



*Using information to improve quality & choice*



**Public Health  
England**



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England



# Informatics in the 'new NHS': PHE and NCIN 1 year on....

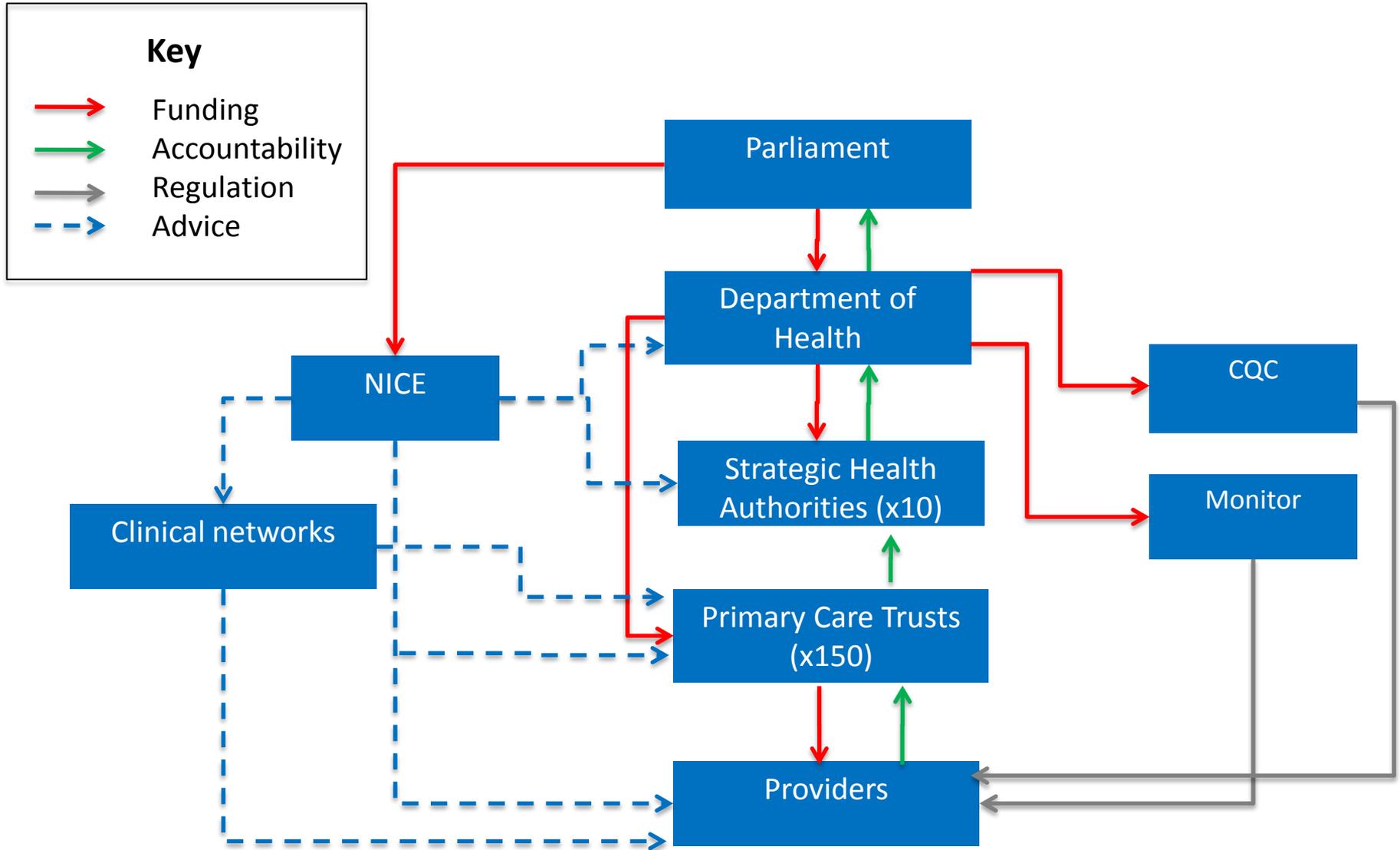
**Dr Mick Peake**

Clinical Lead,

National Cancer Intelligence Network



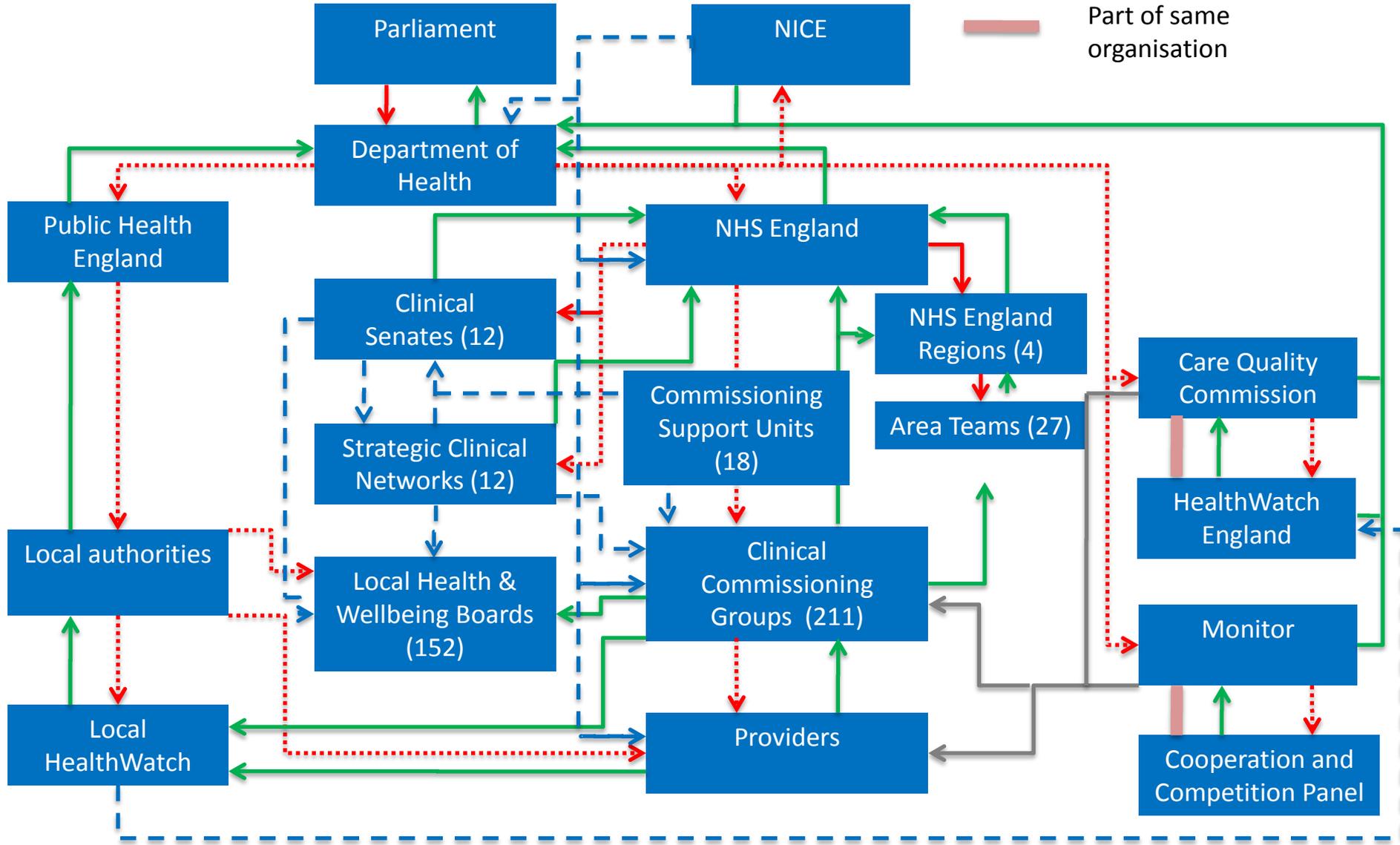
# What was then...



# As of 1.4.13.....

## Key

- Funding
- Accountability
- Regulation
- Advice
- Part of same organisation



# NHS England

- **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

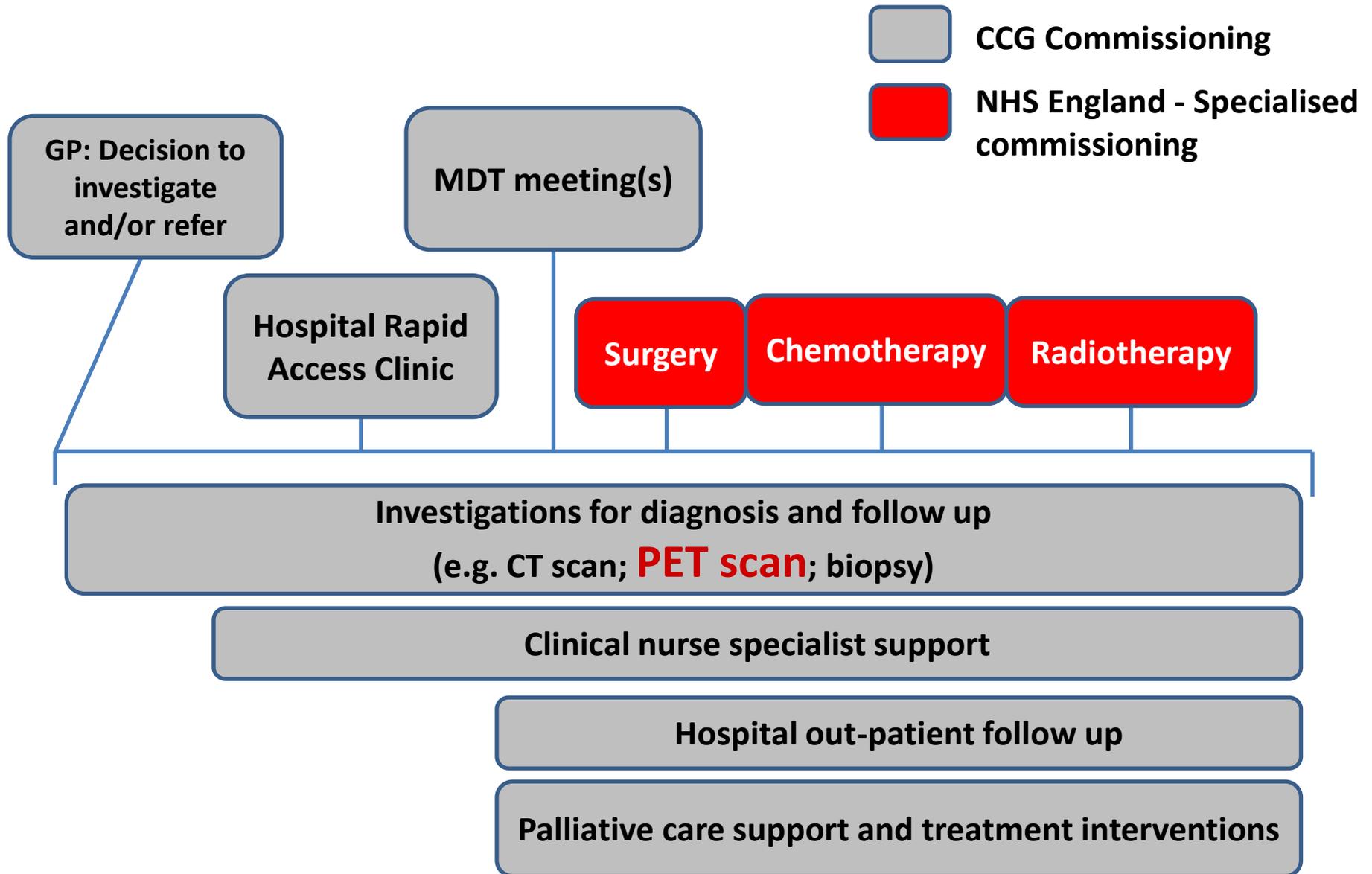
# Specialised commissioning: Clinical Reference Groups - cancer

- 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



# Data Drivers

- Government
  - A spotlight on the role of data
- Commissioning
  - NHS Outcomes Framework
- Regulation
  - New regulation framework
- The 'public', patients and families

# Providers of information in the new NHS



- Four main sources/providers
  - Health & Social Care Information Centre (HSCIC)
    - Audits
  - ONS
  - PHE (Civil Service)
  - NHS England Business Intelligence Teams (ATS/CSU)
- Information Intermediaries (CRUK, Dr Foster, MacMillan)

# 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



- PHE brings together public health specialists from more than 70 organisations into a single public health service.
- The PHE mission is to protect and improve the nation's health and to address inequalities

# 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  
Prof. Julia Verne**

- PHE - Knowledge Directorate
  - NCRS
  - KITs - Analytical workforce from 8 registries moved into regional Knowledge and Intelligence Teams
    - SSCRG Lead Area Work Programmes
    - Local contribution
  - Health Intelligence Networks (HINs) (Mental Health, Maternity, & Children, Cardiovascular, End of Life, **NCIN**)

# The English National Cancer Registration System

- 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
- Director of Disease Registration
- Evolving operational links with hospital leads
- Pan-England roll-out completed September 2013

# Data sources - patient-level data

## National Feeds



Radiotherapy Data (RTDS)

Cancer Waiting Times

Chemotherapy Dataset (SACT)

ONS - Cancer and non-cancer deaths

Cancer screening programmes - Bowel, Cervix and Breast

National PET-CT imaging

National cancer audits - Lung, Head and Neck, Upper GI and Colorectal

Hospital Episode Statistics (HES)

## Local Feeds



Data from MDT software systems

Pathology full-text reports

Local imaging systems

Patient Administration Systems

Local clinical data systems

## National Pilots

Recurrent/Metastatic Breast Audit Pilot

CRUK Stratified Medicine (Sept 2011)



# ENCRS



# Datasets

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

# Information Services

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

# 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)**



# '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)**





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# Main elements of clinical engagement

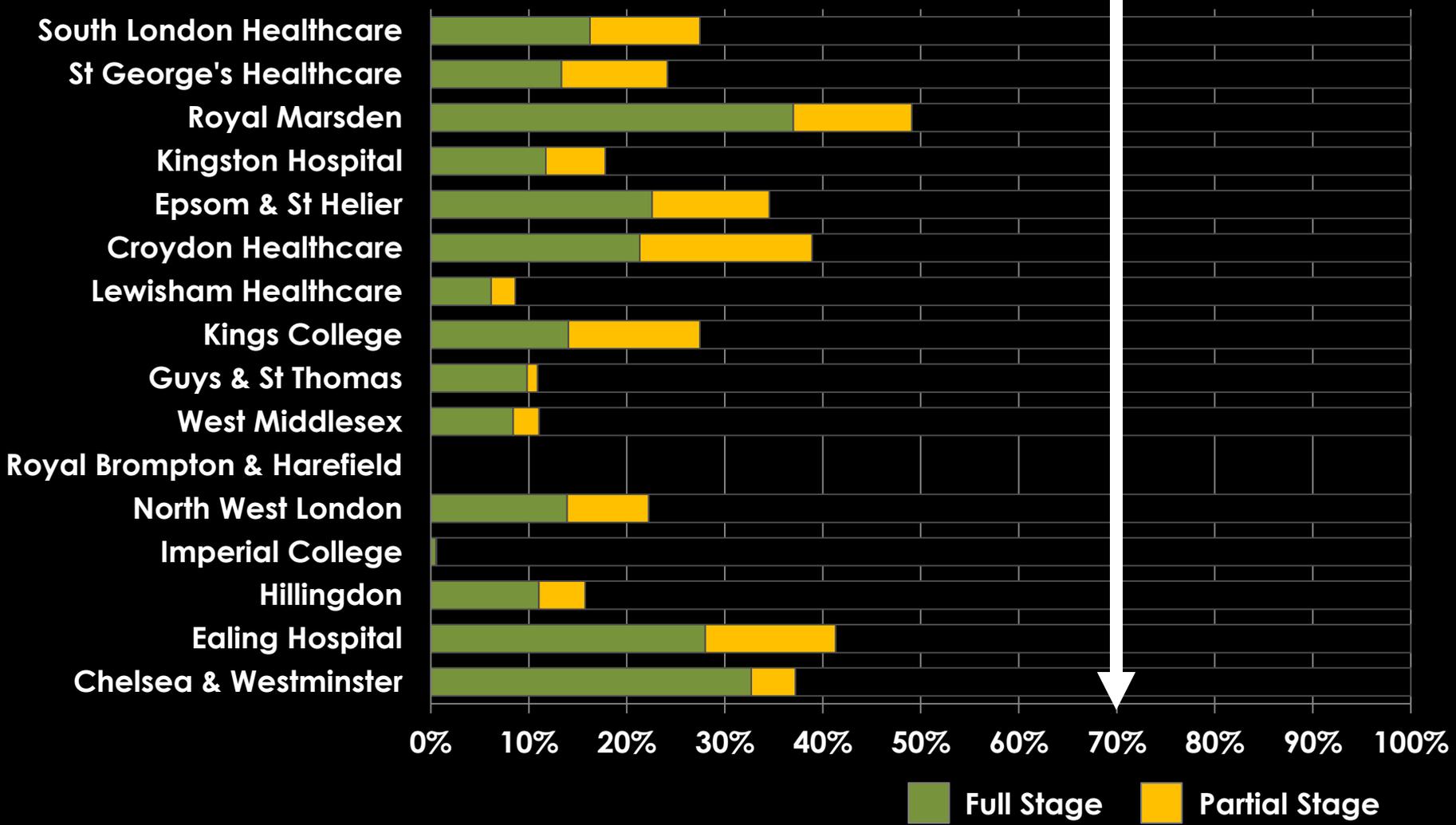


- Identification of key clinical issues & priorities
- ‘Ownership’ of data:
  - Dataset development & revision
  - Championing data collection
  - QA
- Clinical input into the analytical programme
- Communication – colleagues; professional bodies, providers; commissioners
- Promoting the use of routine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

# London Cancer Alliance

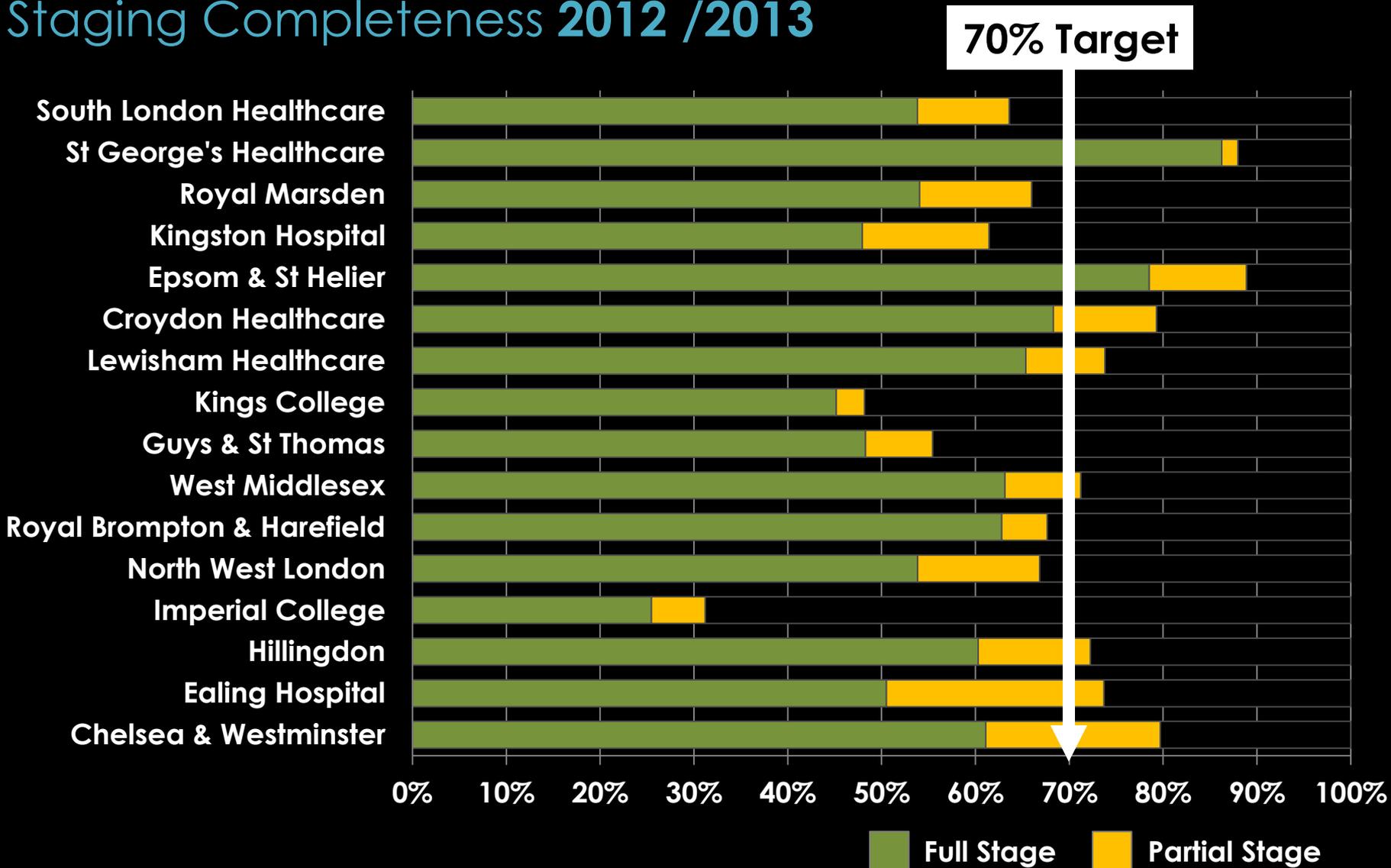
## Staging Completeness 2011 / 2012

70% Target



# London Cancer Alliance

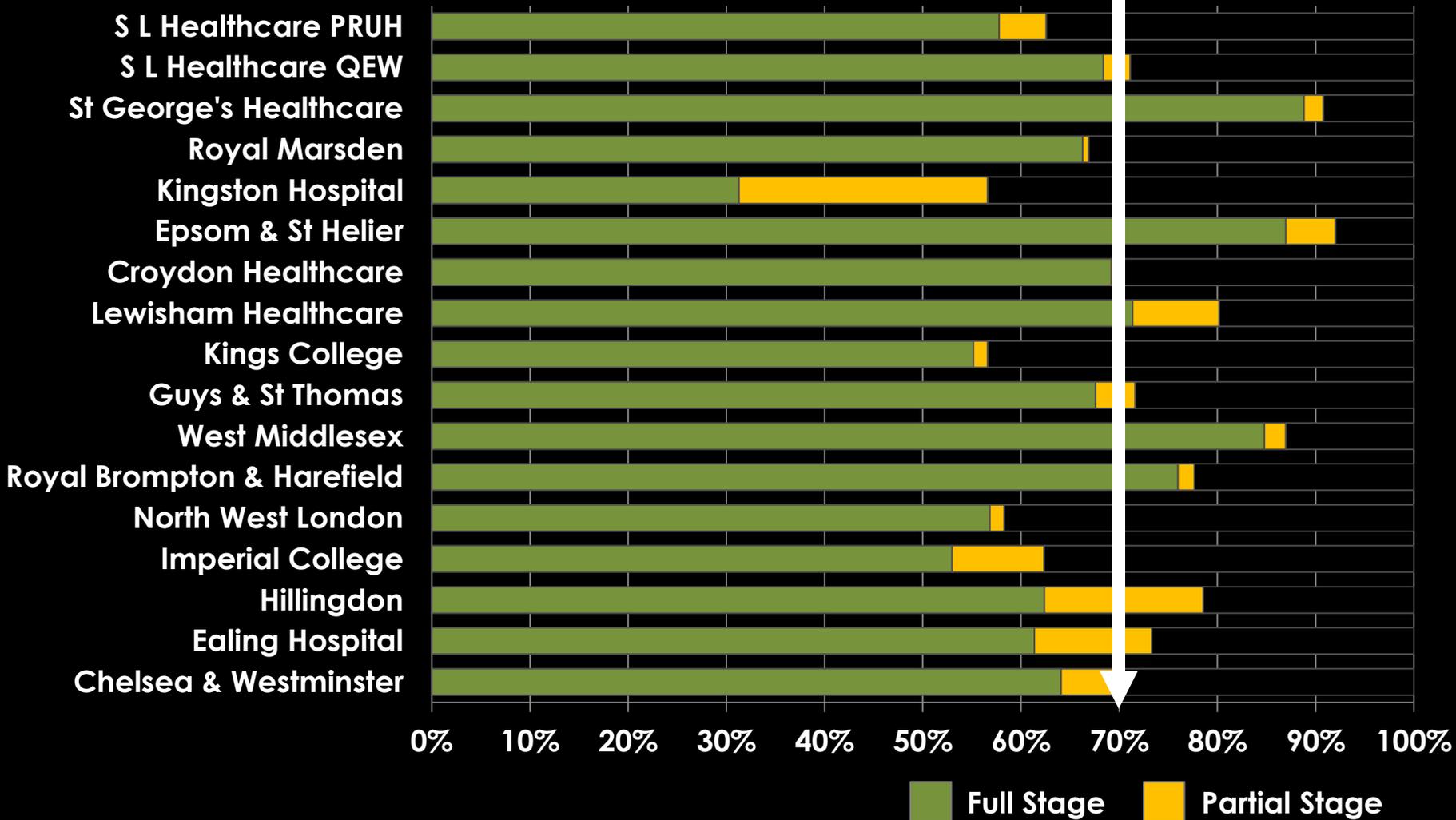
## Staging Completeness 2012 /2013



# London Cancer Alliance

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

70% Target



# 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



# 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’

# Some positives...

- Recognition of the importance of the NCIN – especially its network of senior clinical engagement
- Unification of 8 English Cancer Registrations complete
- Establishment of new data sets, especially COSD and SACT
- Appointment of National Cancer Director (Sean Duffy)
- Continuing support from CRUK and Macmillan
- Opportunities within PHE

# 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

# 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



**Cancer Outcomes Conference**  
**9 & 10 June 2014**  
**Hilton Birmingham Metropole**

**[www.ncin.org.uk/conference](http://www.ncin.org.uk/conference)**



**ukiacr**  
United Kingdom and Ireland  
Association of  
Cancer Registries



**NCIN**  
national cancer  
intelligence network

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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.

To find out more, visit [www.ncin.org.uk/conference](http://www.ncin.org.uk/conference)



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**#NCIN2014**



**NCRI**

National  
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