



Public Health
England

Protecting and improving the nation's health

A brief history of cancer registration

How do we register a cancer patient?

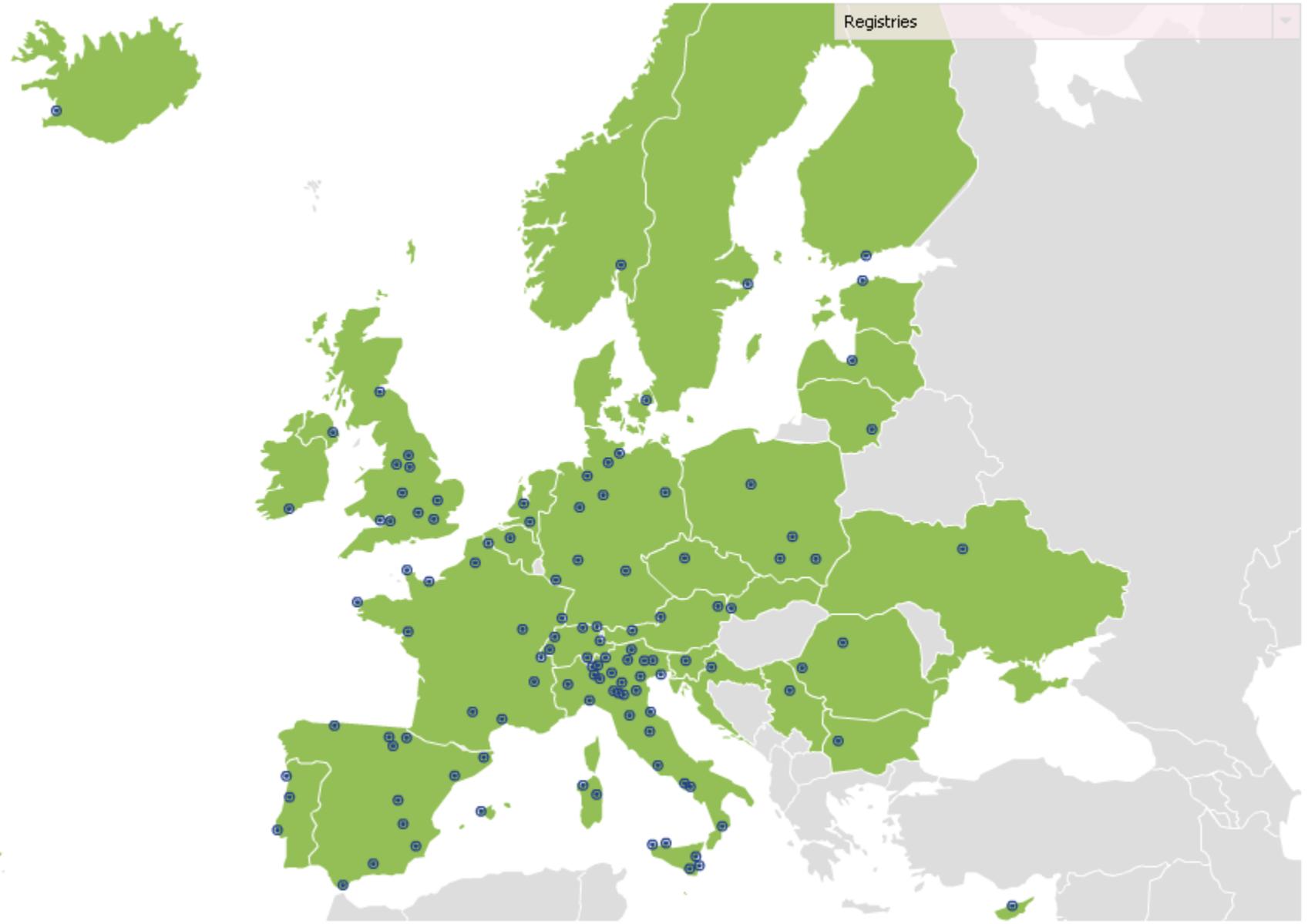
Chris Carrigan, Head, NCIN

Lets start with a test.....

- Question: When was the first cancer census in the UK?
 - London, 1728 (and it didn't work)
- Which countries led the way afterwards?
 - England and Germany @ 1900
 - Then between 1902 and 1908, Netherlands, Spain, Portugal, Hungary, Sweden, Denmark and Iceland
 - US pilot (in Massachusetts) deemed a failure

Some early design questions?

- What's the purpose of a registry?
 - How many people are getting cancer
 - How many people are dying with cancer
 - Are there geographic differences
- And depending on that, do you need to:
 - Count everyone
 - Count a sample, and multiply
 - Count deaths



1728

The speed of light is calculated



The first cancer census in the UK

Tried, failed.....

- Missing data
- Clinicians not taking part
- Data quality differences



1945

ENIGMA is cracked

NHS is founded in July 1948

The gradual emergence of key international bodies and publications:

- WHO, UICC (1950)
- IARC (1965)
- IACR (1966)
- Cancer Registration, Principles and Methods (1991)





1960s

Cash machines, the first pocket calculator

A time of change....

Registries in the UK really move to become population registers

- Coverage is eventually right across the UK
- Though Northern Ireland is patchy until 1994
- Few UK-based standards or groups





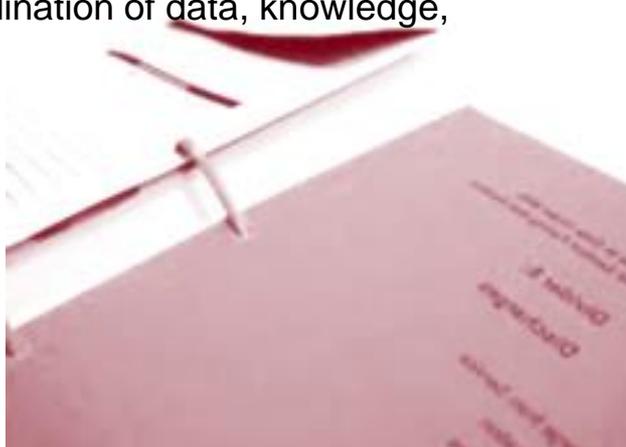
1983

Mainframe Computers - No Internet or Emails

Hospital Records are on Paper

Very little cohesive data on cancer across the UK:

- Difficult to understand the burden of cancer
- Difficult to assess service delivery
- Lack of co-ordination of data, knowledge, intelligence

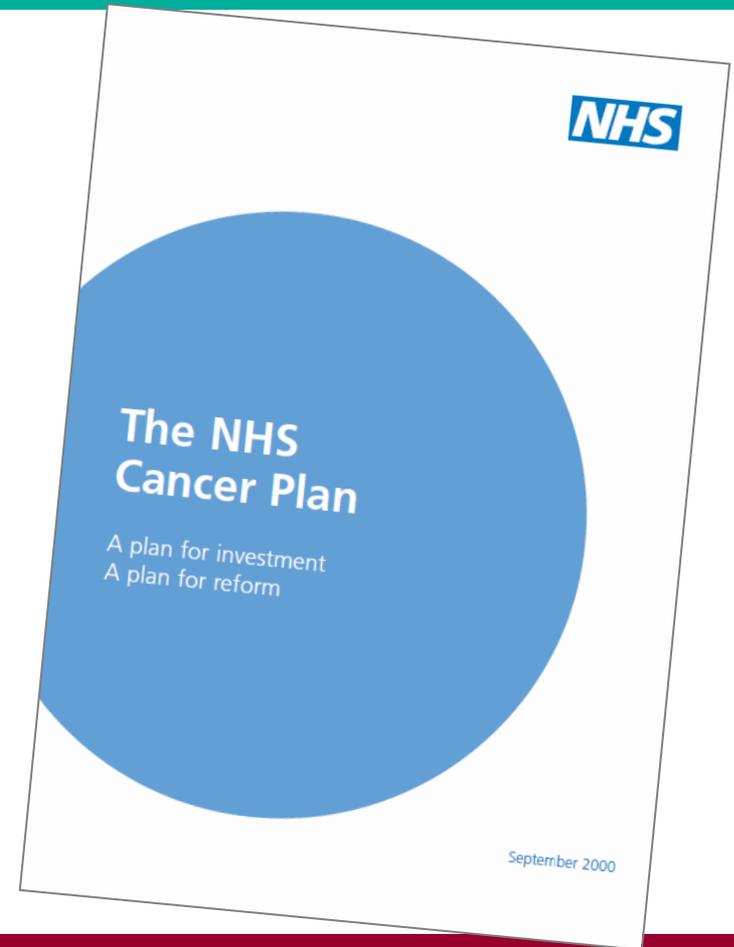


2000

Google is launched

NHS Cancer Plan Published

- Focus on Multi-disciplinary teams (MDT)
- Investment & reform across NHS for cancer services
- Move from bean counting to clinical outcomes
- Gillis review of cancer registration is published
- National Coordinator for Cancer Registration



2008

Mobile Apps



National Cancer Intelligence Network (NCIN) formed

5 key messages :

- Promoting efficient and effective **data** collection
- Providing a common national **repository** for cancer datasets
- Producing expert analyses to monitor **patterns** of cancer care
- Exploiting information to drive improvements in cancer care and **clinical outcomes**
- Enabling use of cancer information to support audit and **research** programmes





2013 **Smartwatch**

National Cancer Registration Service (NCRS) & Encore - A single cancer registration system in England

Following the Scottish lead, 8 regional cancer registries now incorporated into a National Cancer Registration Service for England (NCRS))

- All records now stored on ENCORE (11m cancer registrations migrated)
- Common practice and processes, single national system
- Standardised data, consistency, comparability & efficiency
- Collected electronically from Providers
- Supplemented with other national feeds (eg Cancer Waiting Times, Hospital Episode Statistics, Radiotherapy)
- Regular progress reports to MDTs/Providers



What was held about you...?

1960

- First name
- Second name
- Surname
- Maiden name
- Sex
- Date of birth
- Place of birth
- Occupation*
- Industry*
- Cancer site
- Cancer Morphology
- Date of diagnosis
- Basis of diagnosis
- Date of death

1980

- First name
- Second name
- Surname
- Maiden name
- Sex
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2000

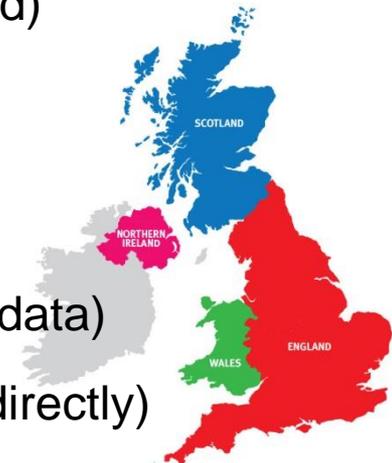
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- ~~Occupation*~~
- ~~Industry*~~
- Cancer site
- Cancer Morphology
- Date of diagnosis
- Basis of diagnosis
- Date of death
- Stage
- Hospital
- Surgery
- Treatment?
- GP Practice
- Pathology
- “Events”

So where do we get your data from now...?

(Largely the same across the UK,
though technology, precise datasets
and timeliness differs)

The main data collections by trusts

- Two main types
 - Cancer Information Standards
 - National Cancer Audits
- Five standards and four audits (at present)
 - Standards - mandated through NHS National contract and commissioning
 - National audits - monitored through CQC and Quality Surveillance Programme (formerly Peer Review)
- Two main collection routes for cancer data from trusts (England)
 - National Cancer Registration Service (NCRS)
 - Health and Social Care Information Centre (HSCIC)
- Other data collections such as ONS deaths
- HSCIC collects most of the NHS data (including some cancer data)
- NCRS collates all cancer related data (some directly, some indirectly)



Data Standards

- Five standards:
 - CWT - Cancer Waits
 - RTDS – Radiotherapy
 - SACT – Chemotherapy
 - DID – Diagnostic imaging
 - COSD – Cancer Outcomes and Services

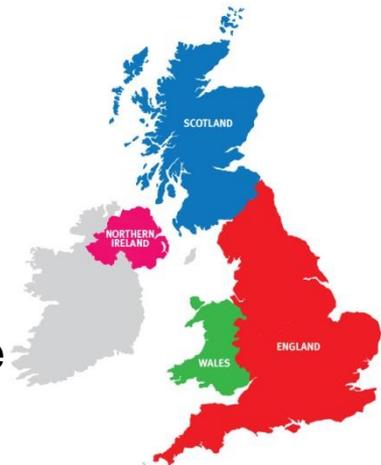
- COSD incorporates key audit fields and CWT fields

England – NHS Data Dictionary (HSCIC)

Wales – NHS Informatics Service (NWIS)

Scotland - National Data Catalogue (ISD)

NI - Health & Social Care Board, Information Standards Service



Radiotherapy dataset (RTDS)

- Currently collected and compiled by NatCanSAT (National Clinical Analysis and Specialised Applications Team) for England and Scotland
- For England, radiotherapy data will be collected and compiled by NCRS from April 2016



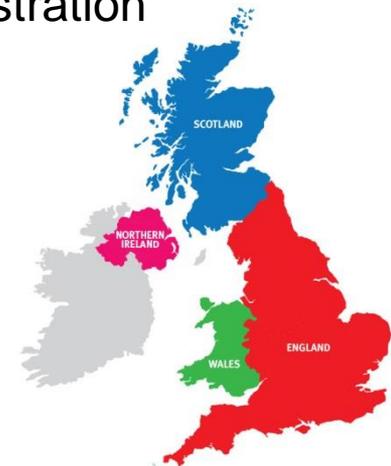
Systemic Anti-Cancer Therapy (SACT)

- Monthly submissions from all trusts providing chemotherapy
 - Currently to Chemotherapy Intelligence Unit in Oxford but moving into NCRS system
- Monthly, quarterly and annual reports available through website
<http://www.chemodataset.nhs.uk/home>
- Coverage not yet complete for all trusts and cases
 - Particularly haematology, paediatric and not hospital settings
- Some poorly collected data items
 - eg Morphology, performance status
- But new information never previously available



Diagnostic Imaging Dataset (DID)

- Record-level data from NHS Radiology Information Systems (RIS) in England
 - Covers pathway – who, what, where, when etc
- Now three years data and ready to link and assess impact of diagnostic imaging on cancer outcomes
- Monthly provisional summary and annual reports by NHS England
 - <http://www.england.nhs.uk/statistics/statistical-work-areas/diagnostic-imaging-dataset/>
- There have been delays in getting this data to flow to the registration system



Cancer Outcomes and Services Dataset (COSD)

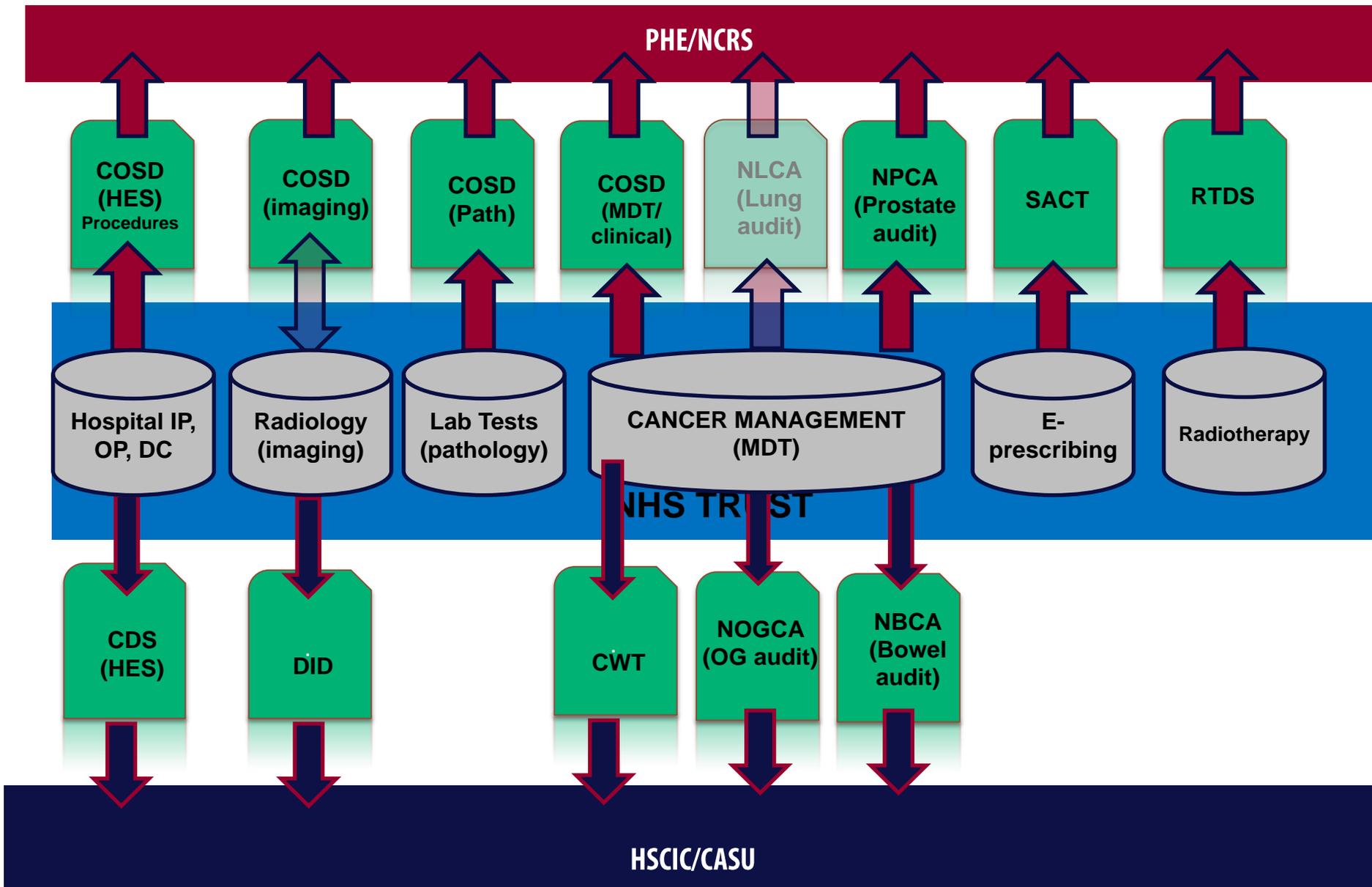
- Aligned and rationalised with other cancer datasets
- Core subset incorporates registration data for national and international epidemiology etc
- 12 site specific subsets include key audit items for service and outcomes analysis etc
- Will include all recurrences and MDT meetings by July 2016
- Key items:
 - Basis of diagnosis and morphology
 - Stage and performance status
 - CNS contact
 - Site specific audit items



National audits

- Partnerships between clinical (Royal Colleges) and information services
 - Four audits
 - NBCA(NBOCAP) – Bowel
 - NOGCA – Oesophago-gastric
 - NLCA – Lung
 - NPCA – Prostate
 - DAHNO – Head & Neck currently no contract
 - Breast Cancer - likely to be commissioned in 2015
- Majority of audit data is also collected through COSD
- Try to upload monthly for audits as well as COSD
- Record in one place only for both COSD and audits

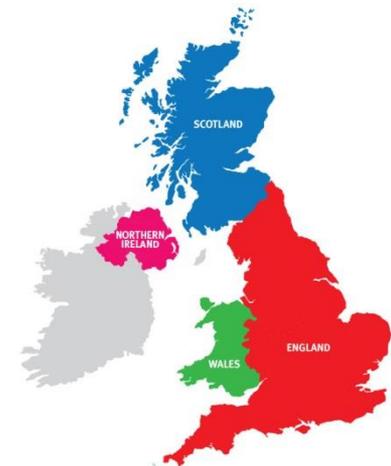




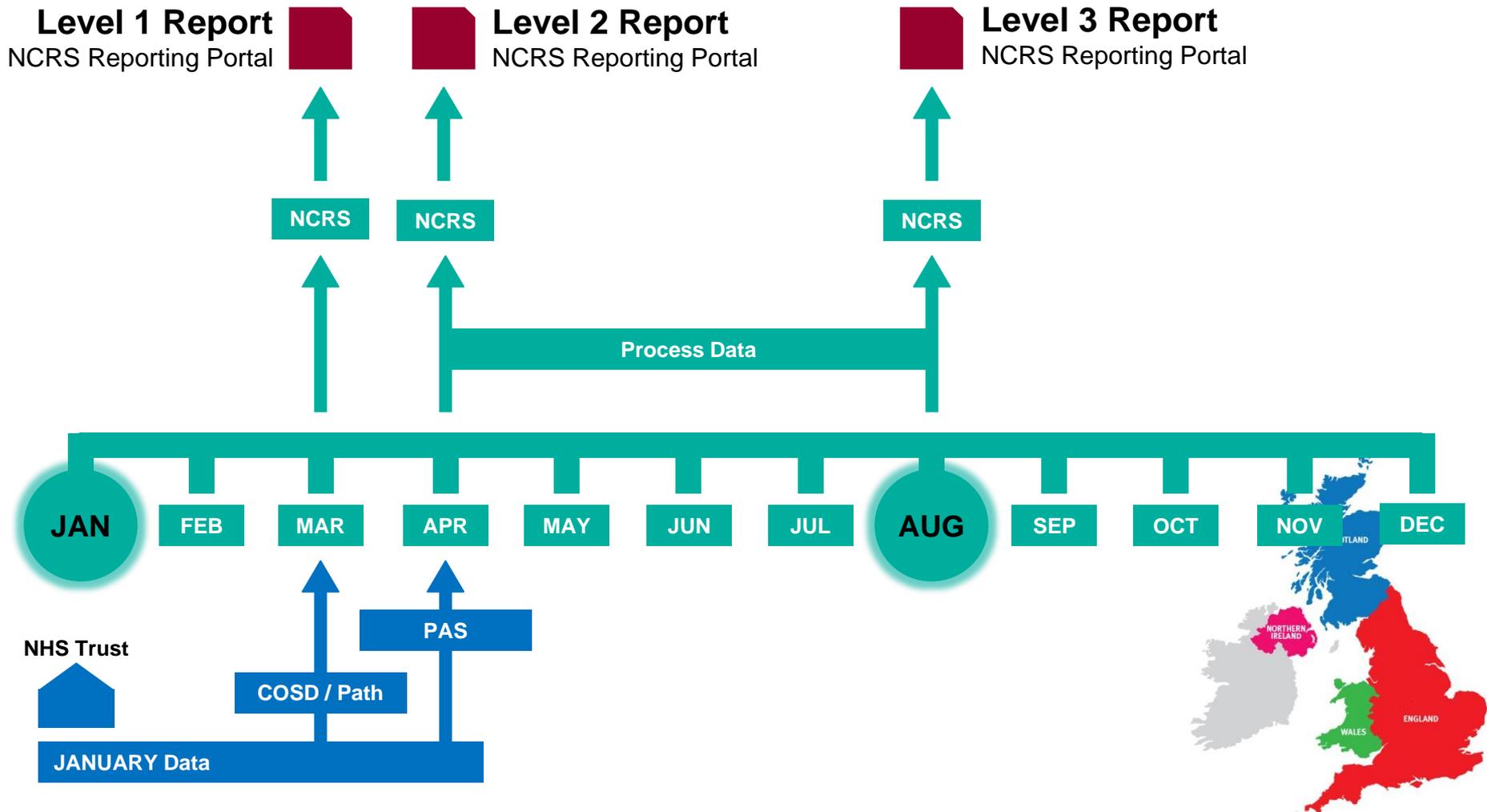
So how do the data get processed?
What do we do with it when we get it?

How do we know it's right?

- Clinicians are responsible for ensuring accurate data is recorded
- Registries provide detailed reporting (portal/reports) for them, so that they can see in detail what's been submitted
- They should:
 - know how and when your data is submitted
 - agree a (manageable) system for checking accuracy
 - use the reporting portal regularly



Clinician Reporting Portal (England)



Reporting portal – feedback reports



Public Health
England

ncrs National Cancer Registration Service
COSD Conformance Reporting Site

Home | Level 1 | Level 2 | Documents Library | Log Out

Level 1 Reports

- Level 1.1 Report
- Level 1.2 Report
- Level 1.3 Report

Report Descriptions

Click headings to show descriptions...

> Level 1.1

Have all the agreed COSD data files been received as per the COSD Data Transfer Partnership Agreement?

Trusts would be expected to send a monthly submission of all files agreed in their COSD Data Transfer Partnership Agreement. For a trust to be compliant with Measure 1.1, ALL the required files must have been received on time for that month. If one or more is missing or late, the trust will be non-compliant. Please refer to Measure 1.2 to see details of individual data feeds.

> Level 1.2

> Level 1.3

Regional Office: East Midlands, Eastern, London, Strategic Clinical Network: Cheshire And Mersey, East Midla

Region: Essex, Kent & Medway, North Ea Year:

1 of 1 100% Find | Export

Trust	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec
Stockport NHS Foundation Trust	Red	Red	Green									
Tameside Hospital NHS Foundation Trust	Red	Red	Green									
The Christie NHS Foundation Trust	Red	Red	Green									
Trafford Healthcare NHS Trust	Green											
University Hospital Of South Manchester NHS Foundation Trust	Red	Red	Red	Green								
Wrightington, Wigan and Leigh NHS Foundation Trust	Red	Red	Red	Green								
London Cancer												
Essex												
The Princess Alexandra Hospital NHS Trust	Green											
North London												
Barnet and Chase Farm Hospitals NHS Trust	Green											
Barnet and Chase Farm Hospitals NHS Trust - MDT	Green											
Barnet and Chase Farm Hospitals NHS Trust - PAS	Green											
Barnet and Chase Farm Hospitals NHS Trust - Pathology	Green											
Great Ormond Street Hospital For Children NHS Trust	Red	Red	Red	Green								
Moorfields Eye Hospital NHS Foundation Trust	Red	Green										
North Middlesex University Hospital NHS Trust	Red											
Royal Free Hampstead NHS Trust	Green											
Royal National Orthopaedic Hospital NHS Trust	Green											
The Whittington Hospital NHS Trust	Red											
University College London Hospitals NHS Foundation Trust	Red											



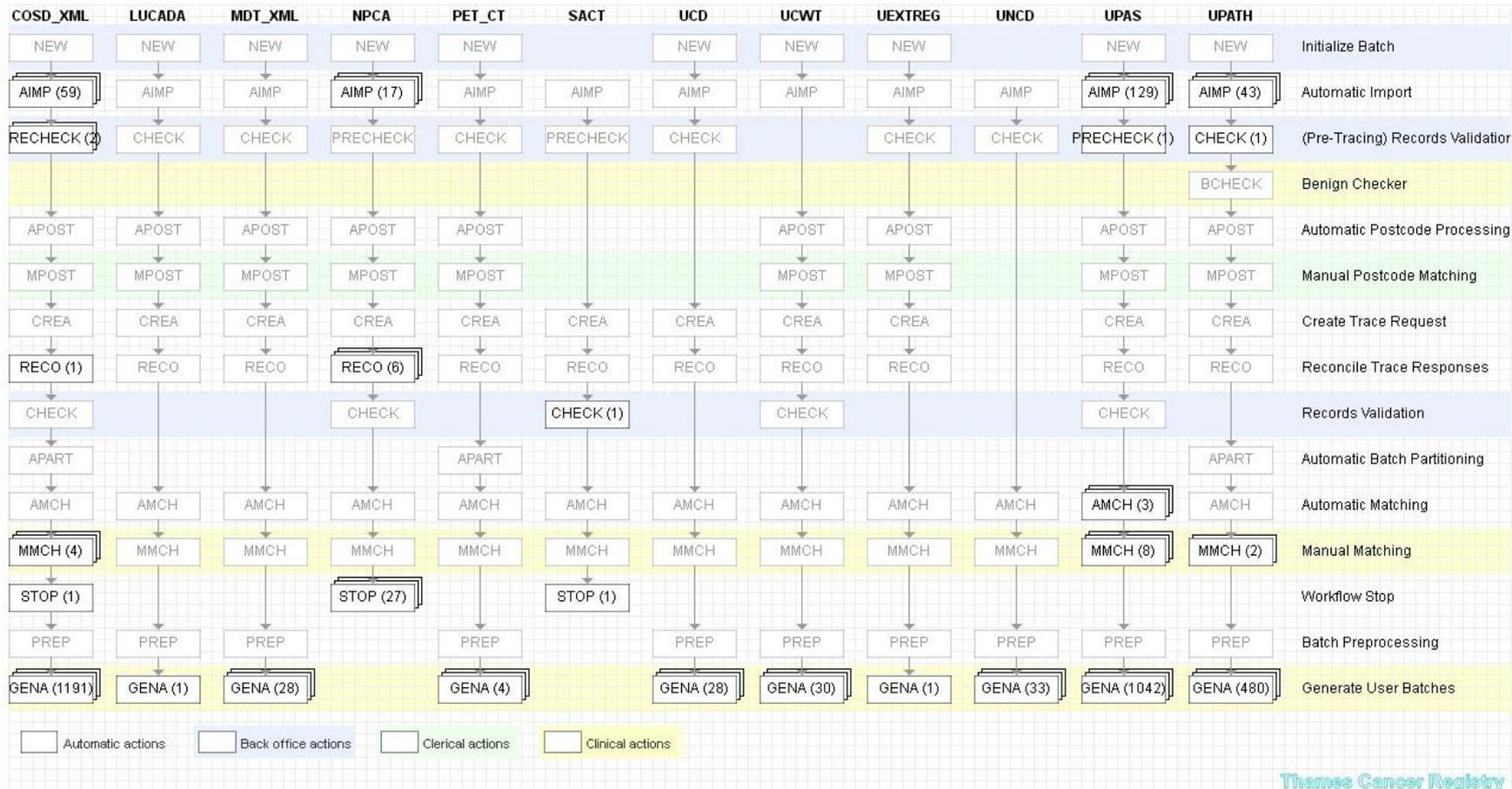
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What does the record look like...?

Batch Summary

Thames Cancer Registry



Help Help 50325660

[Edit](#) [Audit](#) [Audit Timeline](#)

[Delete Patient](#)

Born on 01.02.1964 **Alive** on 28.07.2015 NHS number: unknown Ethnicity: White British

Aliases

[None]

In 1 Analysis Cohort Study

cpp

Addresses

Test Address
CB22 3AD
ECRIC (Y0401)

GPs

A S Hussey (G9313015)
The Queen Edith Med.Pract (D81066)

H E M Ahling Smith (G8139874)
Dykes Way (L85027)

Local Identifiers

0100719 Ecric

19 Tumours

[Add Tumour](#)

01.01.1979	C857 9715/3	Not Applicable	Reference	Edit Share
Actions: Proforma (08-01-2008)				
01.01.1995	C857 9715/3 C857 9715/3	Not Applicable	Reference	Edit Share
Actions: Complete (13-12-2006)				
01.01.2001	C444 8010/3 C444 8010/3	Not Applicable	Reference	Edit Share
0402-06-55934 Actions: Complete (13-12-2006)				
01.01.2010	C509 8500/9 C509 8500/9	Left	Final	Edit Share
0401-11-38029 Actions: PathI (04-10-2005) Proforma Tag Qa Proforma Complete Check Search Qa Wait Complete				
01.01.2010	C180 8246/3 C180 8246/3	Not Applicable	Final	Edit Share
0401-15-01059 Actions: Complete (29-01-2015-15-15)				

Status of registration Final (F)

Diagnosis date 01.01.2010

Postcode at diagnosis CB223AD ECRIC (Y0401)

Primary site ICD-O-3 (2011) C509: Breast, Nos

Histology ICD-O-3 (2011) C509: Breast, Nos
ICD-O-3 C509: Breast, Nos

Grade 3 / iii / poorly differentiated (3)

Laterality L: Left (L)

Tumour size mm

Clinically +ve nodes (at diagnosis)

Cyto/Histo +ve nodes (at diagnosis)

Nodes Involved Excised

Extra nodal infiltration

Sentinel lymph node

Excision margin

Multifocal

ER

PR

HER2 Status

Skin involvement / Inflammatory / Peau d'Orange / Fixed to chest wall

BRCA mutation

Post neoadjuvant size mm

No scans found

Staging

Registry (REGISTRY) Date

T N M edition

TNM Stage Unstageable (L) Revised **NPI Score** 0.00 - 14.00

Imaging (IMAGING) Date

c T c N c M UICC 7 (22) edition

TNM Stage **NPI Score** 0.00 - 14.00

Basis of diagnosis BASIS41_1 [historical code]

Screened (*diagnostic route*)

No treatment reason 8: Palliative care only (8) has treatments

Lab number*

Further information

So how does *your* data arrive...?

When a cancer-referral is made by your family doctor

When you have a positive screening result

When a cancer diagnosis code is entered onto a hospital system

Every time you visit the hospital after that point

If you arrive in A&E

Whenever you get some form of NHS treatment, or paid for by the NHS

When you go for your follow up appointment

When you have any subsequent tests

When you reach the end of your life (as we all will at some point)

And what of *your* data doesn't arrive...?

When you get screened and its negative

When you pick up your prescription from the chemist

When you visit your local GP

When the GP sends you anything

When you pay for private treatment yourself

Any x-rays or scans (the actual images)

Tissue samples and data

Your DNA information

Details about your family

How important is data quality...?

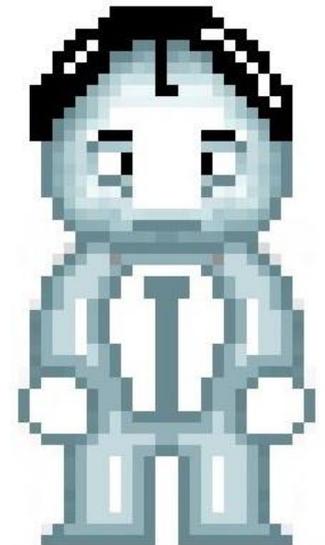
It could affect you, and others

It skews any statistical findings, making some of them unusable

Errors compound each other - “Lean 6 sigma”

You could be a banana

Remember these two people.....?



Between July 2000 and June 2007

- Chronic tonsillitis (Royal United Bath, overnight)
 - Bilateral dissection tonsillectomy
- Hypopituitarism (Radcliffe Oxford, day case)
- Sleep apnoea (Radcliffe Oxford, overnight)
- Malignant neoplasm of placenta (Great Western Hospital Swindon, overnight)
- Observation for other suspected diseases and conditions (Radcliffe Oxford, 13 days)
- Myoclonus (Great Western Hospital Swindon, 4 days)
- Epilepsy, unspecified (Great Western Hospital Swindon, day case)
- Dystonia, unspecified (Great Western Hospital Swindon, 9 days)
- Other and unspecified convulsions (Radcliffe Oxford, 12 days)

How do we know that the data held about you is right?

We check, but even then.....

You don't.....

But have you ever heard of Experian...?

- Getting a credit card

- Getting a mortgage

- Going on holiday

- Buying a car

So how can you check your record....?

- Make a Subject Access Request

- Use a patient portal

Welcome to the Cancer Patient Portal

This portal is a personal space for you to keep track of your cancer journey including notes on your experiences, on-going surveys of your quality of life, and access to your tumour records from the National Cancer Registration Service.



My cancer record

This is where you can see the information held about you by the National Cancer Registration Service. You can add your own comments to the records, perhaps to define a technical term, or to remind yourself to follow something up with your clinical team.



My notes

This is your own personal space where you can **create and store notes** of any kind - your thoughts, observations, worries and hopes, or perhaps even your shopping lists.



My quality of life

Use this **survey** to track your quality of life regularly and inform discussions with your clinical team. Your answers will also help us understand the impact of cancers on people during and after treatment.



My contacts

A handy place to store all your **contact information** for your clinical team and any others involved in your treatment and care.





My cancer record

This page shows you the information held about your cancer by the National Cancer Registration Service. If you need any help interpreting these records you might find [this glossary](#) useful—or feel free to [contact us](#).

Please note that viewing these records does not substitute discussion with your clinical team. Also note that the commenting feature is for your use and reference only—your comments will not be distributed to the clinical team via this system.

1 Nov 2012



Medical record

Type: Surgery and Other Procedures

Tumour Type: Brain tumour

[View detail](#)

[Add comment](#)

[View Glossary](#)

1

 8 Sept 2014

+

1 Nov 2012



Medical record

Type: Pathology

Tumour Type: Brain tumour

[View detail](#)

[Add comment](#)

[View Glossary](#)

31 Oct 2012



Medical record

Type: Imaging

Tumour Type: Brain tumour

1



Medical record

Type: Pathology

Tumour Type: Brain tumour

[View detail](#)

[Add comment](#)

[View Glossary](#)

Organisation Site Code (Pathology Test Requested By): DUMMY HOSPITAL NAME (XYZ99)

Care Professional Code (Pathology Test Requested By): MADE UP (C1234567)

Primary diagnosis ICD: C713: BRAIN, PARIETAL LOBE

Date sample taken: 01.11.2012 (Date on which the specimen was obtained from the patient)

Date sample received: 01.11.2012 (Date received by path lab)

Date of investigation result: 07.11.2012 (Date path lab wrote the report)

Histology Snomed: Left parietal lobe : TA2303 : Neurosurgical biopsy : T : Glioblastoma NOS : M94403 : . . . :

Glioblastoma NOS : M94403 :

Full pathology text:

Clinical Details

SPECIMEN: Details not given on green form Presented with acute days in GCS. (History of colorectal Ca in 2004). CT - Intracerebral ...(illegible) to intraventricular extension. MRI - Cystic lesion in right parietal lobe and splenium. Dx: High grade intrinsic tumour.

Macroscopy

SPECIMEN 1 - Specimen consists of multiple cream and haemorrhagic fragments of tissue that measure in aggregate 5 x 5 x 2mm. [N(1)NR] SPECIMEN 2 - Specimen consists of multiple cores of creamy tissue that measure in aggregate 10 x 10 x 3mm. [N(1)NR]

Microscopy Text

Sections show a Glioblastoma composed of close-packed small undifferentiated cells with minimal cytoplasm in a fibrillary background and focally forming nodules. The tumour has only moderate nuclear pleomorphism but numerous mitotic figures. Foci of tumour necrosis and vascular endothelial cell proliferation are present.



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Chris.Carrigan@PHE.gov.uk