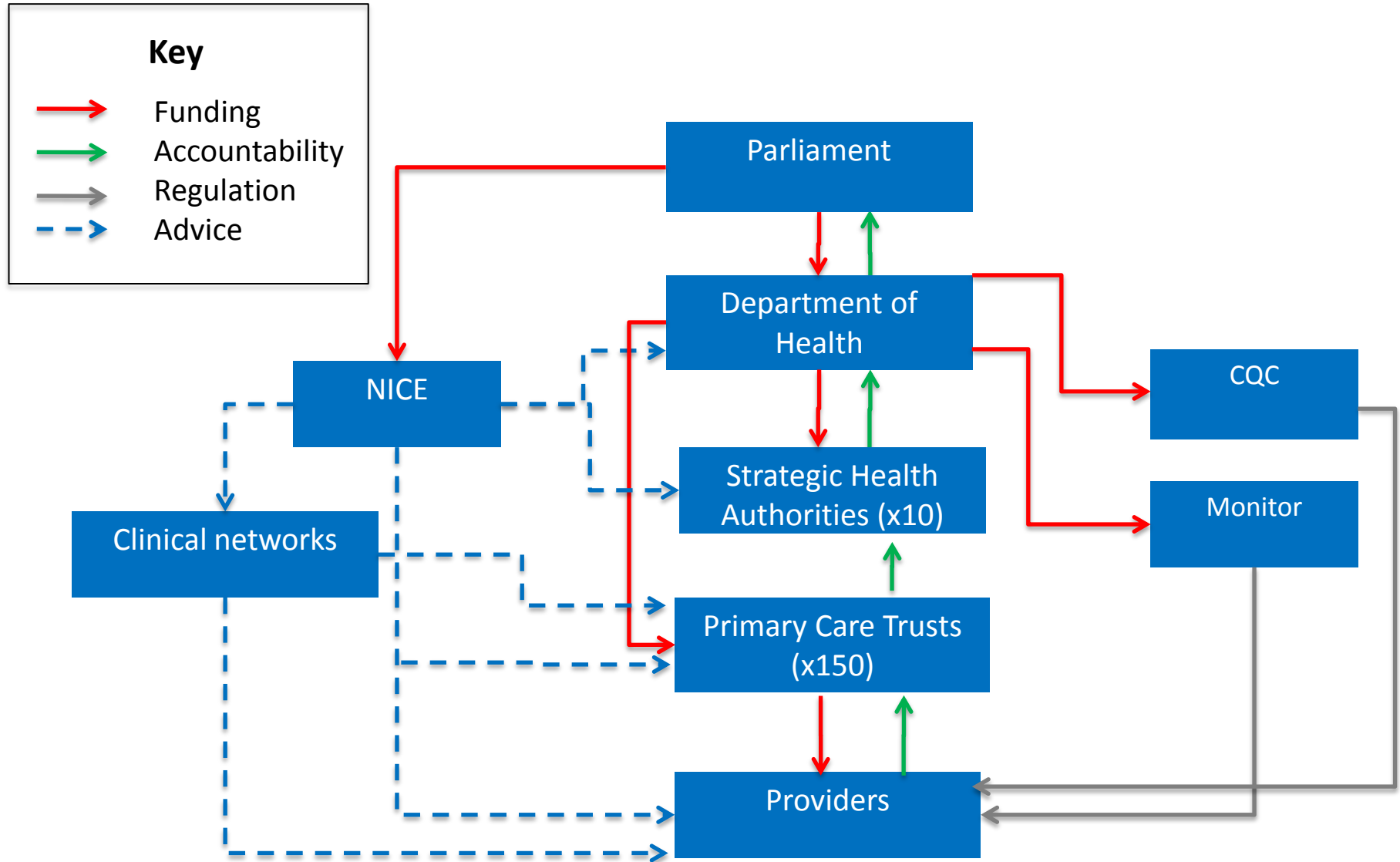# Informatics in the 'new NHS':

The NCIN 6 months on….

Di Riley
National Cancer Intelligence Network

What was then...

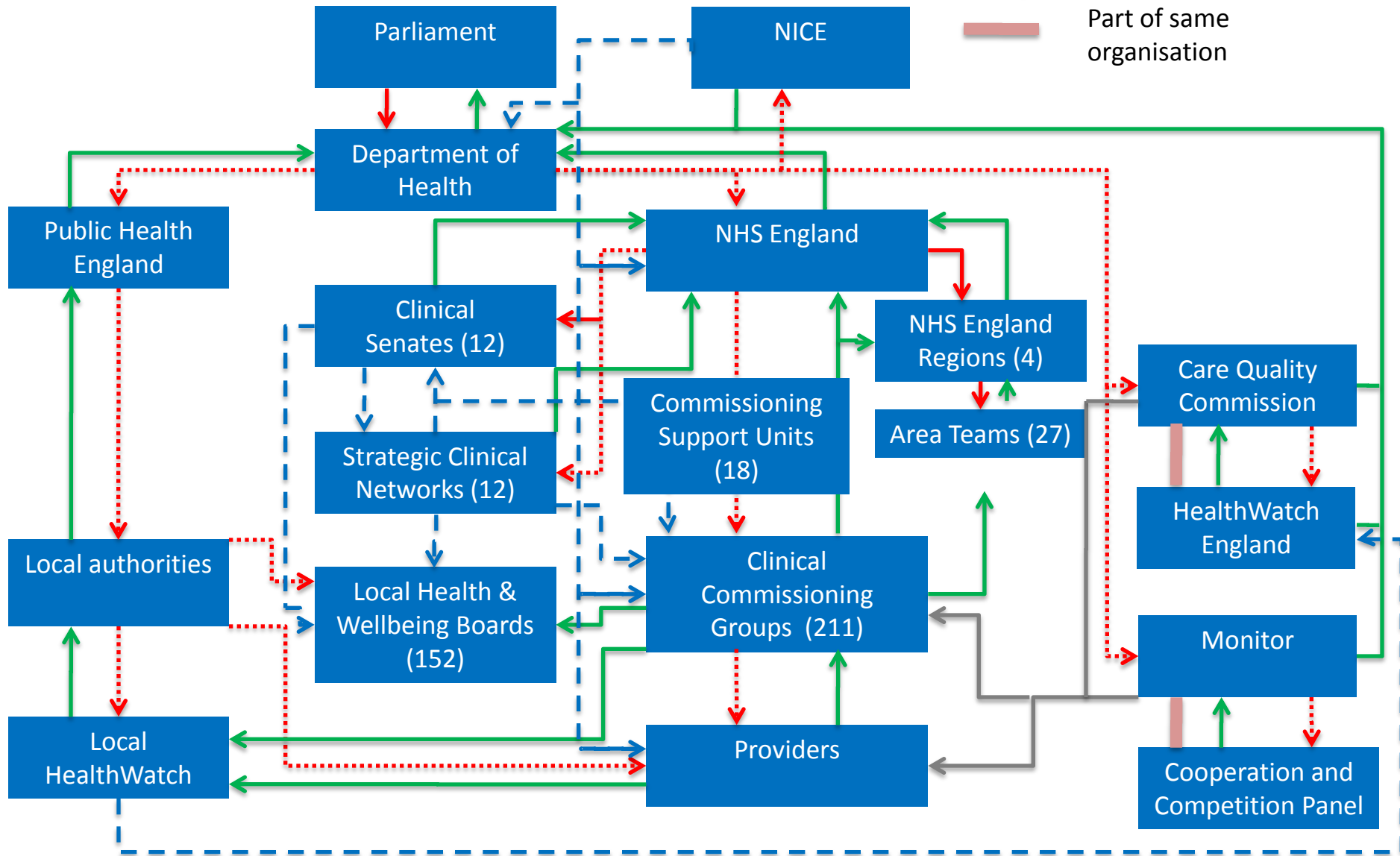# What was then...

As of 1.4.13...........

Key
- ···▶ Funding
- ──▶ Accountability
- ──▶ Regulation
- --▶ Advice
- ▬▬ Part of same organisation

Parliament

NICE

Department of Health

Public Health England

NHS England

Clinical Senates (12)

Commissioning Support Units (18)

NHS England Regions (4)

Care Quality Commission

Strategic Clinical Networks (12)

Area Teams (27)

HealthWatch England

Local authorities

Local Health & Wellbeing Boards (152)

Clinical Commissioning Groups (211)

Monitor

Local HealthWatch

Providers

Cooperation and Competition Panel

What is now...

NHS England

- 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

The Health & Social Care Bill 2012: Two New Organisations

- **NHS England**
    - "The purpose of NHS England will be 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

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.......)
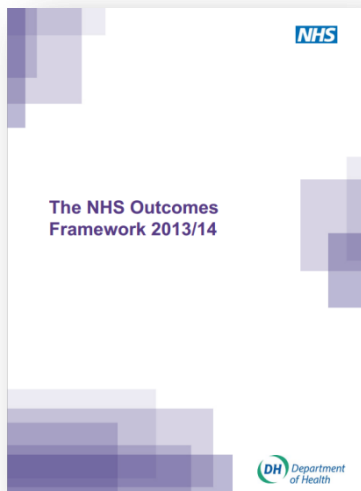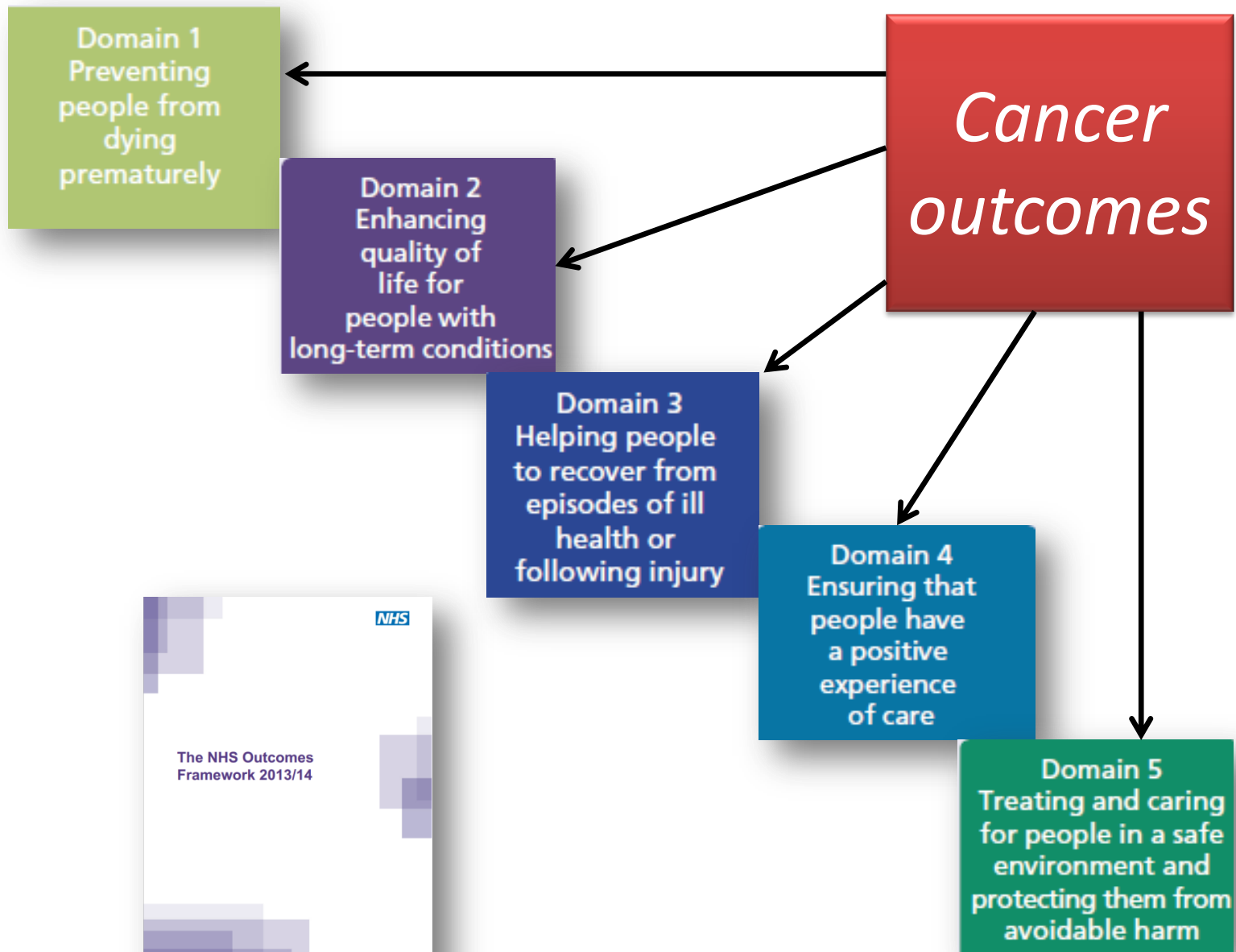
Clinical Reference Groups - cancer

- **Radiotherapy -** *Nick Slevin*
- **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*

Clinical Commissioning Groups

- Diagnostics

- Referrals

- 'Common cancers'
  - Service specifications – advisory

- Follow up

- Palliative Care

Cancer outcomes

Domain 1
Preventing people from dying prematurely

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

Domain 3
Helping people to recover from episodes of ill health or following injury

Domain 4
Ensuring that people have a positive experience of care

Domain 5
Treating and caring for people in a safe environment and protecting them from avoidable harm

The NHS Outcomes Framework 2013/14

NHS

DH Department of Health

Some problems

- 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 highly influential National Cancer Director

- Loss of old Cancer Network / PCT links

- Uncertainty around roles and responsibilities

- Loss of focus on cancer

Some positives…

- Recognition of the importance of the NCIN – especially its network of senior clinical engagement

- Unification of 8 English Cancer Registration completed in September 2013

- Establishment of new data sets, especially COSD and SACT

- Appointment of new National Cancer Director (Sean Duffy)

- Continuing support from CRUK and Macmillan

- Opportunities within PHE

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

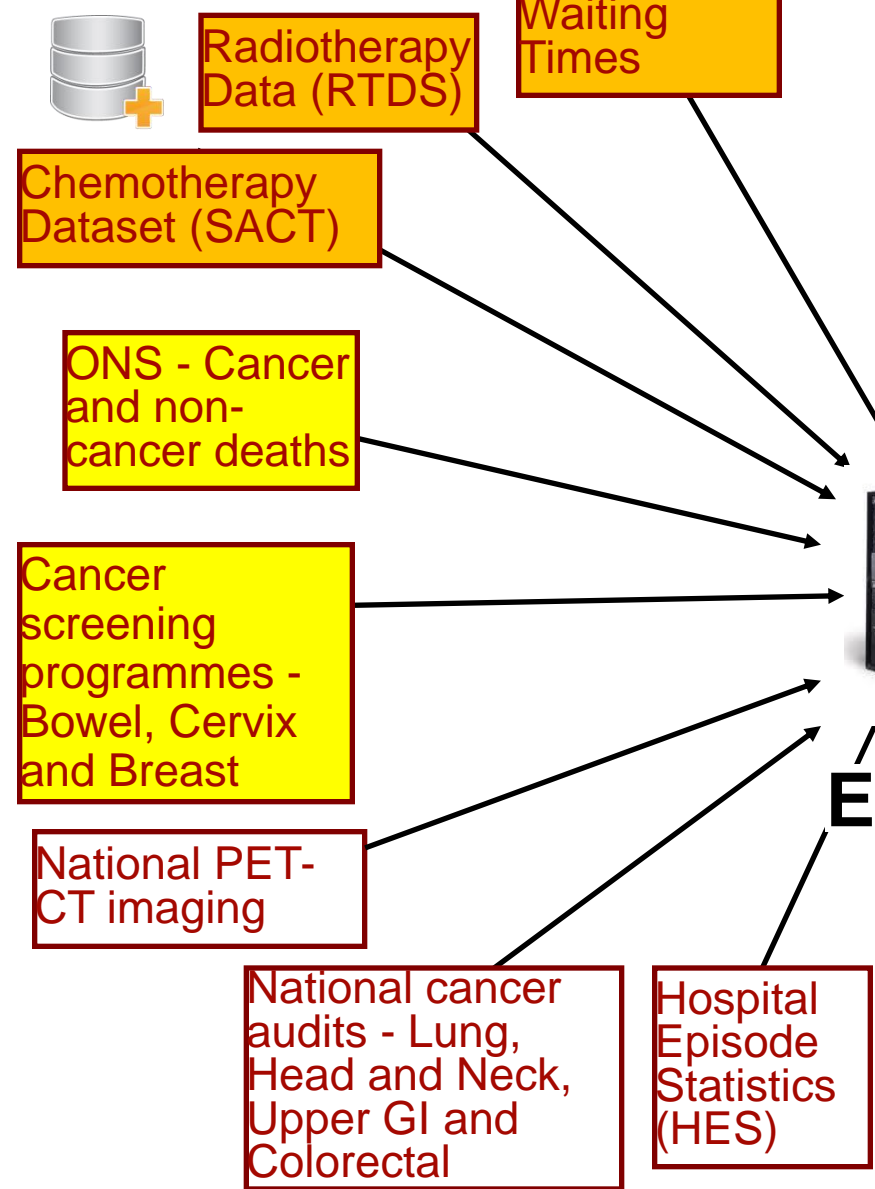**Knowledge & Intelligence Teams (KITs)**

National Cancer Intelligence Network

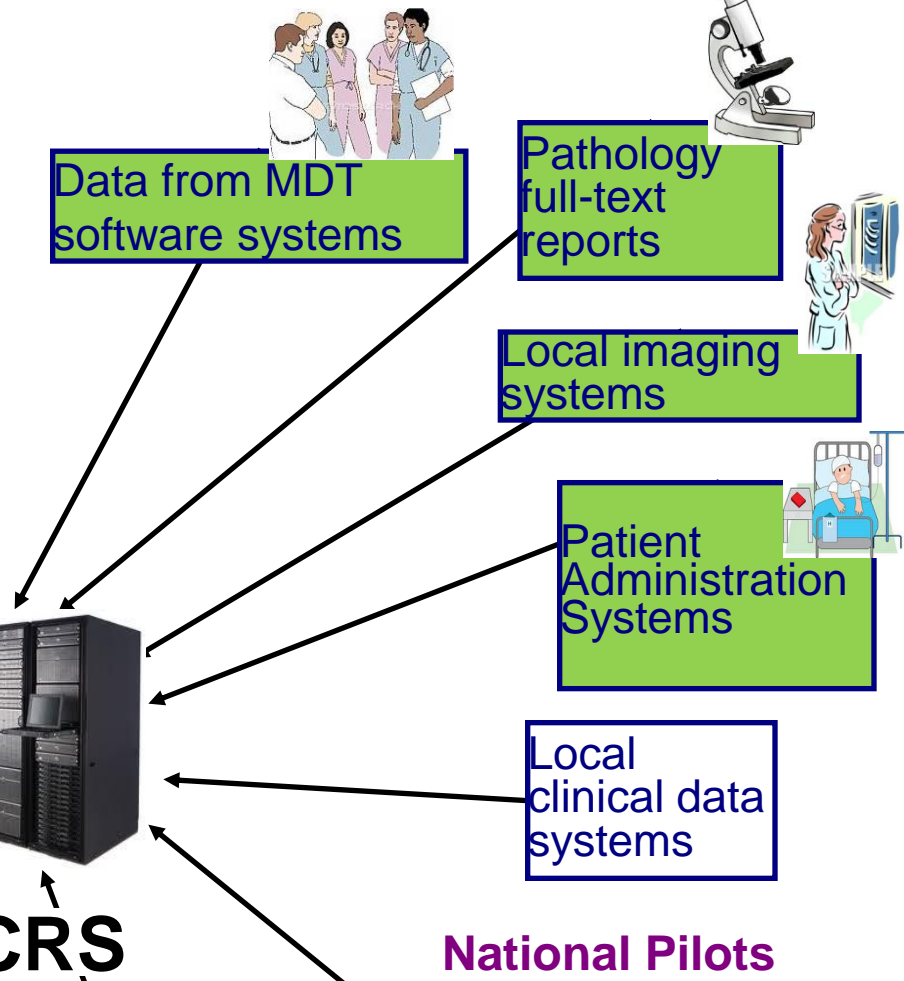# The English National Cancer Registration System

- English National Cancer Registration System

- Near real-time 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
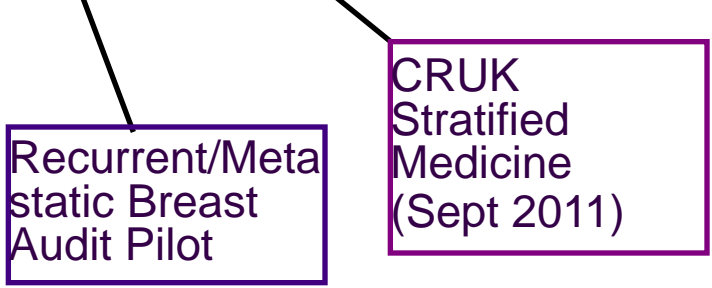
Data sources - patient-level data

National Feeds

Local Feeds

Radiotherapy Data (RTDS)

Cancer Waiting Times

Data from MDT software systems

Pathology full-text reports

Chemotherapy Dataset (SACT)

Local imaging systems

ONS - Cancer and non-cancer deaths

Patient Administration Systems

Cancer screening programmes - Bowel, Cervix and Breast

Local clinical data systems

National PET-CT imaging

ENCRS

National Pilots

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

Hospital Episode Statistics (HES)

Recurrent/Meta static Breast Audit Pilot

CRUK Stratified Medicine (Sept 2011)

Datasets

- Radiotherapy Dataset (RTDS), 2009…..

- Diagnostic Imaging Dataset (DIDs), 2012..

- Systemic Anti-Cancer Therapy Dataset (SACT), 2012….

- Cancer Outcomes & Services Dataset (COSD), 2013…..

Staging completeness - 2012

Table No. & Parameters	England Average	ECRIC	NWCIS	NYCRIS	OCIU	SWCIS	Thames	Trent	WMCIU
All Invasive (xnmsc)	**51%**	**76%**	**54%**	**46%**	**24%**	**72%**	**30%**	**34%**	**73%**
Breast	66%	92%	68%	78%	36%	87%	29%	50%	87%
Colorectal (inc' anal canal)	70%	90%	76%	66%	35%	84%	63%	61%	85%
Gynaecological	61%	89%	56%	71%	4%	80%	59%	54%	77%
Haematological	25%	60%	20%	4%	6%	41%	15%	12%	41%
Head & Neck	58%	75%	62%	64%	31%	78%	44%	28%	82%
Hepatobilliary & Pancreas	32%	35%	30%	27%	20%	55%	10%	16%	63%
Lung	71%	86%	68%	54%	67%	84%	54%	62%	90%
Male Reproductive Organs	49%	84%	55%	56%	1%	73%	20%	12%	89%
Malignant Melanoma of Skin	57%	89%	64%	42%	36%	89%	5%	35%	92%
Prostate	44%	94%	53%	25%	4%	80%	15%	7%	74%
Sarcoma	12%	7%	24%	4%	10%	17%	4%	6%	25%
Upper Gastro Intestinal	49%	63%	66%	53%	19%	68%	25%	22%	78%
Urological	44%	91%	37%	31%	5%	79%	13%	10%	84%

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'

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

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