Public Health England

# Data Quality Summary & Workshop Feedback

National Cancer Intelligence Network (NCIN)
Central Nervous System SSCRG Workshop
Camden, 18th February 2015

Sarah Miller, Senior Cancer Analyst, Knowledge & Intelligence Team (East)
*With special thanks to Sally Vernon, Head of Quality and Analysis, National Cancer Registration Service*

# Overview

**Data Quality Summary**

- Aspirations for better cancer data of good quality

- Strengths and weaknesses of data and system

    – Focus on brain tumours

- Conclusions

**CNS SSCRG Workshop Feedback and Work Programme**

- Workshop Feedback

- CNS SSCRG work programme

# Aspirations for better data quality

"Cancer registration and careful monitoring

of treatment and outcomes are essential"

*Calman-Hine 1995*

**Calman-Hine Report Published**

**Report on commissioning Cancer Services :**

- Reviewed cancer services in England & Wales
- Proposed restructuring of cancer services
- Development of Cancer Networks
- Required more equal services across England
- Identifies areas of high clinical expertise
- Aim - improve outcomes/reduce inequalities

**Improving Outcomes: A Strategy for Cancer**

- Puts the patient at the heart of cancer services
- Delivery focussed on improvements in patient outcomes
- NHS requirement to Improve Cancer survival through earlier diagnosis (using data to identify patterns of care and variation in service)
- Empower local organisations to drive improvements in services
- NAEDI/EOL & Appropriateness of treatment for each patient group

"Our aspiration is that England

should achieve cancer outcomes which

are comparable with the best in the world"

*Improving Outcomes: a Strategy for Cancer, 2011*

# Strengths of the data

- Population-level cancer data covering the whole country

- Some countries only register a sample

- Population-based registrration since 1960s

- Population registration reduces bias / positive   sampling of cancer cases

- Centralisation of English cancer data – ENCORE.  Hosted by the National Cancer Registration Service at Public Health England

**National Cancer Registration Service (NCRS) & Encore - A single cancer registration system**
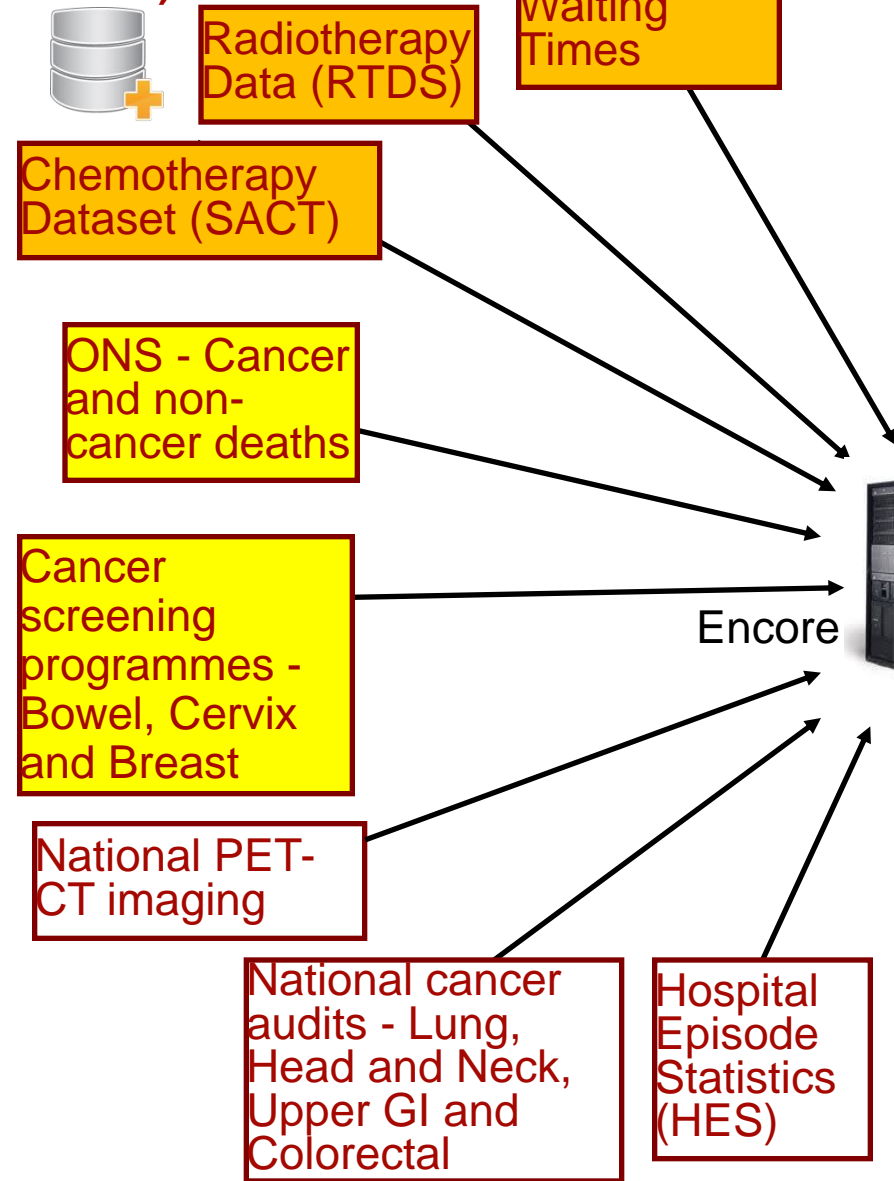
8 regional cancer registries now incorporated into a National Cancer Registration Service for England (NCRS) using one database (ENCORE)

- All records now stored on ENCORE (11m cancer registrations migrated)
- Common practice and processes, single national system
- Standardised data, consistency, comparability & efficiency
- Collect Cancer Outcomes and Services dataset from Providers
- Data direct from Providers supplemented with other national feeds (eg Cancer Waiting Times, Hospital Episode Statistics (HES), Radiotherapy (RTDS)
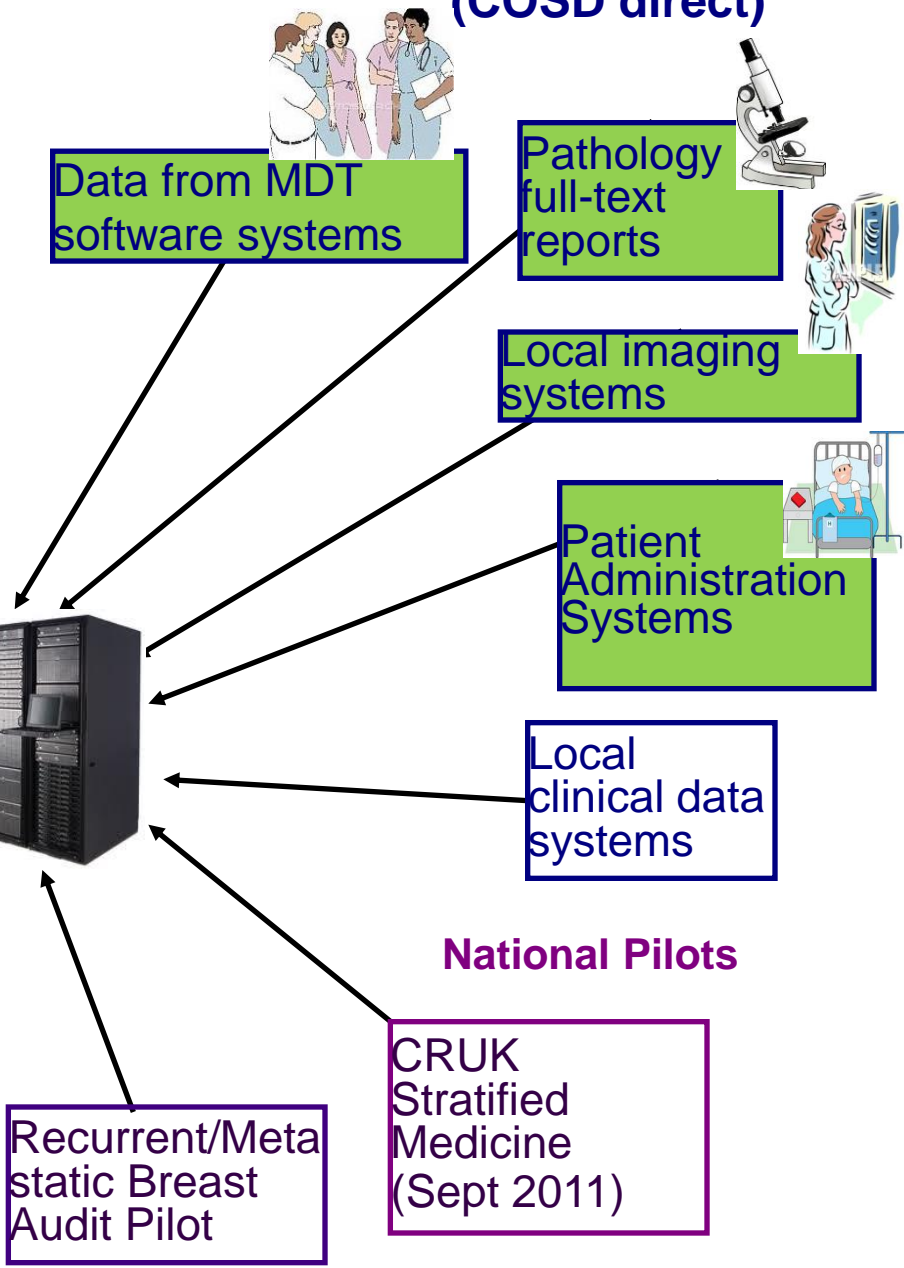- Regular progress reports to MDTs/Providers

Northern & Yorkshire

North West

East Midlands

West Midlands

Eastern

Oxford

London

South West

# Data sources  - patient-level data

**National Feeds (inc COSD indirect)**

**Local Feeds (COSD direct)**

Radiotherapy Data (RTDS)

Cancer Waiting Times

Chemotherapy Dataset (SACT)

Data from MDT software systems

Pathology full-text reports

Local imaging systems

ONS - Cancer and non-cancer deaths

Patient Administration Systems

Cancer screening programmes - Bowel, Cervix and Breast

Encore

Local clinical data systems

National PET-CT imaging

**National Pilots**

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

Hospital Episode Statistics (HES)

Recurrent/Metastatic Breast Audit Pilot

CRUK Stratified Medicine (Sept 2011)

*Thank you to Trish Stokes, Datasets Programme Manager at NCIN for this image*

# Strengths of the data

- Data processed by specialist staff

  - Registration officers focus on cancer only

  - Detailed training programme to understand cancer sites and coding systems

  - Specialist QA officers develop data validations, checks and reports

  - Clinical engagement/liaison with Trusts


- Good links with other datasets…

# Cancer data flows

## PHE National Cancer Intelligence Network (NCIN)

This data flow illustrates how the PHE National Cancer Intelligence Network and PHE Knowledge & Intelligence Teams transform cancer data into intelligence. Our analyses help to drive improvements in prevention, standards of cancer care and clinical outcomes for cancer patients.

The cancer landscape in England has changed considerably in recent times, to reflect a move towards a more integrated public health approach to disease.

Cancer remains a significant public health burden, and is the leading cause of death in all UK nations.

**PATIENT**

**Public Health England**

Clinicians
Charities
Commissioners
Policymakers

## Cancer Outcomes and Services Dataset (COSD)

Specification for standardised, mandatory and optional data fields; applicable to some datasets below.

**Direct COSD feeds; trust-level**
- Patient Administration Systems
- Data from MDT software
- Pathology full-text reports
- Imaging systems

**Indirect COSD feeds; national**
- Cancer Waiting Times
- Systemic Anti-Cancer Dataset (SACT) *Chemotherapy*
- Radiotherapy Dataset (RTDS)

**Other**
- HSCIC Hospital Episode Statistics
- Cancer screening programmes
- ONS – cancer and non-cancer deaths
- National Cancer Audits
- National PET-CT imaging (*in testing*)

## PHE National Cancer Registration Service (NCRS)

**8 regional registration teams**
Eastern, East Midlands, London, Northern and Yorkshire, North West, Oxford, South West and West Midlands

*includes*
- Coding and Classification Group
- Data Quality and Registration

**Single cancer registration system**

English National Cancer Online Registration Environment
**ENCORE**

*Anonymised patient/tumour level cancer registrations data from:*
- Information and Services Division **Scotland**
- **Welsh** Cancer and Intelligence Surveillance Unit
- **Northern Ireland** Cancer Registry

## Cancer Analysis System (CAS) & Cascade

**CAS** holds a large number of datasets
**Cascade** holds UK incidence, mortality and survival statistics only

**Data linkage in CAS at patient/tumour level**

**Current data in CAS**
Incidence, Mortality and Survival
Historical registry data    Geographical lookups
Radiotherapy (RTDS)    PROMs
Populations    Audit

**Hospital Episode Statistics (HES):**
*Admitted Patient Care (Inpatients and Day Case), Outpatients and Accident & Emergency*
**Cancer Waiting Times** (*treatment dataset*)

Derived fields eg
**Ethnicity, Routes to Diagnosis, Deprivation**

*Coming soon...*
**Chemotherapy** (SACT)    **Screening**
**Patient Experience** (CPES)    **Biobank**
**Comorbidities**

**PHE Office for Data Release**
Dealing with data access requests

**Researchers**

## NCIN Outputs

**Tools**
- Cancer Commissioning Toolkit, including GP Practice, CCG and Service Profiles
- Cancer e-atlas: incidence, mortality, prevalence, survival and gynaecological hub

**Information**
- NCIN central analytical projects
- NCIN Site-Specific Clinical Reference Group (SSCRG) projects

**Examples of geographies analysed by: NHS ENGLAND**
- c. 7,600 GP Practices
- 211 Clinical Commissioning Groups CCG
- 161 Acute Hospital Trusts
- 27 Local Area Teams LAT
- 23 Commissioning Support Units CSU
- 15 Academic Health Science Networks
- 12 Strategic Clinical Networks SCN
- 12 Clinical Senates
- 10 Specialised Commissioning Hubs

**PUBLIC HEALTH ENGLAND**
- c. 150 Local Authorities
- c. 140 Health & Wellbeing Boards
- 8 Disease Registration Teams
- 8 Knowledge and Intelligence Teams*

**UK CONSTITUENT NATIONS**
- 5 N. Ireland Health & Social Care Trusts
- 14 Scotland Health Boards
- 7 Wales Health Boards

**\*PHE Knowledge and Intelligence Teams (KITs)**

| | |
|---|---|
| East | East Midlands |
| London | North West |
| Northern & Yorkshire | South East |
| South West | West Midlands |

# Weaknesses - timescales

| | |
|---|---|
| 2010 | COSD not mandated<br>SACT did not exist<br>Registries using regional systems |
| 2011 | COSD not mandated<br>First registries migrated to national system<br>Still waiting for full linkages to HES, RTDS etc |
| 2012 | COSD not mandated<br>Majority of registries on national system but not all<br>Still waiting for full linkages to HES, RTDS etc |
| 2013 | COSD core data items mandated<br>All registrations on national system<br>Year not yet fully processed<br>December diagnosis cases only had first three months of treatment |
| 2014 | COSD core and site specific data items mandated<br>All registrations on national system |
| 2015 | More speedy processing of cancer registrations |

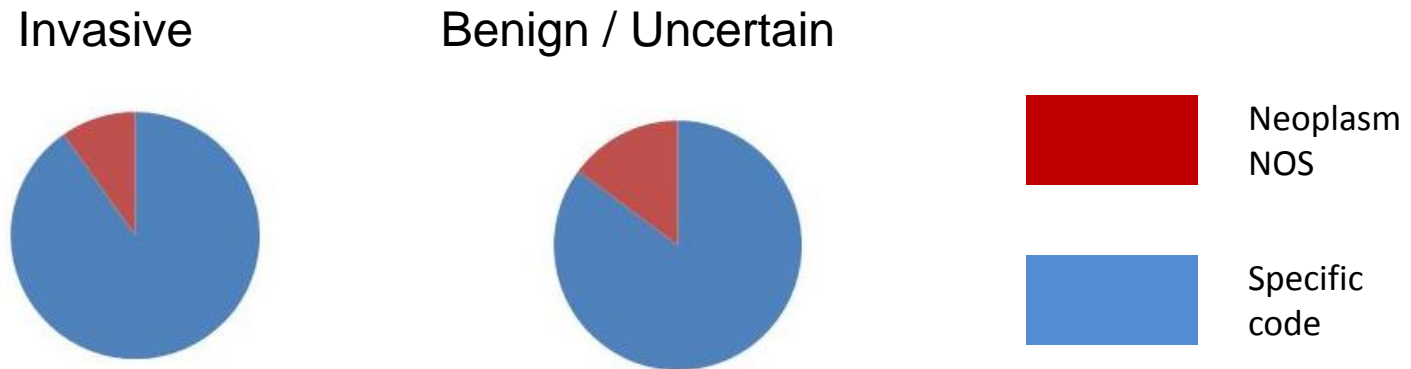# Weaknesses

## Older data

- Rare cancers or small geographies

    - need multiple years of data to have significant numbers of cases for analysis

- Can't use five-year survival as outcome measure if five years has not passed!

- Older data do not have the full dataset, so trend analysis difficult

## UK nation data

- Work with Wales, Scotland, Northern Ireland and Ireland in partnership as the UKIACR

- Attempts made to standardise, but **variation can occur**

- Routine datasets available for English data (eg HES, CWT, audit data) often not available to us from Celtic nations

# Weaknesses – CNS bucket codes

- Different brain cancers have very different care pathways and outcomes

- Cannot identify type of brain cancer without good morphological coding

- Historically, many brain cancers have been given bucket diagnoses

Invasive                    Benign / Uncertain

Neoplasm NOS

Specific code

2005 tumours – over 1 in 10 coded as Neoplasm NOS

# Weaknesses – non-invasive tumours

- All brain tumours are a registrable condition

- But national statistics have historically focused on **invasive** tumours

- When the data are not being used, hard to identify data quality issues

  *"One regional registry stopped submitting D32 (benign neoplasm of meninges) to ONS for over 10 years, and this wasn't spotted as no-one was analysing the data!"*

- Pituitary tumours: reported incidence rates strongly depend on:
  - ➢ Amount of imaging being done, leading to incidental findings
  - ➢ Access of cancer registries to imaging data – better data, higher incidence rate

# Weaknesses – brain metastases

- Primary brain tumours only part of workload

- Metastases of other primary cancers to the brain are a significant proportion of all tumours in the brain

- National data on metastases historically poor

- Good at saying 'it has metastasized' but not 'where to'

- Reviewing the data we collect on recurrence and metastases now COSD data is being collected

- Progressive Cancers project by Macmillan and the National Cancer Intelligence Network, assessing second cancers, recurrence and metastases for selected cancer sites

# Conclusions on data quality

- NCRS data is a **great resource**
  - world leading data set
  - understand and improve patient care across the country

- There are **known weaknesses** in the available cancer data.
  - It is important to consider these when National Cancer Intelligence Network Analysts are planning analysis projects and interpreting data

- **Recent developments** - one English National Cancer Registration Service, COSD and SACT = hugely improved data quality
  - but if we are looking at outcomes like 5-year survival there is a delay before these data are available.

- Improving and using data about cancer patients helps to **drive up standards** of cancer care. ***But we must understand the data quality issues of the data we use***, to understand the findings we get.

- Data Quality project in CNS SSCRG 2015/2016 work programme.

# CNS SSCRG workshop feedback

- March 2014
  - *"which metrics would you like to see us calculate?"*
  - *"what questions do you want answered?"*

Metrics – popular responses *n*=>5

| Metrics |
| --- |
| Quality of Life - measure a baseline QOL and then at an interval after diagnosis |
| Number of open trials/ % recruited into a trial/ access to clinical trials |
| Disability (motor / cognitive / hormonal / visual) |
| How many excisions does a surgeon need to make? (I assume this is caseload per surgeon per year?) |
| Survival (1 year / median) (by certain tumour types) |
| How many times do patients visit a GP before a diagnosis? |
| Patients referred to supportive therapies (OT, psych, SLT/SALT, (tailored)neuro rehab) |
| Patients per oncologist |
| Time to radiotherapy after surgery |

Red text – topics addressed since the workshop, or part of next year's CNS SSCRG work programme

# CNS SSCRG workshop feedback

*"what questions do you want answered?"*

responses $n=>1$

| Questions |
|---|
| Do rehab services make a difference and if so what outcomes are they making a difference on |
| What causes brain tumours?  Why do some people get brain cancer?  Any trigger factors?  Genetic / environmental? |
| Are we ignoring benign tumours and quality of life? |
| How do you follow up the quality of life post supportive therapy for different therapies? |
| Do patients go back to work?  If so, is it successful? |
| What is the economic situation of patients with brain tumours?  Do they get benefits they're entitled to? |

# CNS SSCRG work programme

- Workshop programmes created each financial year.

- 2014/15

  – <u>Glioblastoma epidemiology report</u> – published open access in EJC, February 2015

  – Service Profiles – generated and awaiting publication

  – Data quality – carry over to next year's programme

  – Meningiomas – ongoing project, analysis led by David Greenberg at NCRS

- 2015/16

  – Being finalised

- Future plans

  – Look at topics suggested at March 2014 workshop

  – Pick up again for future workshop

# Thank you

**Information about CNS SSCRG membership list, publications, meeting/workshop dates:**

http://www.ncin.org.uk/cancer_type_and_topic_specific_work/cancer_type_specific_work/central_nervous_system_cancers/

**Please feel free to contact:**

sarah.miller@phe.gov.uk or eastKIT@phe.gov.uk

SSCRG/Cancer Intelligence/Analysis: enquiries@ncin.org.uk

NCRS/Data Quality/Registration: analysis-req@ecric.nhs.uk