

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





#### 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

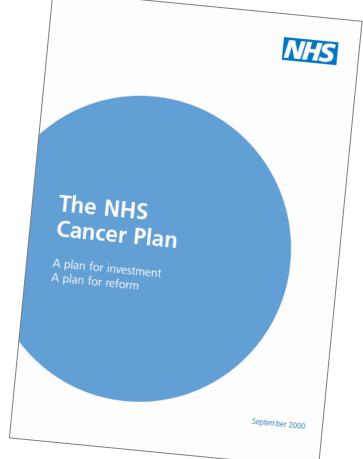




# 2000 Google is launched

#### 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



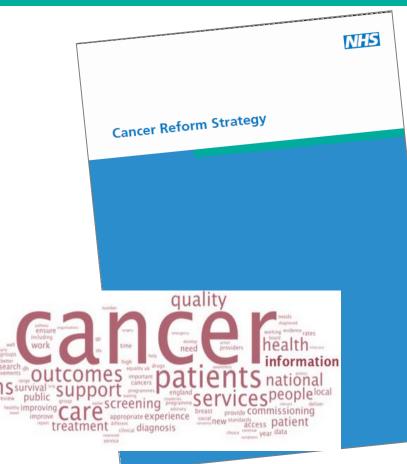


# 2007 First Generation iPhone

#### **Cancer Reform Strategy Published**

#### Builds on progress of Cancer Plan of 2000

- Spreading 'best practice'
- Aim to to improve
  - Clinical outcomes,
  - Drive up quality and increase value for money.
- Chapter 8 "using information" led to formation of the NCIN







## 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



twelve

thirty

five

28:56

4.08m

7:05

min/mi

## 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
- Date of birth
- Place of birth
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• 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
   <u>http://www.chemodataset.nhs.uk/home</u>
- 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 diagnostiic 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)

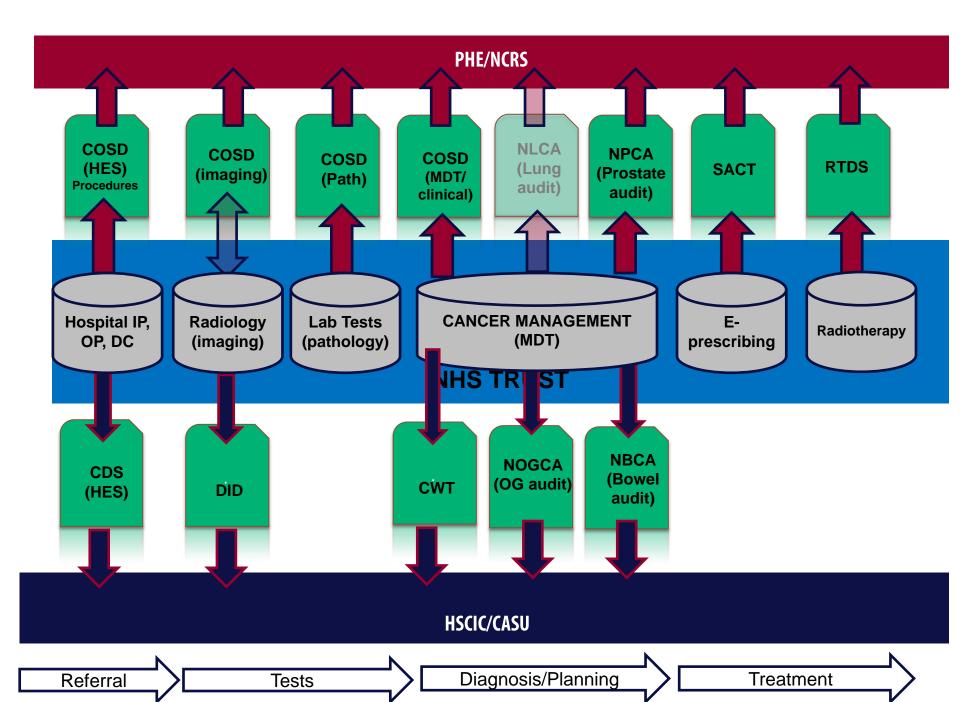
- Aligned and rationalised with other cancer datasets
- Core subset incorporates registration data for national and international epidemiology etc
- 12 site specific subsets include key audit items for service and outcomes analysis etc
- Will include all recurrences and MDT meetings by July 2016
- Key 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





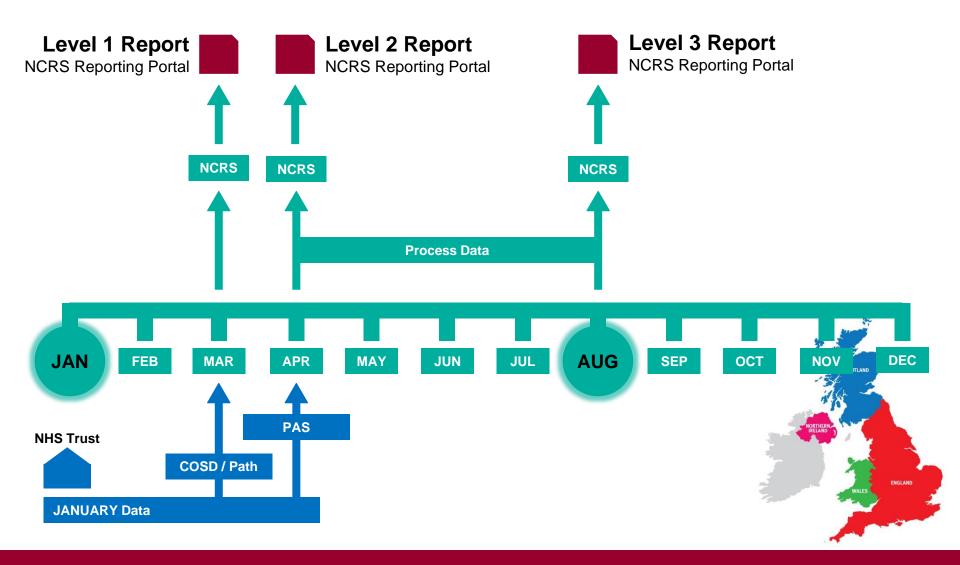
## So how do the data get processed? What do we do with it when we get it?

## 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



## **CInician Reporting Portal (England)**



## Reporting portal – feedback reports

**NCLUS** National Cancer Registration Service COSD Conformance Reporting Site

Log Out

Documents Library

England

#### Level 1 Reports

Level 1.1 Report

**Public Health** 

Level 1

Level 2

- 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.

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# What does the record look like...?

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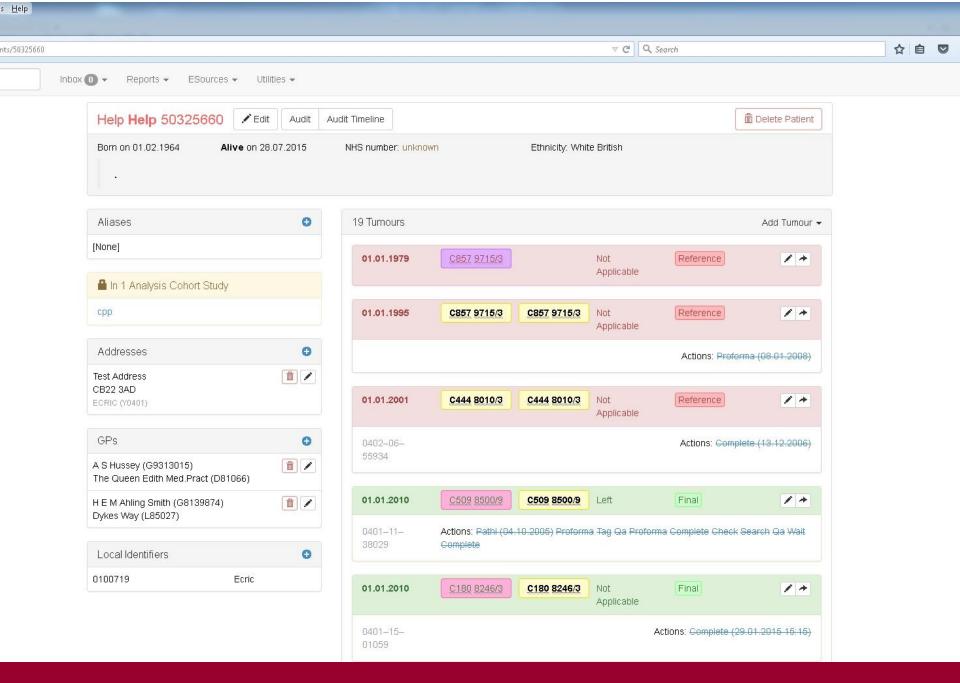
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#### **Batch Summary**

#### **Thames Cancer Registry**

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C T T C N C M ULCC 7 (22) edition   TNM Stage   Basis of diagnosis   BASIS41_1 [historical code]   Screened   ('diagnostic route')   No treatment reason   B Palliative care only (8)   Basis of diagnosis   BASIS41_1		Imaging (IMAGING)	
TNM Stage   Basis of diagnosis   BASIS41_1 [historical code]   Screened ('diagnostic route')   No treatment reason   B. Palliative care only (8)   A streatments   I anumber   Further information			
Screened ('diagnostic route')     Image: Screened ('diagnostic route')       No treatment reason     8 : Palliative care only (8)       Lab number*     Image: Screened (Screened)       Further information     Image: Screened (Screened)			
('diagnostic route')         No treatment reason         B : Palliative care only (8)         Lab number*         Further information	Basis of diagnosis	BASIS41_1 [historical code]	
No treatment reason       8 : Palliative care only (8)       Image: has treatments         Lab number*       Further information			
Lab number* Further information			
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



Using information to improve quality & choice

- 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

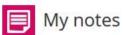
This portal is a personal space for you to keep track of your cancer journey including notes on your experiences, on-going surveys of your quality of life, and access to your tumour records from the National Cancer Registration Service.



#### 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.





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 you clinical team. Your answers will also help us understand the impact of cancers on people during and after treatment.



#### My contacts

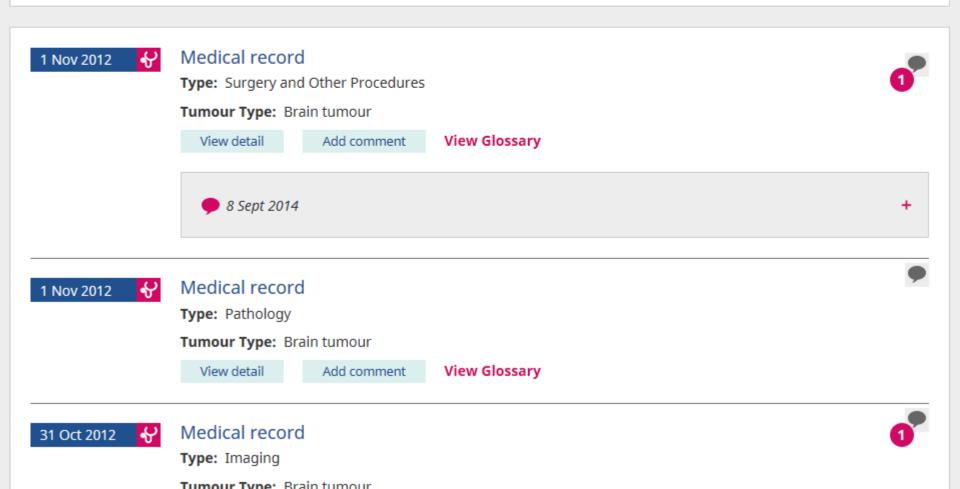
A handy place to store all your contact information for your clinical team and any others involved in your treatment and care.





This page shows you the information held about your cancer by the National Cancer Registration Service. If you need any help interpeting 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.





<del>ہ</del>

Type: Pathology

Tumour Type: Brain tumour

View detail

A

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.



Protecting and improving the nation's health

## Chris Carrigan

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