



Public Health  
England

Protecting and improving the nation's health

# 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

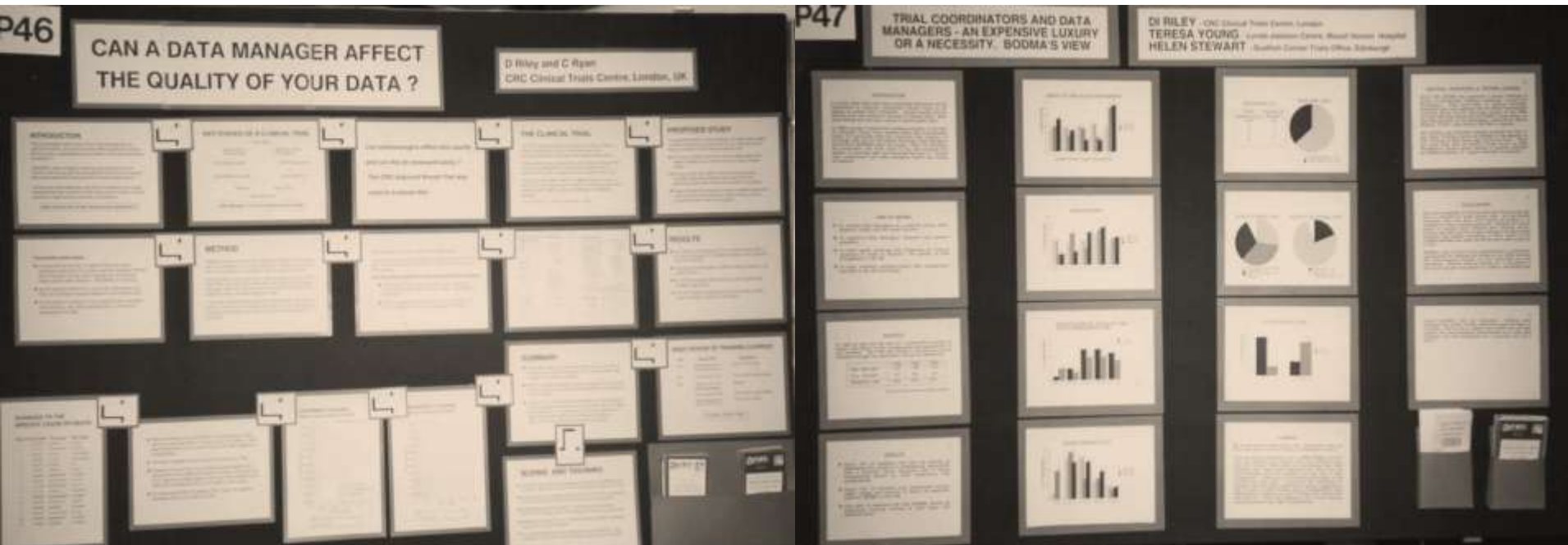




# 1988

## Mobile Phones, Fax Machines & Overhead Projectors

### British Oncology Data Managers Association (Di Riley)



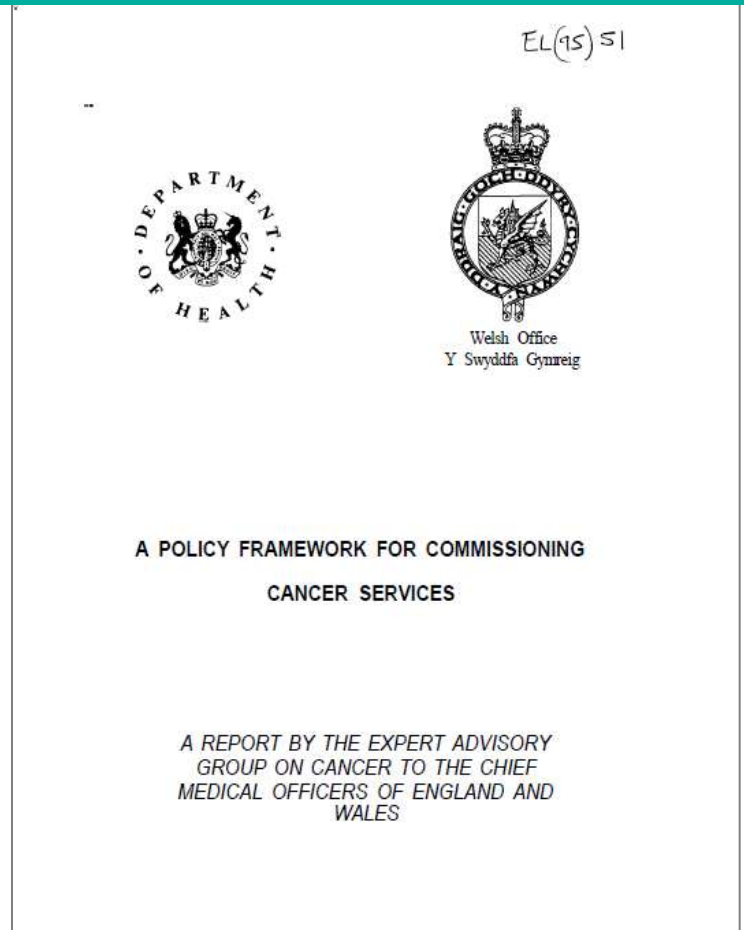
# 1993

## 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

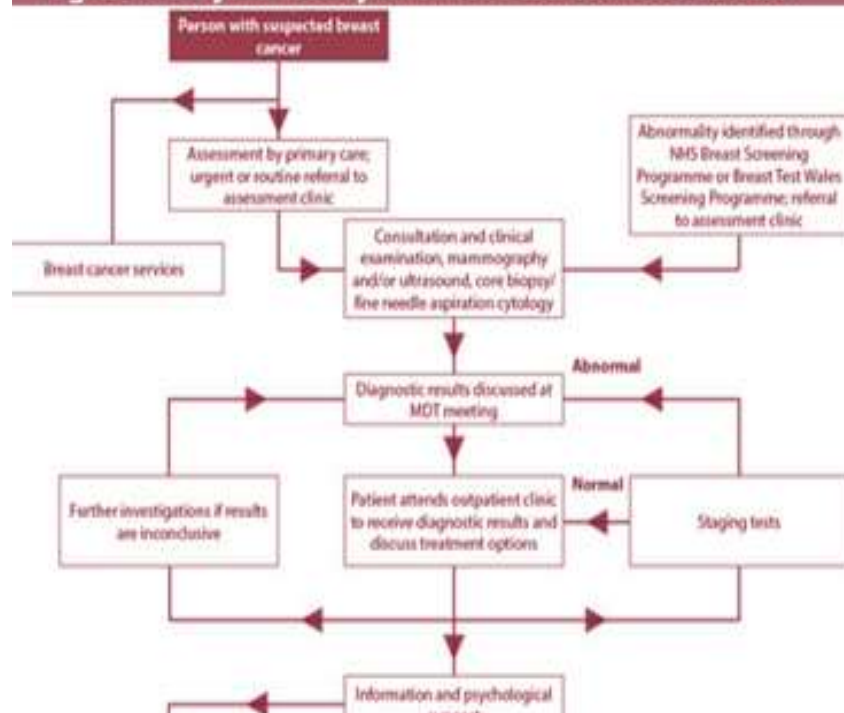
## First PC's in NHS Trusts

### 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



Figure 1: Early and locally advanced breast cancer overview<sup>8</sup>



# 1998

Wi-Fi

## 1<sup>st</sup> 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.

ALL PARTY PARLIAMENTARY GROUP ON CANCER



## Cancer across the Domains

### A vision for 2020

This is not an official publication of the House of Commons or the House of Lords. It has not been approved by either House or its committees. All-Party Groups are informal groups of Members of both Houses with a common interest in particular issues. The views expressed in this report are those of the Group. This report was compiled by Macmillan Cancer Support who provide the Secretariat to the All Party Parliamentary Group on Cancer.



## 1999-2000 Google

### 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

	Operational standard (% of patients)	Compliance (% 2nd quarter 2009/10)
A maximum wait of two weeks to see a specialist after urgent referral by a GP	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

**NHS**

### 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.

Chapter One	The challenge of cancer
Chapter Two	Improving prevention
Chapter Three	Improving screening
Chapter Four	Improving cancer services in the community
Chapter Five	Cutting waiting for diagnosis and treatment
Chapter Six	Improving treatment
Chapter Seven	Improving care
Chapter Eight	Investing in staff
Chapter Nine	Investing in facilities
Chapter Ten	Investing in the future: research and genetics
Chapter Eleven	Implementing the NHS Cancer Plan
	The NHS Cancer Plan: next steps

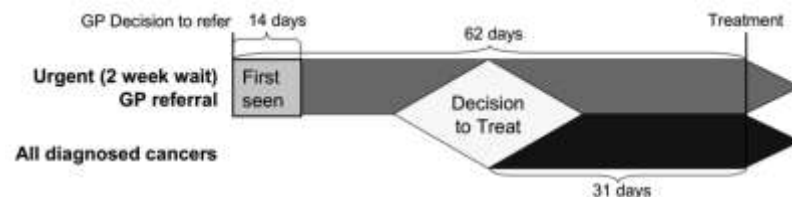


# 2000

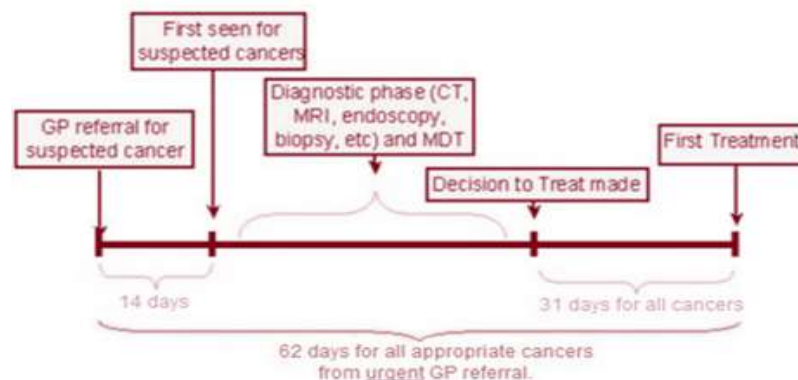
## New Computer terminals rolled out in NHS Trusts

### 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.



- Patient first seen within 14 days of GP urgent suspected cancer referral
- Patient treated within 62 days of GP urgent suspected cancer referral
- Acute leukemia, testicular and paediatric referrals treated within 31 days
- All cancers to be treated within 31 days of decision to treat





# 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.

### National Lung Cancer Audit

**NHS**  
Health and Social Care  
Information Centre

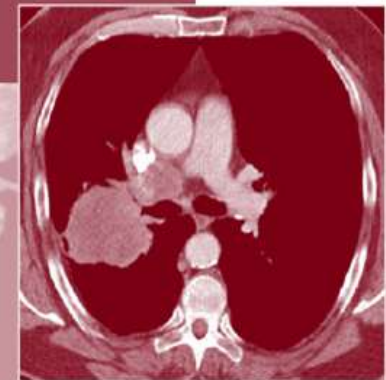


Table 2: Field completeness

Network	Hospital	Code	% Pathology Completion	% Pre-operative Stage 2 Completion	% Post-operative Stage 2 Completion	% Pathology Stage 2 Completion	% Pathology Stage 2 Completion	% Pathology Stage 2 Completion	% Pathology Stage 2 Completion
ALL	ALL	ALL	85	85	85	85	85	85	85
MD1	Levenshaye & South Cumbria Cancer Network								
MD2	Greater Manchester & Cheshire Cancer Network								
	MANCHESTER DISTRICT GENERAL HOSPITAL	MAN20	71	45	45	57	55	52	15
	WHITENSHAW HOSPITAL	MAN20	24	81	100	98	100	100	89
	THE ROYAL BOLTON HOSPITAL	MAN20	19	100	100	11	100	100	94
	ROYAL ALBERT EDWARD HOSPITAL	MAN20	89	84	77	87	88	71	12
	THURFOLD GENERAL HOSPITAL	MAN20	91	100	100	71	100	100	94
	NORTH MANCHESTER GENERAL HOSPITAL	MAN20	70	100	100	100	100	100	10
	ROYAL OLDHAM HOSPITAL	MAN20	100	100	100	91	100	100	97
	ROCHDALE HOSPITAL	MAN20	21	100	100	94	100	100	100
	STOCKPORT HOSPITAL/STATION TRUST	MAN20	85	100	100	84	100	100	100
MD3	Merseyside & Cheshire Cancer Network								
	WARRINGTON HOSPITAL	MAN20	43	100	100	81	100	100	81
	WARRINGTON HOSPITAL	MAN20	87	100	100	87	100	100	86
	LIVERPOOL HOSPITAL/STATION TRUST	MAN20	100	100	100	100	100	100	100

Annual Report for the audit period ending  
December 2005

Conducted in association with:  
Healthcare Commission  
Royal College of Physicians

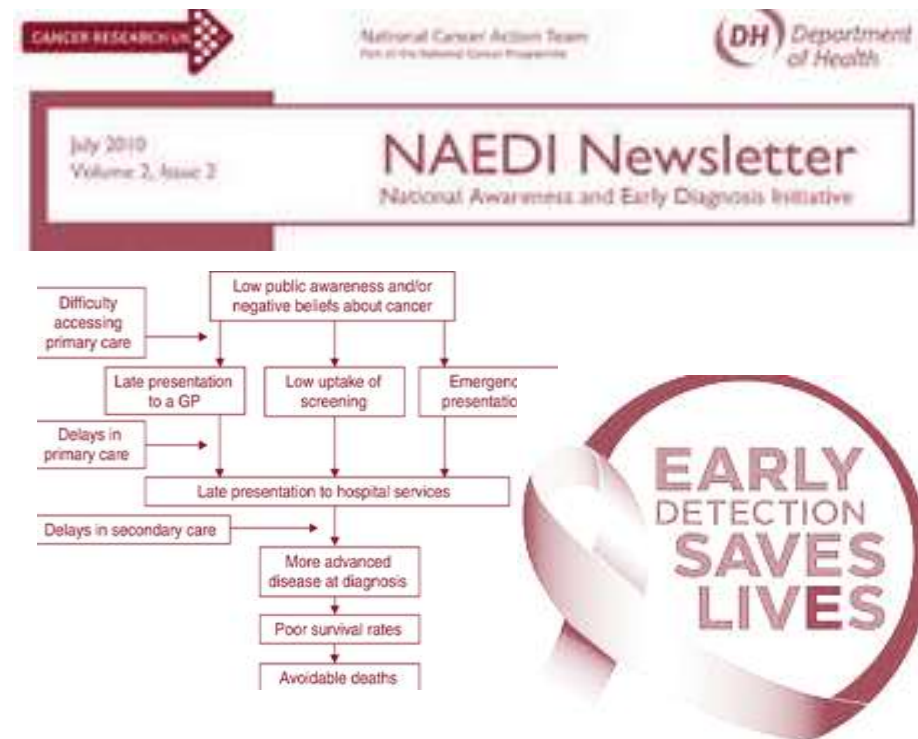


# 2007

Kindle

## 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.



# 2008

## Mobile Apps



### 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



# 2008

## Mobile Apps



### 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



SEARCH

[About NCIN](#)

[News and Events](#)

[Collecting and Using Data](#)

[Publications](#)

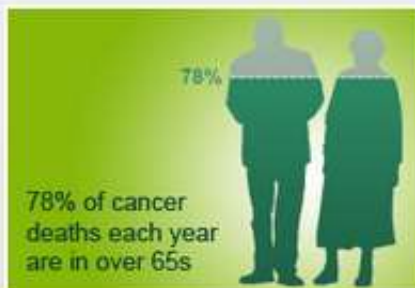
[Cancer Information Tools](#)

[Cancer Type and Topic Specific Work](#)



### Cancer Outcomes Conference 2015

8th - 10th June  
Europa Hotel Belfast



### Older people and cancer

A comprehensive summary of information, evidence and inequalities.



### Survival by stage 2012

One year survival for five cancer sites in England by stage, 2012



### Cancer Commissioning Toolkit

One stop shop for cancer data

# 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.



Public Health England

National Cancer Intelligence Network

### Cancer Commissioning Toolkit

Commissioner1 x

Home Dashboards Comparisons Profiles Charts Background Updates

Home



#### Dashboards

Making the data count  
View a snapshot of data by  
organisation group to support  
quality, services & outcomes.



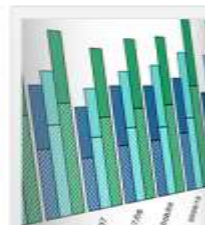
#### Comparisons

Comparative reporting of data  
Compare your organisation/service,  
establish baselines & identify  
issues.



#### Profiles

Improving outcomes  
Understanding variation at both  
patient experience & service  
delivery using data indicators.



#### Charts

Increase the value of data  
View or download trends to  
benchmark along the patient  
pathway by accessing in depth  
data.

i Background

? Help

Updates

For more information on the CCT go to:  
[www.cancertoolkit.co.uk](http://www.cancertoolkit.co.uk)

# 2009

## NCIN Increased from 5-30 Staff to Support Delivery



# 2009 Windows 7

## 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.

All Persons		Screen detected	Two Week Wait	GP referral	Other outpatient	Inpatient elective	Emergency presentation	Death Certificate Only	Unknown	Total	Number of patients
Acute leukaemia			3%	17%	14%	4%	57%	0%	4%	100%	2,551
Bladder			32%	28%	15%	2%	18%	0%	4%	100%	7,665
Brain & CNS			1%	17%	14%	4%	58%	0%	6%	100%	4,147
Breast		21%	42%	12%	9%	0%	4%	0%	12%	100%	34,232
Cervix		14%	16%	25%	16%	2%	12%	0%	13%	100%	2,085
Chronic leukaemia			10%	30%	12%	2%	30%	1%	16%	100%	2,859
Colorectal			26%	24%	15%	4%	25%	1%	6%	100%	27,903
Kidney			20%	29%	18%	1%	24%	1%	6%	100%	5,172
Larynx			31%	32%	21%	1%	12%	0%	3%	100%	1,583
Lung			22%	20%	13%	1%	38%	1%	5%	100%	29,420
Screen Detected	Presented via the breast, cervical or bowel screening programmes							0%	16%	100%	8,117
Two Week Wait	Urgent GP referral with a suspicion of cancer							0%	6%	100%	3,145
GP Referral	Routine and urgent referrals where the patient was not referred under the Two Week Wait referral route							0%	7%	100%	7,777
Other Outpatient	An elective route starting with an outpatient appointment, either self-referral, consultant to consultant, other or children referral							1%	4%	100%	6,001
Inpatient Elective	Where no waiting admission can be found prior to admission from a waiting list, booked or planned							0%	9%	100%	3,062
Emergency Presentation	An emergency route via A&E, emergency GP referral, emergency transfer, emergency consultant outpatient referral, emergency admission or attendance							1%	7%	100%	27,730
								1%	6%	100%	5,012
Death Certificate Only	No data available from Inpatient or Outpatient HES, CWT, Screening and with a death certificate only diagnosis flagged by the registry in the NCDR							1%	6%	100%	5,989
								0%	14%	100%	28,362
Unknown	No data available from Inpatient or Outpatient HES, CWT, Screening							1%	5%	100%	5,841
								1%	5%	100%	5,841
Testis		40%	14%	16%	2%	10%		10%	100%	1,569	
Uterus		35%	31%	16%	1%	8%	0%	8%	100%	5,733	
Total		3%	25%	24%	14%	2%	23%	1%	8%	100%	225,955

# 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)



National Cancer Action Team

#### Multidisciplinary team members' views about MDT working:

Results from a survey commissioned by the National Cancer Action Team

September 2009

Report prepared by:

Cath Taylor, Research Manager &  
Professor Amanda Ramirez, National Clinical Lead  
National Cancer Action Team MDT Development Programme

Cancer Research UK Promoting Early Presentation Group  
Kings College London  
St Thomas' Hospital  
London  
SE1 7EH  
020 7188 0907  
cath.taylor@kcl.ac.uk  
amanda-jane.ramirez@kcl.ac.uk

# 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).



REPORT BY THE  
COMPTROLLER AND  
AUDITOR GENERAL  
HC 568  
SESSION 2010-2011  
19 NOVEMBER 2010

Department of Health

Delivering the Cancer Reform Strategy

# 2010 iPad



**NCIN Launches Profiles via the Cancer Commissioning Toolkit to Support Service Delivery across England [www.cancertoolkit.co.uk](http://www.cancertoolkit.co.uk)**

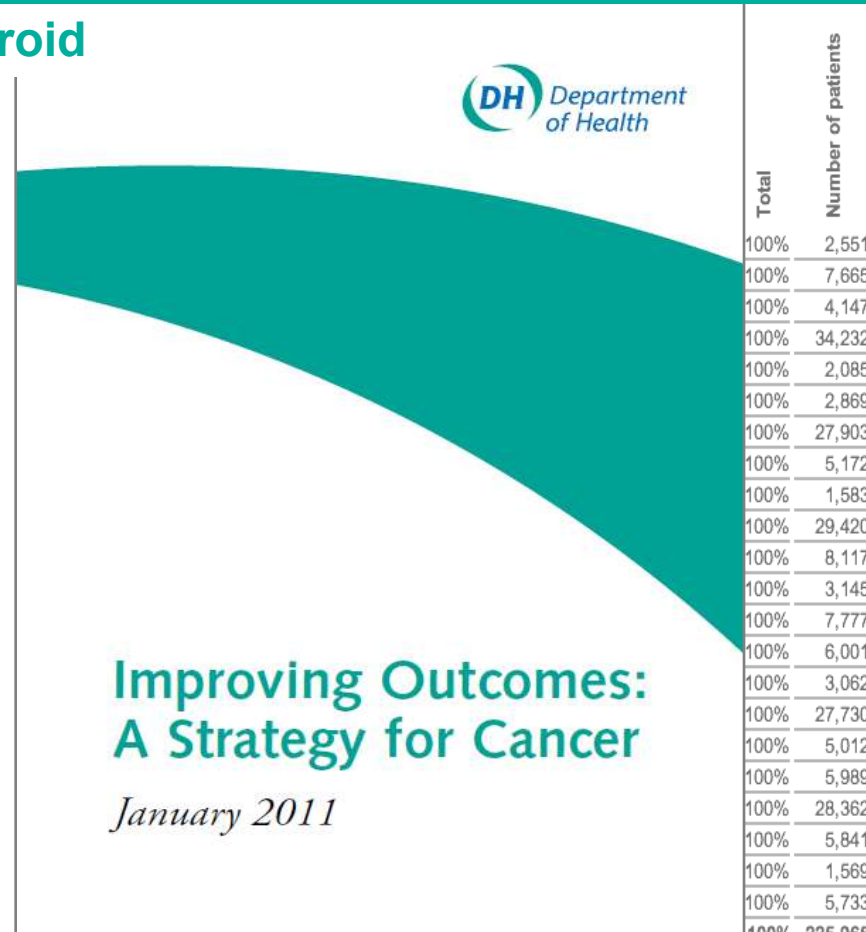
Domain	Indicator (Rate or Proportion in brackets)	Practice indicator value	Practice indicator rate or proportion	Lower 95% confidence limit	Upper 95% confidence limit	PCT mean	England mean	Lowest practice	Range
Demographics	1 Practice Population aged 65+ (% of population in this practice aged 65+)	1493	14.8%	14.1%	15.5%	17.0%	15.6%	10.1%	
	2 Socio-economic deprivation, "Quintile 4" = affluent (% of population income deprived)	Quintile 4	10.6%	18.8%	20.4%	19.7%	15.9%	10.2%	
	3 New cancer diagnoses (Incidence rate per 100,000 population)	504	375	663	504	412	235		
	4 Cancer deaths (Crude mortality rate per 100,000 population)	257	376	278	236	66			
	5 Prevalence of cancer (Proportion on practice register)	1	8%	1.8%	1.1%	1.3%	0.3%		
Cancer screening	6 Females, 50-64, screened for breast cancer in last 36 months (3 year coverage, %)	8	1%	6.6%	72.6%	71.5%	71.8%	49.7%	
	7 Females, 50-64, invited for breast cancer within 6 months (Invitation rate, %)	1	9%	43.4%	65.5%	74.0%	74.0%	40%	
	8 Females, 25-64, attending cervical screening within target period (Attendance rate, %)	1	80.2%	78.0%	81.5%	81.5%	81.5%	80%	
	9 Persons, 60-69, screened for bowel cancer in last 30 months (2.5 year coverage, %)	1	54.8%	57.7%	51.9%	51.9%	40.0%	31%	
Cancer Waiting Times	10 Persons, 60-69, screened for bowel cancer within 6 months of invitation (Up to date, %)	2	60.2%	55.6%	64.5%	57.2%	55.0%	4%	
	11 Two-week wait referrals (Number per 100,000 population)	10	60	136	11	11	11	57	
	12 Two-week wait referrals (Number per 100,000 population)	10	10.9%	65.9%	117.0%	117.0%	117.0%	117.0%	
	13 Two-week wait referrals with cancer (Number per 100,000 population)	29	14.8%	10.2%	14.5%	14.5%	11.2%	10.7%	
	14 Number of new cancer cases treated (Number per 100,000 population)	36	36.4%	67.0%	67.0%	67.0%	67.0%	67.0%	
	15 Two-week wait referrals with suspected breast cancer (Number per 100,000 population)	47	34	618	34	29	29	29	
	16 Two-week wait referrals with suspected lung cancer (Number per 100,000 population)	37	26	515	27	251	251	251	
	17 Two-week wait referrals with suspected skin cancer (Number per 100,000 population)	7	69	28	143	70	66	0	
	18 Two-week wait referrals with suspected skin cancer (Number per 100,000 population)	10	99	47	182	146	280	0	
	19 In-patient or day-case colonoscopy procedures (Number per 100,000 population)	103	1018	831	1234	877	513	302	
Cancer Services	20 In-patient or day-case colonoscopy procedures (Number per 100,000 population)	10	99	47	182	146	280	0	
	21 In-patient or day-case colonoscopy procedures (Number per 100,000 population)	10	99	47	182	146	280	0	

# 2011

## Google + and Rise of Android

### 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





# 2012

## Google Glass

### 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)

# 2012

## 3D Printers for Domestic use

### 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.



Professionally Accredited by the Institute of Healthcare Management

Launched 2 April 2012

#### Key features include:

- flexibility to work at your own pace from work or home
- ability to stop and resume at any point from any computer
- reference guides
- colourful images throughout
- glossary of terms
- learning objectives
- quizzes
- certificate of achievement
- unrestricted access to UK users

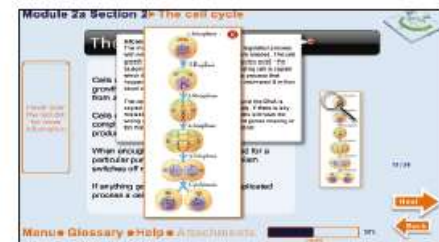
**What to do next**  
For more information, visit [www.ncin.org.uk](http://www.ncin.org.uk). You can then self register onto the e-learning website by creating a new account.

#### Who it is for and what you will learn

This new e-learning tool is aimed primarily at Multi-disciplinary Team Co-ordinators and Cancer Registration staff who need to know:

- about cancer—medical terminology, diagnostic tests and treatments
- how cancer services are organised in the NHS
- about cancer types—key risks, including causes, risk factors, signs and symptoms, anatomy and physiology

Other NHS staff can also use it to improve their understanding of cancer



# 2013

## Smartwatch



# Public Health England

## NCIN transition to Public Health England (PHE)

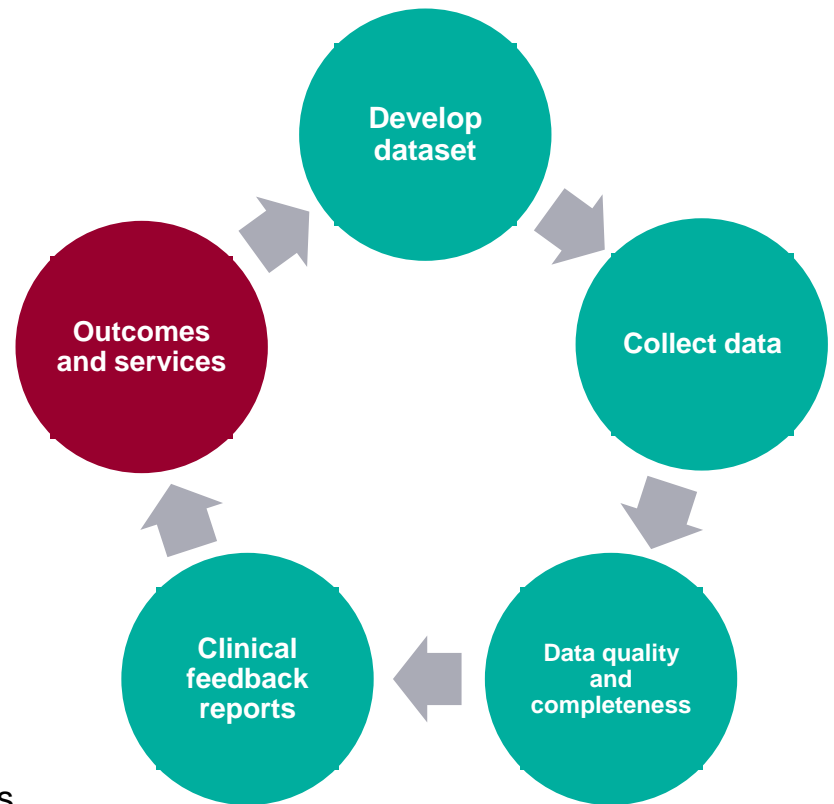
- Digital Health Intelligence Programme (transition tools into PHE digital model)
- Five Health Intelligence Networks
- Reduce duplication
- Utilise best practice in current tools for other areas of health
- On going partnership work with key stakeholders

# 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



# 2013 **Smartwatch**



## **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



# 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



Dr Anant Sachdev



**If you notice blood in your pee, even if it's 'just the once', tell your doctor.**

It could be an early sign of kidney or bladder cancer. Finding it early makes it more treatable, so tell your doctor straight away.

**BE CLEAR ON CANCER**



# 2014

## Curved Screen TVs

### 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>

#### Local Cancer Intelligence



Produced by Public Health England's National Cancer Intelligence Network and Macmillan Cancer Support

##### Headlines for NHS Camden CCG

###### Prevalence

As of the end of 2010, around 5,200 people in your CCG were living with and beyond cancer up to 20 years after diagnosis. This could rise to an estimated 10,100 by 2030.

[For more information](#)

###### Incidence

There are 551 new cancer diagnoses per 100,000 people each year. This is lower than the England average.

[For more information](#)

###### Mortality

There are 267 cancer deaths per 100,000 people each year. This is similar to the England average.

[For more information](#)

###### One Year Survival

###### Five Year Survival

Search for your Clinical Commissioning Group

NHS Camden CCG



##### Headlines

Cancer Prevalence

Cancer Incidence

Cancer Mortality

Cancer Survival

Patient Experience

Routes To and From Diagnosis

Breast

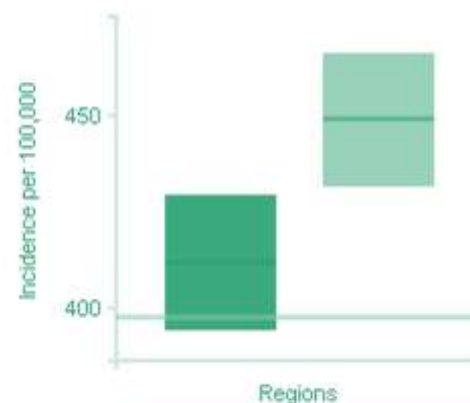
# 2014

## Curved Screen TVs

### 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](http://www.cancerresearchuk.org/cancer-info/cancerstats/local-cancer-statistics)



[Detailed graph view](#)

*This is the average European age standardised incidence rate per 100,000 population per year for the period 2008-2010.*



# 2014

## Curved Screen TVs

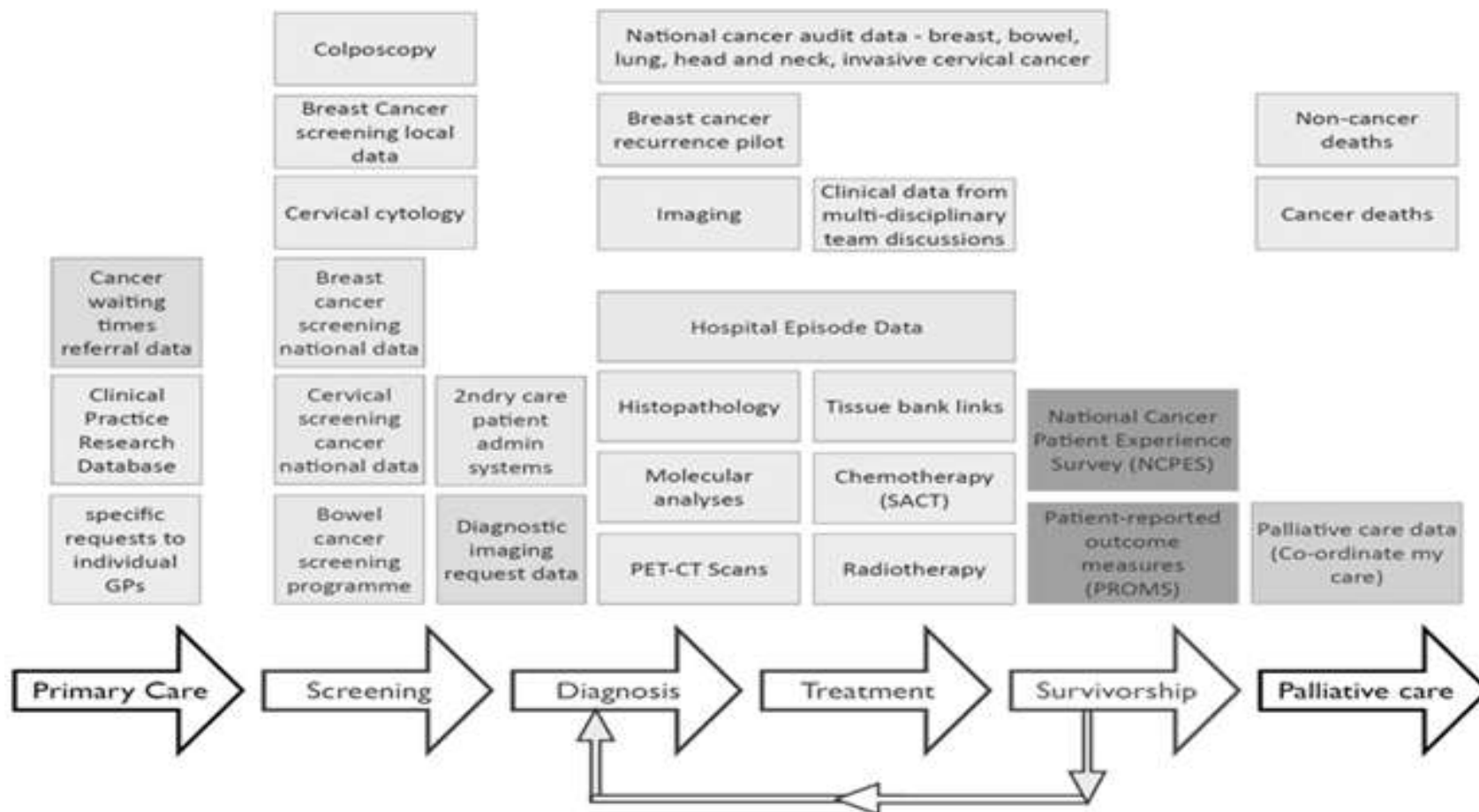
### **PHE Knowledge Strategy & NCIN**

#### **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.

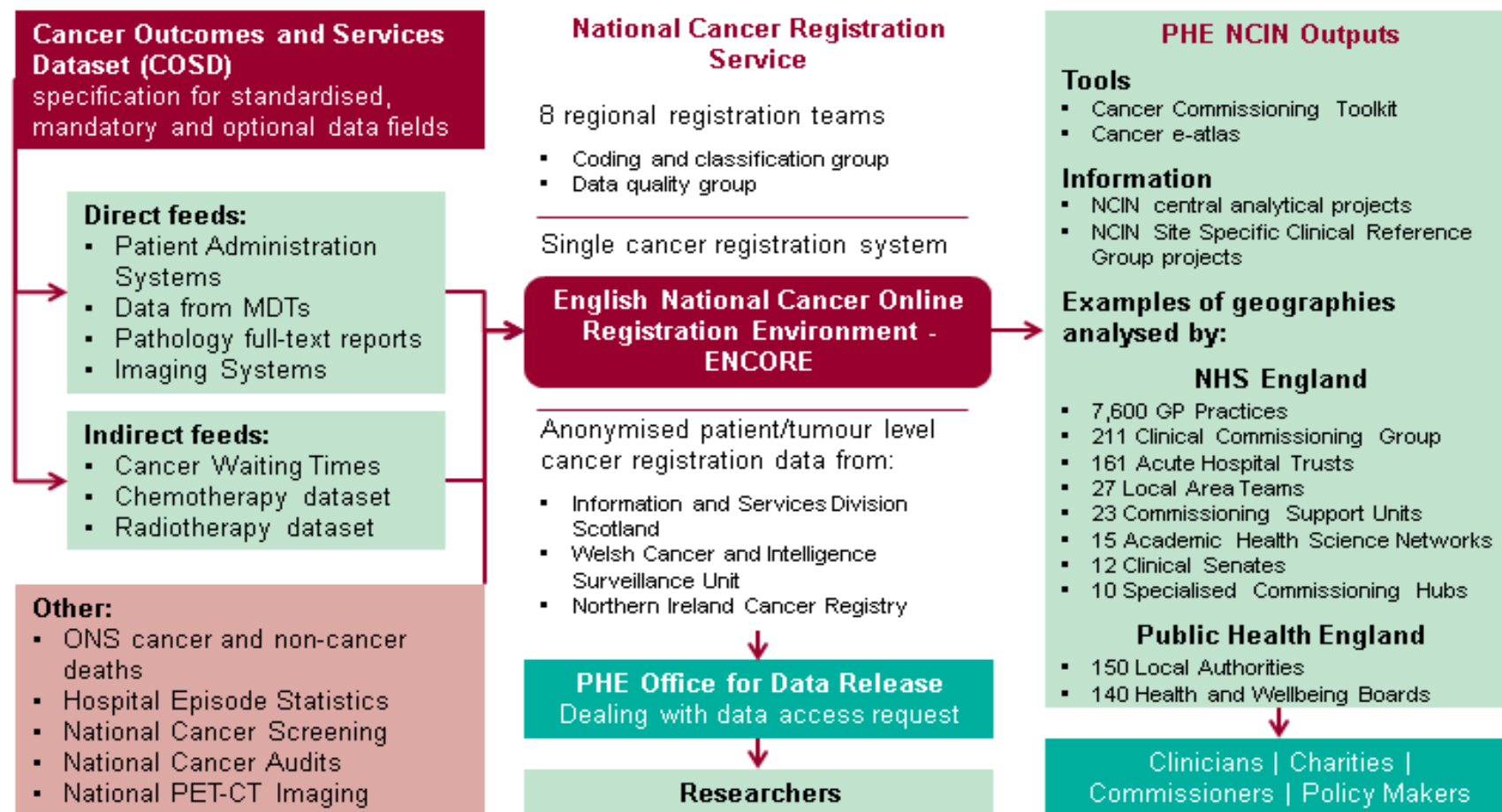
# 2014

## NCIN - Cancer Data Sources



# 2014

## Cancer data flows



# 2015

## Apple Watch

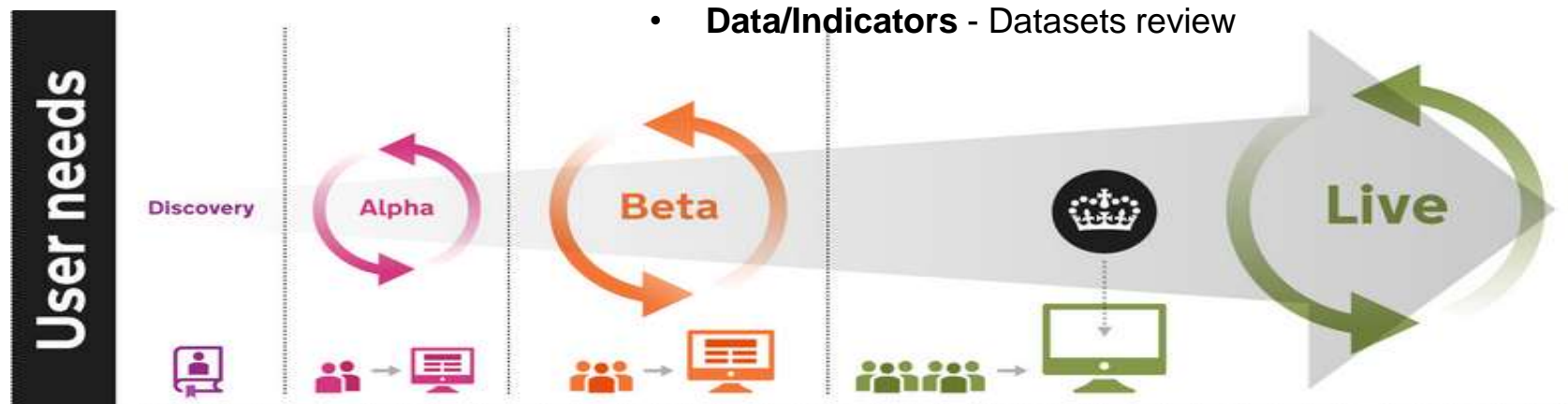


### Digital transformation...

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



# 2015 Apple Watch



## 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.



# 2015



Public Health  
England

## **National Cancer Intelligence Network Cancer Outcomes Conference 2015: United Against Cancer**

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>**

