



Public Health  
England

Protecting and improving the nation's health

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

# Providers of information



# Where are we now?

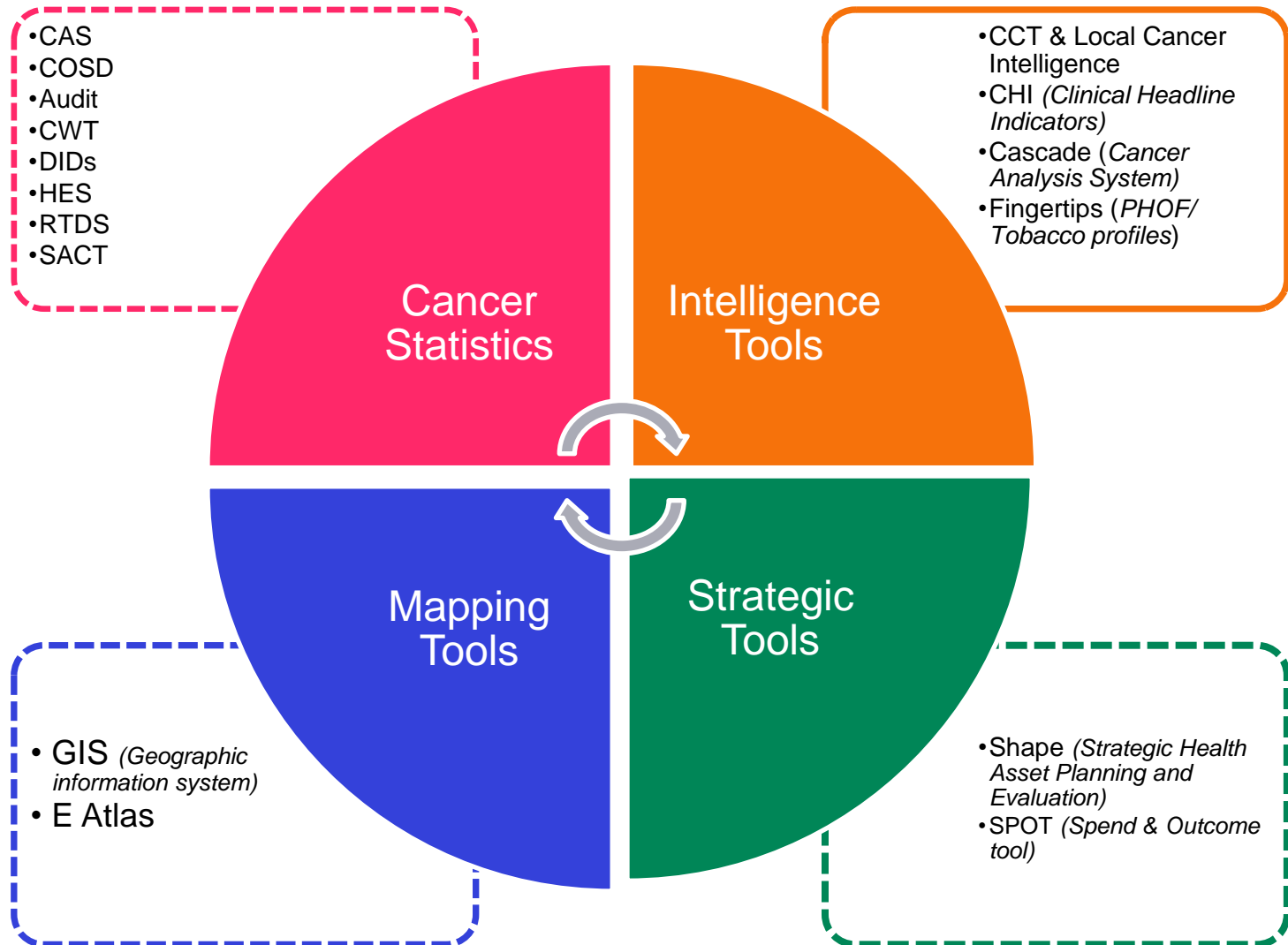
Multiple organisations moved to PHE

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/>

## Data and knowledge gateway

Beta site

A single point of access to data and analysis tools from across Public Health England

The [gateway](#) is in development. If you need more information you need or if you

See [latest updates](#) for information. please [let us know](#) if you do not find the

### Resources

Resources that require a login will open in a new tab or window. If you see a padlock symbol (🔒). When you select a resource

### Select a category

[Cancer](#)

[Cancer commissioning toolkit](#)

[Cancer e-atlas](#)

[Cancer mortality profiles](#)

[Cancer patient experience](#)

[Cascade \(the UKCIS replacement\)](#)

[GP practice profiles](#)

[Gynaecological cancer hub](#)

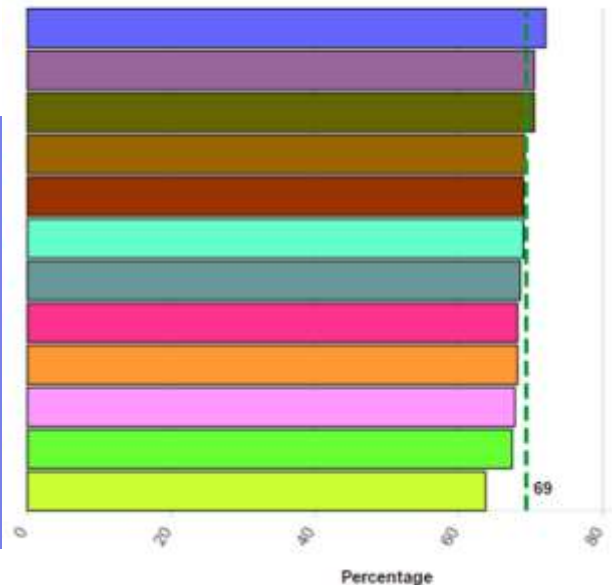
[Gynaecological cancer profiles](#)

[Head and neck cancer e-atlas \(profiles\)](#)

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

[Home](#)
[Dashboards](#)
[Extracts & Reports](#)
[Profiles](#)
[Charts](#)
[Background](#)
[Log In / Register](#)

## Interactive



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.

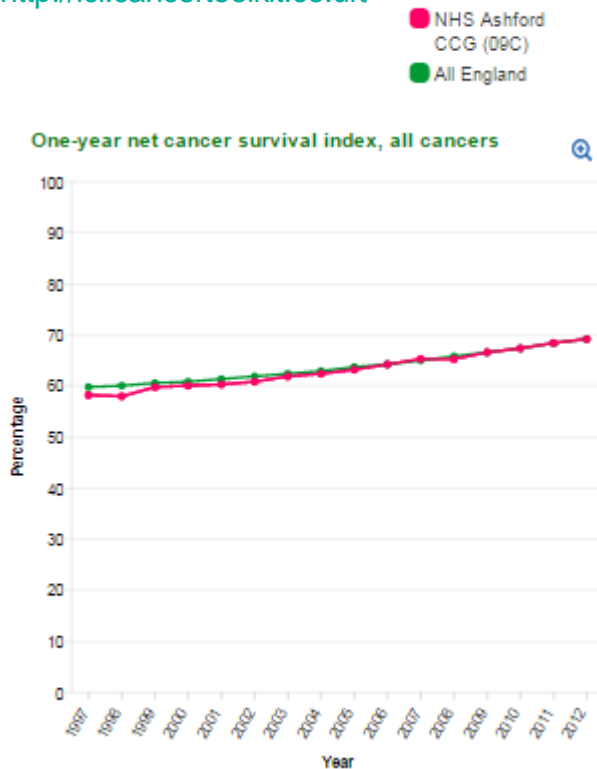
The CCT will be the first tool to be decommissioned by PHE in March 2016 and some of it will be incorporated into a PHE tool –Clinical headline Indicators (which is not yet live but requires N3 connection to see the tool).

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.

## Local Cancer Intelligence



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

### Headlines for NHS Ashford CCG

#### ► Prevalence

As of the end of 2010, around 3,000 people in your CCG were living with and beyond cancer up to 20 years after diagnosis. This could rise to an estimated 5,800 by 2030.

[For more information ►](#)

#### ► Incidence

There are 499 new cancer diagnoses per 100,000 people each year. This is lower than the England average.

[For more information ►](#)

#### ► Mortality

There are 254 cancer deaths per 100,000 people each year. This is lower than the England average.

[For more information ►](#)

#### ► One Year Survival

One-year cancer survival is 69%. This is similar to the England average of 68%.

[For more information ►](#)

#### ► Five Year Survival

Five-year cancer survival is 47% in your Area Team. The England average is 48%.

[For more information ►](#)

Search for your Clinical Commissioning Group:

NHS Ashford CCG



#### ▼ Headlines

◀ Cancer Prevalence

◀ Cancer Incidence

◀ Cancer Mortality

◀ Cancer Survival

◀ Patient Experience

▼ Routes To and From Diagnosis

◀ Breast

◀ Lung

◀ Prostate

◀ Brain and CNS tumours



# Cancer Stats: CHI

[https://nwww.cancerstats.nhs.uk/users/sign\\_in](https://nwww.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

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## Clinical Headline Indicators

Diagnosed per year - Lung tumours 2013

Year:	Clear	2013
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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%

10What data are available, and how are they accessed?

# Cancer Stats: CASCADE


[https://nwww.cancerstats.nhs.uk/users/sign\\_in](https://nwww.cancerstats.nhs.uk/users/sign_in)

[Cascade](#) [Incidence ▾](#) [Mortality ▾](#) [Survival ▾](#)

## Incidence

An incident case of cancer is a new case of cancer, counted once when the cancer is diagnosed.

Base numbers of cases, crude and age standardised rates can be found by following the links below:

Signed in successfully. 

### Base Numbers

Click here for numbers of new cases of cancer. Numbers can be presented for different cancer sites, different time periods, and different geographies. Numbers are useful when trying to estimate the burden of cancer - how many tumours have been diagnosed?

### Crude Rates

Click here for crude cancer incidence rates. Rates can be presented for different cancer types, different time periods, and different geographies. Crude rates are useful when trying to compare the incidence of cancer in two populations. Because of the strong link between age and risk of cancer, crude rates are often highest in populations with a high proportion of elderly people.

### Standardised Rates

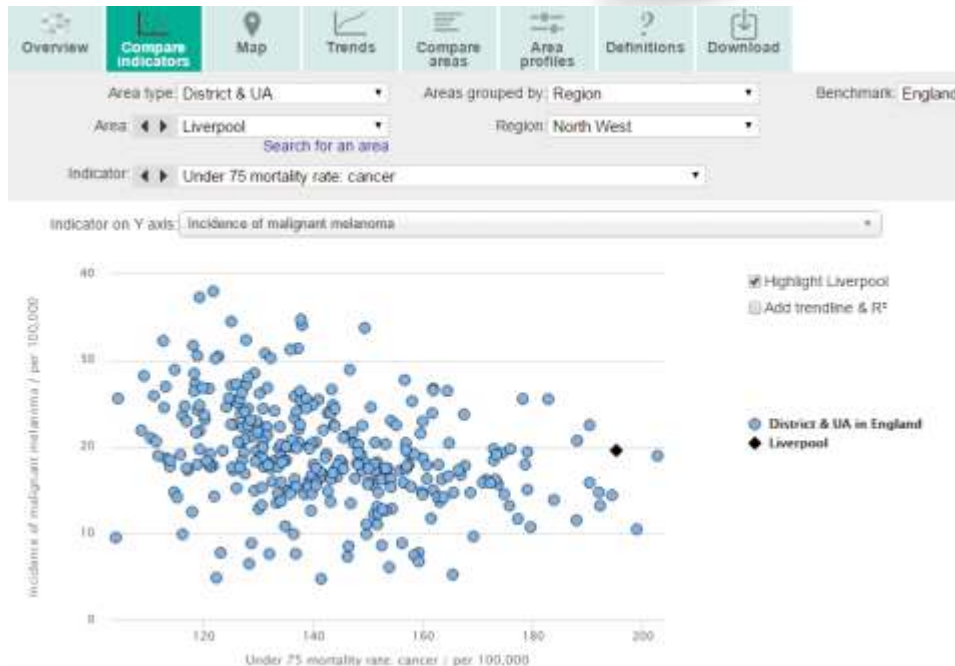
Click here for age-and-sex standardised cancer incidence rates. Rates can be presented for different cancer sites, different time periods, and different geographies. Standardised rates are useful when trying to compare two measurements (such as whether cancer risk has increased over time, or whether risks are greater in one area of the country than another).

# Public Health Profiles

## (Fingertips)

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

Type in 'cancer' in the search box



## Public Health Profiles

Indicator keywords

### National Public Health Profiles

#### Public Health Outcomes Framework

The Public Health Outcomes Framework sets out a vision for public health, desired outcomes and the indicators that will help us understand how well public health is being improved and protected.

#### NCMP Local Authority Profile

Data from the National Child Measurement Programme (NCMP) 2006/07 to 2013/14 are now available in this online data tool. Prevalence of underweight, healthy weight, overweight, and obesity for children in Reception (age 4-5 years) and Year 6 (age 10-11 years) can be examined at local authority level. Data quality indicators are also available, for example rate of participation in the NCMP.

#### Sexual and Reproductive Health Profiles

Provides a snapshot of sexual and reproductive health across a range of topics including teenage pregnancy, abortions, contraception, HIV and sexually transmitted infections.

#### Diabetes

This is a companion profile for **Healthier Lives: Diabetes** which shows trend data for CCGs and local authorities and allows users to create LA and CCG spine charts.

#### Inhale - Interactive Health Atlas of Lung conditions in England

INH-ALE - Interactive Health Atlas of Lung conditions in England draws together indicators on (mainly) COPD and asthma from a range of sources into a single portal, and presents these indicators in a variety of formats. This is a beta version using PHE's Fingertips software and we welcome feedback.

#### Local Tobacco Control Profiles

Provide a snapshot of the extent of tobacco use, tobacco related harm, and measures being taken to reduce this harm at a local level.

#### Longer Lives

Highlights premature mortality across every local authority in England, giving people important information to help them improve their community's health. We have expanded the tool to include a suite of maps under the title **Healthier Lives**. This includes diabetes, high blood pressure and NHS Health Check.

#### NHS Health Check

The NHS Health Check programme aims to help prevent heart disease, stroke, diabetes, kidney disease and certain types of dementia.

#### TB Strategy Monitoring Indicators

Key TB monitoring indicators for the Collaborative TB Strategy 2015-2020.

#### Health Profiles

Health Profiles provide summary information on health (and factors affecting health) to support local authority members, officers and community partners to lead for health improvement. Health Profiles are available for counties, districts and unitary authorities in England.

#### Learning Disability Profiles

This set of indicators brings together nationally available data to inform improvements in health and social care for people with learning disabilities. The data can be used by clinical commissioning groups (CCGs), Health and Wellbeing Boards and local authorities to help ensure they are commissioning appropriate and useful services for people with learning disabilities.

#### National General Practice Profiles

Designed to support GPs, clinical commissioning groups (CCGs) and local authorities to ensure that they are providing and commissioning effective and appropriate healthcare services for their local population.

#### Mental Health Dementia and Neurology

A suite of indicator tools which bring together nationally available data presented at local level to support benchmarking, commissioning and service improvement. Topics covered include: Children and young people's mental health & wellbeing, Co-existing substance misuse and mental health, Common mental health disorders and Severe mental illness. There are also summary Community mental health profiles and profiles for Neurology.

#### Children and Young People's Health Benchmarking Tool

Brings together a selection of the most relevant indicators to inform discussions and encourage improvements in services and health outcomes for children and young people.

#### Health Protection

The Health Protection Profiles cover a range of health protection issues in order to help inform choices regarding health and lifestyle, and improve awareness of local health protection risks.

#### Liver Disease Profiles

Local Authority Liver Disease Profiles: A new resource for one of the main causes of premature mortality nationally, providing disease-specific key facts and resources, practical prevention strategies for local implementation and questions for you to ask locally.

# 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.**



## 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](mailto: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

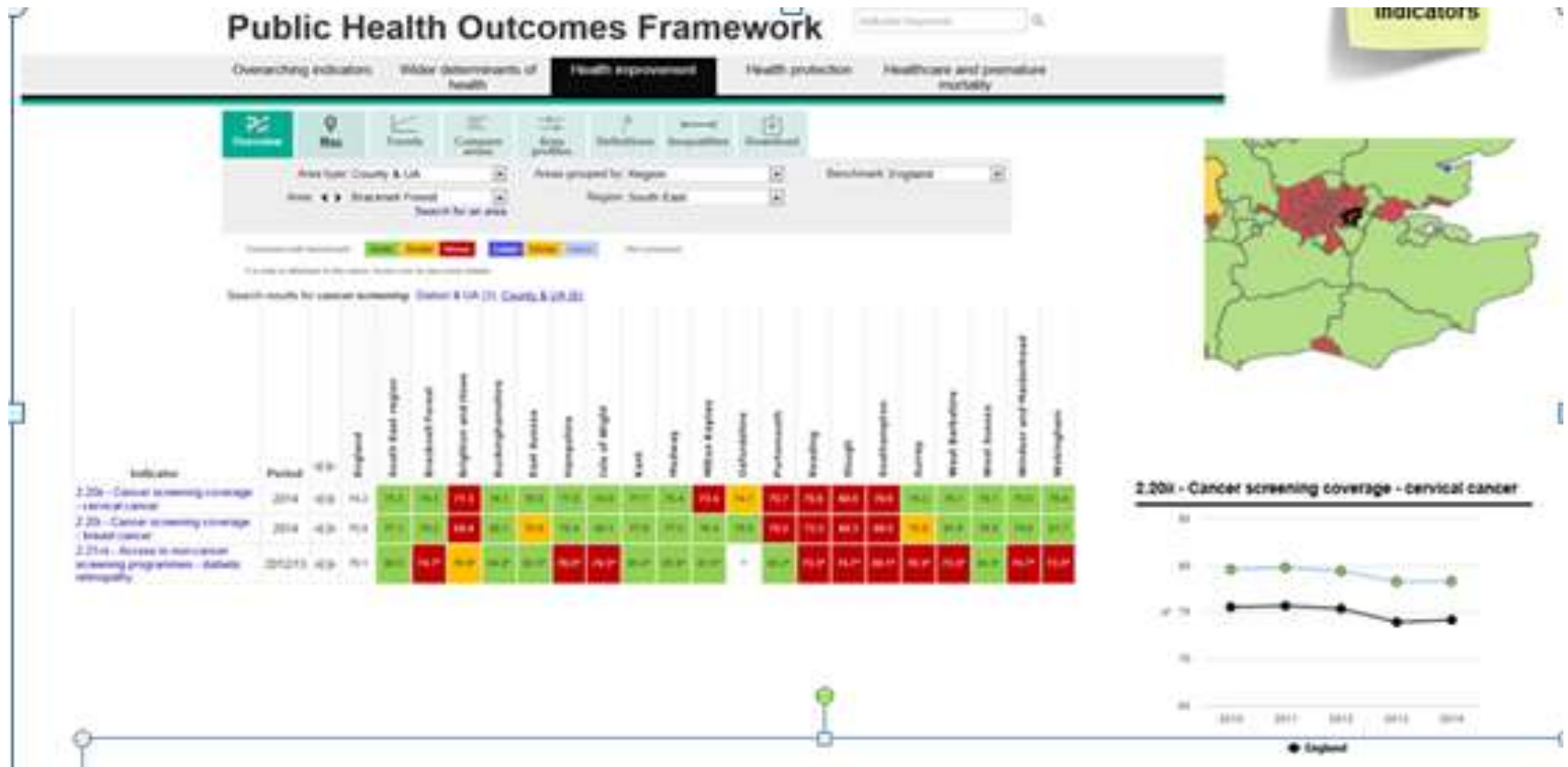
13 What data are available, and how are they accessed?



# Public Health Outcomes Framework

NEW:  
compare  
indicators

<http://phoutcomes.info/>

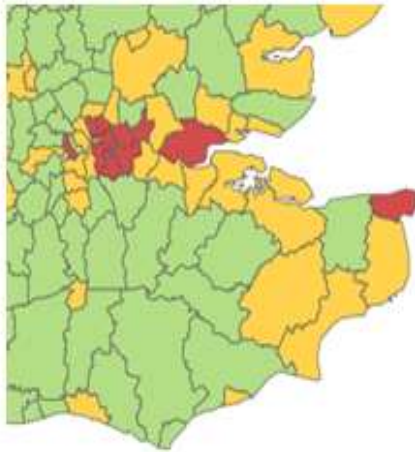
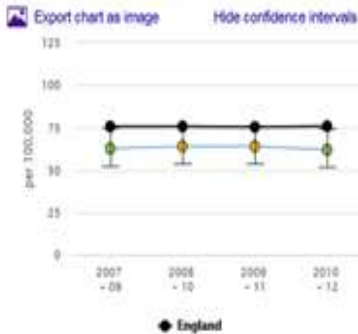


14 What data are available, and how are they accessed?

# Local Tobacco Control Profiles

<http://tobaccoprofiles.info/>

## Lung cancer registrations



## Local Tobacco Control Profiles

Indicator keywords

### Key Indicators

### Smoking prevalence

### Smoking related mortality

### Smoking related ill health

### Impact of smoking

### Smoking quitters

### Overview

### Compare indicators

### Map

### Trends

### Compare areas

### Area profiles

### Definitions

### Legislations

### Download

Area type: County & UA

Areas grouped by: Region

Benchmark: England

Area: Kent

Region: South East

Search for an area

Compared with benchmark: Better Same Worse Not compared

A note is attached to the table, hover over to see more details

### Export table as image

Indicator	Period	England	South East region	Brecknell Forest	Brighton and Hove	Buckinghamshire	East Sussex	Hampshire	Isle of Wight	Kent	Midway	Milton Keynes	Oxfordshire	Portsmouth	Reading	Slough	Southampton	Surrey	West Berkshire	West Sussex	Windsor and Maidenhead	Wokingham
Smoking Prevalence in adults - current smokers (HIS)	2013	18.4	17.2	18.3	25.2	14.3	15.4	15.4	15.1	15.5	21.8	19.0	14.7	22.9	17.1	22.8	21.5	14.8	15.4	17.2	15.3	12.5
Smoking prevalence in adults in routine and manual occupations - current smokers (HIS)	2013	25.8	28.2	25.5	34.3	25.4	27.4	27.5	28.3	25.4	33.8	30.2	25.1	35.7	31.3	25.1	30.3	32.7	25.4	25.8	30.2	22.5
Successful quitters at 4 weeks	2013/14	3514	3148	4058	3033	3052	3104	3387	3271	2432	3345	4335	4507	3147	4028	5233	2512	1902	3180	2383	4200	3356

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

# Longer Lives

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



# Longer Lives

In 2012, one in three deaths in England was under the age of 75<sup>1</sup>

Longer Lives highlights premature mortality across every local authority in England, giving people important information to help them improve their community's health.

See how your local authority compares

Enter postcode, town or local authority



## To use the map

1. Select an indicator below to see variations across England
2. Then select an area on the map to get the local picture
3. Or search for your area, postcode or town

[See national County & District Authority comparison table](#)

## Show data for

Overall premature deaths

### Cancer

Lung cancer  
Breast cancer  
Colorectal cancer  
Heart disease and stroke  
Mental diseases  
Stroke  
Lung disease  
Liver disease  
HIV  
[Epidemiological distribution](#)

## Premature mortality outcomes

- Worst
- Worse than average
- Better than average
- Best
- Not available

Change map to show

Countries & territory

Authorities

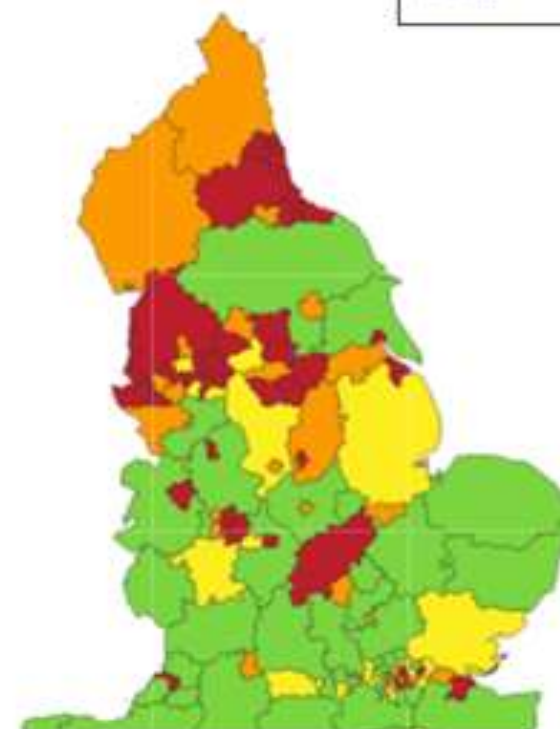
Postcodes & towns

Authorities

Zoom

+

-





# NCIN

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



**national cancer intelligence network**  
Using information to improve quality & choice

Search  **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.

**Cancer staging data 2013**  
Breakdowns of stage by cancer site for England, 2013

**Cancer Commissioning Toolkit**  
One stop shop for cancer data

### The National Cancer Intelligence Network

The NCIN is a UK-wide initiative, working to drive improvements in standards of cancer care and clinical outcomes by improving and using the information collected about cancer patients for analysis, publication and research.

[NCIN - 30 years of cancer intelligence](#) - a look back on the history.

[Find out more about NCIN.](#)

**Achieving World Class Cancer Outcomes - A strategy for England - [Executive summary-](#) and [Report-](#)**

#### Most recent publications

The following is a list of the most recent publications produced by NCIN

**Most recent** [show](#)

#### [Rare and less common cancers report](#)

Incidence and mortality for many rare and less common cancers (2010-2013) in England, produced in partnership with Cancer52

#### [New report on major resections by](#)

#### [Cancer roadshows 2015](#)

We are holding a series of half day roadshows in collaboration with the NHS Strategic Clinical Networks to provide commissioners, clinicians and data managers with an update on the cancer data collected and available. For further details of events near you please see the [roadshows events page](#).

11 July 2015

#### [Cancer and equality groups: key metrics 2015 report](#)

The most recent national and equality groups

Follow NCIN on Twitter!

Join the NCIN mailing list!

#### Understanding Cancer E-learning

Oncology training for NHS and Public Health non-clinical staff

07 Nov 2014

#### What cancer stats are available?

Download our useful reference guide.

24 July 2015

#### Links to recent cancer statistics

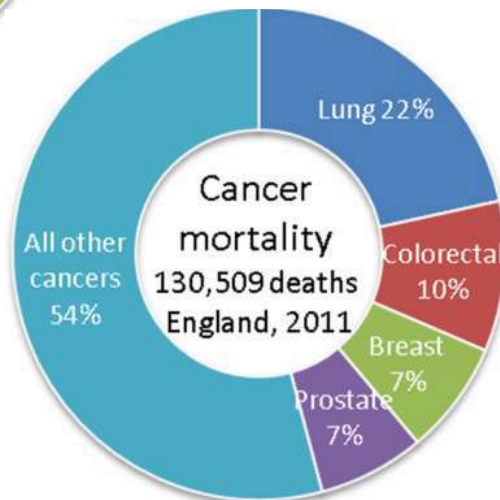
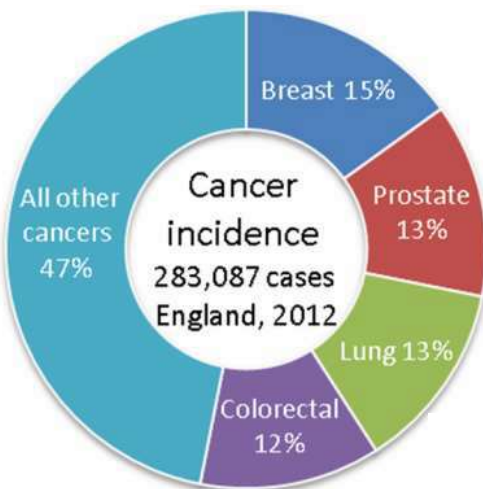
The most recent cancer incidence, mortality and survival statistics can be found here.

#### Health Intelligence

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# Bespoke analyses

## Rare and less common cancers



## Cancer of Unknown Primary

### Coding Cancer of Unknown Primary: registration and reporting survey of the UK, Ireland and Australia

Claudia Oehler<sup>1</sup>, Claire Vajdic<sup>2</sup>, Nicola Cooper<sup>1</sup>, John Symons<sup>3</sup>

<sup>1</sup> National Cancer Intelligence Network, Public Health England, UK;  
<sup>2</sup> University of New South Wales, Australia; <sup>3</sup> Cancer of Unknown Primary Foundation, UK

#### Cancer of unknown primary

- Cancer of Unknown Primary (CUP) is commonly a term for cancers that have spread from the primary site (i.e. metastases), for which site of origin cannot be determined with confidence, involving single or multiple metastatic sites.
- CUP can also cover a primary cancer of an ill-defined site, possibly limited to a single anatomical site, with or without the presence of metastases.
- In Australia and the UK, latest figures leave CUP as the 12th most common cancer diagnosis and 16th most common cause of death, respectively.
- Prognosis for these cancers is generally poor, although there are a small proportion of subtypes with better outcomes.

#### Spotlight: Why might CUP registration be problematic?

CUP is clinically heterogeneous, comprising a range of aetiologies and often complex presentations.

This clinical uncertainty leads to ambiguous notifications using varying terminologies, which can result in coding differences at registration.

Codes used for reporting CUP also vary substantially:

- England tends to use ICD-10<sup>a</sup> codes C77-C80;
- Some countries use just C80;
- Others again use C80, C83 and/or C85 in addition to either of the above.

This obscures an accurate assessment of the CUP burden, both nationally and internationally.

Figure 1: Definition of ICD-10 codes used to reporting CUP

#### The registration and reporting survey

- This survey is a first attempt at documenting existing cancer registration and reporting with direct participation of cancer registration services.
- The aim is to compare CUP registration and reporting practices in Australia, the UK and Ireland, with a view to supporting improved national/international standardisation.
- 32 registration services in Australia (n=1), the UK (England n=1, Northern Ireland n=1, Scotland n=1) and Wales (n=1) participated.
- The questionnaire consisted of two parts: the first covering registration coding rules, coding practices, death certificate notifications, classification processes, the second reporting practices (rates, level and incidence by site code, source of diagnosis and morphology).

#### Results from the survey

All registries responded to the questionnaire. Results confirm variation in registration and reporting practices on almost every aspect covered, though a few displayed greater consistency than others.

	Australia	England	Ireland	Scotland	Wales	Total	Percent
Q2: Does your registry have a definition that specifically defines the registration of CUP?	Yes	1	0	0	1	2	100%
Q3: Do you use additional terminology (non-working ICD)	Yes	1	1	0	0	2	100%
Q4: Do you use additional terminology (non-working ICD)	Yes	1	1	0	0	2	100%
Q5: Do you use additional terminology (non-working ICD)	Yes	1	1	0	0	2	100%

Figures 2a and 2b: Coding CUP using preferred ICD-10 codes. Response rates of the countries in order of increasing consistency for first question.

Figures 3a and 3b: Report of cases of CUP by site code and morphology in prior registrations.



# 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<sup>1</sup>, Sam Johnson<sup>1</sup>, David Greenberg<sup>2</sup>, Michael Peake<sup>1</sup>, Brian Rous<sup>2</sup>

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<sup>1</sup> (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 86% (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

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

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

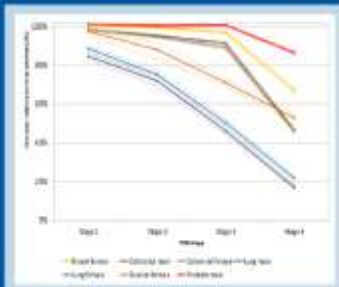


Figure 1.0 Age-standardised one-year relative survival estimates by imputed third stage at diagnosis, cancer site, sex, England, 2012

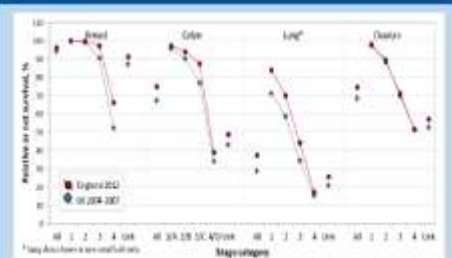


Figure 2.0 One-year unstandardised relative survival, by stage, in the ICBP and England 2012 data

## 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<sup>1</sup>, S McPhail<sup>2</sup>, J Shelton<sup>2</sup>, L Irvine<sup>2</sup>, M Peake<sup>2</sup>

<sup>1</sup>Knowledge & Intelligence Team (East); <sup>2</sup>National Cancer Intelligence Network, both Public Health England

#### Introduction

In 2012/13 there were

**75 million outpatient attendances**

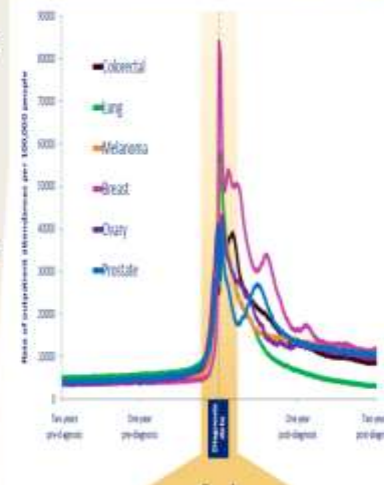
across all disease types in England NHS hospitals.

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

Figure 1. Outpatient activity two years either side of cancer diagnosis date



#### 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<sup>1</sup>, S McPhail<sup>1</sup>, A Ives<sup>2</sup>, M Greenslade<sup>2</sup>, J Shelton<sup>1</sup>, S Hiom<sup>3</sup>, M Richards<sup>4</sup>

<sup>1</sup>) National Cancer Intelligence Network, London; <sup>2</sup>) Public Health England Knowledge and Intelligence Team (South West), Bristol; <sup>3</sup>) Cancer Research UK, London; <sup>4</sup>) 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<sup>1</sup>, Sean McPhail<sup>1</sup>, Lucy Elliss-Brookes<sup>1</sup>, Matthew Greenslade<sup>2</sup>, Alex Ives<sup>2</sup>, Jon Shelton<sup>1</sup>

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'<sup>1</sup>. 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?

20What data are available, and how are they accessed?



# Bespoke analyses

## Inequalities: deprivation

## ethnicity

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

C Oehler<sup>1</sup>, J Yiallourou<sup>2</sup>, N Ormiston-Smith<sup>2</sup>, L Ellis-Brookes<sup>1</sup>, S McPhail<sup>1</sup>

<sup>1</sup> National Cancer Intelligence Network, Public Health England;  
<sup>2</sup> Statistical Information Team, Cancer Research UK

### Introduction

Although cancer outcomes in the UK are improving they still appear to lag behind comparable countries in Europe<sup>1</sup>. Improving Outcomes: A Strategy for Cancer<sup>2</sup> 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 least 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<sup>3</sup>, 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<sup>4</sup> datasets.

Age-standardised rates were calculated using the 1976 European Standard Population<sup>5</sup> 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 (8,002 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 300 female deaths per year, during the 5 years.

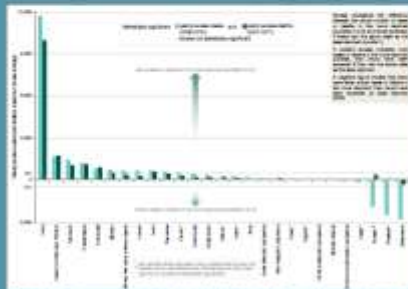


Figure 1: Yearly new cancer cases and deaths for 37 sites in England, broken down by deprivation quintile (1-5) for incidence (2006-2010) and mortality (2007-2011).

- For prostate, 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 6 most substantial of these 10 sites.
- Mortality trends showed no statistically significant change from 2002 to 2011.

**There would have been around 15,300 fewer cases and 19,200 fewer deaths per year for all cancers combined<sup>3</sup>, 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, oesophagus, while smaller in absolute terms, nevertheless show strong association with increasing deprivation, as shown to 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.

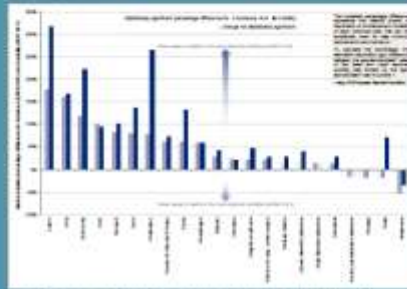


Figure 3: Male worst-off percentage difference for incidence, 1996-2010, and mortality, 2007-2011, in England.

**Breast cancer screening uptake in ethnic groups in London**

Ruth H Jack<sup>1</sup>, Henrik Moller<sup>2</sup>, Tony Robson<sup>3</sup>, Elizabeth A Davies<sup>1,2</sup>

<sup>1</sup>Knowledge & Intelligence Team (London), <sup>2</sup>King's College London, Public Health England <sup>3</sup>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 50-59 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 159,070 women were included in the first call analysis, and on 400,438 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 Pakistan and Bangladesh 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.

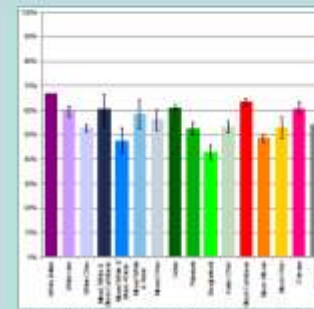


Figure 1: Women invited for their first call breast cancer screening appointment, aged 50-52. Proportion of women attending appointment in different ethnic groups, adjusted for age at invitation, socioeconomic deprivation and screening area. White British women used as baseline.

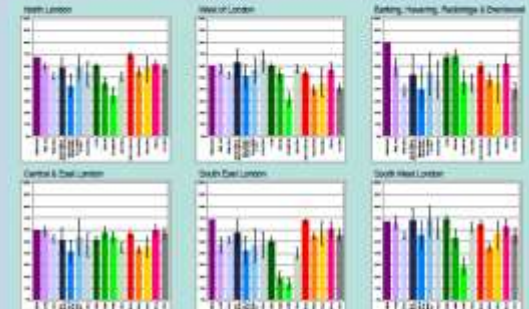


Figure 2: Women invited for their first call breast cancer screening appointment, aged 50-52, by screening area. Proportion of women attending appointment in different ethnic groups, adjusted for age at invitation, socioeconomic deprivation and screening area. White British women used as baseline.

# Bespoke analyses

Tumour specific: breast cancer

lung cancer



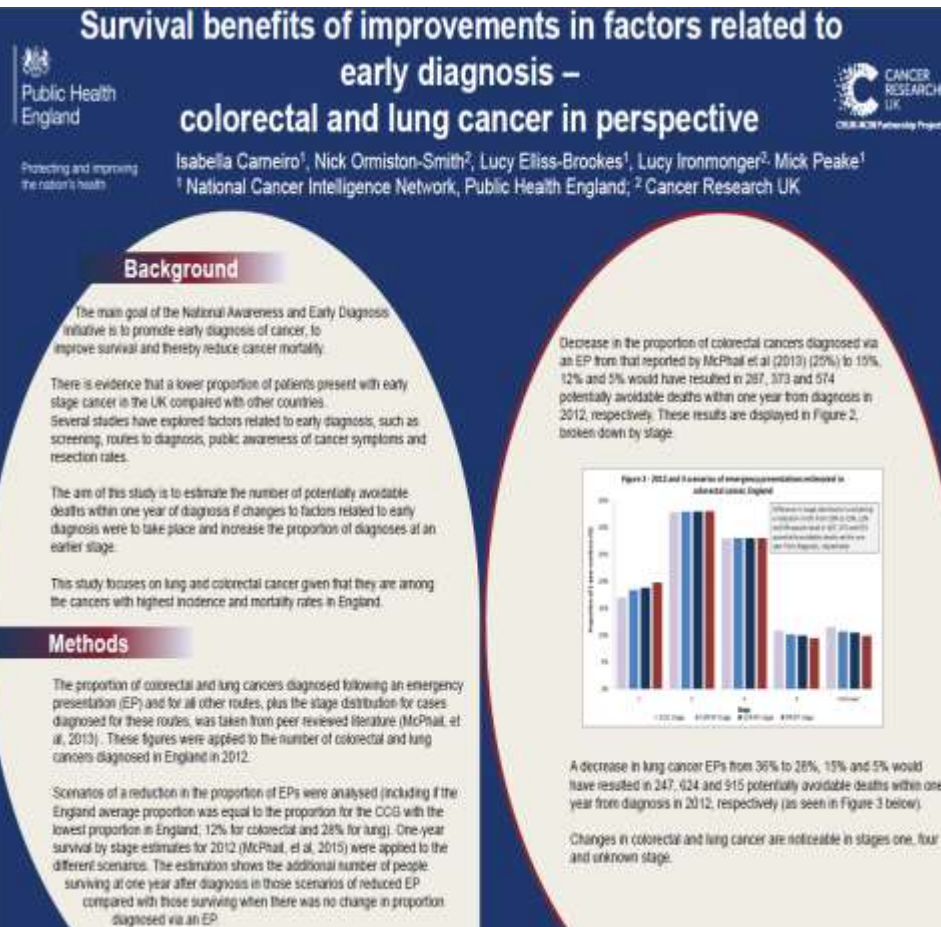
Protecting and improving the nation's health

## 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



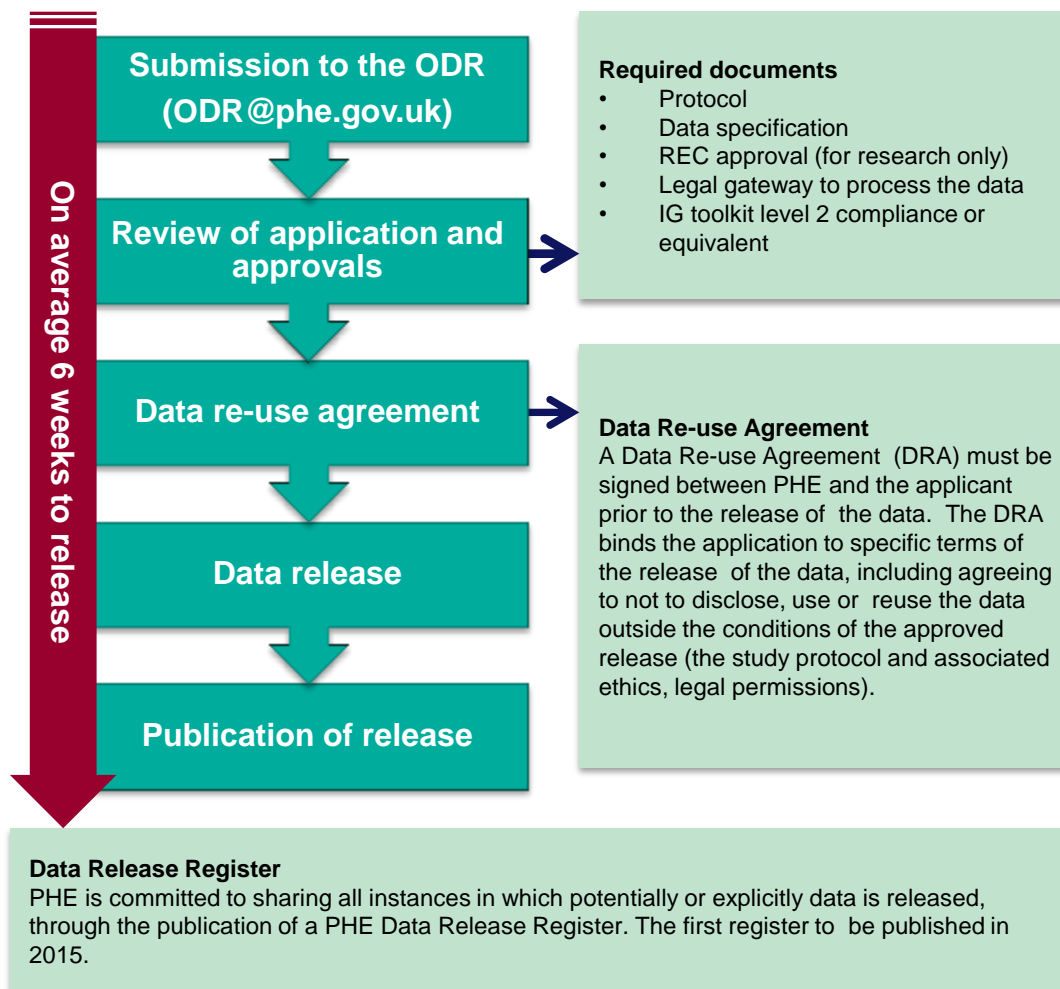
# PHE Office for Data Release

**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.

## **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





# Understanding Cancer e-learning

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



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Here you will find Understanding Cancer e-learning modules and also archived material from the East Midlands Cancer Network on cancer / End of life e-learning and evaluation toolkit.

This site can be viewed from any computer with access to the internet. It is completely free to use this site – to create an account [click here](#)

More information on how to use this site can be accessed [here](#).

For help with this site please contact us at [mylearningspace@ncin.org.uk](mailto:mylearningspace@ncin.org.uk) or telephone Steve on 07906 067 215

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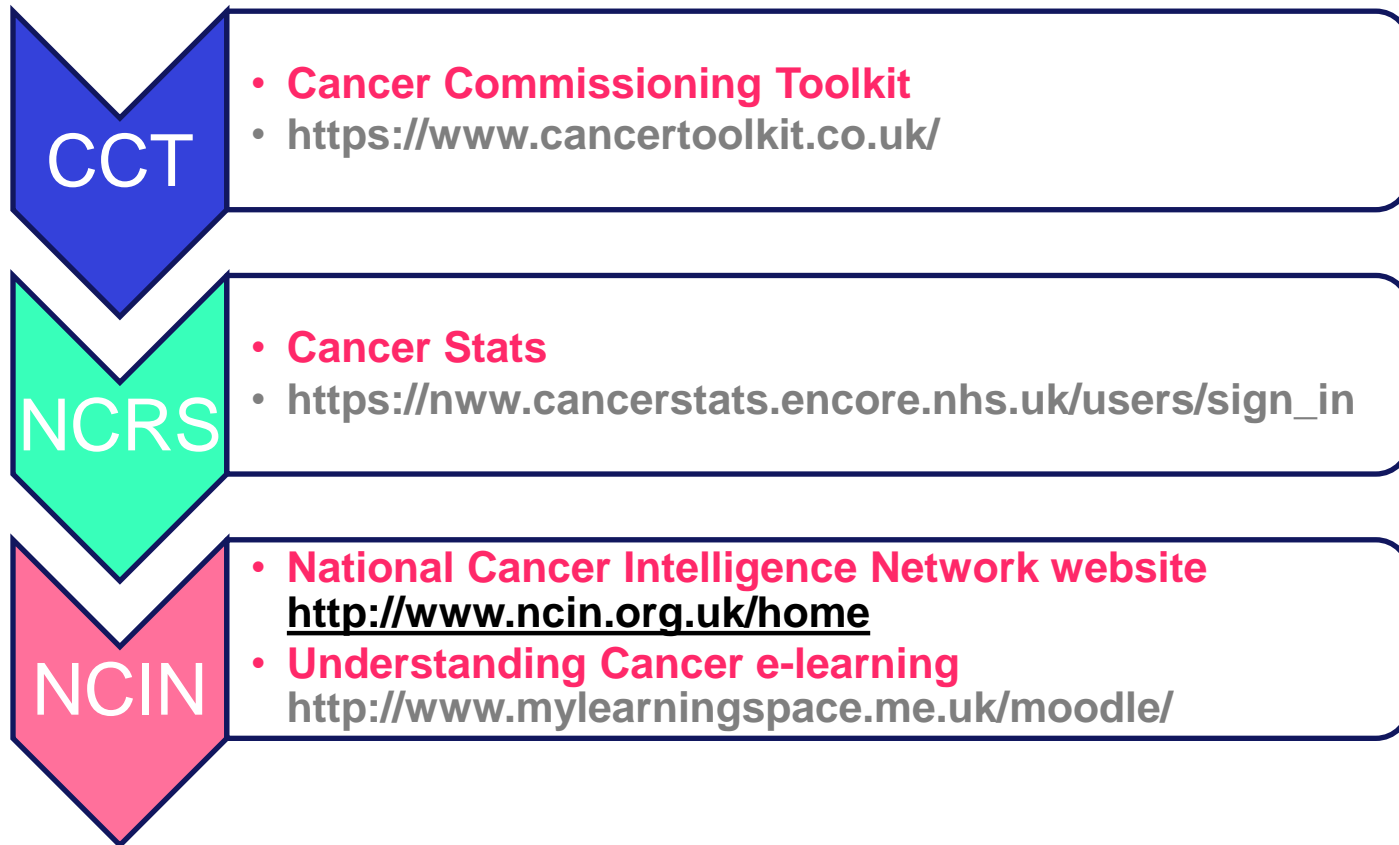


[User Survey Report is now available to download from the NCIN website](#)

24What data are available, and how are they accessed?



# Cancer data URL



# Other data URLs

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

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