Public Health England

Protecting and improving the nation's health

What data are available, and how are they accessed?

Providers of information

Health & Social Care Information Centre
HSCIC

Office for National Statistics
ONS

UK and Ireland Cancer Registries
UKIACR

National Audits

PHE
including
Health Intelligence Networks

NHS England
Business Intelligence Teams

Incisive Health

Macmillan Cancer Support

Cancer Research UK

Dr Foster and other intermediaries

Where are we now?

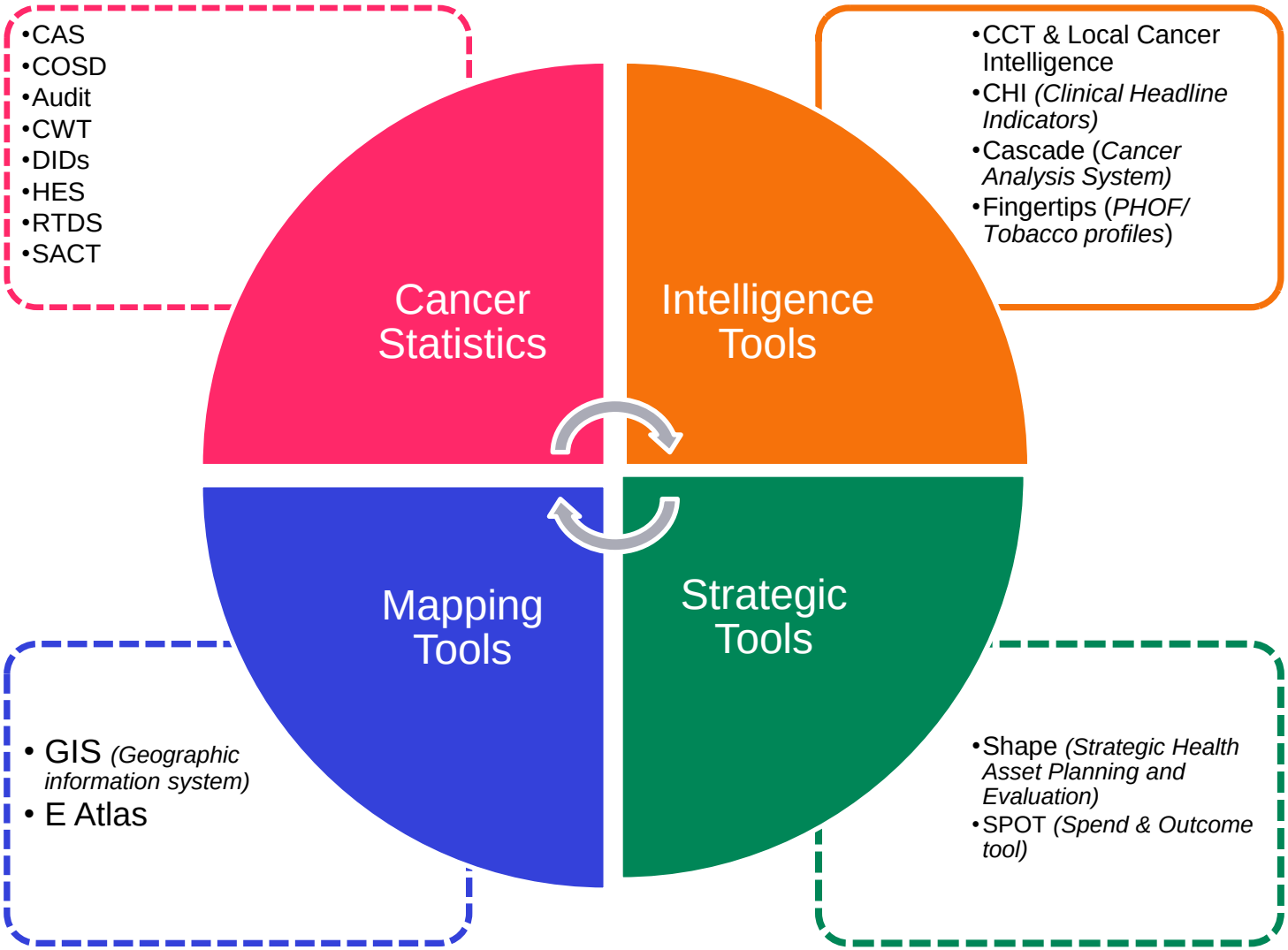
Multiple organisations moved to PHE

Multiple tools and products

Meet digital requirements and Knowledge and Information Strategy by:

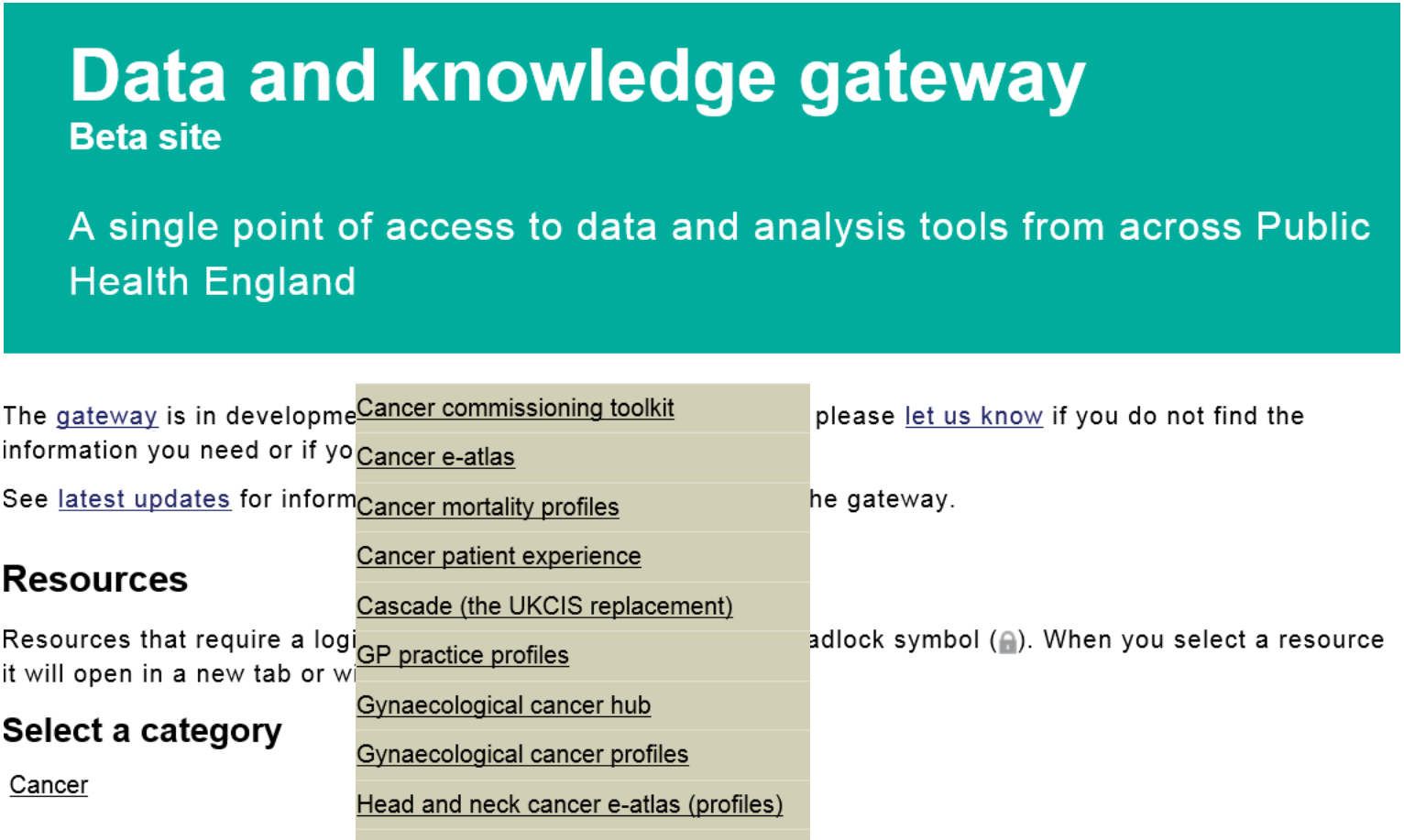
- Reducing duplication of processes
- Reducing the number of digital tools
- Meet open data transparency commitments
- Help users find data they need

Cancer data tools



PHE data and knowledge gateway

http://datagateway.phe.org.uk/



Cancer Commissioning Toolkit (CCT)

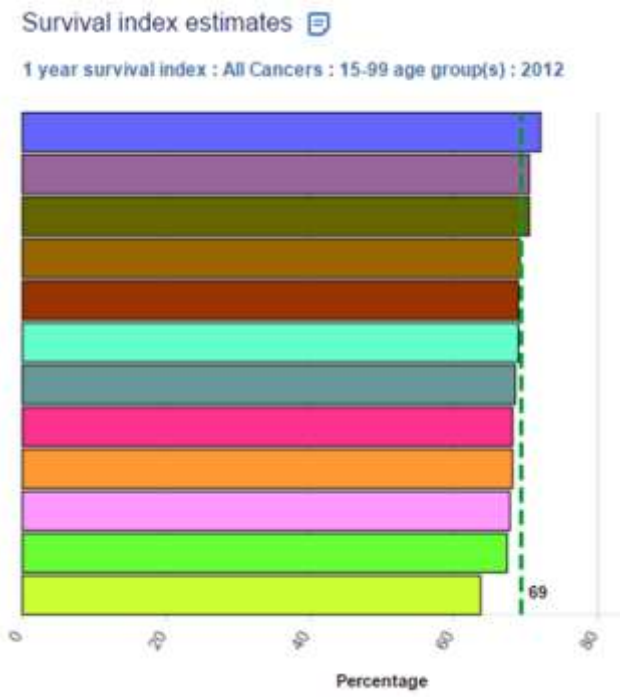
https://www.cancertoolkit.co.uk/

'Supporting World Class Commissioning of Cancer services across the NHS'

Types of Data available by charts:
Incidence; Emergency Presentations; Mortality; Place of Death; Survival; Smoking Cessation; Peer Review; Screening; Staging, Referrals; Waiting Times; Radiotherapy; National Audit; Expenditure.

Profiles :
Service profiles; CCG & GP profiles.

Extracts & Reports :
Cancer Prevalence; Enhanced Recovery; horizon Scanning; HES; LAPCO; Routes to Diagnosis;; Cancer Nurse Specialist; Chemotherapy Nursing Workforce; Peer Review reports; Dashboards.



Cancer Commissioning Toolkit (CCT) – decommissioned March 2016

https://www.cancertoolkit.co.uk/

User Requirements

The CCT is currently used as a 'Gold standard –one-stop shop' for providing accessible, reliable, timely and comparable information to users across the patient cancer pathway.

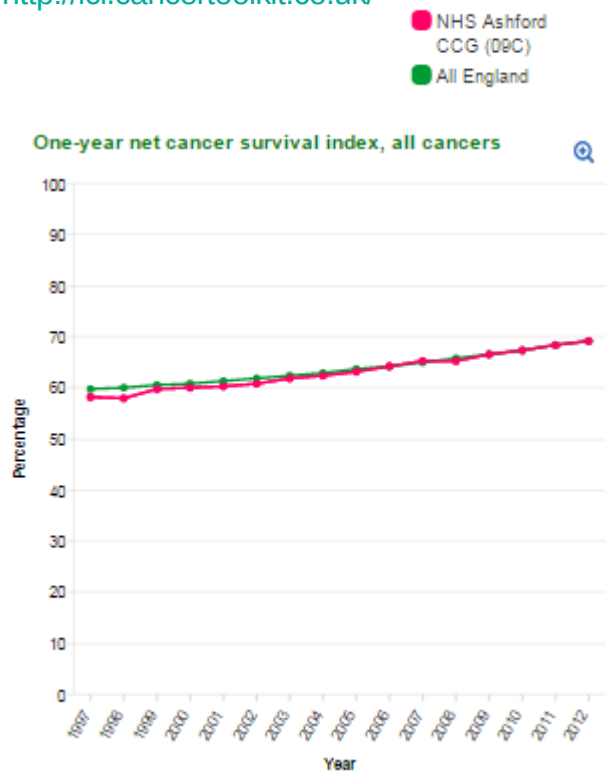
The CCT will be the first tool to be decommissioned by PHE in March 2016 and some of it will be incorporated into a PHE tool –Clinical headline Indicators (which is not yet live but requires N3 connection to see the tool).

A User requirements survey is being sent out to confirm what is '***essential or nice to have***' from the CCT – please ask users to fill in and return asap:

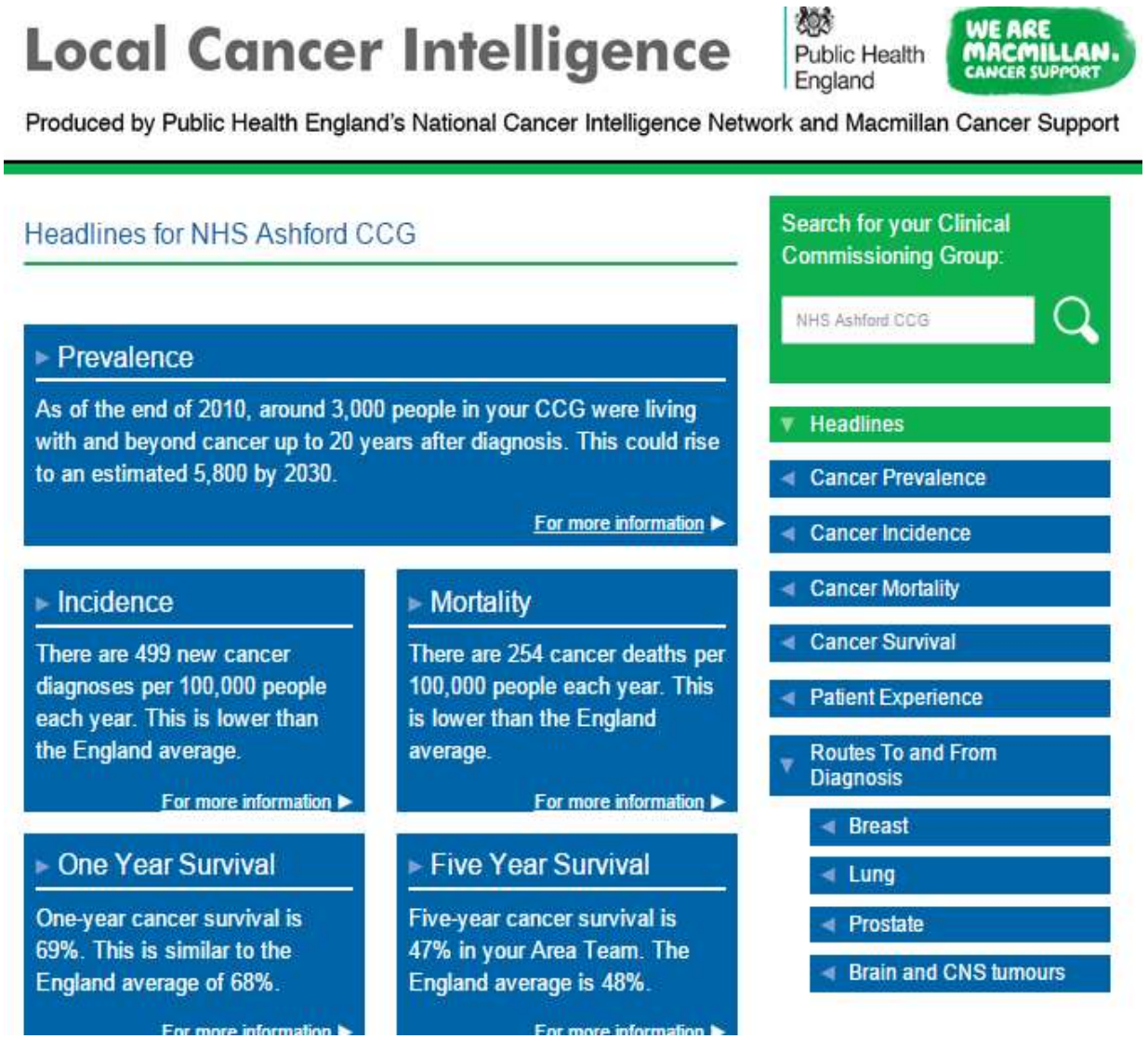
https://surveys.phe.org.uk/TakeSurvey.aspx?PageNumber=1&SurveyID=ml1Jmm81&Preview=true

Local Cancer Intelligence

http://lci.cancertoolkit.co.uk/



Source: Office for National Statistics and London School of Hygiene and Tropical Medicine. 2013. A Cancer Survival Index for Clinical Commissioning Groups, Adults Diagnosed 1996-2011 and Followed up to 2012. Extracted June 2014 from the National Cancer Intelligence Network's Cancer Commissioning Toolkit.



Cancer Stats: CHI

https://nww.cancerstats.nhs.uk/users/sign_in

Clinical Headline Indicators

Diagnosed per year - Lung tumours 2013

Year:	Clear	2013
SCN:	Clear	All
Measure:	Clear	Diagnosed per year
Tumour Site:	Clear	Lung
Report View	Clear	Quarterly

	Total	Q1	Q2	Q3	Q4
− South East Coast	2575	594	652	689	640
Ashford and St Peter's Hospitals NHS Foundation Trust (RTK)	121	23	37	35	26
Brighton and Sussex University Hospitals NHS Trust (RXH)	244	55	53	80	56
Dartford and Gravesham NHS Trust (RN7)	143	37	40	31	35
East Kent Hospitals University NHS Foundation Trust (RVV)	414	99	93	111	111
East Sussex Healthcare NHS Trust (RXC)	262	68	66	70	58
Frimley Park Hospital NHS Foundation Trust (RDU)	325	76	82	74	93
Maidstone and Tunbridge Wells NHS Trust (RWF)	271	56	66	71	78
Medway NHS Foundation Trust (RPA)	199	48	56	54	41
Queen Victoria Hospital NHS Foundation Trust (RPC)	1	1	0	0	0
Royal Surrey County NHS Foundation Trust (RA2)	107	19	36	30	22
Surrey and Sussex Healthcare NHS Trust (RTP)	185	43	51	47	44
Western Sussex Hospitals NHS Foundation Trust (RYR)	303	69	72	86	76

Cancer Stats: CHI

https://nww.cancerstats.nhs.uk/users/sign_in

Clinical Headline Indicators

Diagnosed per year - Lung tumours 2013

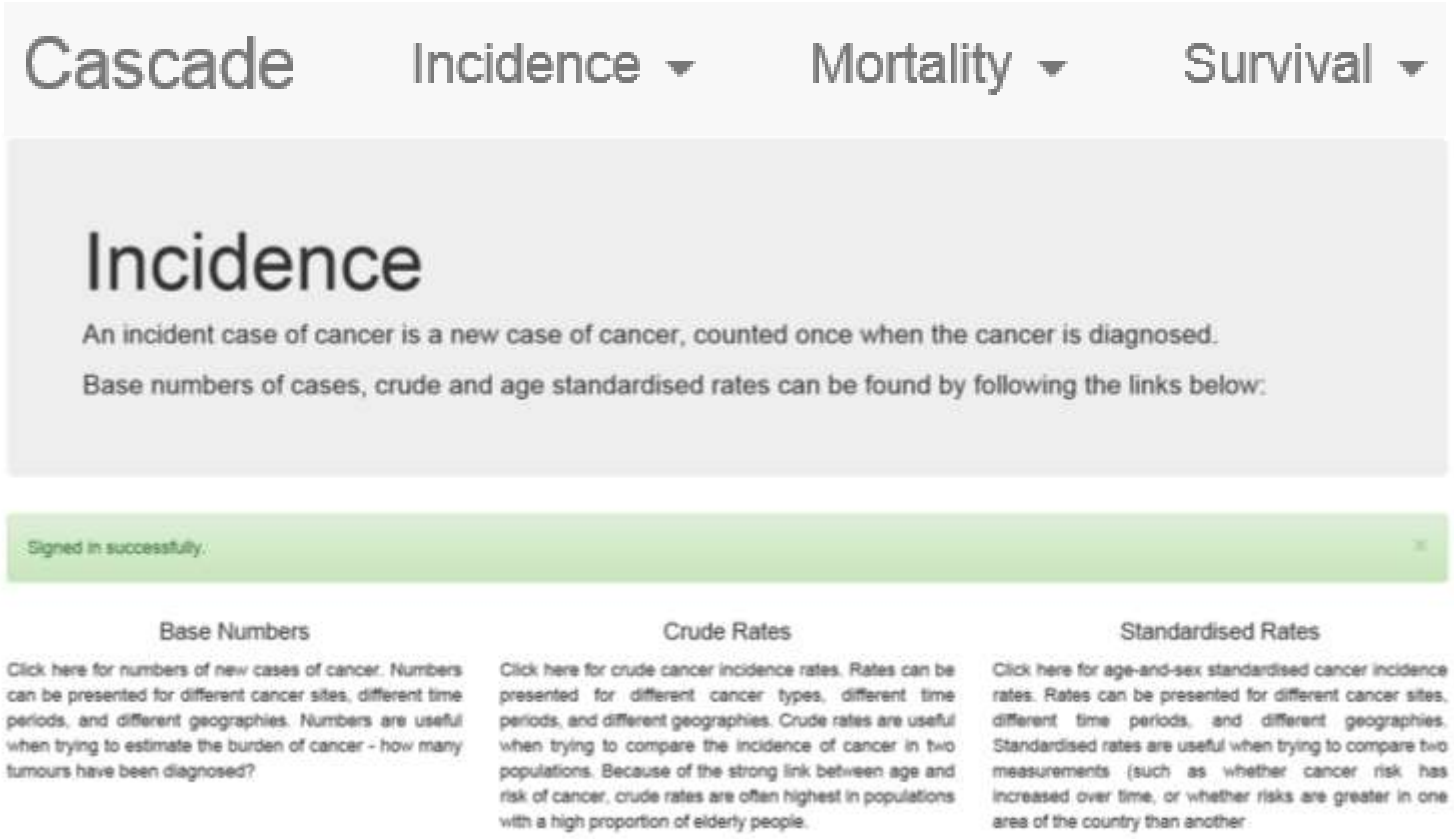
Year:	Clear	2013
SCN:	Clear	All
Measure:	Clear	Diagnosed per year
Tumour Site:	Clear	Lung
Report View	Clear	Quarterly

Generic Measures

	Total		Q1		Q2		Q3		Q4	
4.1										
4.1a Diagnosed per year	121		23		37		35		26	
4.2										
4.2a Aged 70+	79	65%	13	57%	31	84%	19	54%	16	62%
4.2b Male patients	69	57%	14	61%	19	51%	22	63%	14	54%
4.2c With recorded ethnicity	94	78%	20	87%	29	78%	24	69%	21	81%
4.2d – Which is not White-British	8	7%	1	4%	1	3%	3	9%	3	12%
4.2e With an index of multiple deprivation score of 5 (most deprived)	0	0%	0	0%	0	0%	0	0%	0	0%
4.3										
4.3a With a performance status of 0-1 recorded	31	26%	4	17%	5	14%	10	29%	12	46%
4.4										
4.4a Discussed at MDT	58	48%	9	39%	14	38%	18	51%	17	65%
4.4b Having CNS contact recorded (codes Y1/Y2)	0	0%	0	0%	0	0%	0	0%	0	0%
4.4c Presenting via GP referral (referral source 03)	48	40%	10	43%	10	27%	12	34%	16	62%
4.4d Presenting via emergency referral (referral source 01, 04, 10)	9	7%	0	0%	2	5%	5	14%	2	8%
4.5										
4.5a With a valid stage recorded	102	84%	15	65%	30	81%	32	91%	25	96%
4.5b With early stage (stage 1 or 2) recorded	14	12%	2	9%	4	11%	4	11%	4	15%
4.5c With a histological confirmed diagnosis (basis 5, 6 or 7)	94	78%	16	70%	27	73%	29	83%	22	85%

Cancer Stats: CASCADE

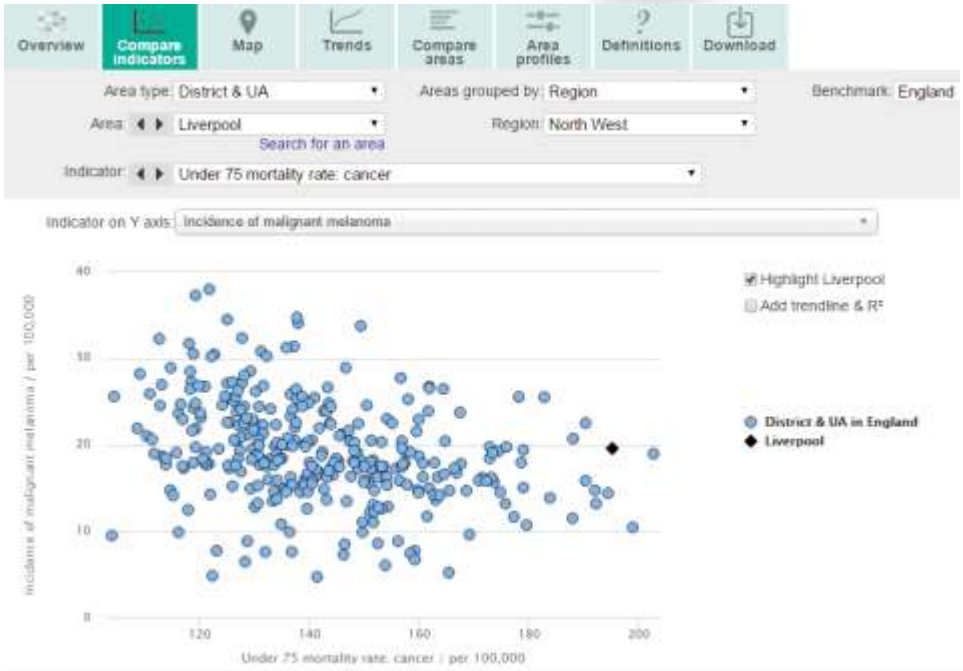
https://nww.cancerstats.nhs.uk/users/sign_in



Public Health Profiles (Fingertips)

http://fingertips.phe.org.uk/

Type in 'cancer' in the search box



SHAPE

http://shape.dh.gov.uk/index.asp

Public Health England

Strategic Health Asset Planning and Evaluation NHS

SHAPE | Who is SHAPE for? | Get into SHAPE | Indicators | Themes | User resources

Optimising future healthcare delivery

Welcome to SHAPE

Strategic Health Asset Planning and Evaluation

SHAPE is a web-enabled, evidence-based application which informs and supports the strategic planning of services and physical assets across a whole health economy.

The Strategic Health Asset Planning and Evaluation application:

- Links national datasets for clinical analysis, public health, primary care and demographic data with estates performance and facilities location;
- Enables interactive investigations by Local Area Teams, Providing Trusts, CCGs, GP practices and Local Authorities;
- Supports key policy initiatives such as QIPP, JSNA, Pharmaceutical Needs Assessment and Transforming Community Services;
- Provides you with a range of flexible capabilities; you drive it in the direction you want it to go.

SHAPE is free to NHS professionals and Local Authority professionals with a role in Public Health or Social Care. Access to the application is by formal registration and licence agreement.

Pharmaceutical Needs Assessment: opening times.

Sign in for registered users

Access is only available to registered SHAPE users. Please use your email address as your username. The first time you sign in you'll be asked for your initial temporary SHAPE password and then prompted to provide a new secure password to be used for future access.

Sign into the SHAPE application...

Registration for new users

SHAPE is free to NHS professionals and Local Authority professionals with a role in Public Health or Social Care. Access to the application is by formal registration and licence agreement. Applications to use SHAPE can be made by:

Email: shape@phe.gov.uk

Telephone: 0191 374 2219

Update

October 2015 updates:

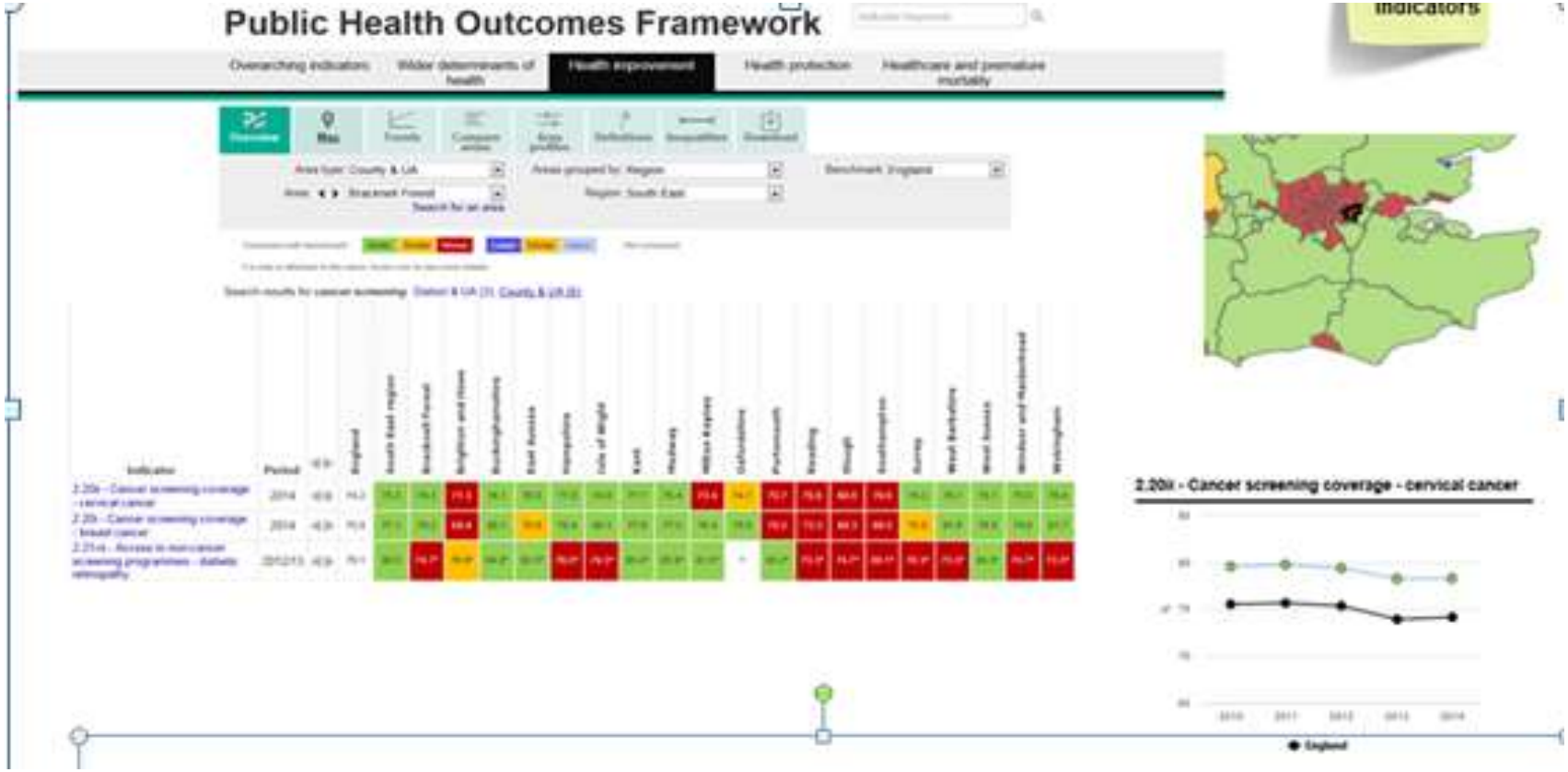
- ODS updated: September 2015 data: Trust, CCG, GP, Dentist update:
  - Organisations: 0 added, 6 changed, 1 closed
  - Sites: 263 added, 7,206

13What data are available, and how are they accessed?

Public Health Outcomes Framework

NEW: compare indicators

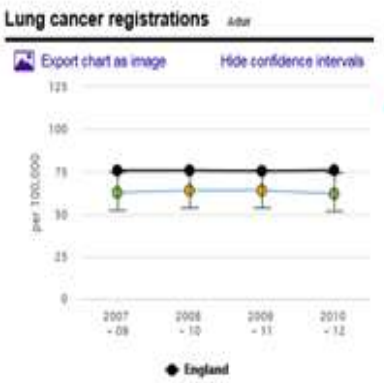
http://phoutcomes.info/

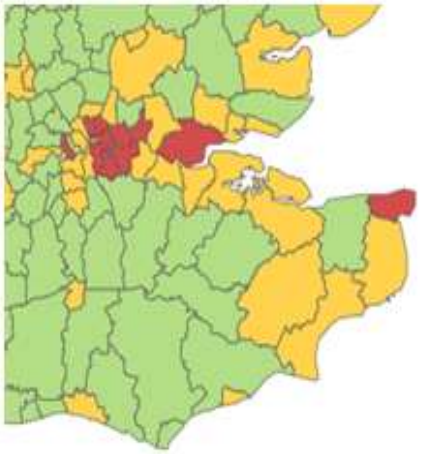


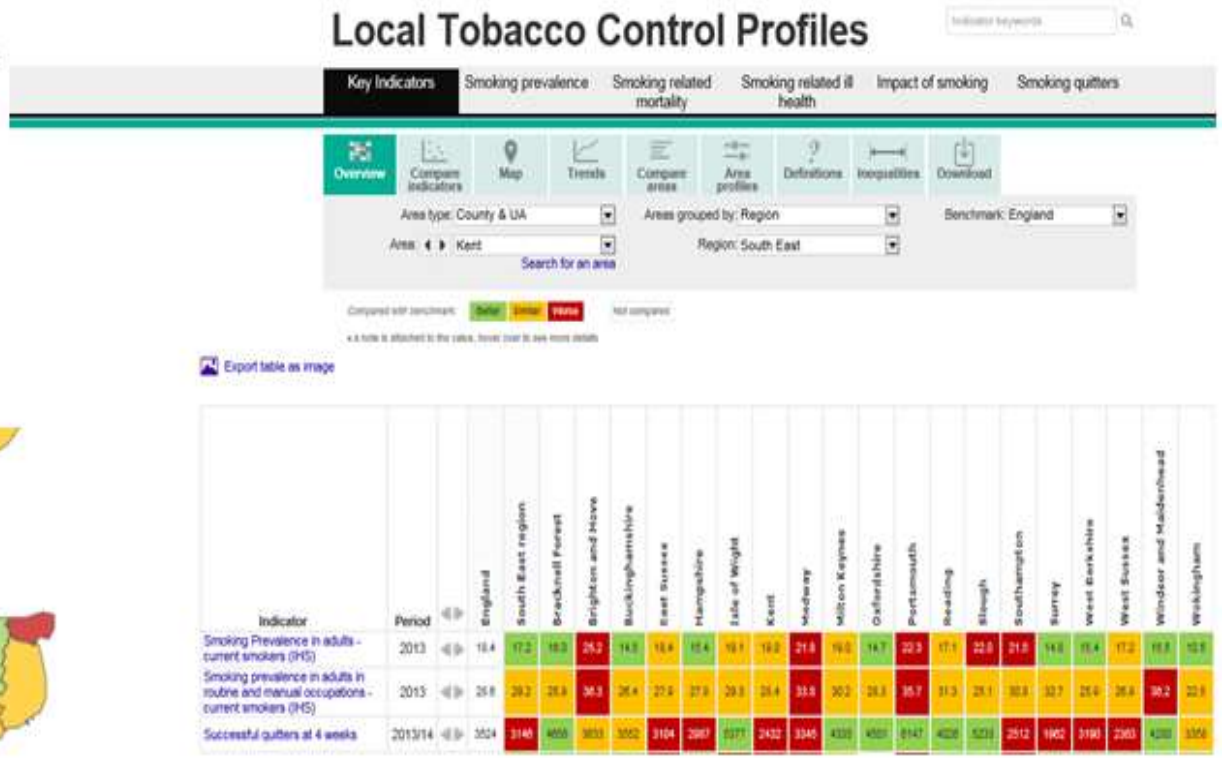
What data are available, and how are they accessed?

Local Tobacco Control Profiles

http://tobaccoprofiles.info/



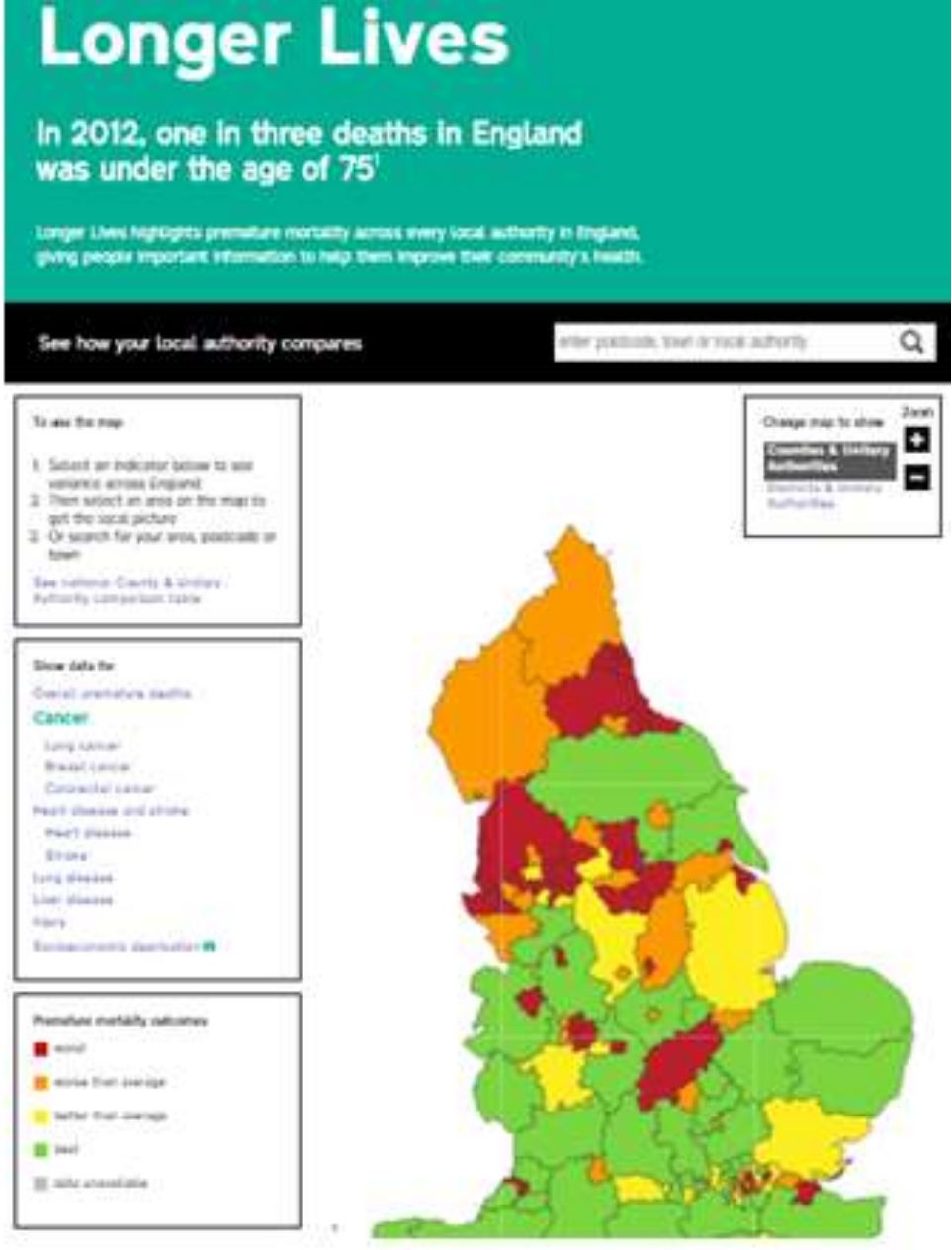




What data are available, and how are they accessed?

Longer Lives

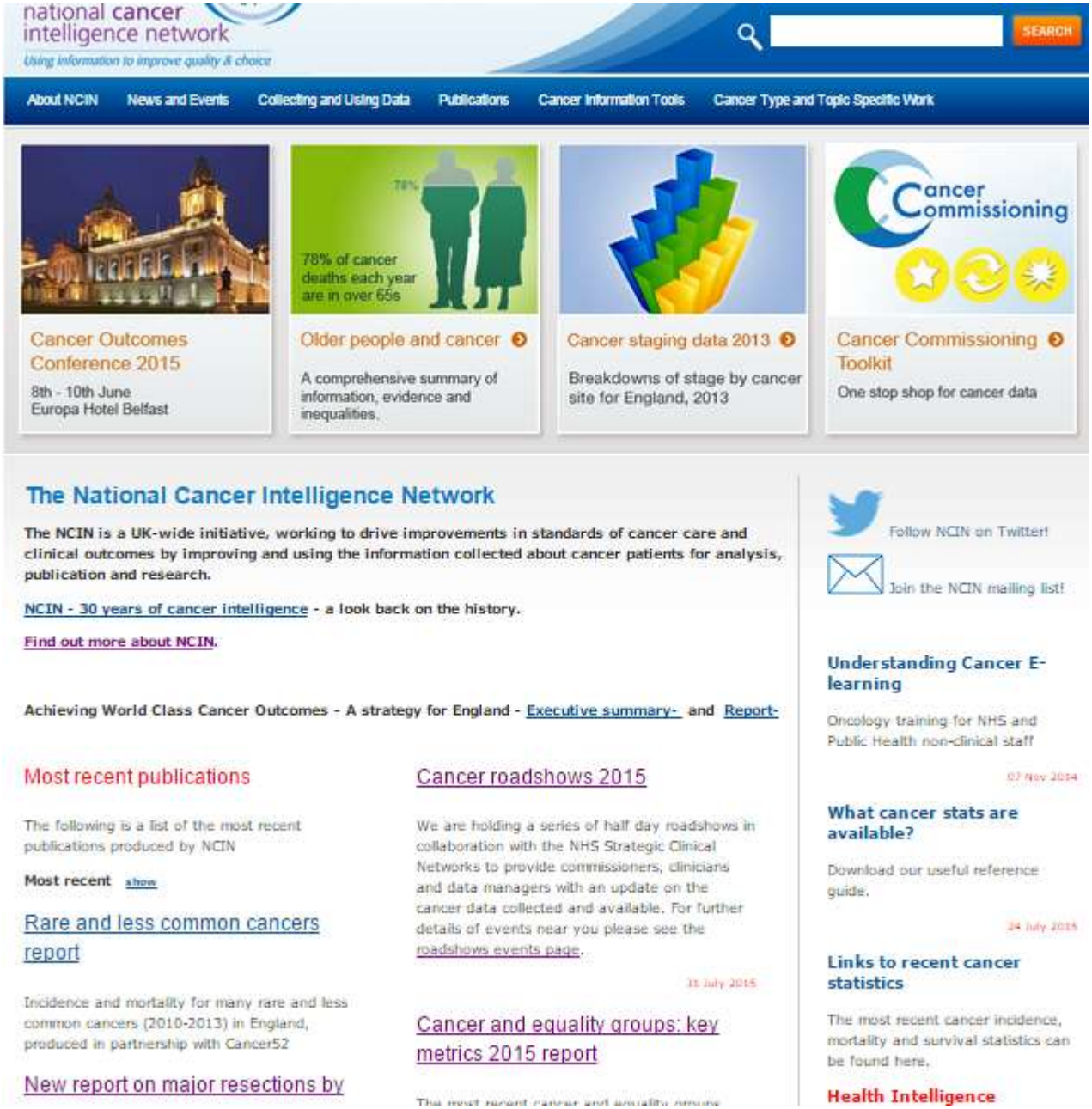
http://healthierlives.phe.org.uk/topic/mortality



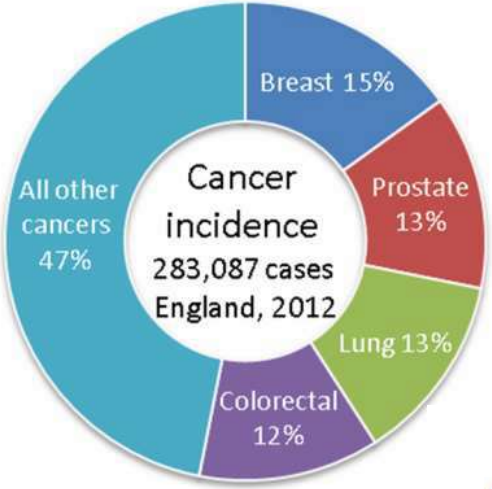
NCIN

http://www.ncin.org.uk/home

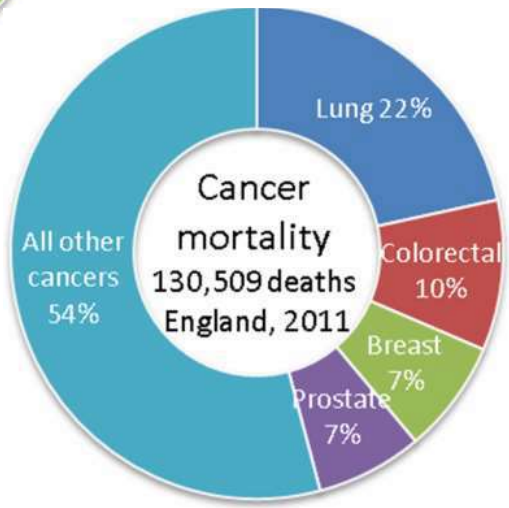
Download the 'What cancer stats are available?' guide



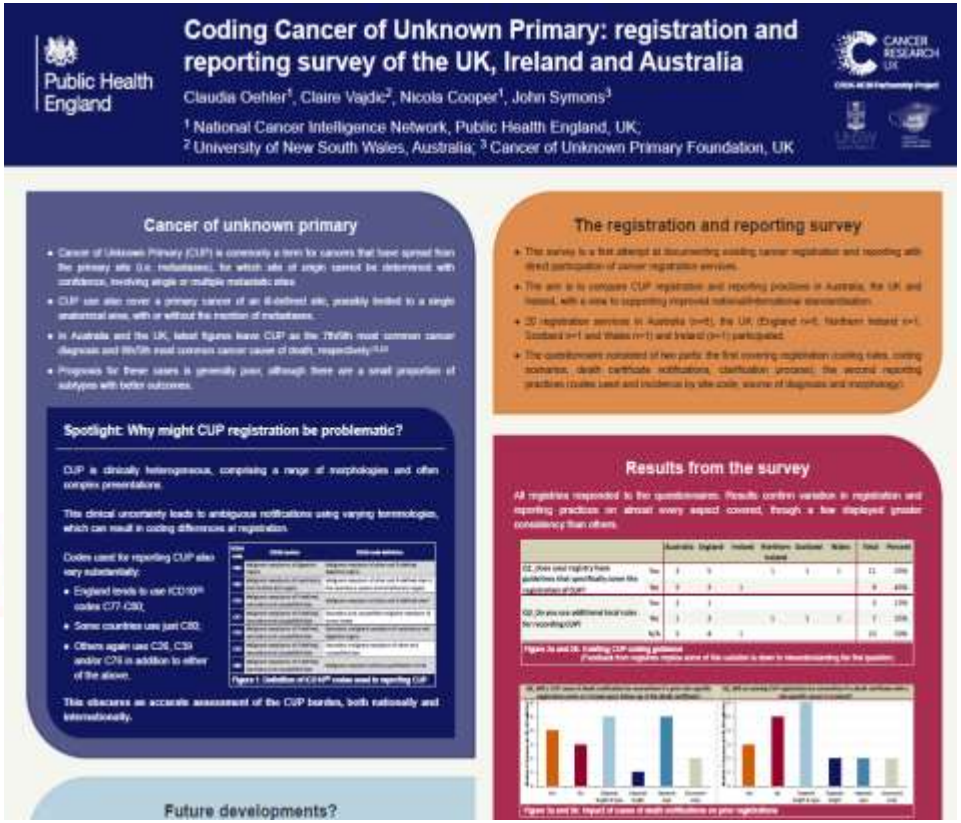
Bespoke analyses



Rare and less common cancers

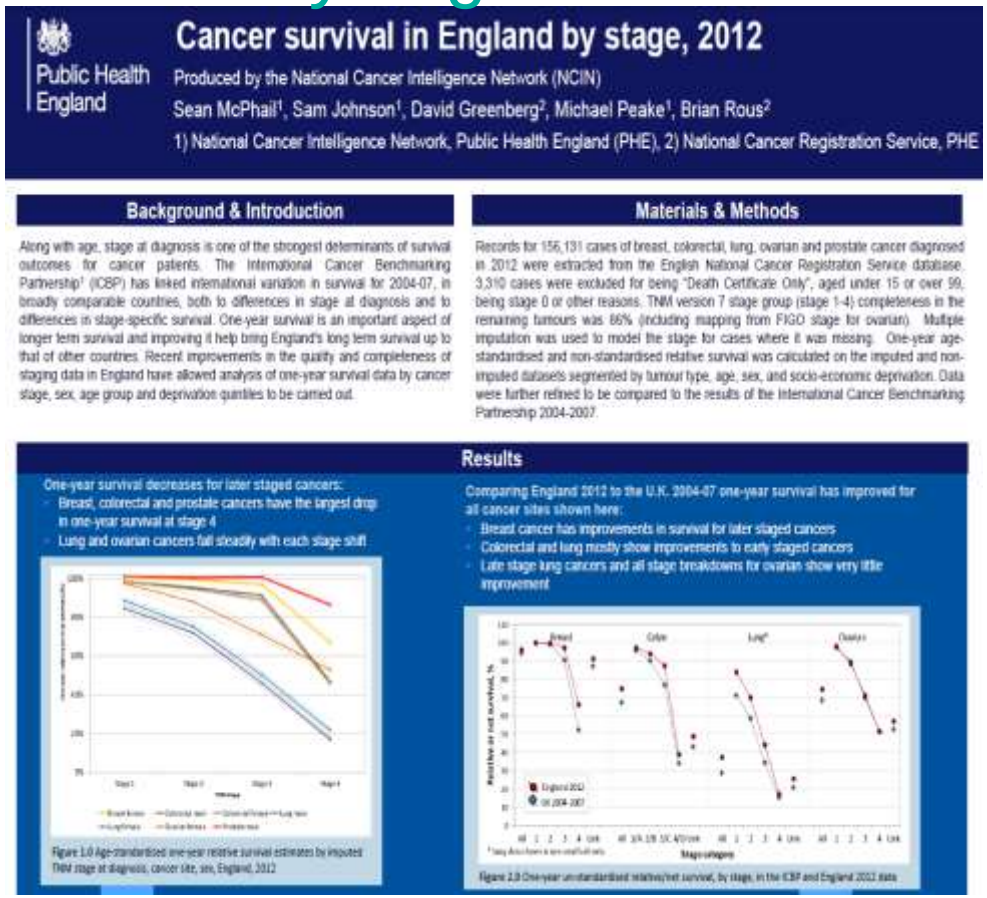


Cancer of Unknown Primary



Bespoke analyses

Survival by stage



Public Health England

Cancer survival in England by stage, 2012

Produced by the National Cancer Intelligence Network (NCIN)

Sean McPhail[1], Sam Johnson[1], David Greenberg[2], Michael Peake[1], Brian Rous[2]

1) National Cancer Intelligence Network, Public Health England (PHE), 2) National Cancer Registration Service, PHE

Background & Introduction

Along with age, stage at diagnosis is one of the strongest determinants of survival outcomes for cancer patients. The International Cancer Benchmarking Partnership[1] (ICBP) has linked international variation in survival for 2004-07, in broadly comparable countries, both to differences in stage at diagnosis and to differences in stage-specific survival. One-year survival is an important aspect of longer term survival and improving it help bring England's long term survival up to that of other countries. Recent improvements in the quality and completeness of staging data in England have allowed analysis of one-year survival data by cancer stage, sex, age group and deprivation quintiles to be carried out.

Materials & Methods

Records for 156,131 cases of breast, colorectal, lung, ovarian and prostate cancer diagnosed in 2012 were extracted from the English National Cancer Registration Service database. 3,310 cases were excluded for being "Death Certificate Only", aged under 15 or over 99, being stage 0 or other reasons. TNM version 7 stage group (stage 1-4) completeness in the remaining tumours was 66% (including mapping from FIGO stage for ovarian). Multiple imputation was used to model the stage for cases where it was missing. One-year age-standardised and non-standardised relative survival was calculated on the imputed and non-imputed datasets segmented by tumour type, age, sex, and socio-economic deprivation. Data were further refined to be compared to the results of the International Cancer Benchmarking Partnership 2004-2007.

Results

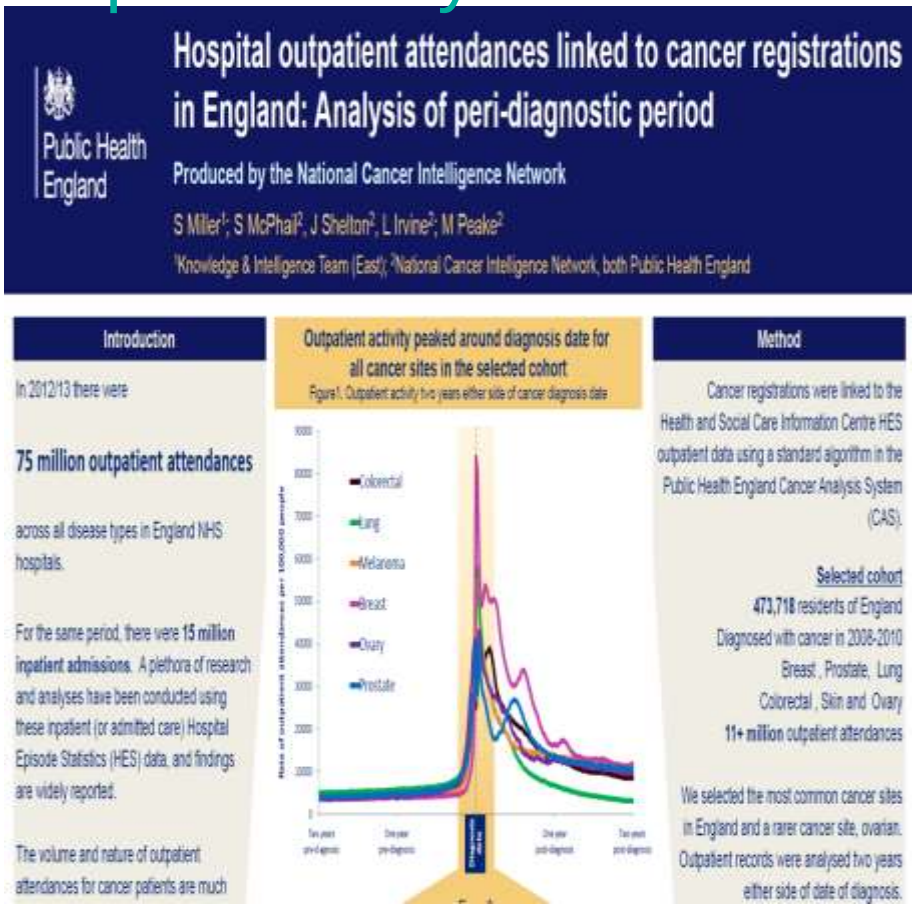
One-year survival decreases for later staged cancers:

- Breast, colorectal and prostate cancers have the largest drop in one-year survival at stage 4
- Lung and ovarian cancers fall steadily with each stage shift

Comparing England 2012 to the U.K. 2004-07 one-year survival has improved for all cancer sites shown here:

- Breast cancer has improvements in survival for later staged cancers
- Colorectal and lung mostly show improvements to early staged cancers
- Late stage lung cancers and all stage breakdowns for ovarian show very little improvement

Outpatient analysis



Public Health England

Hospital outpatient attendances linked to cancer registrations in England: Analysis of peri-diagnostic period

Produced by the National Cancer Intelligence Network

S Miller[1]; S McPhail[2], J Shelton[2], L Irvine[2]; M Peake[2]

[1]Knowledge & Intelligence Team (East); [2]National Cancer Intelligence Network, both Public Health England

Introduction

In 2012/13 there were

75 million outpatient attendances

across all disease types in England NHS hospitals.

For the same period, there were **15 million inpatient admissions**. A plethora of research and analyses have been conducted using these inpatient (or admitted care) Hospital Episode Statistics (HES) data, and findings are widely reported.

The volume and nature of outpatient attendances for cancer patients are much

Outpatient activity peaked around diagnosis date for all cancer sites in the selected cohort

Figure1. Outpatient activity two years either side of cancer diagnosis date

Colorectal
Lung
Melanoma
Breast
Ovary
Prostate

Method

Cancer registrations were linked to the Health and Social Care Information Centre HES outpatient data using a standard algorithm in the Public Health England Cancer Analysis System (CAS).

Selected cohort

473,718 residents of England

Diagnosed with cancer in 2008-2010

Breast , Prostate, Lung

Colorectal , Skin and Ovary

11+ million outpatient attendances

We selected the most common cancer sites in England and a rarer cancer site, ovarian. Outpatient records were analysed two years either side of date of diagnosis.

Bespoke analyses

Routes to diagnosis

Routes to Diagnosis, a novel English methodology

LE Elliss-Brookes 1, S McPhail 1, A Ives 2, M Greenslade 2, J Shelton 1, S Hiom 3, M Richards 4
1) National Cancer Intelligence Network, London 2) Public Health England Knowledge and Intelligence Team (South West), Bristol 3) Cancer Research UK, London 4) NHS England, London

Nationally, what didn't we know?
- How people come to get diagnosed with cancer
- Whether late diagnosis arises where patients have not gone through the screening or suspected cancer route

Nationally, what did we want to know?
- Can we use routinely available datasets to define the route to diagnosis for patients diagnosed with cancer?
- If so, how do routes differ by cancer site, age, sex, ethnicity, deprivation or geography?
- Are there differences in survival for different routes?

Method: Routes to Diagnosis uses routinely collected data sources to work backwards through patient pathways to examine the sequence of events that led to a cancer diagnosis. The methodology identifies over 70 individual pathways and then categorises patients into one of eight broad Routes (see table to right).

1. Registration records for cancers newly diagnosed in 2006 to 2008 (ICD-10 C00-C97 excluding C44) for England residents were extracted from the National Cancer Data Repository.

2. Records were linked at patient level to national datasets for inpatient and outpatient activity, Cancer Waiting Times (CWT) monitoring and breast, cervical and bowel cancer screening.

3. Hospital Episode Statistics (HES) data were used to categorise the Route for each cancer individually, **the algorithm is described in the three flow diagrams below.**

4. Screening and CWT data were then examined with the Route potentially changing to either a Screening or Two Week Wait (urgent referral for suspected cancer) Route.

Public Health England

Routes to Diagnosis: Does it matter when or how a cancer is diagnosed?

Produced by the National Cancer Intelligence Network (NCIN)
Sam Johnson[1], Sean McPhail[1], Lucy Elliss-Brookes[1], Matthew Greenslade[2], Alex Ives[2], Jon Shelton[1]
1) National Cancer Intelligence Network, Public Health England, 2) Knowledge & Intelligence Team (South West)

Introduction

Cancer survival in England is lower than the European average, which has been at least partly attributed to later presentation in England. The Routes to Diagnosis study defines a methodology by which the entry route into secondary care can be categorised for each tumour, in order to understand how different presentation pathways lead to different outcomes. The latest update covers all cancers diagnosed in 2006-2010 and expands the number of sites analysed as well as examining the role day of the week has on a patient's route and subsequent survival.

Methodology

Hospital Episode Statistics (HES) are combined with Cancer Waiting Times (CWT) data, cancer screening records and cancer registrations data. Using these datasets every newly diagnosed malignant cancer and selected benign and in-situ cancers in England, 2006-2010, has been categorised into one of eight 'Routes to Diagnosis'[1]. A sample of results from these data are shown here, broken down by day of week, cancer site and year of diagnosis.

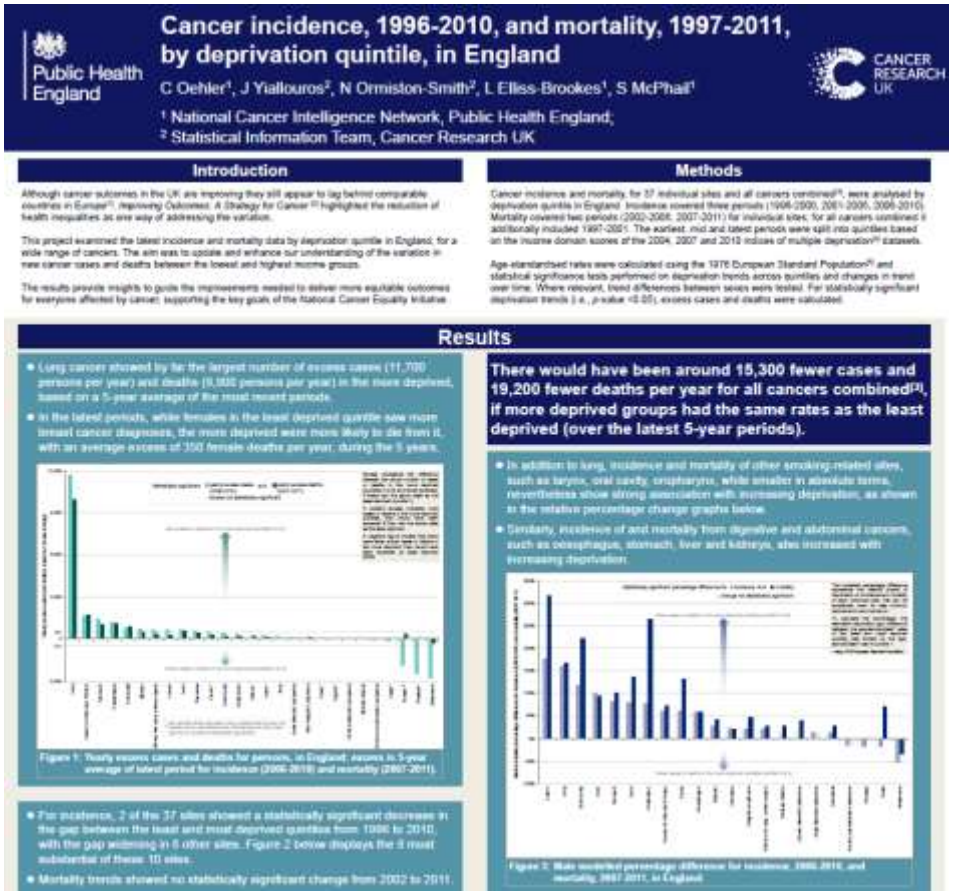
Does it matter when a cancer is diagnosed?

What data are available, and how are they accessed?

Bespoke analyses

Inequalities: deprivation

ethnicity



Public Health England

Cancer incidence, 1996-2010, and mortality, 1997-2011, by deprivation quintile, in England

C Oehler[1], J Yiallouros[2], N Ormiston-Smith[2], L Elliss-Brookes[1], S McPhail[1]

[1] National Cancer Intelligence Network, Public Health England;
[2] Statistical Information Team, Cancer Research UK

CANCER RESEARCH UK

Introduction

Although cancer outcomes in the UK are improving they still appear to lag behind comparable countries in Europe[1]. Improving Outcomes: A Strategy for Cancer [2] highlighted the reduction of health inequalities as one way of addressing the variation.

This project examined the latest incidence and mortality data by deprivation quintile in England, for a wide range of cancers. The aim was to update and enhance our understanding of the variation in new cancer cases and deaths between the lowest and highest income groups.

The results provide insights to guide the improvements needed to deliver more equitable outcomes for everyone affected by cancer, supporting the key goals of the National Cancer Equality Initiative.

Methods

Cancer incidence and mortality, for 37 individual sites and all cancers combined[3], were analysed by deprivation quintile in England. Incidence covered three periods (1996-2000, 2001-2005, 2006-2010). Mortality covered two periods (2002-2006, 2007-2011) for individual sites; for all cancers combined it additionally included 1997-2001. The earliest, mid and latest periods were split into quintiles based on the income domain scores of the 2004, 2007 and 2010 indices of multiple deprivation[4] datasets.

Age-standardised rates were calculated using the 1976 European Standard Population[5] and statistical significance tests performed on deprivation trends across quintiles and changes in trend over time. Where relevant, trend differences between sexes were tested. For statistically significant deprivation trends (i.e., p-value <0.05), excess cases and deaths were calculated.

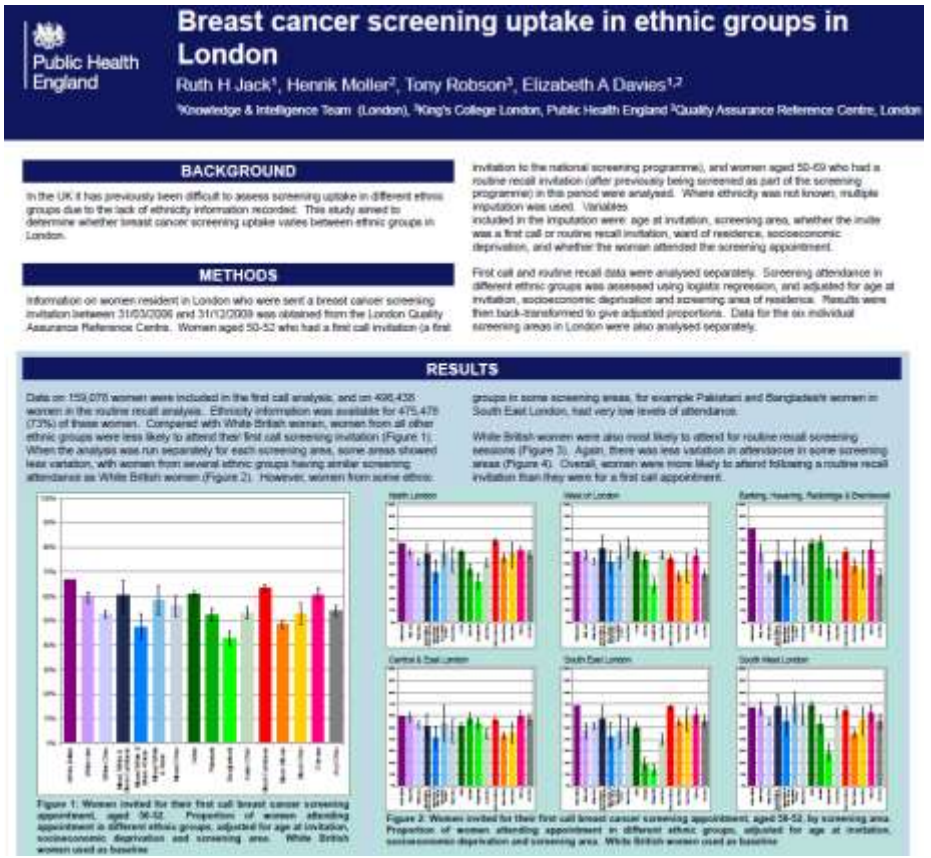
Results

- Lung cancer showed by far the largest number of excess cases (11,700 persons per year) and deaths (9,900 persons per year) in the more deprived, based on a 5-year average of the most recent periods.
- In the latest periods, while females in the least deprived quintile saw more breast cancer diagnoses, the more deprived were more likely to die from it, with an average excess of 350 female deaths per year, during the 5 years.

There would have been around 15,300 fewer cases and 19,200 fewer deaths per year for all cancers combined[3], if more deprived groups had the same rates as the least deprived (over the latest 5-year periods).

- In addition to lung, incidence and mortality of other smoking-related sites, such as larynx, oral cavity, oropharynx, while smaller in absolute terms, nevertheless show strong association with increasing deprivation, as shown in the relative percentage change graphs below.
- Similarly, incidence of and mortality from digestive and abdominal cancers, such as oesophagus, stomach, liver and kidneys, also increased with increasing deprivation.

- For incidence, 2 of the 37 sites showed a statistically significant decrease in the gap between the least and most deprived quintiles from 1996 to 2010, with the gap widening in 6 other sites. Figure 2 below displays the 8 most substantial of these 10 sites.
- Mortality trends showed no statistically significant change from 2002 to 2011.



Public Health England

Breast cancer screening uptake in ethnic groups in London

Ruth H Jack[1], Henrik Moller[2], Tony Robson[3], Elizabeth A Davies[1,2]

[1]Knowledge & Intelligence Team (London), [2]King's College London, Public Health England [3]Quality Assurance Reference Centre, London

BACKGROUND

In the UK it has previously been difficult to assess screening uptake in different ethnic groups due to the lack of ethnicity information recorded. This study aimed to determine whether breast cancer screening uptake varies between ethnic groups in London.

METHODS

Information on women resident in London who were sent a breast cancer screening invitation between 31/03/2006 and 31/12/2009 was obtained from the London Quality Assurance Reference Centre. Women aged 50-52 who had a first call invitation (a first invitation to the national screening programme), and women aged 50-69 who had a routine recall invitation (after previously being screened as part of the screening programme) in this period were analysed. Where ethnicity was not known, multiple imputation was used. Variables included in the imputation were: age at invitation, screening area, whether the invite was a first call or routine recall invitation, ward of residence, socioeconomic deprivation, and whether the woman attended the screening appointment.

First call and routine recall data were analysed separately. Screening attendance in different ethnic groups was assessed using logistic regression, and adjusted for age at invitation, socioeconomic deprivation and screening area of residence. Results were then back-transformed to give adjusted proportions. Data for the six individual screening areas in London were also analysed separately.

RESULTS

Data on 159,078 women were included in the first call analysis, and on 496,435 women in the routine recall analysis. Ethnicity information was available for 475,479 (73%) of these women. Compared with White British women, women from all other ethnic groups were less likely to attend their first call screening invitation (Figure 1). When the analysis was run separately for each screening area, some areas showed less variation, with women from several ethnic groups having similar screening attendance as White British women (Figure 2). However, women from some ethnic groups in some screening areas, for example Pakistani and Bangladeshi women in South East London, had very low levels of attendance.

White British women were also most likely to attend for routine recall screening sessions (Figure 3). Again, there was less variation in attendance in some screening areas (Figure 4). Overall, women were more likely to attend following a routine recall invitation than they were for a first call appointment.

Figure 1: Women invited for their first call breast cancer screening appointment, aged 50-52. Proportion of women attending appointment in different ethnic groups, adjusted for age at invitation, socioeconomic deprivation and screening area. White British women used as baseline.

Figure 2: Women invited for their first call breast cancer screening appointment, aged 50-52, by screening area. Proportion of women attending appointment in different ethnic groups, adjusted for age at invitation, socioeconomic deprivation and screening area. White British women used as baseline.

What data are available, and how are they accessed?

Bespoke analyses

Tumour specific: breast cancer

Public Health England

Protecting and improving the nation's health

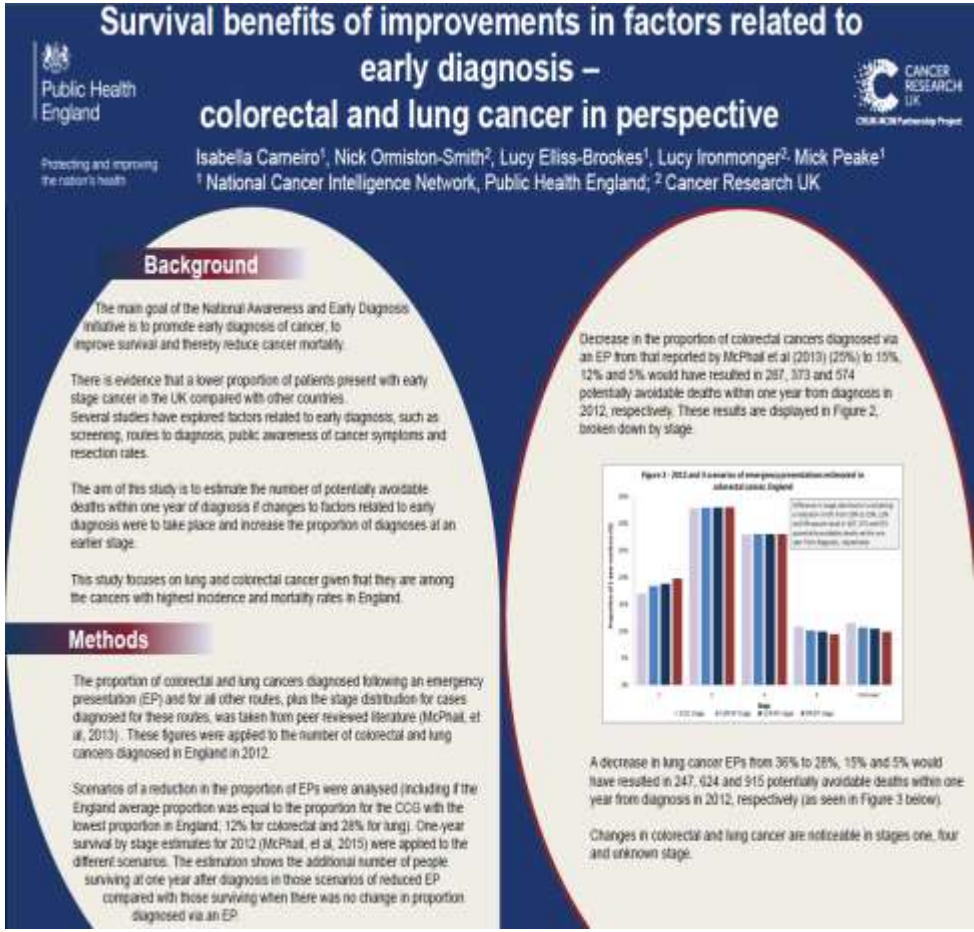
The third all breast cancer report

Back to basics:

Breast cancer incidence and mortality

West Midlands Knowledge and Intelligence Team, Public Health England and the National Cancer Intelligence Network Breast Site Specific Clinical Reference Group

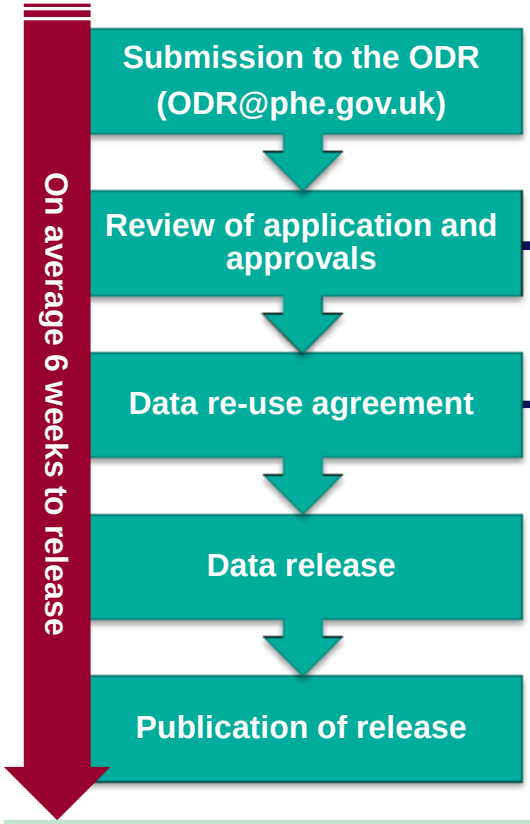
lung cancer



PHE Office for Data Release

The PHE Office for Data Release (ODR) ensures that requests for potentially or explicitly identifiable data are managed in line with PHE's statutory responsibilities as a data controller, so that:

- Any data sharing complies with the rights of the data subject, Data Protection Act and Caldicott principles;
- There is an appropriate legal gateway for the receiving organisation to receive and process patient or personal data;
- The physical transfer of the data is secure; and,
- The receiving organisation can satisfy that they have in place comparable controls to ensure that the data is held securely.



Required documents
- Protocol
- Data specification
- REC approval (for research only)
- Legal gateway to process the data
- IG toolkit level 2 compliance or equivalent

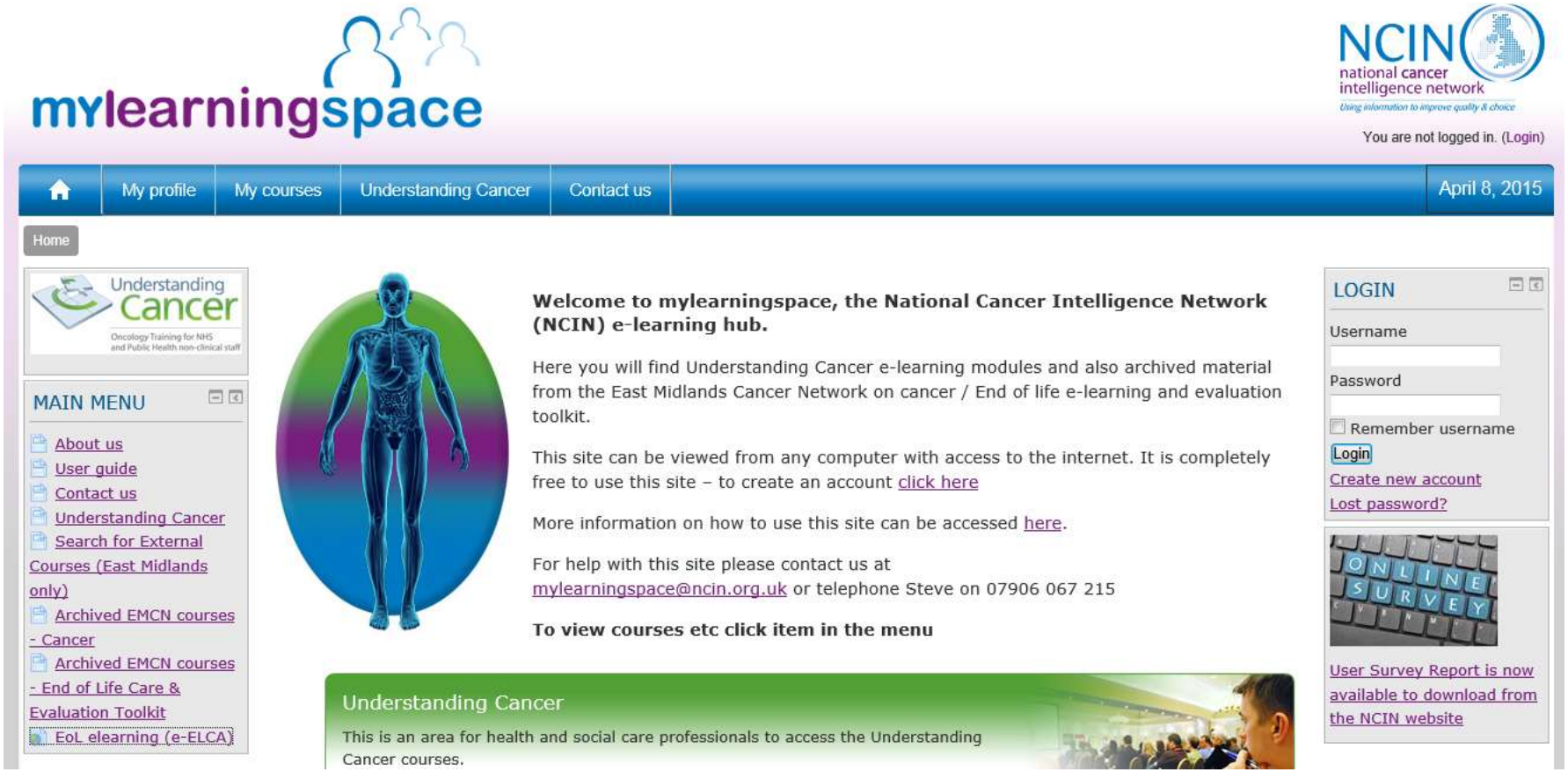
Data Re-use Agreement
A Data Re-use Agreement (DRA) must be signed between PHE and the applicant prior to the release of the data. The DRA binds the application to specific terms of the release of the data, including agreeing to not to disclose, use or reuse the data outside the conditions of the approved release (the study protocol and associated ethics, legal permissions).

Data available through the ODR:
- NCRS cancer registration data
- National Cervical Cancer Screening
- National Breast Screening Programme
- National Bowel Cancer Screening Programme
- National Drug Treatment Monitoring Dataset
- Congenital Anomalies Register

Data Release Register
PHE is committed to sharing all instances in which potentially or explicitly data is released, through the publication of a PHE Data Release Register. The first register to be published in 2015.

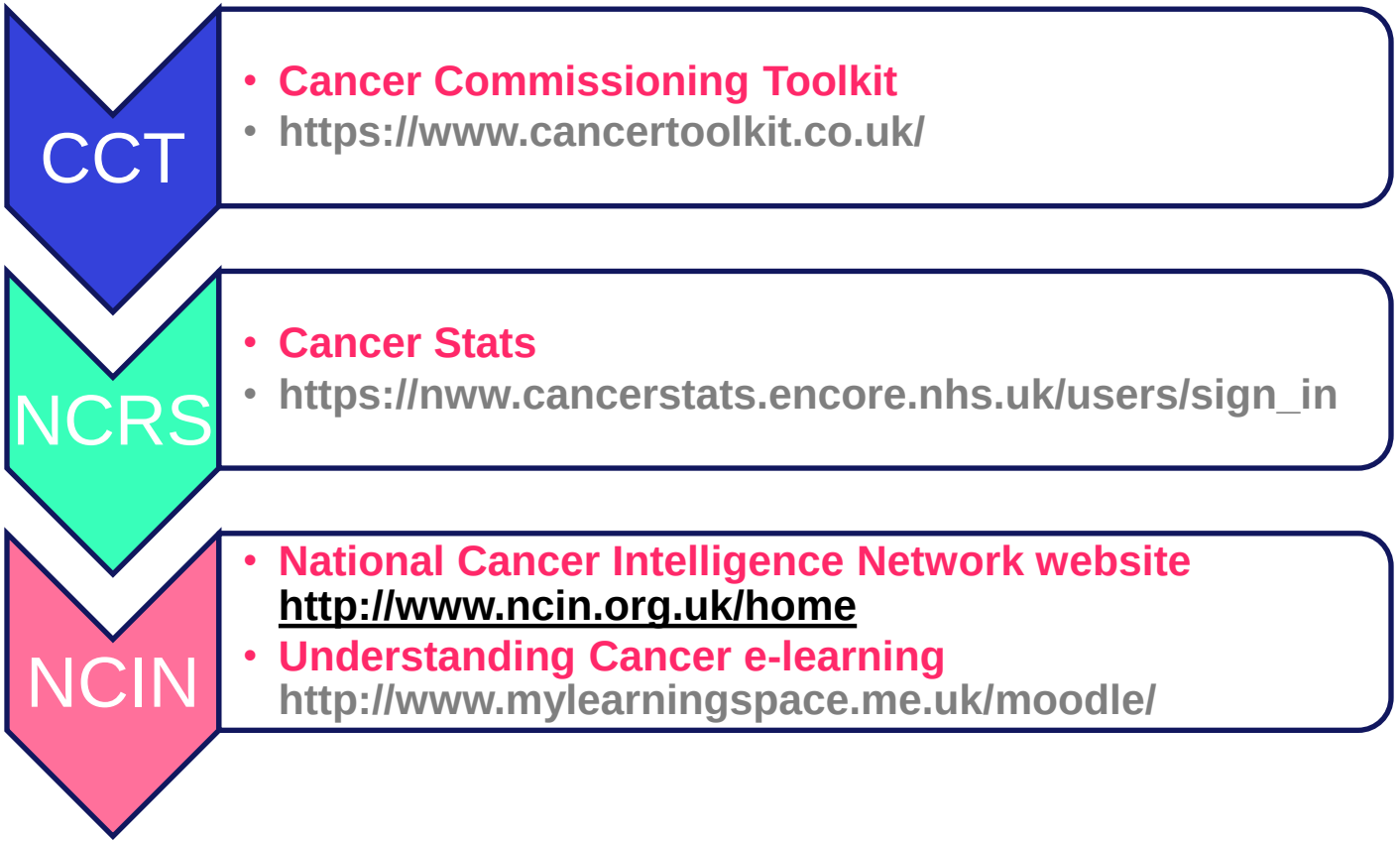
Understanding Cancer e-learning

http://www.mylearningspace.me.uk/moodle/



What data are available, and how are they accessed?

Cancer data URL



Other data URLs

UK Cancer Tools & Intelligence	
National CancerStats *(Cascade / COSD)*	https://nww.cancerstats.nhs.uk
Cancer Commissioning Toolkit	https://www.cancertoolkit.co.uk/
Macmillan / NCIN Local Cancer Intelligence Tool	http://lci.cancertoolkit.co.uk/
National Cancer Audits	http://www.hscic.gov.uk/Article/1806
NHS Cancer Screening Programmes in England	http://www.cancerscreening.nhs.uk
Understanding Cancer e-learning	http://www.mylearningspace.me.uk/moodle/
Public Health Profiles	http://fingertips.phe.org.uk/
Local Tobacco Control Profiles	http://www.tobaccoprofiles.info/
Healthier Lives	http://healthierlives.phe.org.uk/topic/mortality
Strategic Health Asset Planning and Evaluation (SHAPE)	http://shape.dh.gov.uk/index.asp
PHE Data and Knowledge Gateway	http://datagateway.phe.org.uk/
Cancer Research UK – Cancer Statistics	http://www.cancerresearchuk.org/cancer-info/cancerstats/
NHS Evidence	http://www.evidence.nhs.uk/

Contact us

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