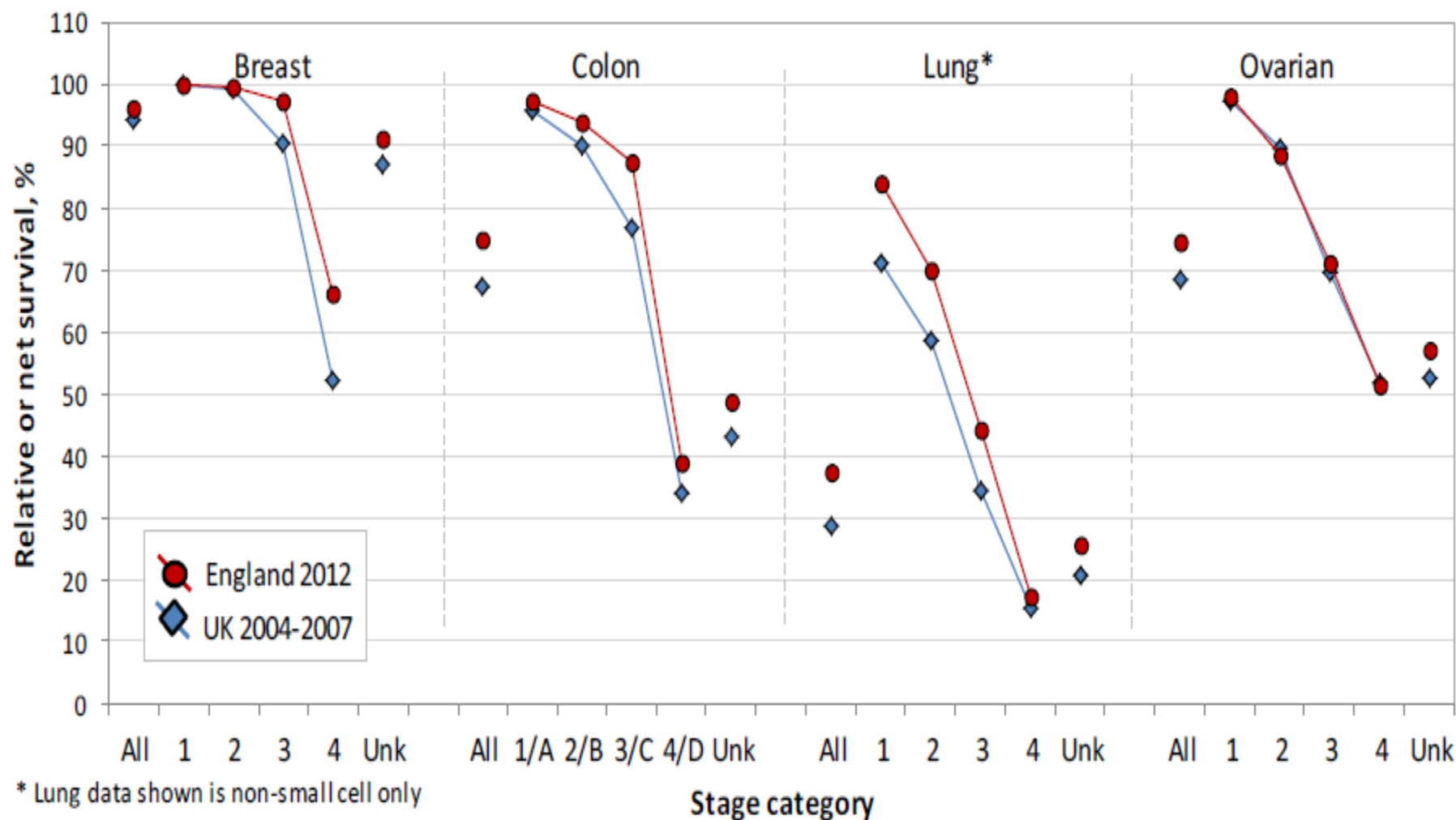




Figure 4 One-year relative/net survival, by stage, in the ICBP and England 2012 data





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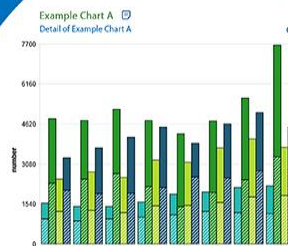
Cancer Commissioning Toolkit

https://www.cancertoolkit.co.uk



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?

[Register Now](#)

[How do I register?](#)

[Contact Us](#)

www.ncin.org.uk



Welcome **Mick Peake** [Log out](#)

1 year relative survival estimates benchmarked by Network

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

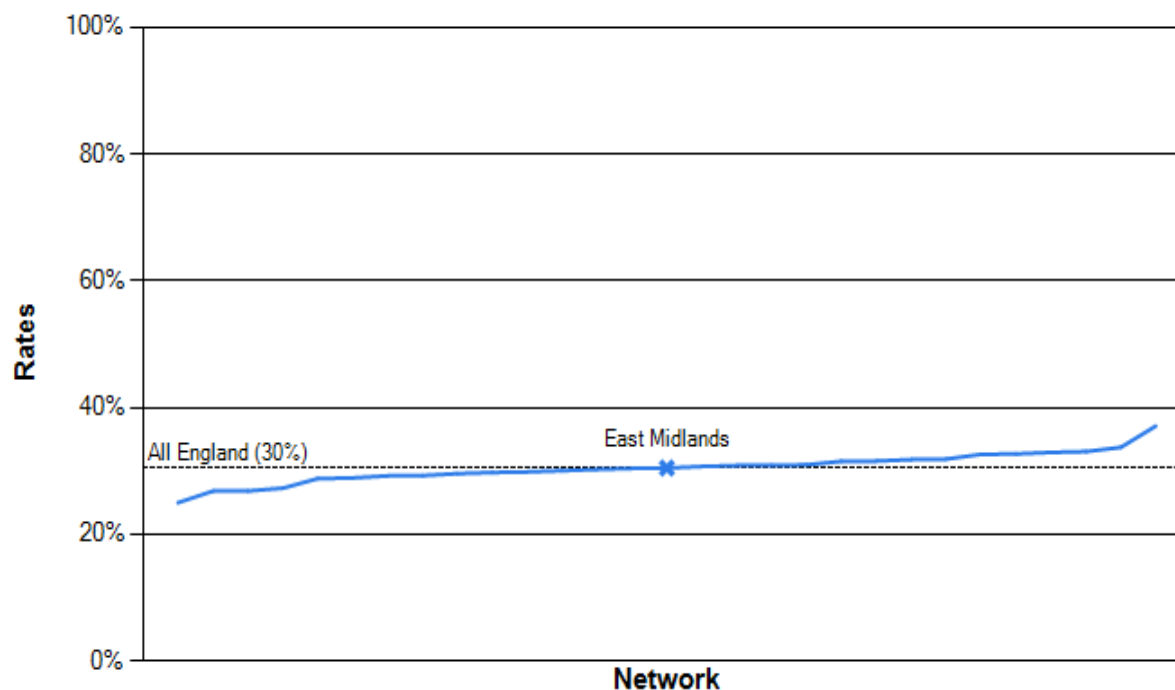


Chart by:

☐ 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](#)

Overview

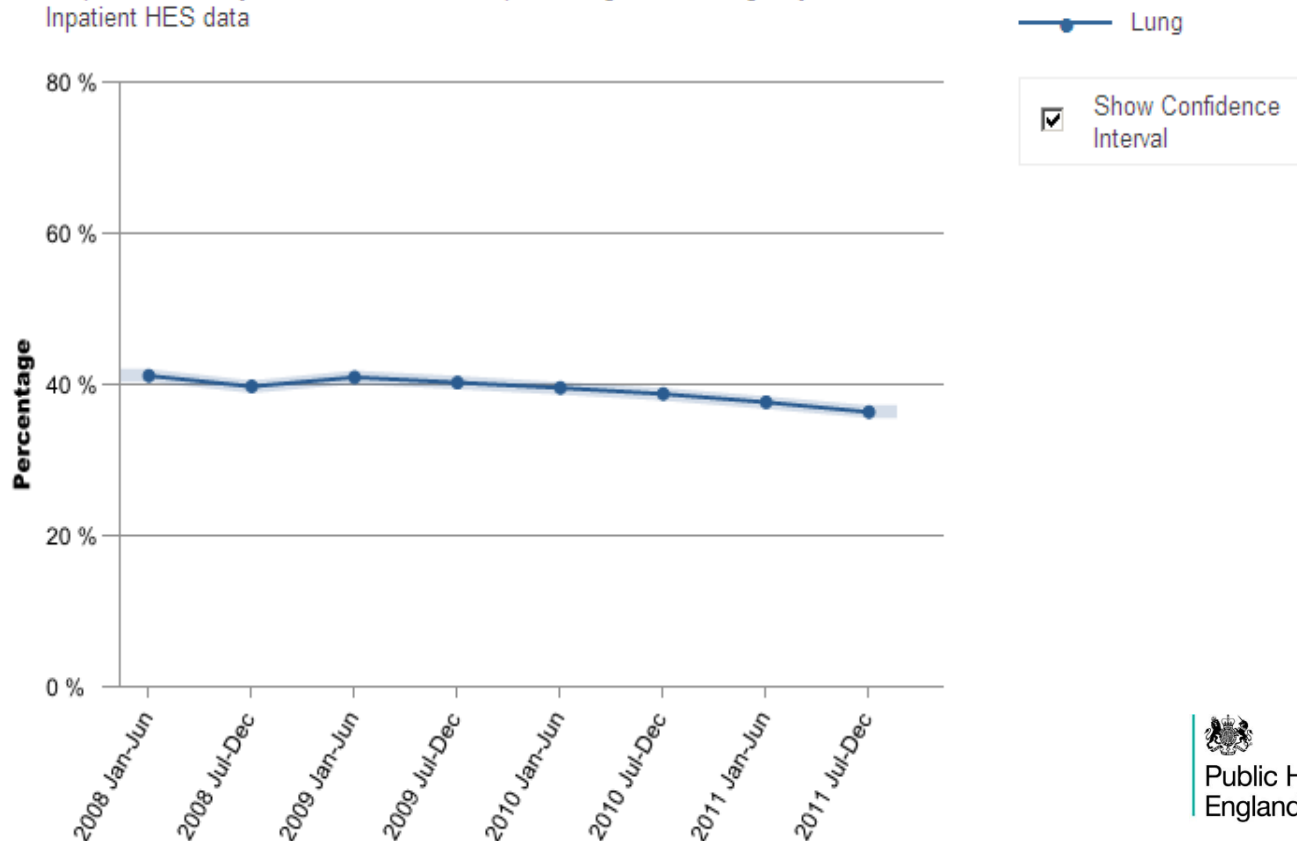
Filters
Cancer Type

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



Public Health
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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



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

