National Cancer Intelligence Network (NCIN)

30 + years of cancer intelligence - challenges of technologies of the time
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
1988
Mobile Phones, Fax Machines & Overhead Projectors

British Oncology Data Managers Association (Di Riley)
1993 The World Wide Web

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
1995
First PC’s in NHS Trusts

Calman-Hine Report - Local Challenges

- Local Trusts proposed that Cancer registration data to be collected
- Start to review ‘Data v Pathway’
- Datasets driven by Royal colleges & clinical groups (rather than patient outcomes)
- Patient Admin Systems (PAS) is key
- Requirement - To find out how many cancer patients within an NHS Trust/position on cancer pathway
- 1st Dept. of Health Cancer Waiting Times Audit produced
- 1st Clinical Peer Review held in London
1st Britain Against Cancer Conference

- The APPGC's landmark event is the annual Britain Against Cancer conference.
- This event brings together everyone with an interest in improving cancer services and outcomes in the UK.
1999-2000

NHS Cancer Plan Published

- Focus on Multi-disciplinary teams (MDT)
- Investment & reform across NHS for cancer services
- To reduce death rates
- Improve prospects of survival

| Box 1: Progress against selected targets in NHS Cancer Plan |
|-----------------------------------|--------------------------|
| **A maximum wait of two weeks to see a specialist after urgent referral by a GP** | Operational standard (% of patients) | Compliance (% 2nd quarter 2009/10) |
| 93 | 94.4 |
| **A maximum wait of 31 days from diagnosis to first treatment for all cancers** | 96 | 97.5 |
| **A maximum wait of 62 days from an urgent GP referral to first treatment** | 85 | 85.8 |

The NHS Cancer Plan

A plan for investment
A plan for reform
2000 Millennium Bug Risk

NHS Cancer Plan - Local Challenges

- Improving prevention and screening
- Reducing waiting times
- Implementing the cancer plan locally - old technology/lack of software to support data collection.
Cancer Waiting Times

- Cancer Waiting Times dataset launched - NHS Trusts mandated to collect data to improve the services for patients.
- Somerset Cancer Register developed and rolled out across England to support the CWT dataset and link it with the audit datasets.
2005-06 PDAs in hospitals. Twitter & Facebook go Public

1st Lung Audit Published LUCADA

- Audit demonstrated large variations in outcomes for patients with lung cancer
- Data collection varied across the country
- Personal Digital Assistances used to support hospital workload.
Cancer Reform Strategy Published

Builds on progress of Cancer Plan of 2000

- Spreading ‘best practice’
- Recommending what more needs to be done by cancer networks and the NHS.
- Aim to improve
  - Clinical outcomes,
  - Drive up quality and increase value for money.
- Chapter 8 - using information led to formation of NCIN
National Awareness and Early Diagnosis (NAEDI)

- National awareness and early diagnosis announced in the Cancer Reform Strategy
- The aim to coordinate a programme of activity supporting local interventions to raise public awareness of the signs and symptoms of early cancer and encourage people to seek help sooner.
National Cancer Intelligence Network (NCIN) Formed

5 key messages:

• Enabling use of cancer information to support audit and research programmes
• Exploiting information to drive improvements in cancer care and clinical outcomes
• Providing a common national repository for cancer datasets
• Producing expert analyses to monitor patterns of cancer care
• Promoting efficient and effective data collection
NCIN - Site Specific Clinical Reference Groups (SSCRG)
Set up by NCIN to advise on what data needs to be collected and what analyses conducted.

Key measures include:
• Identify important clinical outcomes for each tumour type
• Promote use of cancer information in the commissioning process
• Implement best practice (defined by National Guidance such as Improving Outcomes Guidance and NICE Quality Standards)

Support linkage of dataset and data to analysis to improve services:
• Clinical activity, performance and outcomes
• Infrastructure and process (e.g. Peer Review)
• Patient experience and patient-reported outcomes
2008

NCIN Website Launched to Support Commissioners & Providers
2008

Mobile Apps

NCIN - The Cancer Commissioning Toolkit (CCT) launched across England

- A one stop shop of cancer information and data covering the patient journey.
- Supporting National Health Service (NHS) commissioners and providers.
- Data presented in a graphical manner.
- Benchmarked variables between comparable organisations and populations.
- Information breakdowns at different levels of detail.

For more information on the CCT go to: www.cancertoolkit.co.uk
2009
NCIN Increased from 5-30 Staff to Support Delivery
NCIN - Routes to Diagnosis

- Routes to Diagnosis analysed and launched by NCIN.

- Data identified that early Diagnosis can save lives and Lead to change in policy to support Patient outcomes.
2009 Windows 7

Multidisciplinary Teams

- Focus on MDT - local/regional to support local services
- Going further on cancer waits requirements released,
- Radiotherapy dataset launched (RTDS)

Multidisciplinary team members’ views about MDT working:

Results from a survey commissioned by the National Cancer Action Team

September 2009

Report prepared by:
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2010
iPad

**Delivering the Cancer Reform Strategy**

- Builds on progress of Cancer Plan of 2000
- Identified improved approach to data on cancer services across England (though using data as evidence).
- Identified and reduced the GAPs in service delivery (to improve services for patients which lead to better patient experience).
2010 iPad

NCIN Launches Profiles via the Cancer Commissioning Toolkit to Support Service Delivery across England [www.cancertoolkit.co.uk]
Improving Outcomes: A Strategy for Cancer

- Puts the patient at the heart of cancer services
- Delivery focused 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
NCIN Launches Systemic Anti-Cancer Dataset (SACT)

- Brings together all current information on the Systemic Anti-Cancer Therapy (SACT) Dataset and its collection by the Chemotherapy Intelligence Unit (CIU).
- It provides guidance on the background to the dataset, what it covers and how to prepare for data submission via the upload portal.

For more information go to: [www.chemodataset.nhs.uk](http://www.chemodataset.nhs.uk)
NCIN Launches Understanding Cancer E-learning

- Aimed primarily at MDT Co-ordinators/ Cancer Registration staff.
- Online training to support NHS staff to understand cancer terminology and assist with driving change.
2013

Smartwatch

NCIN transition to Public Health England (PHE)

- Digital Health Intelligence Programme (transition tools into PHE digital model)
- Five Health Intelligence Networks
- Reduce duplication
- Utilise best practice in current tools for other areas of health
- On going partnership work with key stakeholders
2013 Smartwatch

NCIN - Cancer Outcomes and Services (COSD)

- New National Cancer Dataset
- Generic care and 12 site specific datasets
- Patient management - Pathway referral to treatments
- Key clinical information
- Proposed and supported by clinicians
- Incorporates previous cancer registration dataset
- Updated and aligned with other datasets
- Clearly defined data items
- Specifies provider submissions
- Compiled by registries from providers and other sources
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 (e.g., Cancer Waiting Times, Hospital Episode Statistics (HES), Radiotherapy (RTDS))
• Regular progress reports to MDTs/Providers
2013 | Smartwatch

Be Clear on Cancer campaigns - Centrally co-ordinated by NCIN

Aims of campaigns:
- Raise public awareness of cancer symptoms
- Encourage those with symptoms to see their GP
- Supporting initiatives to diagnose cancer earlier

Campaign activity:
- Adverts appear on national TV and radio, in the press and online
- More local face-to-face events
- Clinical engagement
NCIN and Macmillan Partnership Project - Local Cancer Intelligence Tool

Collaboration partnership between Macmillan Cancer Support and Public Health England's National Cancer Intelligence Network.

Combining the best data and insights from NCIN (via the cancer commissioning toolkit) and Macmillan.

Aim - to help the public understand the local burden of cancer.

The tool is developed and supported by NCIN and includes data by clinical commissioning group.

For more information go to: http://lci.cancertoolkit.co.uk
NCIN and CRUK Partnerships - Local Cancer Statistics

Collaboration partnerships sharing data/methodologies to support Cancer Research (CRUK) Local Cancer Statistics.

For more information go to: www.cancerresearchuk.org/cancer-info/cancerstats/local-cancer-statistics

This is the average European age standardised incidence rate per 100,000 population per year for the period 2008-2010.
PHE Knowledge Strategy & NCIN

Using the PHE Knowledge Strategy to support cancer data, patient needs

• Understand and meet the needs of users, particularly local government and local NHS.
• Assess priorities for the support, conduct and translation of public health research.
• Work with others to build and manage linked datasets that are safe and available for use.
• Bridge the current gap in the translation of knowledge into action.
• Build and develop health intelligence networks.
• Extend the use of surveillance to inform health responses.
• Connect people to share experience.
• Develop a web portal to report and provide access to information and evidence.
NCIN - Cancer Data Sources

- Colposcopy
- Breast Cancer screening local data
- Cervical cytology
- Breast cancer screening national data
- Bowel cancer screening programme
- 2ndry care patient admin systems
- Diagnostic imaging request data
- National cancer audit data - breast, bowel, lung, head and neck, invasive cervical cancer
- Breast cancer recurrence pilot
- Imaging
- Clinical data from multi-disciplinary team discussions
- Hospital Episode Data
- Histopathology
- Tissue bank links
- Molecular analyses
- Chemotherapy (SACT)
- PET-CT Scans
- Radiotherapy
- National Cancer Patient Experience Survey (NCPES)
- Patient-reported outcome measures (PROMs)
- Palliative care data (Co-ordinate my care)

Primary Care → Screening → Diagnosis → Treatment → Survivorship → Palliative care
Cancer data flows

Cancer Outcomes and Services Dataset (COSD)
- Specification for standardised, mandatory and optional data fields

Direct feeds:
- Patient Administration Systems
- Data from MDTs
- Pathology full-text reports
- Imaging Systems

Indirect feeds:
- Cancer Waiting Times
- Chemotherapy dataset
- Radiotherapy dataset

Other:
- ONS cancer and non-cancer deaths
- Hospital Episode Statistics
- National Cancer Screening
- National Cancer Audits
- National PET-CT Imaging

National Cancer Registration Service
- 8 regional registration teams
  - Coding and classification group
  - Data quality group

English National Cancer Online Registration Environment - ENCORE
- Anonymised patient/tumour level cancer registration data from:
  - Information and Services Division Scotland
  - Welsh Cancer and Intelligence Surveillance Unit
  - Northern Ireland Cancer Registry

PHE Office for Data Release
- Dealing with data access request

Researchers

PHE NCIN Outputs
Tools
- Cancer Commissioning Toolkit
- Cancer e-atlas

Information
- NCIN central analytical projects
- NCIN Site Specific Clinical Reference Group projects

Examples of geographies analysed by:

NHS England
- 7,600 GP Practices
- 211 Clinical Commissioning Group
- 161 Acute Hospital Trusts
- 27 Local Area Teams
- 23 Commissioning Support Units
- 15 Academic Health Science Networks
- 12 Clinical Senates
- 10 Specialised Commissioning Hubs

Public Health England
- 150 Local Authorities
- 140 Health and Wellbeing Boards

Clinicians | Charities | Commissioners | Policy Makers
Digital transformation…

Alignment of Digital websites and Digital Health Intelligence Programme (DHIP) Tools.

DHIP Three work streams:

- **Tools** - On going work programme to improve tools, reduce duplication and increase transparency with data across PHE
- **Digital** - Transition of NCIN tools to PHE tools
- **Data/Indicators** - Datasets review
PHE - NCIN moving forward...

Four work streams:

- **Analysis** - On going work programme for cancer analysts cross England & UK
- **Tools** - Transition of NCIN tools to PHE tools
- **Data** - Maintenance and development of cancer datasets, cancer data roadshows
- **Communications** - Clinical Engagement/Reference Groups/ Partnership Board/ Health Intelligence Network cross-working/ NHS England engagement.
From enabling commissioners to provide the best care to giving patients greater power, protection and informed choice, information is central to the overall quality of each cancer patient's experience.

For more information go to: http://www.qub.ac.uk/sites/NCIN2015