



*Using information to improve quality & choice*



Public Health  
England



Public Health  
England

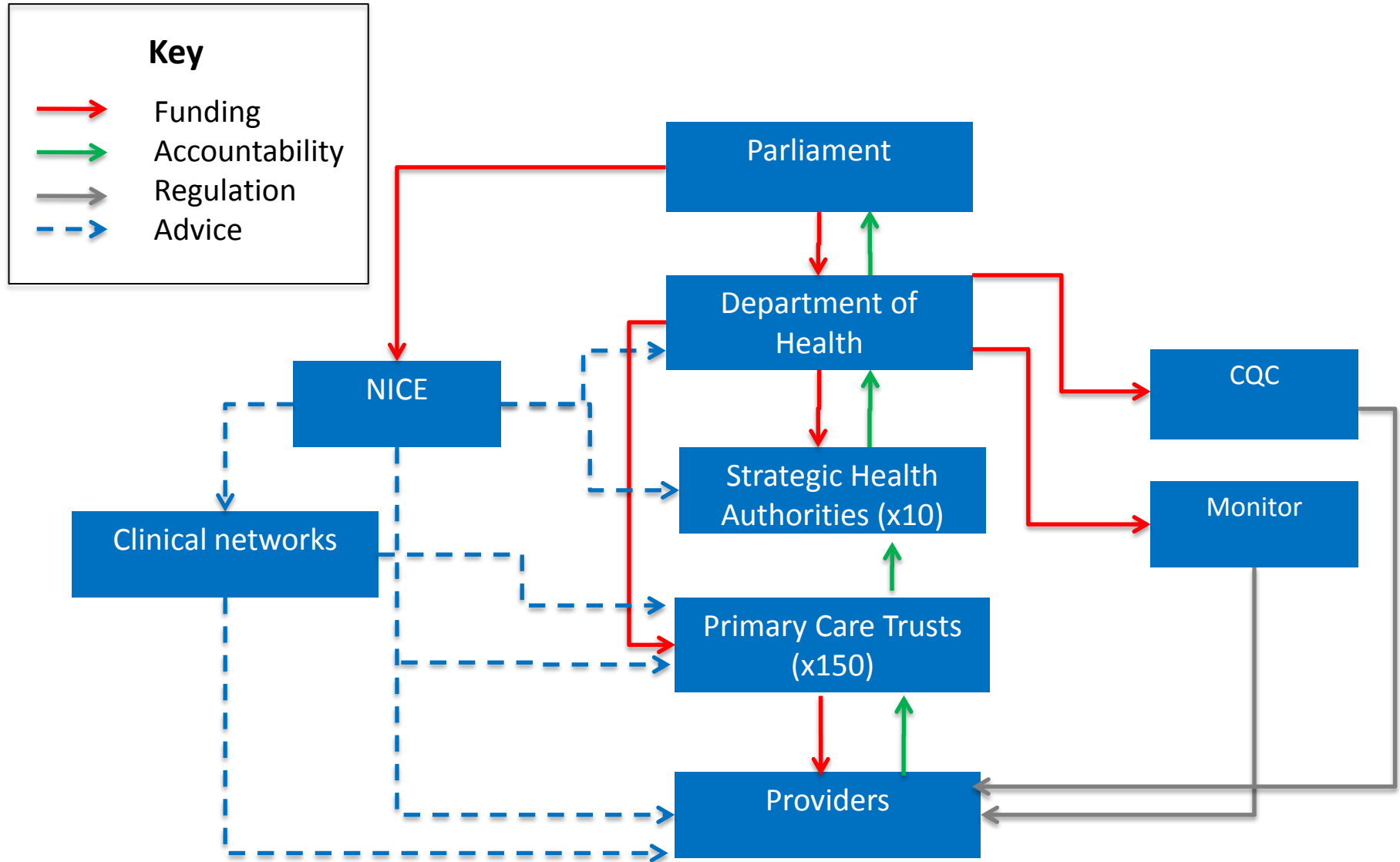
# The NCIN in the 'new world'

**Dr Mick Peake**

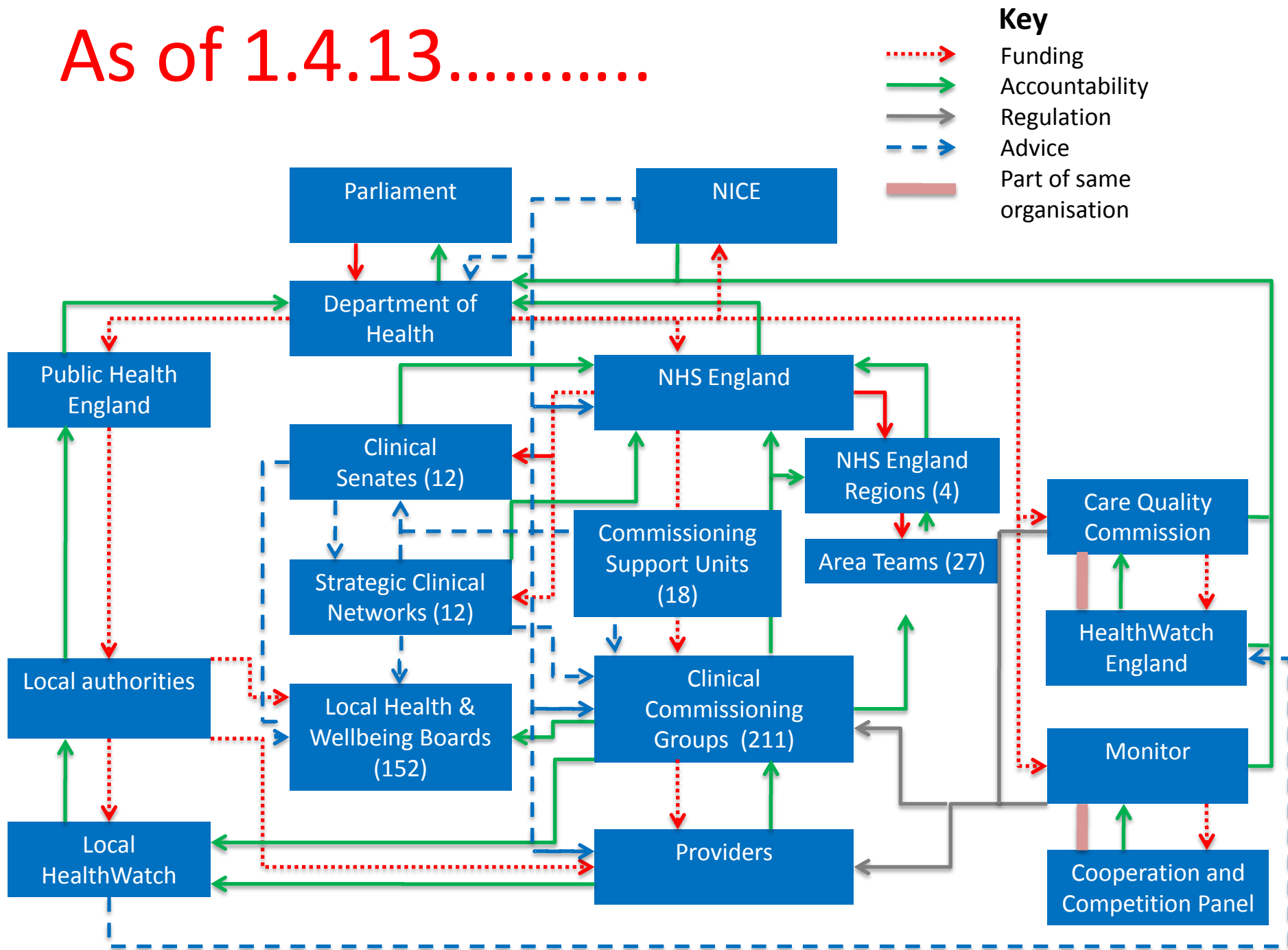
Clinical Lead,

National Cancer Intelligence Network

# What was then...



# As of 1.4.13.....



- **One national office in Leeds**
- Four regions – directly commission primary care and specialist services
- **10 specialised commissioning hubs provided within 27 Area Teams (ATs)**
- 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
- **17? Commissioning Support Units – support to CCGs commissioning local services (very few have cancer specialists as yet)**
- 27 Area Teams to support CCG development
- **211 Clinical Commissioning Groups (CCGs)**
- **152 Health and Well Being Boards**

# Specialised Commissioning

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

# Specialised commissioning: Clinical Reference Groups - cancer

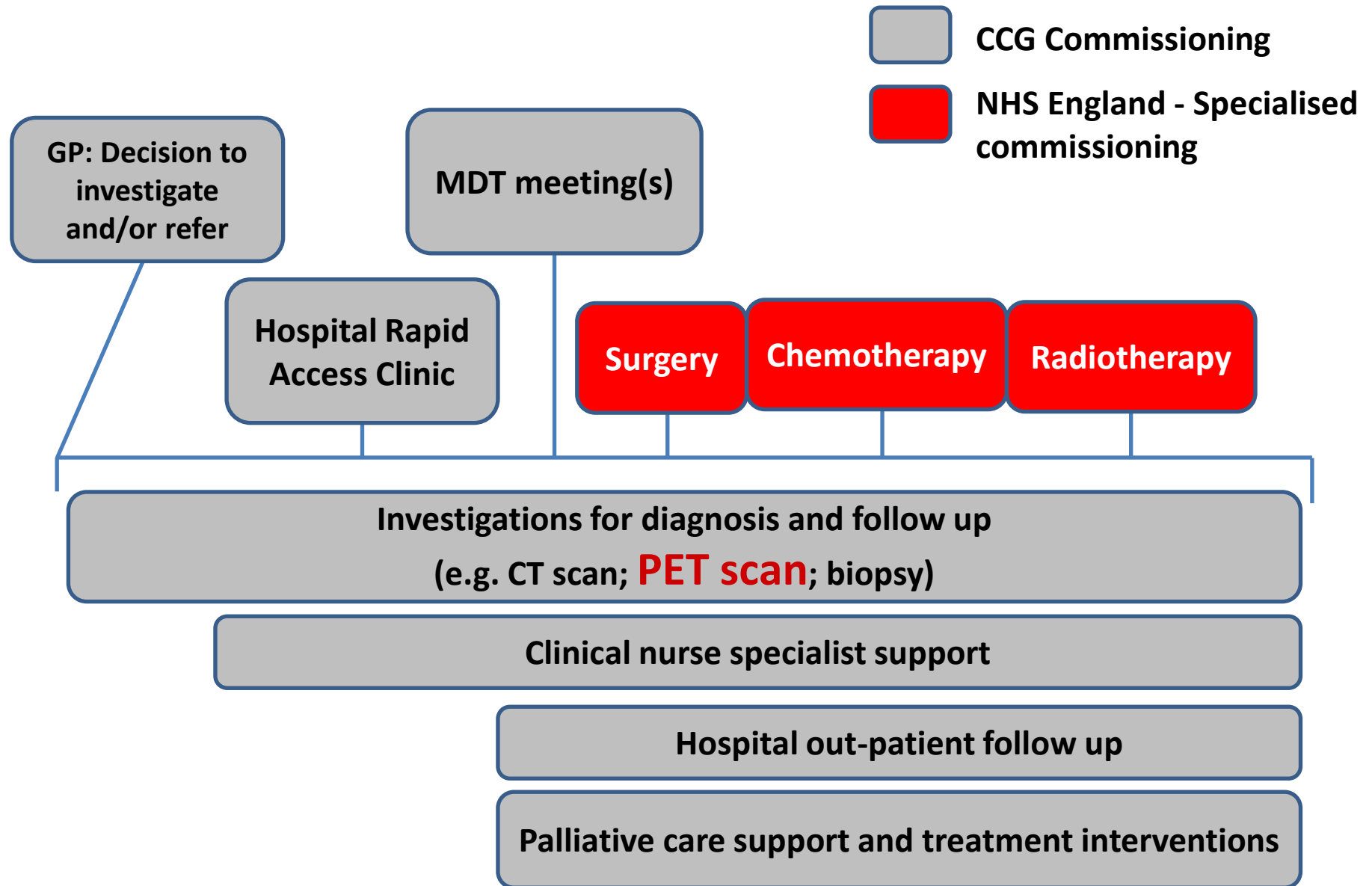
- Radiotherapy
- PET-CT
- Specialised (rarer) Cancer
- Blood and Marrow transplantation
- Thoracic surgery
- Upper GI Surgery
- Sarcoma
- CNS tumours
- Specialised urology
- Chemotherapy
- Complex Head & Neck
- Teenage and Young People Cancer

# Role for Clinical Commissioning Groups (Primary care)

- **‘Common cancers’**
- **Service specifications – advisory**
- **New Clinical Reference Groups to be established**
- **Diagnostics**
- **Referrals**
- **MDT / data collection costs**
- **Clinical Nurse Specialists**
- **Follow up**
- **Palliative Care (including complex palliative procedures)**



# Fragmented patient pathway



# NCIN core objectives

- Promoting efficient and effective data collection throughout the cancer journey
- Providing a common national repository for cancer datasets
- Producing expert analyses, based on robust methodologies, to monitor patterns of cancer care
- Exploiting information to drive improvements in standards of cancer care and clinical outcomes
- Enabling use of cancer information to support audit and research programmes



# 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  
(Prof. Julia Verne)**

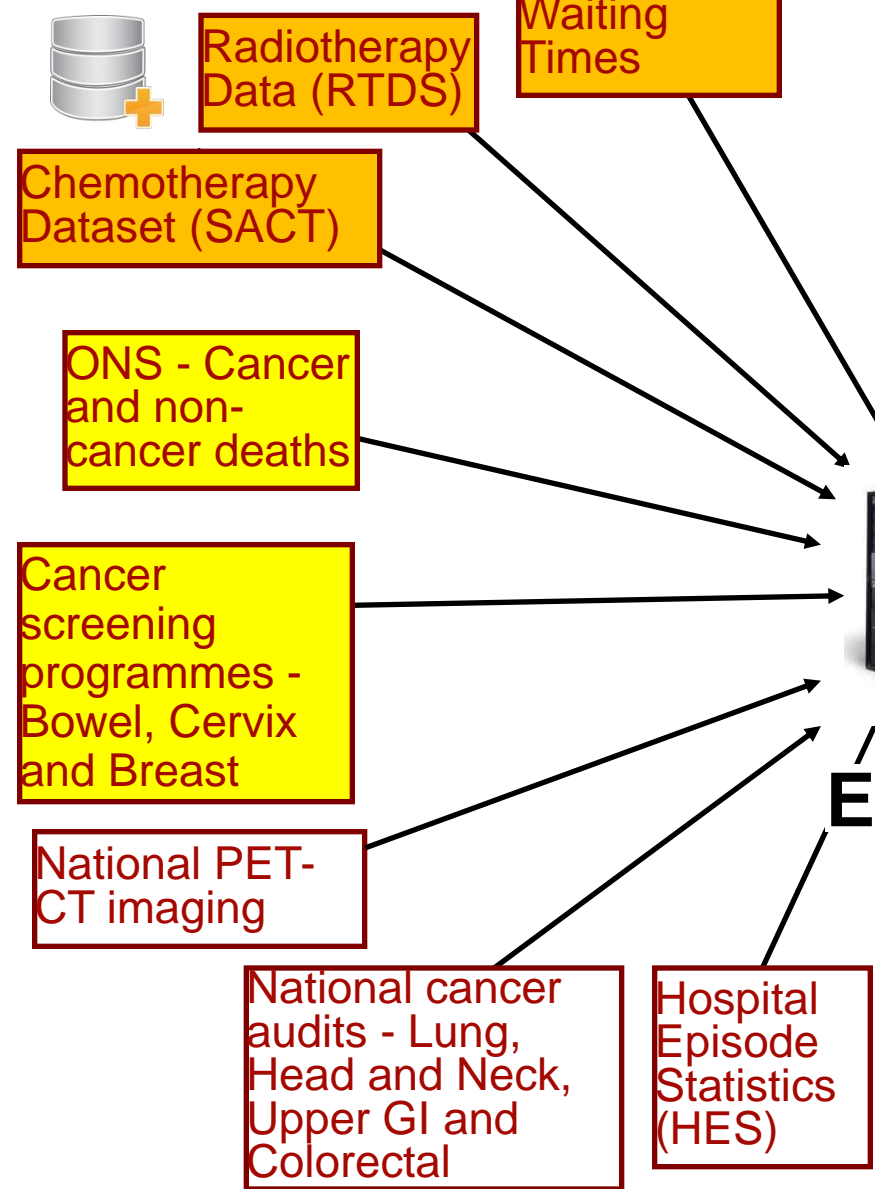
**National Cancer  
Intelligence Network**



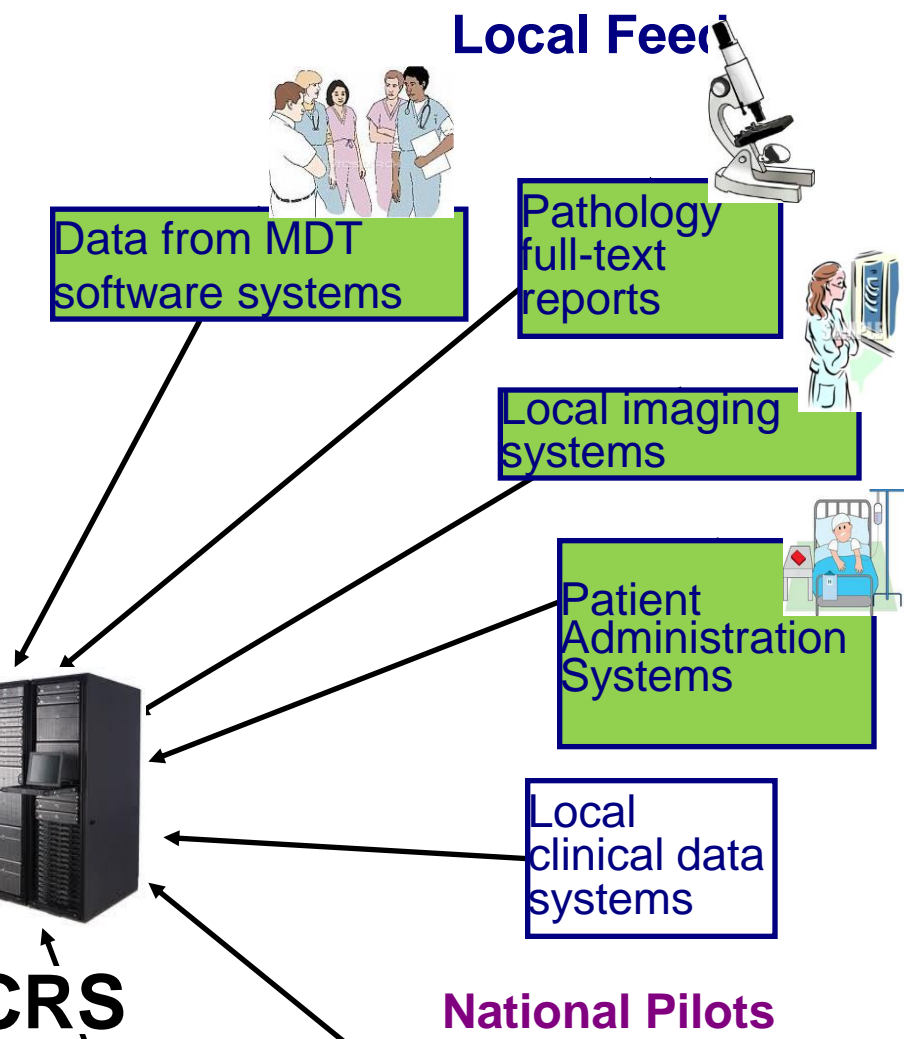
**Public Health  
England**

# Data sources - patient-level data

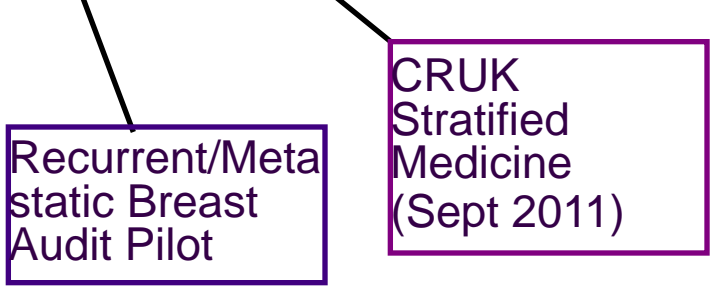
## National Feeds



## Local Feeds



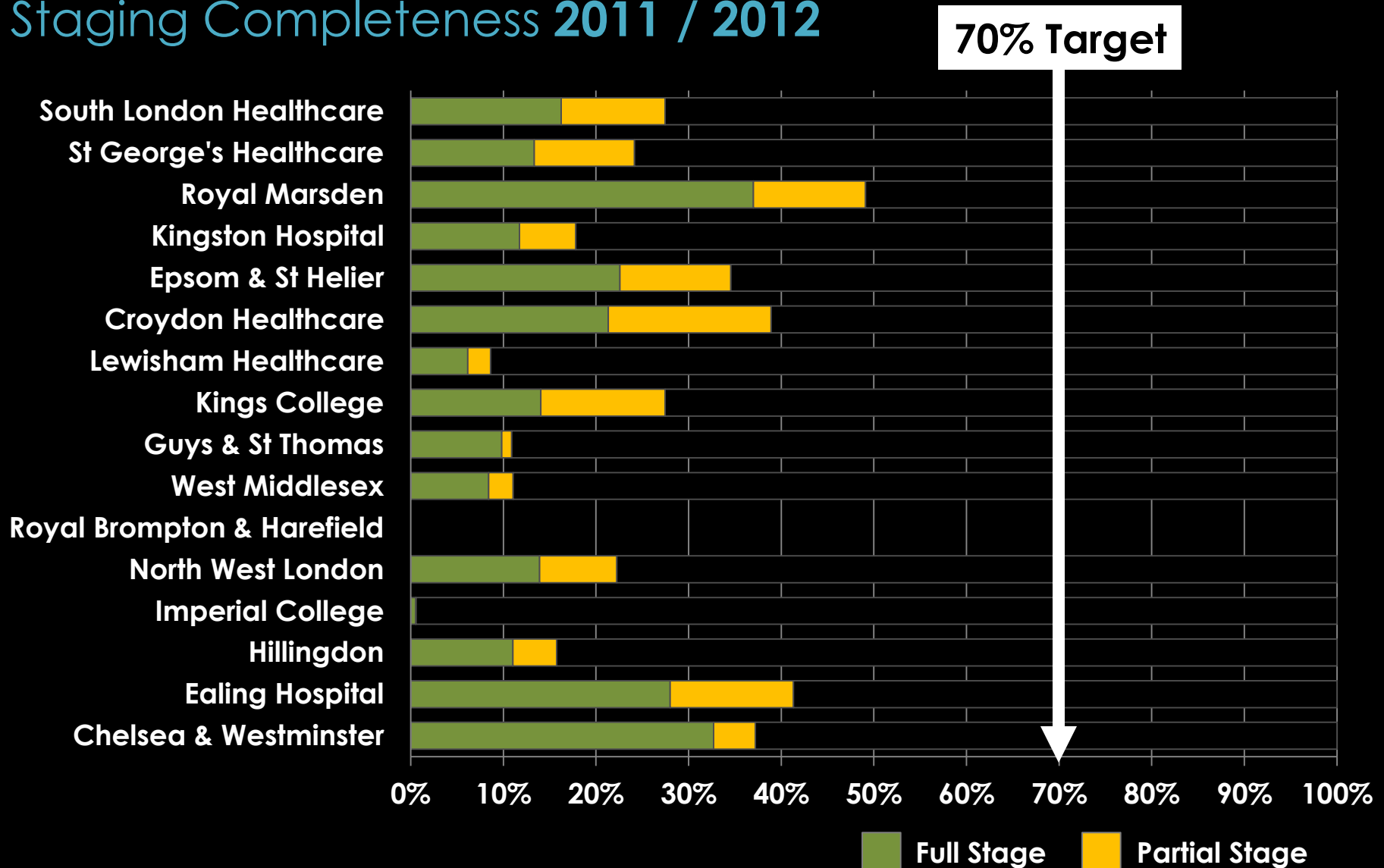
## National Pilots



**ENCRS**

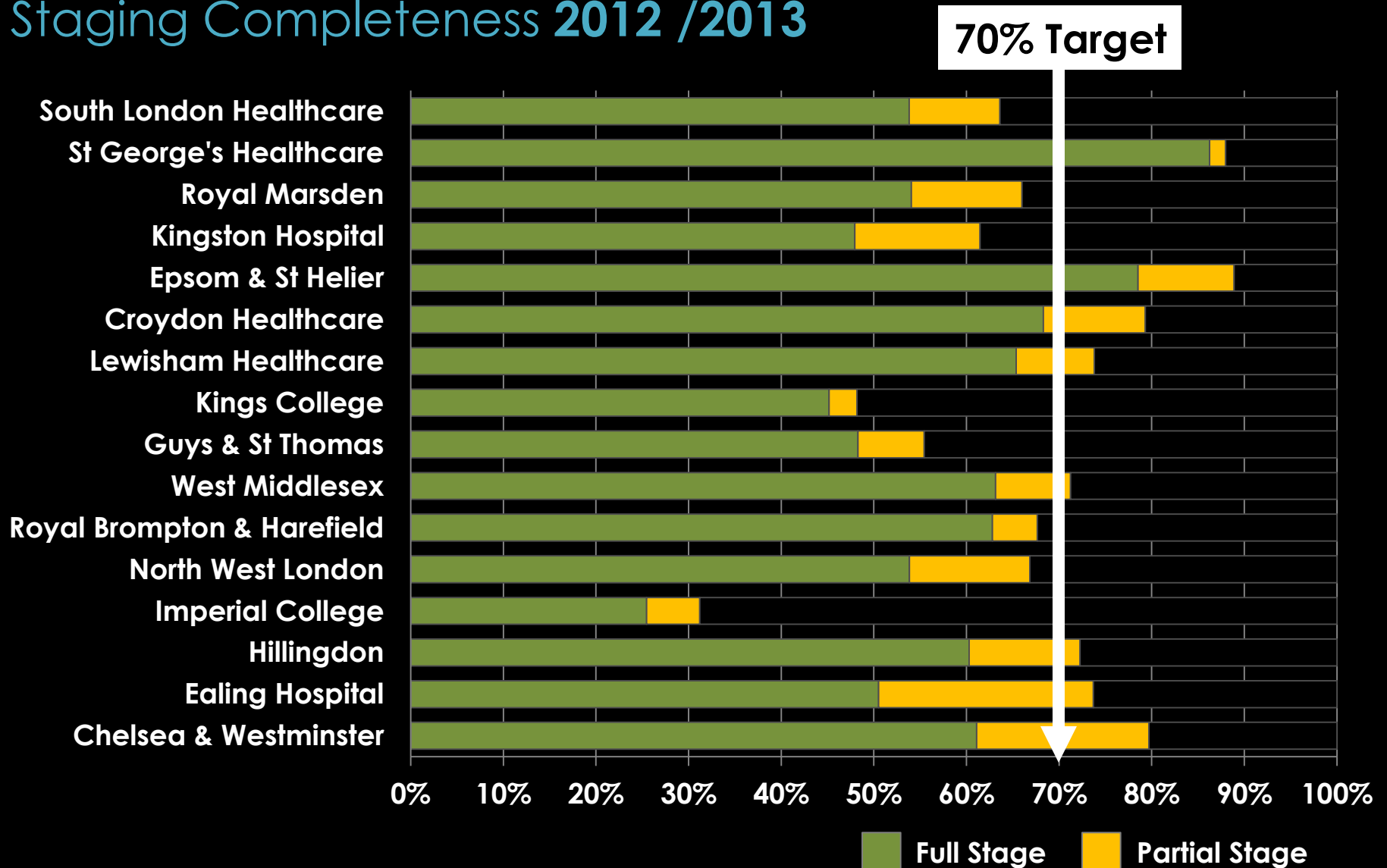
# London Cancer Alliance

## Staging Completeness 2011 / 2012



# London Cancer Alliance

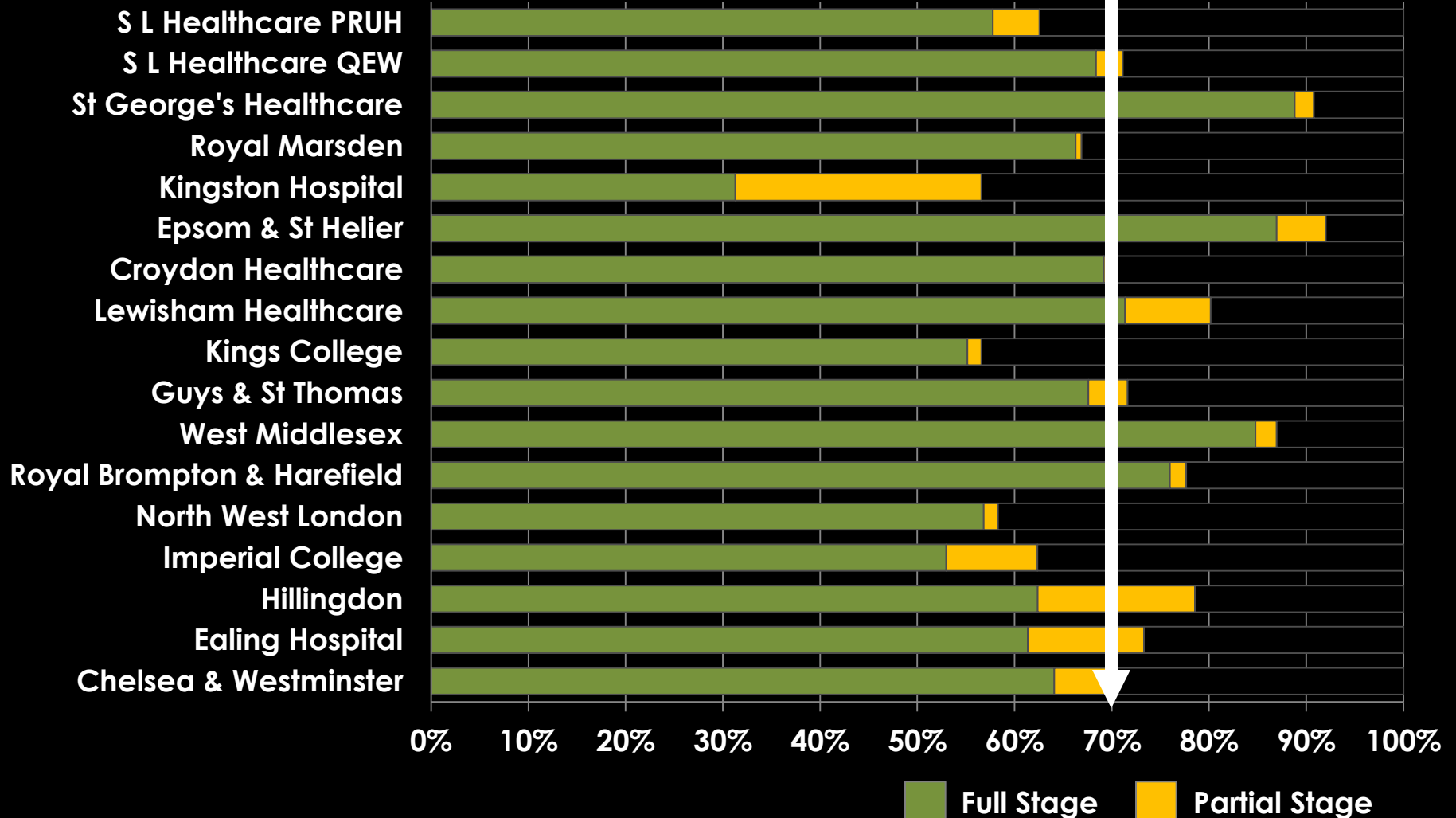
## Staging Completeness 2012 /2013



# London Cancer Alliance

## Staging Completeness 13/14 (Apr-Oct)

70% Target



# Health Intelligence Networks

- Cancer (NCIN)
- Cardiovascular (including renal and diabetes)
- Mental Health
- Maternal and Child Health
- End of Life





- Data governance
- Data access
- Data linkage to external sources (e.g. primary care)
- Rapid access to data (e.g. Parliamentary Questions, media coverage)



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# Main elements of clinical engagement



- Identification of key clinical issues & priorities
- 'Ownership' of data:
  - Dataset development & revision
  - Championing data collection
  - QA
- Clinical input into the analytical programme
- Communication – colleagues; professional bodies, providers; commissioners
- Promoting the use of routine data in research

# Site-Specific Clinical Reference Groups

- **Brain/CNS**
- **Breast**
- **Children, Teenage & Young Adults**
- **Colo-rectal**
- **Gynaecological cancers**
- **Haematological cancers**
- **Head & Neck**
- **Lung**
- **Bone & soft tissue Sarcoma**
- **Skin (including non-melanoma)**
- **Upper GI (including Hepato-biliary)**
- **Urology (all 4 sub-types)**



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# 'Cross-cutting' Groups

- **Radiotherapy**
- **Chemotherapy**
- **Pathology (with RCPATH)**
- **Radiology (with RCR)**
- **Co-morbidity**
- **National Cancer Staging Panel**
- **Primary Care (with RCGP)**
- **Health Economics (with Macmillan)**



- ❑ > 150 senior clinicians highly engaged in understanding & using cancer data
- ❑ >600 clinicians attending annual workshops
- ❑ wide range of publications, presentations at professional conferences, network meetings, etc.
- ❑ strong emerging links with clinical researchers
- ❑ strong patient, public and charity involvement

**= A new community of “clinical data champions”**

- National Cancer Data Repository
- Review of National Cancer Data Repository
- Work programmes
- Production of ‘data briefings’
- Supporting Peer Review (Clinical Lines of Enquiry)



# Who do we produce intelligence for?

- Clinicians & Clinical Teams
- NHS England (e.g. specialist commissioning)
- Clinical Commissioning Groups
- Public Health England
- Health Care Providers
- NICE
- Research Community
- National Statistics
- International Cancer Benchmarking Partnership
- Patients and the public
- Pharmaceutical Industry



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# NCIN – Main outputs

- National Cancer Registration Service
- National level reports
- Data briefings
- E-Products, e.g.:
  - eAtlas
  - Cancer Commissioning Toolkit
  - GP Practice & Service profiles
- Dataset development & implementation
- Clinically-led work programmes & publications
- Analytical programmes with CRUK & Macmillan



# Feeding back: two examples

- Cancer Commissioning Toolkit
- Service & GP Profiles





# Two Examples

- **Cancer Commissioning Toolkit**
- Service & GP Profiles





Welcome **Mick Peake**

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## 1 year relative survival estimates benchmarked by Network

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

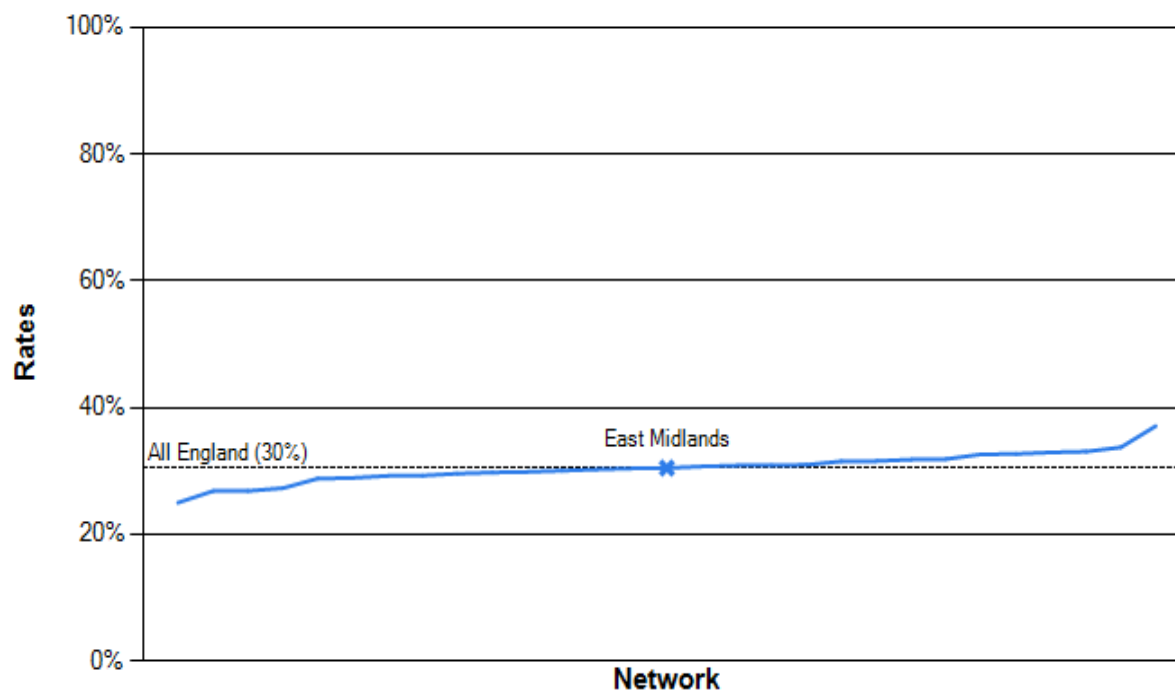


Chart by:

☐ 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](#)



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## 1 year relative survival estimates benchmarked by PCT

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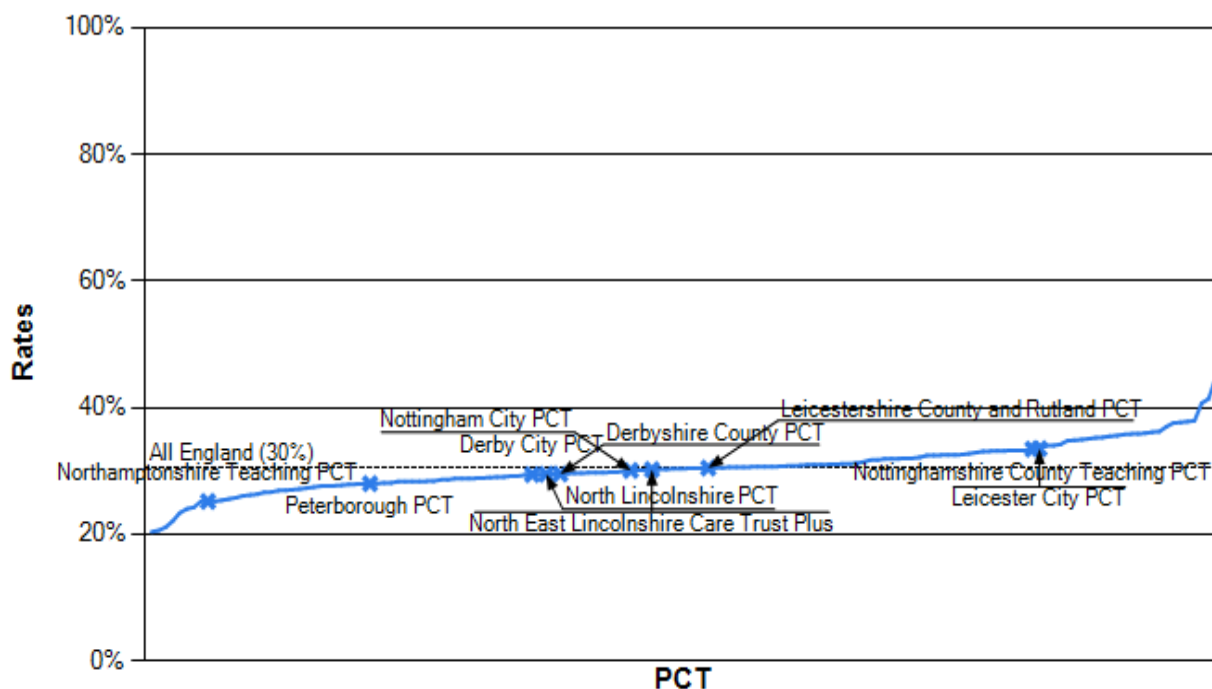


Chart by:

☐ SHA ☐ Network ☒ PCT

Highlight:

\* PCTs Selected ▼

Cancer type:

Lung ▼

Time period:

2007-2009 ▼

Other charts within the module:

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Links

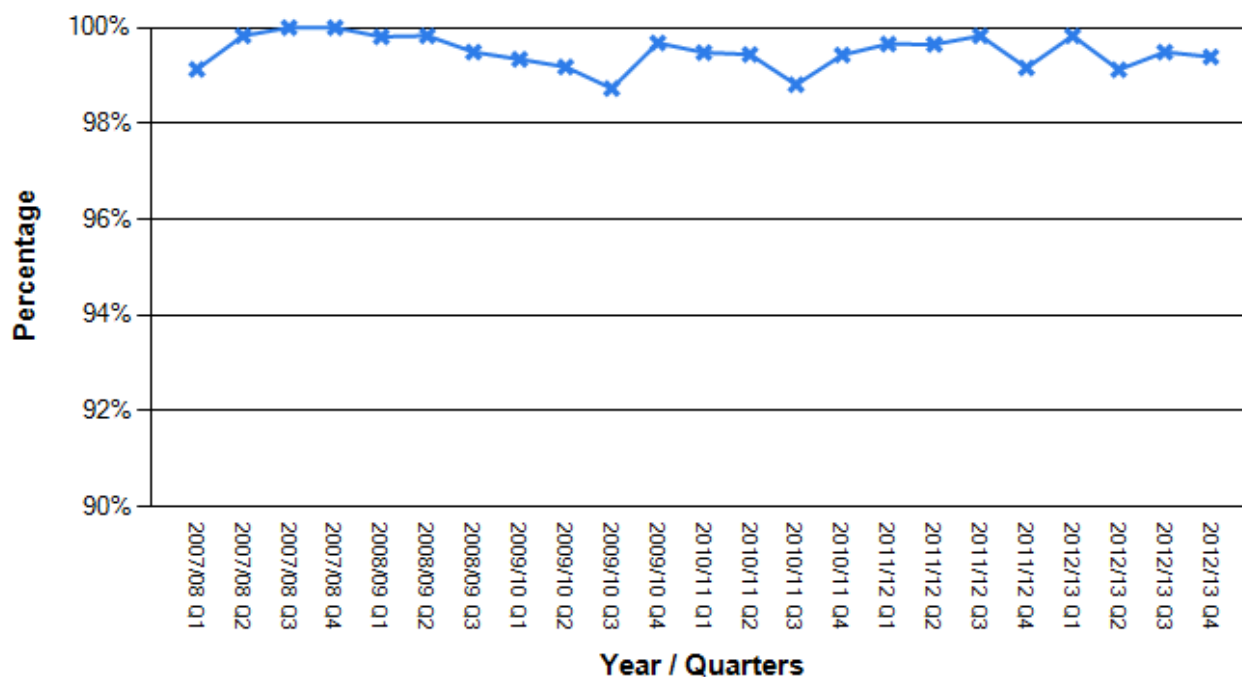
- > [CCT- Website Terms and Conditions](#)



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

Measure (First treatment) Network (East Midlands) Cancer type (Lung)



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

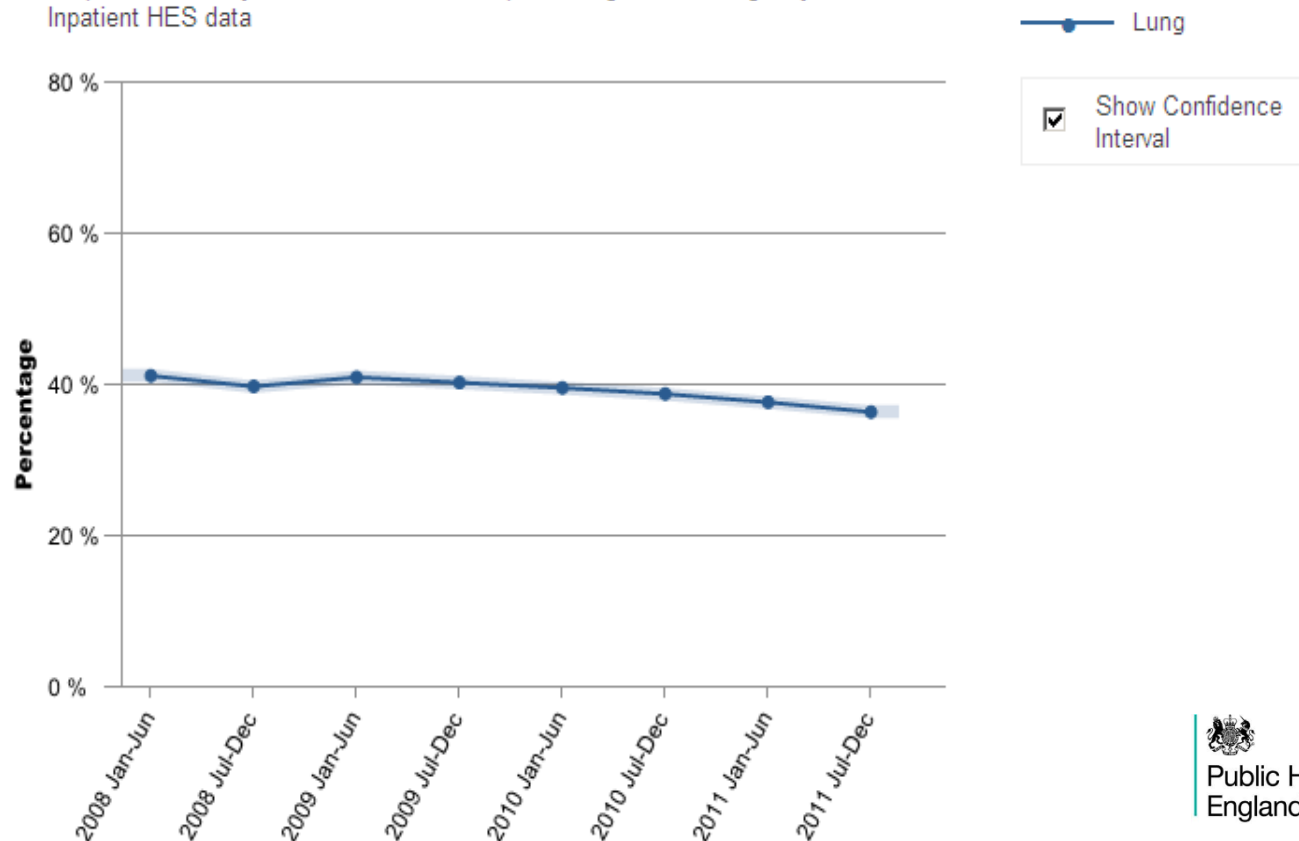
### Cancer Type

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



# Two Examples

- Cancer Commissioning Toolkit
- **Service & GP Profiles**



# Service profiles

- Breast & Colo-rectal cancers - 2012
- Lung cancer (excluding highly specialised MDTs) – 2013
- Late 2013: Sarcoma, Gynaecological, Head & Neck and Upper GI cancers
- GP profiles since 2011



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Notes: (1) Large differences between indicators #1 and #2 are likely to indicate a large fraction of patients referred to or from the trust (2) Based on patient postcode and uses the Index of Multiple Deprivation (IMD) 2010; (3) Peer Review (NCPR) source - IV=Internal Verification, PR=Peer Review, SA=Self-Assessment; Amn=Amnesty; (4) The immediate risks or serious concerns may now have been resolved or have an action plan in place for resolution; (5) CNS = Clinical Nurse Specialist; (6) value = total number of survey respondents for tumour group. (7) Based on scoring method used by the Department of Health - red/green scores given for survey questions where the trust was in the lowest or highest 20% of all trusts. Questions with lower than 20 respondents were not given a score. Italic value displayed = the total number of viable survey questions, used as the denominator to calculate the % of red/greens for the trust; (8) CPES = Cancer Patient Experience Survey.



● Trust is significantly different from England mean  
○ Trust is not significantly different from England mean  
○ Statistical significance cannot be assessed  
◆ England mean

England median

Lowest in England 25th 75th Highest in England

NCIN  
 national cancer  
 intelligence network  
 Using information to improve quality & choice  
 NHS

National Cancer Action Team  
 Part of the National Cancer Programme

Trust rate or percentage compared to England

Notes: (1) Large differences between indicators #1 and #2 are likely to indicate a large fraction of patients referred to or from the trust (2) Based on patient postcode and uses the Index of Multiple Deprivation (IMD) 2010; (3) Peer Review (NCPR) source - N=Internal Verification, PR=Peer Review, SA=Self-Assessment; Amn=Amnesty; (4) The immediate risks or serious concerns may now have been resolved or have an action plan in place for resolution; (5) CNS = Clinical Nurse Specialist; (6) value = total number of survey respondents for tumour group. (7) Based on scoring method used by the Department of Health - red/green scores given for survey questions where the trust was in the lowest or highest 20% of all trusts. Questions with lower than 20 respondents were not given a score. Italic value displayed = the total number of viable survey questions, used as the denominator to calculate the % of red/greens for the trust; (8) CPES = Cancer Patient Experience Survey.  
n/a = not applicable or not available

# Cancer Service Profiles for Lung Cancer

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NHS Acute Trust

Select Trust/MDT

● Trust is significantly different from England mean

○ Trust is not significantly different from England mean

○ Statistical significance cannot be assessed

◆ England mean

Lowest in England

25th

England median

75th

Highest in England

NCIN  
national cancer  
intelligence network

Using information to improve quality & choice

NHS

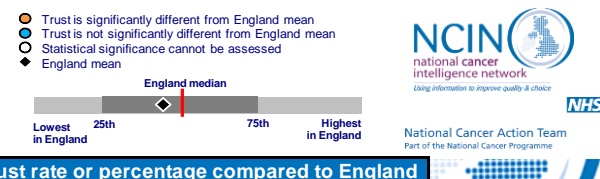
National Cancer Action Team  
Part of the National Cancer Programme

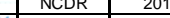



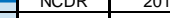


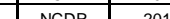
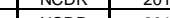
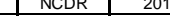

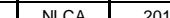
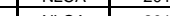
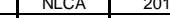



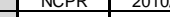
| Section   | #                        | Indicator  | No. of patients/cases or value | Trust   | Lower 95% confidence limit | Upper 95% confidence limit | England | Lowest | Range | Highest | Source  | Period  |
|---|--------------------------|--|--------------------------------|---|----------------------------|----------------------------|---------|--------|-------|---------|---------|---------|
| Size  | 1                        | Number of newly diagnosed lung cancer patients per year, 2010 [experimental] (1)               | 304                            |   |                            |                            | 207     | 41     |       | 588     | NCDR    | 2010    |
|   | 2                        | Number of NLCA patients - lung cancer  | 329                            |   |                            |                            | 191     | 1      |       | 688     | NLCA    | 2011    |
|   | 3                        | Number of NLCA patients - mesothelioma   | 11                             |   |                            |                            | 10      | 0      |       | 34      | NLCA    | 2011    |
| Demographics<br>(based on newly diagnosed patients, 2010) | 4                        | Patients (from #1) aged 70+  | 186                            | 62%   | 56%                        | 67%                        | 61%     | 55%    |       | 76%     | NCDR    | 2010    |
|   | 5                        | Patients (from #1) with recorded ethnicity   | 295                            | 97%   | 94%                        | 98%                        | 93%     | 66%    |       | 100%    | NCDR    | 2010    |
|   | 6                        | Patients (from #5) with recorded ethnicity which is not White-British                          | 3                              | 1%  | 0%                         | 3%                         | 7%      | 0%     |       | 46%     | NCDR    | 2010    |
|   | 7                        | Patients (from #1) who are Income Deprived (2)   |                                | 29%   |                            |                            | 16%     | 7%     |       | 34%     | NCDR    | 2010    |
|   | 8                        | Male patients (from #1)  | 161                            | 53%   | 47%                        | 58%                        | 55%     | 43%    |       | 72%     | NCDR    | 2010    |
|   | 9                        | Number and proportion of patients (from #2) with a stage assigned                              | 326                            | 99%   | 97%                        | 100%                       | 92%     | 36%    |       | 100%    | NLCA    | 2011    |
|   | 10                       | Number and proportion of patients, excluding SCLC, with stage I or II assigned                 | 83                             | 29%   | 24%                        | 35%                        | 24%     | 10%    |       | 68%     | NLCA    | 2011    |
|   | 11                       | Number and proportion of patients, excluding SCLC, with a stage IIIA assigned                  | 36                             | 13%   | 9%                         | 17%                        | 14%     | 4%     |       | 30%     | NLCA    | 2011    |
|   | 12                       | Number and proportion of patients, excluding SCLC, with a stage IIIB and IV assigned           | 105                            | 58%   | 50%                        | 64%                        | 68%     | 16%    |       | 86%     | NLCA    | 2011    |
|   | 13                       | Number and proportion of patients, excluding SCLC, with a stage IIB and IV assigned            | 105                            | 58%   | 50%                        | 64%                        | 68%     | 16%    |       | 86%     | NLCA    | 2011    |
| Sp<br>1<br><br>Thru<br>pat                                | Throughput and pathology |  | 19                             | Number of urgent GP referrals for suspected cancer                                      |                            |                            |         |        |       |         |         |         |
|   |                          |  | 20                             | Number and proportion of patients (from #2) with confirmed NSCLC                        |                            |                            |         |        |       |         |         |         |
|   |                          |  | 21                             | Number and proportion of patients (from #2) with confirmed SCLC                         |                            |                            |         |        |       |         |         |         |
|   |                          |  | 22                             | Number and proportion of patients (from #2) with confirmed NSCLC who are diagnosed NOS  |                            |                            |         |        |       |         |         |         |
|   |                          |  | 23                             | Number and proportion of patients (from #2) with histological confirmation of diagnosis |                            |                            |         |        |       |         |         |         |
|   |                          |  | 24                             | Estimated proportion of tumours with emergency presentations [experimental]             |                            |                            |         |        |       |         |         |         |
| W<br>t<br><br>Pr  | Waiting times            |  | 25                             | Q2 2012/13: Urgent GP referral for suspected cancer seen within 2 weeks                 |                            |                            |         |        |       |         |         |         |
|   |                          |  | 26                             | Q2 2012/13: Treatment within 62 days of urgent GP referral for suspected cancer         |                            |                            |         |        |       |         |         |         |
|   |                          |  | 27                             | Urgent GP referrals for suspected cancer diagnosed with cancer [experimental]           |                            |                            |         |        |       |         |         |         |
|   |                          |  | 28                             | Cases treated that are urgent GP referrals with suspected cancer [experimental]         |                            |                            |         |        |       |         |         |         |
|   |                          |  | 29                             | Q2 2012/13: First treatment began within 31 days of decision to treat                   |                            |                            |         |        |       |         |         |         |
| Outcomes and Recovery                                     | 36                       | First outpatient appointments and proportion of all outpatient appointments                    | 23,053                         | 41%   | 41%                        | 41%                        | 32%     | 15%    |       | 68%     | PBR SUS | 2011/12 |
|   | 37                       | NLCA: Median survival in days and adjusted hazard ratio for mortality                          | 176                            | 0.95  | 0.82                       | 1.11                       | 1.0     | 0.57   |       | 1.49    | NLCA    | 2011    |
|   | 38                       | NLCA: Proportion of patients surviving at one year and adjusted odds ratio of surviving 1 year | 34%                            | 1.43  | 0.97                       | 2.11                       | 1.0     | 0.40   |       | 2.67    | NLCA    | 2011    |
| Patient Experience - CPES (4)                             | 39                       | Patients surveyed & % reporting always being treated with respect & dignity (6)                | 13                             | n/a   |                            |                            | 83%     | 66%    |       | 100%    | CPES    | 2011/12 |
|   | 40                       | Number of survey questions and % of those questions scoring red and green                      | 0                              | n/a   |                            |                            |         | 0%     |       | 78%     | CPES    | 2011/12 |
|   | 41                       | (7)  |                                | n/a   |                            |                            |         | 0%     |       | 69%     | CPES    | 2011/12 |

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Select Trust/MDT



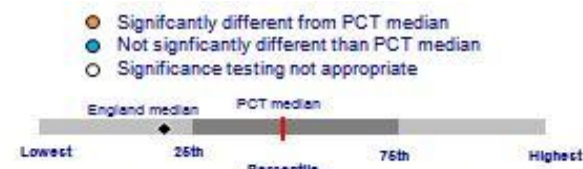
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|  | 12 | Number and proportion of patients, excluding SCLC, with a stage IIIB and IV assigned | 167                                   | 58%   | 53%                              | 64%                              | 62%     | 13%         |  | 80%     | NLCA   | 2011    |
|  | 13 | Proportion of patients (from #2) with a Performance Status assigned                  | 286                                   | 87%   | 83%                              | 90%                              | 89%     | 2%          |  | 100%    | NLCA   | 2011    |
| Specialist<br>Team   | 14 | Peer review: Does the specialist team have full membership? (3)                      | SA                                    | Yes   |                                  |                                  |         |             |  |         | NCPR   | 2010/11 |
|  | 15 | Peer review: Proportion of peer review indicators met                                | SA                                    | 85%   |                                  |                                  | 89%     |             |  |         | NCPR   | 2010/11 |
|  | 16 | Peer review: are there immediate risks? (4)  | SA                                    | No    |                                  |                                  |         |             |  |         | NCPR   | 2010/11 |
|  | 17 | Peer review: are there serious concerns? (4)   | SA                                    | No    |                                  |                                  |         |             |  |         | NCPR   | 2010/11 |
|  | 18 | Number and proportion of patients (from #2) seen by CNS (5)                          | 206                                   | 63%   | 57%                              | 68%                              | 79%     | 0%          |  | 100%    | NLCA   | 2011    |


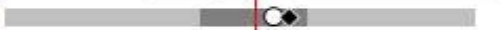























|  |                                     |    |  |         |
|--|-------------------------------------|----|--|---------|
| Through an<br>anatomic<br>pathology<br>report            | Practice                            | 30 | No. and proportion of patients (from #2) receiving surgery, chemotherapy and/or radiotherapy             |         |
| Waiting<br>time  |                                     | 31 | No. and proportion resected of patients (from #2) excluding confirmed SCLC                               |         |
|  |                                     | 32 | No. and proportion resected of patients (from #2) with confirmed NSCLC                                   |         |
|  |                                     | 33 | No. and proportion resected of patients (from #2), excluding confirmed SCLC ,with stage I and II disease |         |
|  |                                     | 34 | No. and proportion of patients (from #2) with confirmed SCLC receiving chemotherapy                      |         |
|  |                                     | 35 | No. and prop. of patients (from #2) with stage IIIB/IV, PS 0-1 excl. conf. SCLC, receiving chemotherapy  |         |
| Practice   | Outcomes<br>and Recovery            | 36 | First outpatient appointments and proportion of all outpatient appointments                              |         |
| Outcomes<br>at<br>Recall                                 |                                     | 37 | NLCA: Median survival in days and adjusted hazard ratio for mortality                                    |         |
|  |                                     | 38 | NLCA: Proportion of patients surviving at one year and adjusted odds ratio of surviving 1 year           |         |
| Patient<br>Experience<br>CPE                             | Patient<br>Experience -<br>CPES (4) | 39 | Patients surveyed & % reporting always being treated with respect & dignity (6)                          |         |
| Notes: (1)<br>IV=Inter-<br>number<br>respond<br>n/a = no |                                     | 40 | Number of survey questions and % of those questions scoring red and green (7)                            | % Red   |
|  |                                     | 41 |  | % Green |



# GP Practice profiles

## Cancer indicators in Practice 6, ANON PCT (1)



| Domain                     | Indicator (Rate or Ratio)   | Number | Rate or Ratio | Median Practice | Lowest Practice | Quartile ranges of practice rates/ratios in PCT                                       | Highest Practice |
|----------------------------|---|--------|---------------|-----------------|-----------------|---|------------------|
| Demographic                | Practice Population (% of average practice in PCT)  | 12874  | 159.9         | 94.5            | 19.8            |    | 261.4            |
|                            | Practice Population aged 65+ (% of population in this practice aged 65+)                    | 1882   | 15%           | 14%             | 0%              |    | 26%              |
|                            | Socio-economic deprivation quintile, 1= affluent (% of practice population income deprived) | 3      | 14%           | 15%             | 5%              |    | 35%              |
|                            | New cancer cases (Crude rate - new cases per 10,000 population)                             | 52     | 383.8         | 421.6           | 190.9           |    | 557.1            |
|                            | Cancer deaths (Crude rate - deaths per 10,000 population)                                   | 22     | 126.0         | 186.6           | 105.0           |    | 282.7            |
|                            | Prevalant cancer cases (% of population with cancer)  | 156    | 1.2%          | 1.2%            | 0.1%            |    | 3.0%             |
| Cancer screening           | Number aged 60-74 screened (breast) in last 30 months (3 year coverage, %)                  | 427    | 74.0          | 66.4            | 34.3            |    | 95.0             |
|                            | Number aged 60-74 screened (breast) within 6 months of invitation (Uptake, %)               | 222    | 77.0          | 70.2            | 35.9            |    | 96.8             |
|                            | Number aged 24-49 screened (cervix) in last 42 months (3.5 year coverage, %)                | 426    | 84.9          | 68.0            | 33.2            |    | 97.4             |
|                            | Number aged 60-69 screened (bowel) in last 30 months (2.5 year coverage, %)                 | 239    | 46.8          | 69.2            | 32.7            |    | 96.0             |
|                            | Number aged 60-69 screened (bowel) within 6 months of invitation (Uptake, %)                | 458    | 68.8          | 66.6            | 33.4            |    | 97.4             |
| Cancer Waiting Times       | Two-week wait referrals (Rate per 10,000 population)  | 218    | 169.3         | 181.4           | 0.0             |    | 403.9            |
|                            | Two-week referrals with cancer (Conversion rate - % of all T/w/w referrals with cancer)     | 29     | 13%           | 9%              | 0%              |    | 24%              |
|                            | Number of new Cancer Waiting Time cases (number per 10,000 population)                      | 56     | 43.5          | 37.9            | 0.0             |   | 92.9             |
| Presentation & Diagnostics | In-patient or Day-case Colonoscopy procedures (Rate per 10,000 population)                  | 5      | 15.5          | 17.4            | 9.0             |  | 23.7             |
|                            | In-patient or Day-Case Flexi-sig procedures (Rate per 10,000 population)                    | 7      | 22.4          | 16.1            | 8.5             |  | 24.0             |
|                            | In-patient or Day-case UGI endoscopy procedures (Rate per 10,000 population)                | 13     | 16.7          | 17.1            | 8.1             |  | 23.9             |
|                            | Two-week referrals with suspected breast cancer (Rate per 10,000 population)                | 47     | 36.5          | 38.4            | 0.0             |  | 88.0             |
|                            | Two-week referrals with suspected lower GI cancer (Rate per 10,000 population)              | 45     | 35.0          | 31.0            | 0.0             |  | 76.5             |
|                            | Two-week referrals with suspected lung cancer (Rate per 10,000 population)                  | 3      | 2.3           | 5.0             | 0.0             |  | 17.2             |
|                            | Two-week referrals with suspected skin cancer (Rate per 10,000 population)                  | 27     | 21.0          | 25.8            | 0.0             |  | 131.1            |
|                            | Number of emergency admissions with cancer (Rate per 10,000 population)                     | 11     | 23.5          | 15.6            | 8.1             |  | 23.9             |
|                            | Number of emergency presentations (Rate per 10,000 population)                              | 15     | 15.9          | 18.2            | 10.4            |  | 29.9             |
|                            | Number of managed presentations (Rate per 10,000 population)                                | 11     | 19.5          | 16.9            | 8.0             |  | 23.9             |
|                            | Number of other presentations (Rate per 10,000 population)                                  | 12     | 15.2          | 18.5            | 10.4            |  | 29.9             |

# Conclusions

- The quality and range of clinically relevant data on cancer is increasing rapidly
- 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 - we need to adapt rapidly to the new NHS structures and commissioning processes
- The collection and intelligent use of data are at the heart of good clinical practice and health care provision



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The Cancer Outcomes Conference 2014 will explore the ‘power of information’ both locally and nationally.

It will examine how UK-wide cancer registration data and other health related datasets are being exploited to reduce cancer incidence, mortality and morbidity.

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