



Public Health
England

Protecting and improving the nation's health

Local engagement: explanation of cancer data, tools, terminology and outputs

Use of cancer intelligence by local teams

National Cancer Registration and Analysis Service

About Public Health England

Public Health England exists to protect and improve the nation's health and wellbeing, and reduce health inequalities. We do this through world-class science, knowledge and intelligence, advocacy, partnerships and the delivery of specialist public health services. We are an executive agency of the Department of Health, and are a distinct delivery organisation with operational autonomy to advise and support government, local authorities and the NHS in a professionally independent manner.

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Executive summary

The National Cancer Registration and Analysis Service registers all cancers diagnosed in England. This information is used to support healthcare purposes at both the local and national level. NCRAS collects detailed data on every patient with cancer into the secure environment within PHE. An overview of the registration process can be found in this [patient leaflet](#), including what data we collect, how it is used and how a patient can opt out if they wish.

The cancer pathway is the patient's journey in the healthcare system from suspicion of cancer to confirmed diagnosis, treatment, and outcome. This report provides an overview of the data available along the cancer pathway, and the metrics and outputs designed to provide intelligence from this data. The issue of data quality will be discussed, to ensure that the appropriate limitations are considered. This report does not aim to provide a list of all possible data sources, but rather aims to equip the reader with the necessary context and key measures to focus on across the cancer pathway.

1. Introduction

Cancer is a public health priority as, among individuals born since 1960, one in two people will be diagnosed with cancer in their lifetime ^[1]. In 2014, 33,759 people were diagnosed with malignant cancer in London (excluding non-melanoma skin cancer) and 296,812 were diagnosed in England. In terms of deaths, there were 13,632 and 133,715 deaths from malignant cancers in London and England, respectively.

A wealth of data is recorded on cancer patients, and it is processed and collated by the National Cancer Registration and Analysis Service (NCRAS) in Public Health England (PHE). NCRAS aims to collect data on all cases of cancer diagnosed in people living in England. There are also a number of other data sources held in PHE that provide further information on diagnostics, treatments, hospital activity and mortality. These data sources provide data throughout the cancer pathway, which is the patient's journey in the healthcare system from suspicion of cancer to confirmed diagnosis, treatment, and outcome.

It is vital to use the data to create intelligence and ultimately improve the experience of all cancer patients including those who will be diagnosed in the future. These data sources can be used to highlight variation across the pathway, and drive improvement in cancer care and outcomes through analyses and the creation of metrics (indicators). The data is used to monitor new cases of cancer in the population and look at trends and geographical patterns so that we can detect risk factors and cancer clusters.

This report provides an overview of the data available along the cancer pathway, and the metrics and outputs designed to provide intelligence from this data. The issue of data quality will be discussed, to ensure that the appropriate limitations are considered. This report does not aim to provide a list of all possible data sources, but rather aims to equip the reader with the necessary context and key measures to focus on across the pathway. Examples of outputs for London will be included where appropriate, but the content is applicable to all local regions.

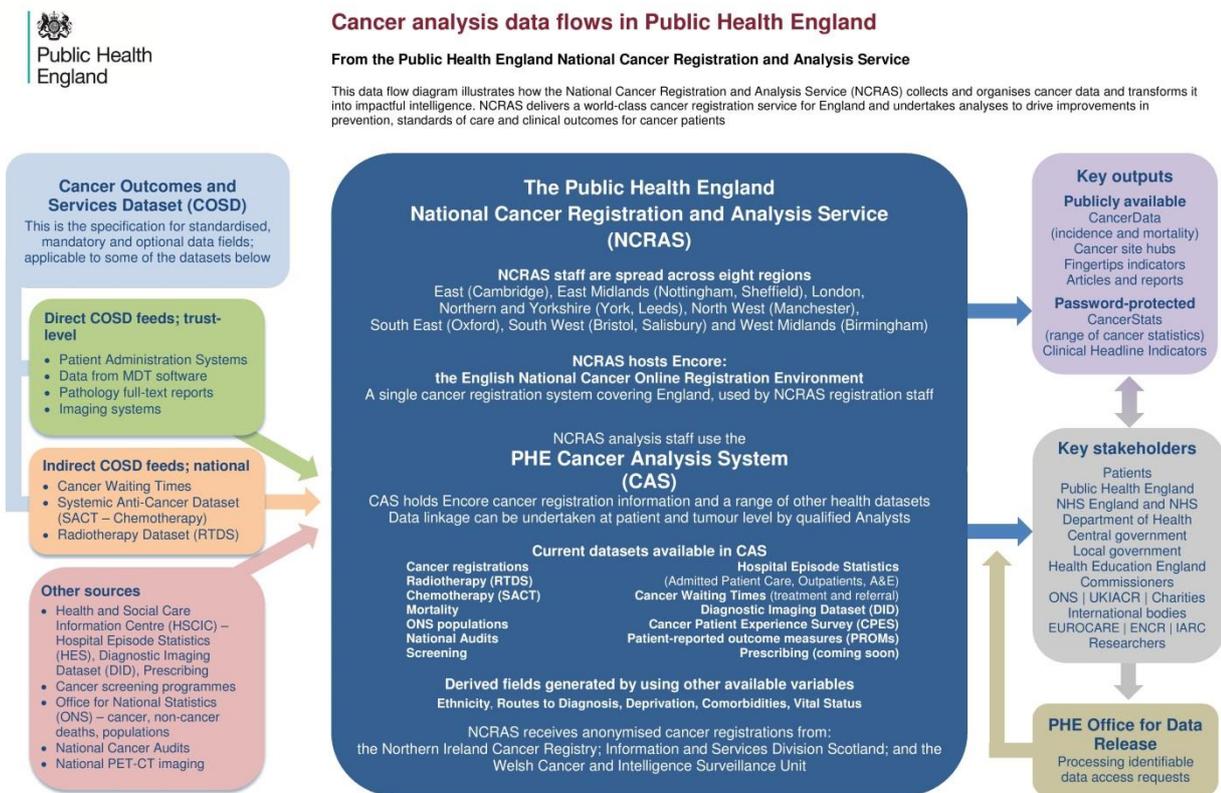
A comprehensive signposting document is available ^[2] that lists the latest statistics publicly available, including information on international comparisons. This document provides more explanatory and contextual information than is available in the signposting document ^[2], including for those readers who may not know what cancer data and information are available.

2. Sources of cancer data in PHE

NCRAS aims to register all cancers diagnosed in England. A number of healthcare data sources are used for this, and Figure 1 summarises these data flows [3]. There is a key distinction between cancer registration data that is collated by NCRAS staff, and additional data sources that we link to the core cancer registration data. These two areas will be addressed in the next two sections.

The different cancer datasets hosted by NCRAS are processed and released for analysis according to data availability, whilst maintaining patient confidentiality at all times. Data processing for cancer registrations is undertaken by NCRAS registration officers and the time lag between receipt of cancer registration details from healthcare providers and data validation by NCRAS has decreased considerably, so that we continue to move towards using more ‘real time’ cancer data.

Figure 1: Cancer analysis data flows in Public Health England



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2.1 Cancer Outcomes and Services Dataset

The Cancer Outcomes and Services Dataset (COSD) is the national standard for reporting cancer in the NHS in England. This has been in place since January 2013. The COSD specifies the items to be submitted electronically by service providers (ie hospital trusts) on a monthly basis. It also identifies the items that NCRAS will obtain from other sources such as Cancer Waiting Times, Cancer Screening Programmes and the Office for National Statistics (ONS). This relates to the green and orange boxes titled the COSD feeds in Figure 1.

Registration staff across the country use the data submitted by hospital trusts, using this standard to create a cancer registration. This will be referred to as the 'core cancer registration data'.

The majority of the core registration items are obtained from multidisciplinary team (MDT) software, and pathology reports are used to supplement the record when needed, as are other data feeds. Information about the various iterations of COSD and other technical details are available on our [website](#).

Each cancer registration record holds information on demographic and clinical details. For example, age, sex, ethnicity, postcode and GP practice, and admission date, diagnosis, stage, pathology and treatment.

2.2 Other sources of information

There are a number of different data sources that are available in NCRAS, and they are listed under the 'Other sources' section of Figure 1. These are all patient-level datasets, and are linked to the core cancer registration data. They provide information on all parts of the patient pathway, and their use will be described later on in this report. The current datasets are listed below and definitions are available on our [website](#):

- CPES: Cancer Patient Experience Survey
- CWT: Cancer Waiting Times
- DID: Diagnostic Imaging Dataset
- HES: Hospital Episode Statistics (Admitted Patient Care, Outpatients and A&E)
- Mortality
- National audit data for bowel, head and neck, lung, oesophago-gastric and prostate cancers
- Primary care prescriptions
- PROMs: Patient-reported outcome measures

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- RTDS: Radiotherapy Dataset
- SACT: Systemic Anti-Cancer Therapy dataset
- Screening for bowel, breast and cervical

There is also non-patient-level information available, namely the ONS populations.

3. Key data tools

The main data tools will be described throughout this document; but below is a reference list of the key cancer data tools available that contain information at the local level:

- **CancerStats** and **CancerData**. These are portals containing the latest cancer statistics. CancerData is publicly accessible and currently contains cancer incidence and mortality statistics. CancerStats contains a wider range of cancer statistics by a range of geographies and requires an account and N3 internet connection. This was formerly known as CASCADE, and contains the Cancer Outcomes and Services Dataset (COSD) data and other cancer metrics. Following the recommendations from the Achieving World Class Outcomes report by the Independent Cancer Taskforce, the cancer dashboard is now available on CancerData. The cancer dashboard, co-produced by NHS England and PHE, is intended as a tool to help clinical leaders, commissioners and providers to quickly and easily identify priority areas for improvement in their cancer services. Data are presented at both clinical commissioning group (CCG), Cancer Alliance and provider levels
- **PHE and Macmillan's Local Cancer Intelligence**. A range of statistics including incidence, mortality, prevalence and survival
- **Fingertips Public Health Profiles tool**. There are a variety of cancer metrics contained within the Fingertips Public Health Profiles data portal, including the Cancer Services Profiles and GP Practice Profiles
- **Local health**. A tool developed by PHE to present data at 'small area' level (MSOA, ward, local authority, CCG and England) with indicators available for incidence of all cancers, breast, colorectal, lung and prostate cancer. The main functionality of this tool is mapping
- **Public Health Outcomes Framework (PHOF)**. This PHE tool includes regional data on a wide range of public health metrics, including cancer metrics on screening coverage and cancer diagnosed at early stage (experimental). This tool can also be accessed through FingerTips
- **Cancer Research UK's Local Cancer Statistics**. A range of statistics on early diagnosis, incidence, survival, mortality, screening, lifestyle factors and patient experience. This tool allows a comparison between geographies

In London, RM (Royal Marsden) Partners, one of the pilot sites of the national vanguard, has produced a comprehensive metrics pack for each cancer type. Figure 2 is a sample contents page that lists the metrics contained in each pack. These packs pull together data from PHE and other sources (many of which are publically available), and are aimed for use within the NHS. To get

more information, or to gain access to this resource (if you are employed by the NHS), please contact: cancerinformatics-manager@rmpartners.kahootz.com

Figure 2: Sample of the metrics provided in the vanguard cancer informatics packs for NHS use

<p>1. Cancer Waiting Times</p> <p>1.1.2 week wait GP urgent referral to 1st seen 1.1.1 By Provider 1.1.2 By Tumour Type</p> <p>1.2.2 week wait breast symptomatic to 1st seen 1.2.1 By Provider</p> <p>1.3. 31 day decision to treat to 1st treatment 1.3.1 By Provider 1.3.2 By Tumour Type</p> <p>1.4. 31 day subsequent surgery 1.4.1 By Provider 1.4.2 By Tumour Type</p> <p>1.5. 31 day subsequent drugs 1.5.1 By Provider 1.5.2 By Tumour Type</p> <p>1.6. 31 day subsequent radiotherapy 1.6.1 By Provider 1.6.2 By Tumour Type</p> <p>1.7. 62 day GP urgent referral to 1st treatment 1.7.1 By Provider – unadjusted 1.7.2 By Tumour Type 1.7.5 Comparison of tumour type by historic cancer network 1.7.6 Distribution by week treated 1.7.7 Performance by area team (England) 1.7.8 Provider performance – Monitor declarations</p> <p>1.8. 62 day screening to 1st treatment 1.8.1 By Provider – unadjusted 1.8.2 By Tumour Type</p> <p>1.9. 62 day consultant update to 1st treatment 1.9.1 By Provider – Unadjusted 1.9.2 By Tumour Type</p> <p>1.10 – Trends in Cancer Waiting Times reported volumes</p>	<p>2. Data collection</p> <p>2.1 Log of COSD feeds received by NCRS</p> <p>2.2 % Data quality of MDT feed to Cancer Registry 2.2.1 Staging data 2.2.2 Basis of diagnosis 2.2.3 Performance status 2.2.4 CNS contact indication</p> <p>2.3. SACT compliance data completeness</p> <p>2.4 National Audits submission rates LUCADA NBOCAP DAHNO OG cancer audit</p> <p>3. Patient experience</p> <p>3.1 NCPES 2013/14 League table – bottom 10 Macmillan method</p> <p>3.2 NCPES 2013/14 League table – top 10 Macmillan method</p> <p>3.3 NCPES 2013/14 League table – LCA alternative</p> <p>3.4 NCPES 2013/14 – League table – Most improved 2012/13 to 2013/14</p> <p>3.5 NCPES 2013/14 – League table – Most improved 2010 to 2013/14</p> <p>3.6 NCPES – Q12 – Patient felt they were told sensitively they had cancer</p> <p>3.7 NCPES Q21 – Patient given name of the CNS in charge</p> <p>3.8 NCPES Q22 – Patient finds it easy to contact CNS</p> <p>3.9 NCPES Q30 – Taking part in cancer research discussed with patient</p> <p>3.10 – NCPES Q38 – Patient had confidence and trust in all doctors treating them</p> <p>3.11 NCPES Q44 – Always/nearly always enough nurses on duty</p> <p>3.12 NCPES Q52 – Patient given clear written information about what should/should not do post discharge</p> <p>3.13 NCPES Q67 – Patient given right amount of information about condition and treatment</p>	<p>3. Patient experience</p> <p>3.14 NCPES Q70 – Patient's rating of care 'very good'/'excellent'</p> <p>4. Prevention/Early diagnosis</p> <p>4.1 Routes of diagnosis</p> <p>4.2 GP practice 2 week wait referral rates</p> <p>4.3 CCG 2 week wait referral rates</p> <p>4.4 CCG 2 week wait conversion rates</p> <p>4.5 Screening 4.5.1 Breast Screening Coverage 4.5.2 Cervical Screening Coverage 4.5.3 Bowel Screening Coverage</p> <p>5. Diagnosis</p> <p>5.1 – Stage at diagnosis</p> <p>6. Treatment</p> <p>6.1 Place of death</p> <p>6.2 JAG accreditation scores endoscopy</p> <p>6.3 HNA/Recovery package 6.3.1 HNA at diagnosis 6.3.2 HNA at end of treatment 6.3.3 Treatment summary at end of treatment 6.3.4 Health and Well Being Events</p>	<p>6. Treatment</p> <p>6.4 Percentage of patients seeing AHP 6.4.1 Physiotherapist 6.4.2 Occupational Therapist 6.4.3 Dietician 6.4.4 Speech and Language Therapist 6.4.5 Lymphedema Specialist</p> <p>6.5 IMRT rates</p> <p>6.6 Chemotherapy mortality rates 6.6.1 – By provider 6.6.2 – By tumour type</p> <p>6.7 Implementation of risk stratified pathways</p> <p>7. Incidence/mortality/survival</p> <p>7.1 – Incidence rates – Overall 7.1.1 – Males 7.1.2 – Females</p> <p>7.2 - Mortality rates – Overall 7.2.1- Males 7.2.2 – Females</p> <p>7.3 – Survival rates - Overall 1 year 3 year 5 year 10 year 1 year survival by Cancer Network 1 year survival by age bracket</p> <p>7.4 – Number of new cases per year Overall Male Female</p> <p>7.5 – Number of deaths per year Overall Male Female</p> <p>7.6 Prevalence of cancer Male Female</p> <p>8. Cancer Research</p> <p>8.1 NCRN clinical trials data</p>
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4. Implications of data quality

Data quality assessments are a vital part of any analysis. Understanding data quality should prevent misinterpretations and incorrect conclusions from being drawn, as data items with poor quality should be identified from the outset and either be excluded from analyses, taken into account with statistical modelling or the limitations made clear in the narrative accompanying the metrics or analyses. Attention should be drawn to items with poor data quality in order to drive improvements. In cancer there are a number of tools that allow the user to assess the data quality before drawing conclusions:

- COSD Level 1 and Level 2 reports on [CancerStats](#) (accessible via a N3 connection)
- SACT data portal (accessible for NHS trusts via the [SACT website](#))
- Audit data portals (accessible via the individual national audit websites, see page 13)
- UKIACR key performance indicators (publically available [online](#))

4.1 Example: data quality of stage at diagnosis using COSD

NCRAS chose a small number of vital data items to focus on improving data quality. Stage at diagnosis describes the size of a cancer and how far it has spread. It helps define the treatment a patient should receive and is very closely linked to patient outcome. A national target of 70% completeness for staging data was defined within the [National Audit Office report on the Cancer Reform Strategy](#), and trusts had to meet this benchmark with their data submissions. This benchmark was achieved for cancer registrations diagnosed from 2012 onwards, which has enabled a number of projects to be published that were not previously possible:

- [routes to diagnosis by stage](#)
- [stage data by CCG](#)
- [survival by stage](#)
- [cancer outcome metrics](#)

If a particular trust or CCG had a low completeness value for this variable, then caution should be applied when drawing conclusions from any outputs with breakdown by stage for that organisation. This measure can be found using our online tool [CancerStats](#), using Level 2 COSD.

Figure 3: Example data quality report for stage at diagnosis from Level 2 COSD in our online tool **CancerStats**

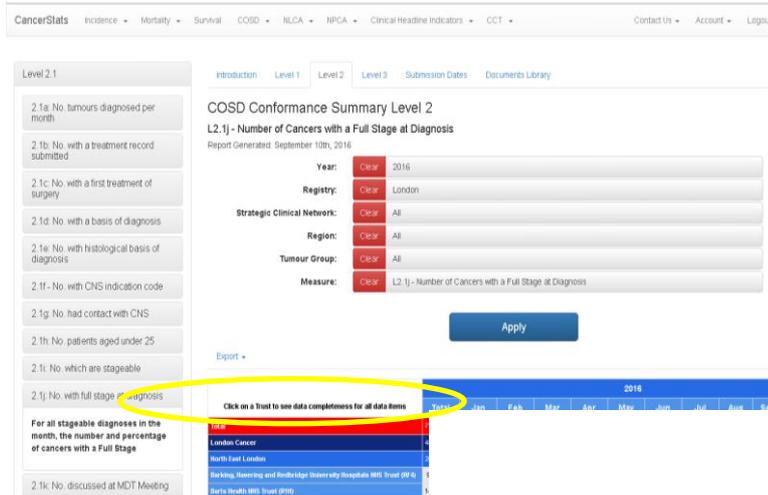
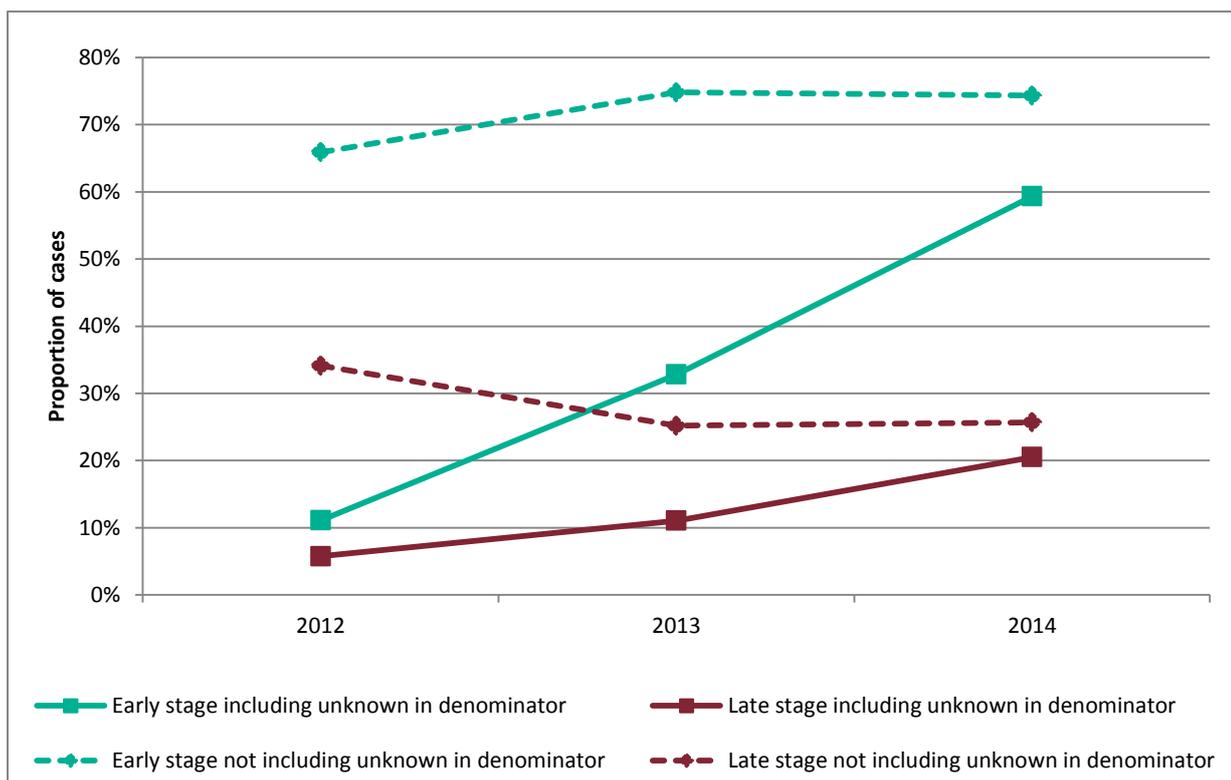


Figure 4 shows the counts using TNM stage group (a particular staging system which stands for Tumour, Nodes, Metastases) for bladder cancer, grouped into early and late stages. Two trends are presented for both early and late stage, which clearly highlight the impact of including the unknown stage in the denominator to calculate the percentage. If the unknowns had not been accounted for, the conclusions drawn could have been very misleading.

Figure 4: Proportion of bladder cancer cases diagnosed in London during 2012 to 2014 by TNM stage (source: **stage data by CCG**, note early stage: stages 1&2 and late stage: stages 3&4)



4.2 Example: audit data

There are a number of national cancer audits: National Lung Cancer Audit (NLCA), National Bowel Cancer Audit Programme (NBOCAP), National Head and Neck Audit (DAHNO), National Oesophago-Gastric Cancer Audit, National Prostate Cancer Audit (NPCA), National Cancer Diagnosis Audit (NCDA). Each audit publishes annual reports which are publically available through their websites. CancerStats provides data quality information on NLCA and NPCA, an example of which is shown in Figure 5. For each data item, the user can view the data completeness for every trust. The annual reports for each audit also provide a wealth of information on data quality and are available in the references listed for each audit above.

Figure 5: Example data quality report from NLCA accessed in our online tool CancerStats

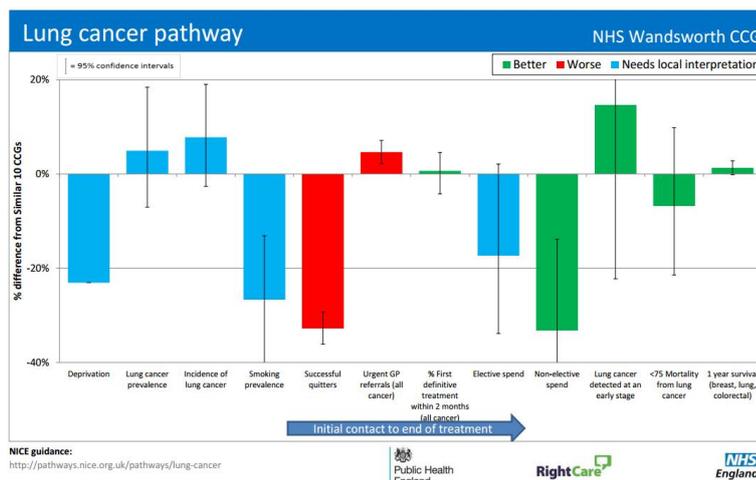
The screenshot shows the CancerStats interface for the NLCA Data Completeness Reports. The top navigation bar includes 'CancerStats' and various filters like 'Incidence', 'Mortality', 'Survival', 'COSD', 'NLCA', 'NPCA', 'Clinical Headline Indicators', and 'CCT'. The sidebar on the left lists data completeness categories from 1 to 7. The main content area is titled 'NLCA - Data Completeness Reports' and shows '1.1 Diagnoses' with a report generated on September 10th, 2016. Below this are several filter buttons: Year (2016), Registry (London), Strategic Clinical Network (All), Region (All), Tumour Group (All), and Measure (1.1 Diagnoses). An 'Apply' button is present. Below the filters is an 'Export' button and a table for the year 2016. The table has columns for 'Total', 'Jan', 'Feb', 'Mar', 'Apr', 'May', 'Jun', 'Jul', 'Aug', 'Sep', 'Oct', 'Nov', and 'Dec'. The rows are 'Total', 'London Cancer', 'North East London', and 'Barking, Havering and Redbridge University Hospitals NHS Trust (RF4)'. A yellow circle highlights a tooltip that says 'Click on a Trust to see data completeness for all data items'.

5. The cancer pathway

The cancer pathway is the patient’s journey in the healthcare system from suspicion of cancer to confirmed diagnosis, treatment, and outcome. There are a number of elements along a cancer pathway, and there are data sources and metrics available throughout the pathway. Each section will be discussed in turn below.

To view an overview of the pathway, NHS RightCare has produced a range of Commissioning for Value **data packs**. These include the ‘Pathways on a Page’ pack, which partially focus on cancer and present data at a CCG level, an example of which is shown in Figure 6. The pathways were based on the relevant NICE guidance.

Figure 6: Lung cancer pathway on a page



5.1 Pre-diagnosis

Lifestyle factors

There are a number of lifestyle factors that have been shown to increase the risk of developing cancer. For example, smoking increases the risk of lung cancer [4]. A number of indicators/metrics on lifestyle can be found on the **Public Health Outcomes Framework Profiles** produced by PHE. As an example ‘Local Tobacco Control Profiles’ include a number of indicators on tobacco use and tobacco harm. The **PHE data gateway** also provides website links to all of the data and analysis tools from across PHE.

A few of the metrics are:

- proportion of individuals aged 65+ years
- smoking prevalence
- excess weight in adults
- deprivation score
- incidence of alcohol-related cancer

Cancer Research UK has a resource for [Local Cancer Statistics](#), and these provide information on lifestyle factors associated to cancer. A number of the metrics have used PHE data tools as their source.

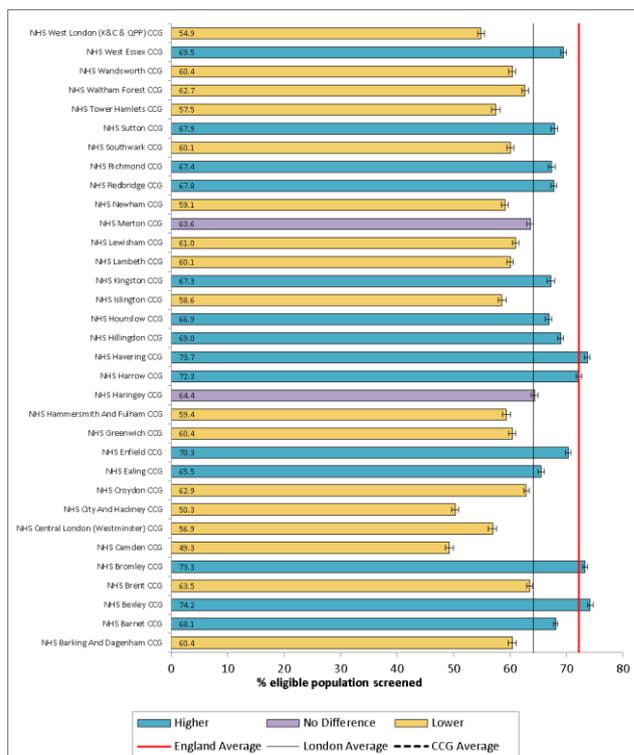
Screening

Cancer screening is an important intervention for early detection. There are currently three national screening programmes, for breast, cervical and bowel cancer. Analysis has shown that screening saves about one life from breast cancer for every 200 women who are screened. This adds up to about 1,300 lives saved from breast cancer by screening each year in the UK ^[5].

There are two key high-level metrics used to measure screening: uptake and coverage. **Coverage** is the number of individuals registered to a practice who were adequately screened in the previous months, divided by the number of eligible individuals on the last day of the review period. The numerator for measuring **uptake** is the number of individuals registered to the practice of the eligible age invited for screening in the previous 12 months who were screened within six months of invitation. The denominator is the total number of individuals of the eligible age invited for screening in the previous 12 months.

[FingerTips](#) is a publically available tool and includes uptake and coverage metrics for breast screening, cervical screening and bowel cancer screening. These metrics have also been used to create [Practice Profiles Plus](#), which provides a summary of the key diagnosis and referral indicators for a General Practice or CCG with regards to cancer. Each indicator is accompanied by a description of key contextual or influencing factors and provides information on local and/or national resources and initiatives which practices can draw on to help improve cancer outcomes. Figure 7 is an example of the graphs available in Practice Profiles Plus.

Figure 7: Area comparison of females, 50-70, screened for breast cancer in last 36 months for London by CCG (3 Year Coverage, %)



5.2 Routes to diagnosis

There are a number of different ways that a patient can be diagnosed with cancer. For example, via a screening programme, a GP appointment, or a visit to an Accident and Emergency department. NCRAS has developed a methodology by which the route the patient follows to the point of diagnosis can be categorised, in order to examine demographic, organisational, service and personal reasons for delayed diagnosis [6]. The route to diagnosis algorithm combines data from HES, CWT, cancer screening programmes and cancer registration data. The route is categorised into the eight groups shown in Table 1.

Table 1: Description of each route to diagnosis

Route	Description
Screen Detected	Detected via the breast, cervical or bowel screening programmes
Two Week Wait	Urgent GP referral with a suspicion of cancer, using the two week wait (TWW) guidelines
GP Referral	Routine and urgent referrals where the patient was not referred under the Two Week Wait referral route

Other Outpatient	An elective route starting with an outpatient appointment: either self-referral, consultant to consultant or other referral
Inpatient Elective	Where no earlier admission can be found prior to admission from a waiting list, booked or planned
Emergency Presentation	An emergency route via A&E, emergency GP referral, emergency transfer, emergency consultant outpatient referral or emergency admission or attendance
Death Certificate Only	No data available from inpatient or outpatient Hospital Episode Statistics (HES), cancer waiting times (CWT), screening and with a death certificate only diagnosis flagged by the registry in the cancer analysis system
Unknown	No data available from inpatient or outpatient HES, CWT, screening within set time parameters or unknown referral

There have been a number of **publications** from this NCRAS work stream, including peer-reviewed papers, data tables and narrative reports for a large range of cancer sites. The routes to diagnosis data workbooks present two types of data: the percentage of total cancers that are diagnosed by each route, and the relative survival for each route. A London-specific workbook has been published, which examined the variation across the five delivery sectors in London.

Figure 8 is taken from a **conference poster** using these results, and highlights the variation within London. National routes to diagnosis work have found that relative survival is lowest for emergency presentations for every tumour group (see section 5.8 for a discussion of survival). Figure 9 presents the relative survival for colorectal cancer as an example of the variation across seven of the eight routes to diagnosis (death certificate only is excluded) individually and various follow-up periods.

Figure 8: Variation in route to diagnosis by sector of London for all malignant cancers for 2006 to 2013 combined

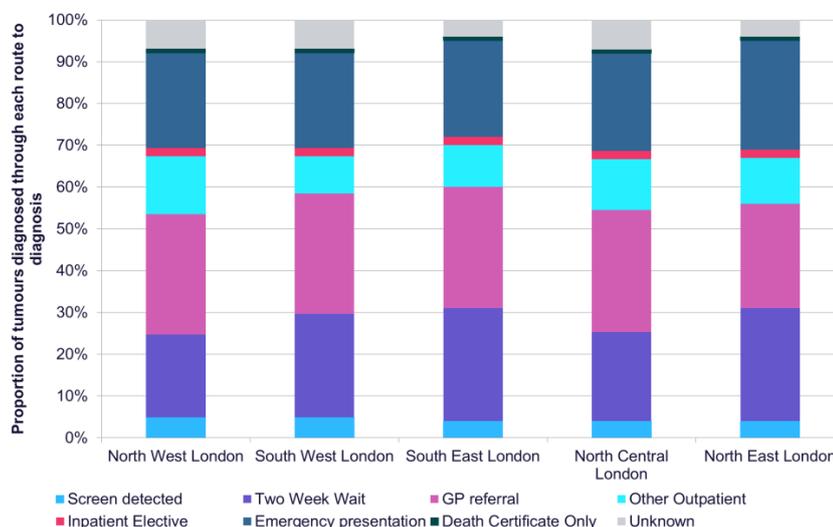
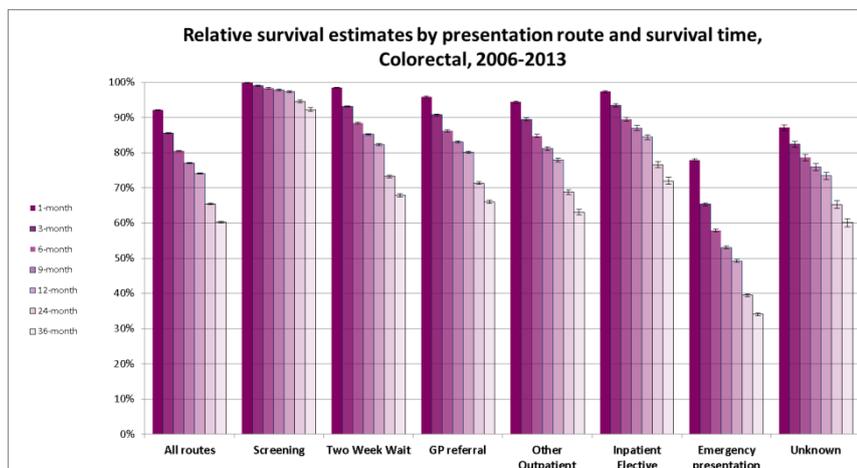


Figure 9: Relative survival estimates by presentation route and survival time for colorectal cancer in England during 2006 to 2013



It is important to note that emergency presentations can be derived using data from HES only, and this is the methodology used in the metrics on **FingerTips** and the **Cancer Outcomes Metrics**.

5.3 Diagnostic imaging

A clinician can use a variety of imaging modalities to diagnose a patient with cancer, for example a chest X-ray for lung cancer. The main data source for information on diagnostic imaging is the Diagnostic Imaging Dataset. This dataset collects monthly information from trusts, and covers data on diagnostic imaging tests on NHS patients in England. This includes estimates of GP usage of direct access to key diagnostic tests for cancer. For example, chest imaging and MRIs.

NCRAS has a patient level DID dataset that is linked to the cancer registration data, and analyses using this are underway. NHS England **publishes** monthly reports that have imaging activity for groups of tests associated with diagnosing cancer.

5.4 Cancer incidence

Cancer incidence is the number of new cancers occurring in a population during a specified time frame, which is typically a year. Incidence can be presented as both counts and rates. The most commonly used rate is the age-standardised rate as it takes into account the age structure of the general population. This is important in cancer as cancer is more commonly diagnosed among the older population.

Specifically, it is the weighted average (using the age distribution of the general population) of the age-specific incidence rates. The rates are typically standardised using the European Standard Population or World Standard Population statistics and rates are typically presented per 100,000 population. Age-standardised rates are the best measure to use if comparisons are being drawn between populations. For example, if the aim is to compare cancer incidence or mortality over different geographies and different time periods. The counts, however, provide a picture of the absolute burden but without the context of the population from which those counts are taken.

When investigating the cancer burden in a sub-national geography, for example in London, a useful benchmark is the national value. When specific statistical tests are not included, if two confidence intervals do not overlap, then this indicates (but does not guarantee) a statistically significant difference between two values. Therefore, if the upper confidence limit for a London value is below the lower confidence limit for the respective England value, then the result in London is significantly lower than the national benchmark. Please note that if two confidence intervals do overlap it cannot be assumed that there is not a statistical difference and some further statistical tests would be needed. For more information, please refer to a [technical briefing](#) published by APHO.

5.5 Stage at diagnosis

Stage at diagnosis is a vital piece of information which has resulted in a number of [important findings](#). Stage helps to assess the impact of early diagnosis campaigns, screening programmes, patients' prognosis and improvements in healthcare. NCRAS collects different types of staging information for each patient. The main types of staging information in our database are:

- registry (the summary stage at diagnosis collected by the registry by amalgamating other sources together)
- pathology (a stage recorded on a pathology report – this could be the biopsy or surgery)
- MDT (a stage recorded at an MDT meeting, with no further detail about what type of stage it is)
- MDT final pre-treatment (a stage recorded at an MDT meeting, following the COSD definition of final pre-treatment stage)
- MDT integrated (a stage recorded at an MDT meeting, following the COSD definition of integrated stage)
- imaging (a stage derived by imaging)
- notes (a stage recorded on patient notes)

NCRAS has developed an algorithm to assign one stage per patient if the patient has more than one stage recorded. The preference is that the registry stage at diagnosis is assigned.

The majority of routine outputs now include a breakdown by stage at diagnosis. Staging information is also publically available on the [Cancer Dashboard](#).

NCRAS has also developed two cancer outcome metrics that promote earlier stage at diagnosis, which is one of the key aims of the National Awareness and Early Diagnosis Initiative (NAEDI) led by the Department of Health, Cancer Research UK and PHE. The stage of cancer describes how far it has spread and the size. Earlier stage at diagnosis is linked to improved survival, and is a key factor for cancer outcomes ^[7]. In addition, patients with cancer that present as an emergency have been shown to have poorer survival for all cancer types ^[6]. This is typically because the cancer is diagnosed at a late/advanced stage.

The two metrics are:

- proportion of cancers diagnosed that are recorded as presenting as an early stage case (stage 1 or 2)
- proportion of all malignant cancers which present as an emergency

These metrics are available at the clinical commissioning group (CCG) level, and the data and technical details are available on the [website](#).

5.6 Cancer waiting times

Cancer waiting times are an NHS standard that contains a series of targets relating to waiting times for treatment. They monitor the length of time that patients with cancer or suspected cancer wait to be seen and treated in England. These were first introduced through the NHS Cancer Plan (September 2000) and extended in the Cancer Reform Strategy (2007). A review of the standards in 2010 led to confirmation in Improving Outcomes: A Strategy for Cancer (2011) that they would be retained. The cancer waiting times standards are applicable to all NHS patients in England with malignant cancer and breast carcinoma in situ. As set out in the Cancer Waiting Times Guide, version 9 ^[8], the standards are.

Maximum two weeks from:

- urgent GP referral for suspected cancer to first outpatient attendance
- referral of any patient with breast symptoms to first hospital assessment

Maximum 31 days from:

- decision to treat to first definitive treatment
- decision to treat to start of second or subsequent treatment(s) for all cancer patients

Maximum 62 days from:

- urgent GP referral for suspected cancer to first treatment
- urgent referral from a NHS Cancer Screening Programme for suspected cancer to first treatment
- consultant upgrade of urgency of a referral to first treatment
- maximum 31 days from urgent referral to first treatment for acute leukaemia, testicular cancer and children's cancers

It is important to note that the two week wait standard is incorporated in the routes to diagnosis work discussed in section 5.2.

NHS Digital **publishes** cancer waiting times statistics on a monthly and quarterly basis, including commissioner and provider based summaries. NCRAS has also recently published a **data briefing** which summarises trends in the cancer waiting times standards over time.

FingerTips publishes a number of metrics using the cancer waiting times standards. The two week wait standard is available in the following metrics:

- referral ratio: the number of Two Week Wait (TWW) referrals observed at the practice, divided by the number expected based on the practice population age and the age-specific rates for England
- conversion rate: the number of TWW referrals resulting in a diagnosis of cancer in the year, divided by the total number of TWW referrals in the year
- detection rate: the number of new cancer cases treated in the year who were referred through the TWW referral route, divided by the total number of patients registered at the practice who have a date of first treatment in the financial year on the Cancer Waiting Times system

A General Practice can be identified as a potential outlier by comparison to the national (or London) average. This has been done in **Practice Profiles Plus** for the metrics published in FingerTips. A number of metrics on cancer waiting times are available in the Cancer Commissioning Toolkit data download on **CancerStats**.

NHS colleagues access the cancer waiting times data using Open Exeter, and produce a variety of reports and metrics. The typical presentation is the number of referrals and breaches by provider trust, including the change from the last time period (typically one quarter or year). This can identify which trusts do not meet the operational standard.

For London, the informatics team in RM Partners and the Transforming Cancer Services Team produce a pack of cancer waiting times metrics and NHS colleagues can request a copy or access to the online portal by contacting: cancerinformatics-manager@rmpartners.kahootz.com and SECSU.tcstlondon@nhs.net respectively.

5.7 Treatment

There are a number of treatments for cancer, and NCRAS has a dedicated data source for radiotherapy (RTDS) and chemotherapy (the Systemic Anti-Cancer Therapy (SACT) dataset).

Treatment overview

For an overview of cancer treatment, cancer waiting times data can be used to analyse the entire pathway of treatment, as it records information on the time period and receipt of cancer treatments. The national audit data also provides valuable information on assessing variations in treatment.

The cancer registration data holds information on all treatment types, and cancer-specific work has been undertaken to assess specific treatment levels and is available on the website. For example, a recent publication assessed the rate of specialist surgery for ovarian cancer in England ^[9].

Treatment information is publically available for colorectal and lung cancer on the [Cancer Dashboard](#) at the provider level. The metrics currently published are:

- percentage of adult lung cancer patients seen by a cancer nurse specialist in 2013
- percentage of adult lung cancer patients receiving surgery in 2013
- percentage of Small Cell Lung Cancer adult patients receiving chemotherapy in 2013
- percentage of Non-Small Cell Lung Cancer stage IIIB-IV, performance status 0-1 adult patients receiving chemotherapy in 2013
- risk-adjusted 90-day post-operative mortality for bowel cancer
- risk-adjusted 90-day unplanned readmission for bowel cancer in 2013
- risk-adjusted 2-year post-operative mortality for bowel cancer in 2013

- 18-month stoma rate (rectal)
- post-operative length of stay > 5 days for bowel cancer patients in 2013

In the future, treatment information will be available in the Clinical Headline Indicators (CHI), which produces a range of indicators for the purposes of informing the commissioning and provision of cancer services and driving up standards of care, activity and performance. The aim of this is to improve outcomes for patients of cancer care in England. This is available on [CancerStats](#). Currently, the only treatment metric available is whether the patient was entered on to a clinical trial.

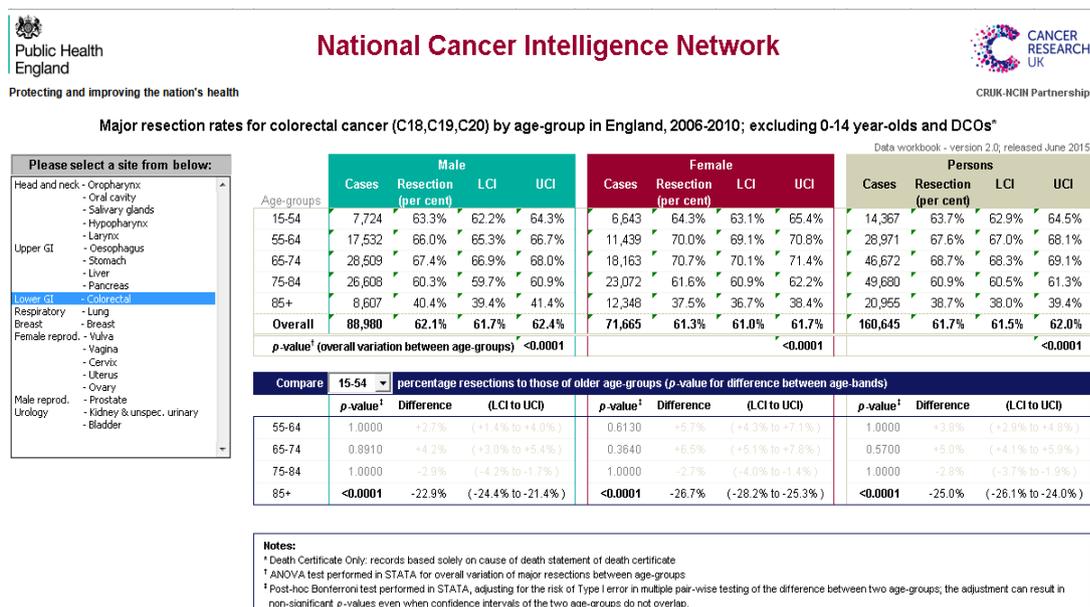
A comprehensive list on all releases using treatment data is available in the signposting document ^[2].

Surgery

Analyses using the Admitted Patient Care (inpatient) HES dataset can provide information on the surgical rates for cancer. NCRAS has created an algorithm that identifies major resections (curative surgeries) using inpatient HES for a subset of cancers.

Outputs using the major resection algorithm have been published in partnership with Cancer Research UK, and a [workbook](#) is available that presents the major resection rates by age group in England from 2006 to 2010. Figure 10 shows the output for colorectal cancer. The London routes to diagnosis [workbook](#) includes information on the proportion of patients who received a major resection, and the variation in proportions within London.

Figure 10: Major resections by cancer site, in England 2006 to 2010 sample workbook



Chemotherapy

The [SACT website](#) holds information on the collection of systemic anti-cancer therapy activity from all NHS England chemotherapy providers, and has a number of reports and publications. These reports include regimen benchmarking by NHS England Area Team in England, and the reader can compare the types of chemotherapy treatment used by cancer type in London. There is considerable variation in data completeness for the SACT dataset. Logging into the portal also shows further variation breakdowns. A recent [publication](#) assessed the completeness of the SACT data as compared to cancer waiting times data. This found that 88% of patients reported to have received SACT in 2014 within CWT also had a corresponding record in SACT.

In September 2016, the SACT team published a peer-reviewed publication ^[10] and an accompanying [report](#) on 30-day mortality among breast and lung cancer patients treated with curative or palliative intent in 2014. The accompanying report examines variation in the 30-day mortality rates between NHS hospital trusts. The Appendix presents tables with the number of deaths within 30 days and the crude and risk-adjusted 30-day post-chemotherapy mortality by NHS hospital trust. Table 2 is taken from this report and presents the findings for London.

Table 2: 30-day post-chemotherapy mortality for patients with breast cancer treated with curative or palliative intent in 2014 by NHS hospital trust in London

Trust	Breast, curative						Breast, palliative					
	Patients	Deaths within 30 days	Crude mortality (%)	Risk-adjusted mortality (%)	Upper limit (2SD)	Upper limit (3SD)	Patients	Deaths within 30 days	Crude mortality (%)	Risk-adjusted mortality (%)	Upper limit (2SD)	Upper limit (3SD)
England	15,626	41	0.3%				7,602	569	7.5%			
Barking, Havering & Redbridge University Hospitals	217	0	0%	0%	1.0%	1.4%	121	9	7.4%	6.2%	12.8%	15.6%
Barts Health	114	1	0.9%	0.8%	1.3%	1.8%	67	2	3.0%	3.4%	14.5%	18.2%
Chelsea and Westminster Hospital	73	0	0%	0%	1.5%	2.2%	28	1	3.6%	4.0%	18.0%	23.8%
Guy's and St Thomas'	258	0	0%	0%	0.9%	1.3%	198	8	4.0%	4.2%	11.8%	13.9%
Homerton University Hospital	1	1	100%	1.6%	10.7%	16.7%						
Imperial College Healthcare	257	0	0%	0%	0.9%	1.3%	139	7	5.0%	4.8%	12.5%	15.1%
King's College Hospital	122	0	0%	0%	1.2%	1.8%	38	2	5.3%	4.1%	16.6%	21.6%
Lewisham and Greenwich	65	0	0%	0%	1.6%	2.3%	33	1	3.0%	2.4%	17.2%	22.6%
London North West Healthcare	23	0	0%	0%	2.5%	3.7%	7	0	0%	0%	28.1%	39.7%
North Middlesex University Hospital	140	0	0%	0%	1.2%	1.7%	56	6	10.7%	9.9%	15.1%	19.2%
Royal Free London	165	1	0.6%	0.7%	1.1%	1.6%	87	5	5.7%	7.1%	13.7%	17.0%
St George's Healthcare	156	0	0%	0%	1.1%	1.6%	89	4	4.5%	11.0%	13.6%	16.9%
The Royal Marsden	259	0	0%	0%	0.9%	1.3%	210	12	5.7%	6.2%	11.7%	13.8%
The Whittington Hospital	33	0	0%	0%	2.1%	3.1%	13	0	0%	0%	22.7%	31.2%
University College London Hospitals	117	0	0%	0%	1.2%	1.8%	34	3	8.8%	6.3%	17.1%	22.4%

Radiotherapy

PHE took responsibility for the Radiotherapy Dataset (RTDS) from 2016 onwards. A RTDS portal will be available for hospital trusts to access, and metrics and results will be published in due course on [CancerStats](#). Currently,

radiotherapy data is available via the Cancer Commissioning Toolkit module in [CancerStats](#).

SACT and RTDS metrics will be added to the [CancerStats](#) website in due course.

5.8 Outcomes

Cancer outcomes can be measured using data on mortality, prevalence, survival, patient experience and quality of life metrics.

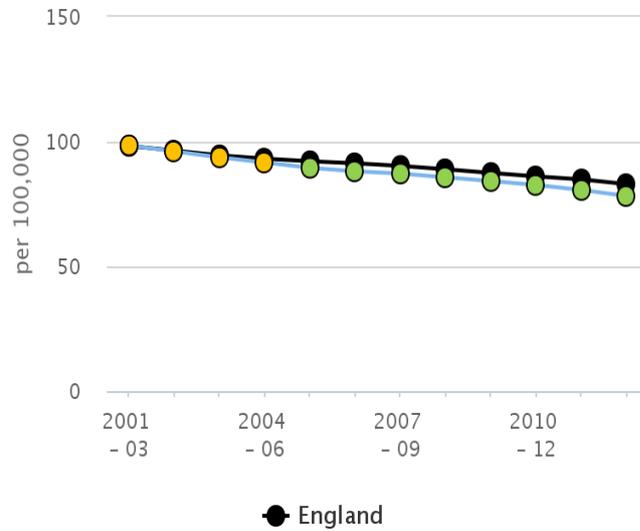
Mortality and place of death

Cancer mortality is the number of people who die from a specified cancer in a defined population and period. A number of metrics are available to assess this. [CancerStats](#) presents the numbers and rates of mortality by geography, year of death registration, age, and gender and cancer type. [CancerData](#) presents the mortality data in broader age groups and sub-national geographical regions to allow public access, and the Cancer Dashboard presents metrics on mortality by provider and CCG.

Cancer mortality under 75 is an important measure, as it is expected that CCGs will be able to impact on this. For example, by encouraging individuals to attend screening when invited and commissioning appropriate treatment services. The [Public Health Outcomes Framework \(PHOF\)](#) publishes indicators on the under 75 mortality rate from cancer.

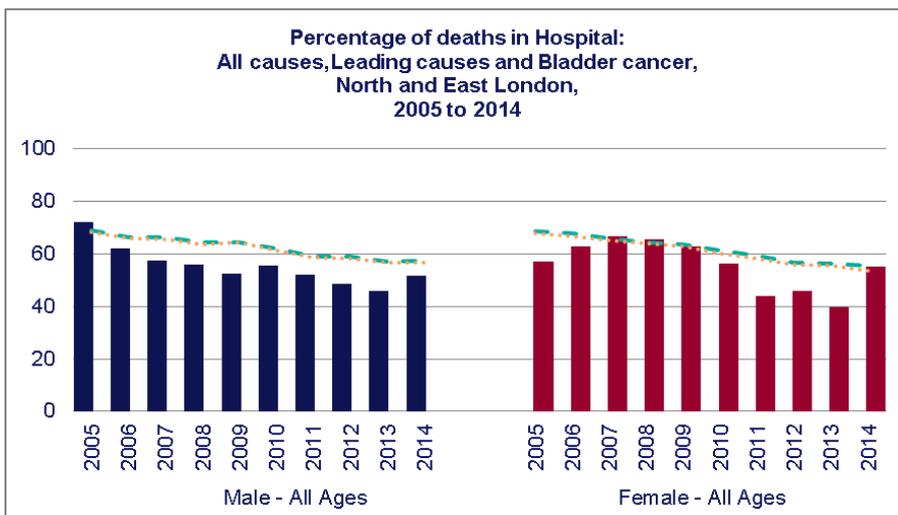
The mortality rate is presented for persons and by sex, and also includes the mortality rate from causes that are considered preventable. Figure 11 is an example chart that can be exported from PHOF, where green points indicate that the mortality rate for the under 75 in London is lower than England, and yellow indicates that there is no significant difference. The rate is calculated as a directly standardised rate per 100,000. The data can also be stratified by deprivation deciles.

Figure 11: Under 75 mortality rate from cancer considered preventable (Persons) for London compared to England from PHOF



Place of death is an important metric, and is very closely linked to patient experience and quality of life. Many cancer patients express a preference to die at home rather than elsewhere. The End of Life Network in PHE has published an Excel-based tool with data on the trends in the percentage of deaths in hospital of cancer patients. Figure 12 presents the trend in hospital deaths for bladder cancer in North and East London for all ages for male and female. The dashed line is the percentage for all causes, and the yellow line is the percentage for the leading causes of death.

Figure 12: Percentage of deaths in hospital for bladder cancer in North and East London from 2005 to 2014



Prevalence

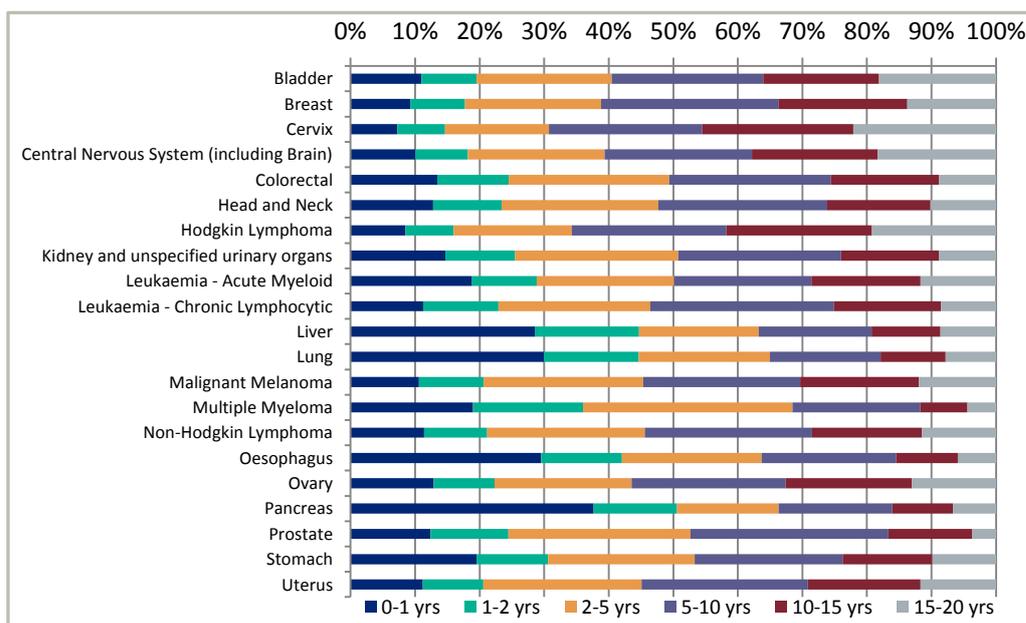
Cancer prevalence can be useful, particularly for service provision and health care planning. Prevalence is the number of people who are alive on a specified

date and were previously diagnosed with cancer. This is typically presented as a crude rate, which is the number of cancers divided by the number of individuals in the corresponding population and multiplied by 100,000.

The Macmillan-NCRAS partnership has undertaken the **UK cancer prevalence project**, which segments information on the UK cancer population. In September 2016, the partnership published a workbook which presents the number of people alive on 31 December 2013 who had been diagnosed with cancer at any time before this date. Data is available for all of the UK combined and at country level. A breakdown has been presented by time since diagnosis, age at diagnosis, sex and cancer type.

Previous **outputs** have included a breakdown by sub-national geographies including former Area Teams, Clinical Networks, CCGs and by local authority in England for 21 common cancers with the end of follow-up on 31 December 2010. Figure 13 is an example output from this publication.

Figure 13: 20-year cancer prevalence in London for persons diagnosed during the period 1991 to 2010 by time since diagnosis and cancer type



Survival

Mortality counts and rates do not consider when the individual was diagnosed with cancer. To do this, survival rates are calculated. This estimates the percentage of patients who are still alive a specified time after their cancer diagnosis. This is typically one-year and five-year, but other time periods can be calculated. There are a number of methods that can be used to calculate survival but, recently, official statistics have used net survival. Net survival is a method that sits within the relative survival framework. This method accounts

for the risk of death from other causes, and the fact that some groups of patients are less likely than others to be observed until death, independently of their cancer prognosis. It represents the proportion of the population, under study, that survive when we ignore all causes of death except for cancer.

Survival estimates can be found on [CancerStats](#), the [Cancer Dashboard](#) and from the Office for National Statistics (ONS) publications. Survival estimates (1-, 2-, 3-, 4-, 5-year) for London are available on [CancerStats](#) for breast, colorectal, lung and prostate cancer. [CancerStats](#) provides 1- and 5-year survival estimates at the CCG level for all cancers combined, breast, colorectal, lung and prostate cancer. Ten-year survival and survival by stage will be available on [CancerStats](#) in due course.

The Office for National Statistics produces a number of outputs on survival in collaboration with NCRAS and the London School of Hygiene and Tropical Medicine. In 2016, the outputs with a regional breakdown have been [Geographical Patterns of Cancer Survival in England](#) and the [Index of cancer survival for Clinical Commissioning groups in England](#). NCRAS has produced briefings which highlight the key results for London. They are available on the local section of our [website](#). In addition, ONS has recently released in collaboration with NCRAS [1-year survival estimates by stage](#). Regional results will be released in due course.

Figures 14 and 15 are examples of how incidence, mortality and survival can be presented.

Figure 14: Age-standardised incidence and mortality rates per 100,000 European population for London and England during 2001 to 2014

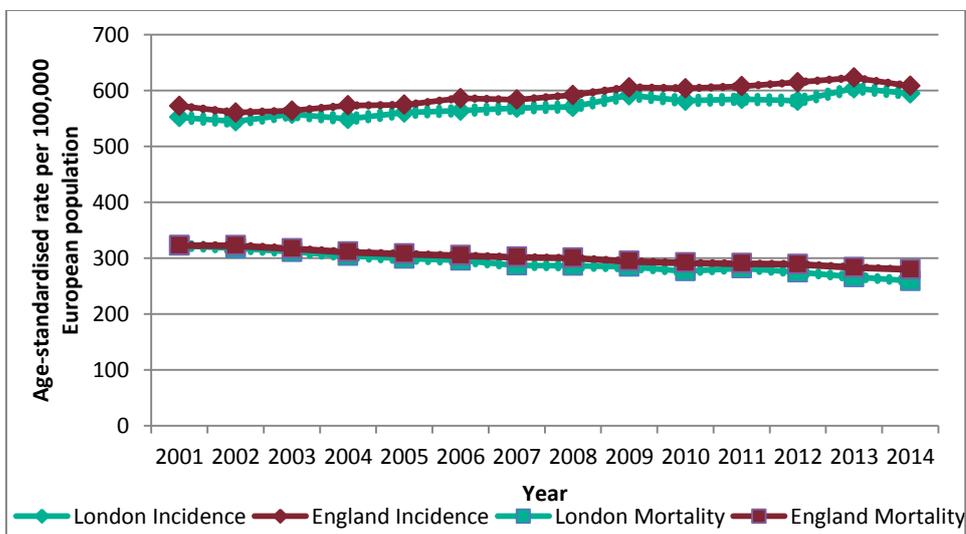
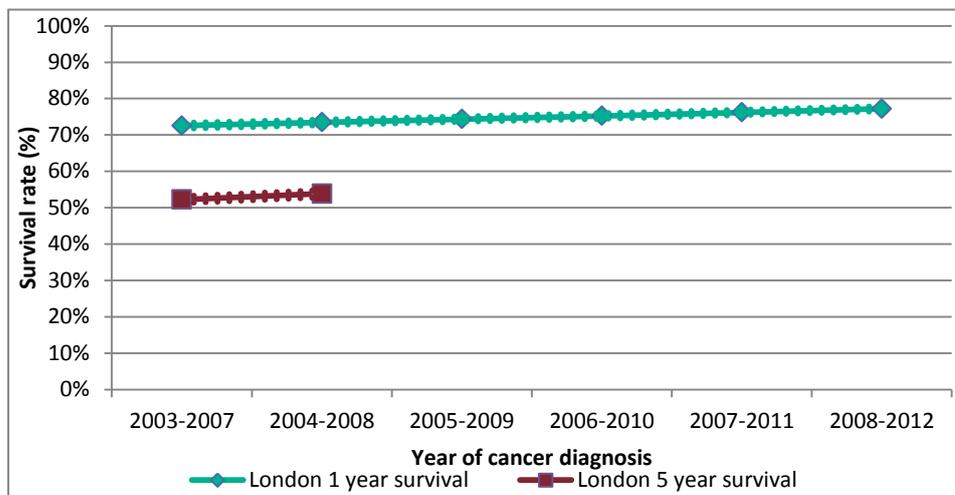


Figure 15: 1- and 5-year survival for colorectal cancer in England during 2003 to 2012



For more information on methodology in cancer epidemiology, please refer to Breslow and Day ^[11].

Patient experience and quality of life

The **Cancer Patient Experience Survey** (CPES) is the biggest survey of cancer patients in the world, and it provides important baselines for taking forward the national cancer strategy, 'Achieving world class cancer outcomes: A strategy for England 2015 to 2020'. The aim of the survey is: to monitor national progress on cancer care; to provide information to drive local quality improvements; to assist commissioners and providers of cancer care; and to inform the work of the various charities and stakeholder groups supporting cancer patients.

There have been five iterations of the survey since 2010. Quality Health has provided reports for every **CCG** and **Trust**, with an executive summary based on the questions which are included in phase one of the **Cancer Dashboard**. A local briefing has also summarised the key results for **London**.

NCRAS also has access to the patient-level CPES data, and a **programme of work** is in place to use this data to provide insights into the care experienced by cancer patients across England.

Cancer charities have a keen interest in quality of life metrics, and **Macmillan** has a particular focus on living with and beyond cancer programme. The **Cancer Dashboard** will include key metrics on quality of life in due course.

Routes from diagnosis

Macmillan has a programme of work on **Routes from Diagnosis**, which aims to describe the clinical journeys that a patient follows after their cancer diagnosis. The aim is to use this information to improve the commissioning agenda and service development. Currently, there is not a regional breakdown of this information but there are a number of national recommendations which are relevant at the local level.

6. Data for commissioning intentions

In high level terms, **Commissioning Intentions** set out what services commissioners expect providers to deliver during the next financial year. They provide a basis for constructive engagement between commissioners and providers of these services and inform business plans and contracts. They are intended to drive improved outcomes for patients, and transform the design and delivery of care, within the resources available.

There are a number of metrics used directly by commissioners to measure performance. Examples of some of the metrics used in London as of 2015 to 2016 are:

- JAG (Joint Advisory Group) **accreditation**
- ultrasound waiting times (median time)
- direct access chest x-ray
- results of Cancer Peer Review
- proportion of patients entered onto risk stratified pathway (breast, colorectal and prostate) which is a clinical pathway selected based on the patient's clinical condition
- breast reconstruction at the same time as mastectomy
- CNS present at diagnosis
- implementation of the recovery package (Holistic Needs Assessment, Attendance at Health and Wellbeing events and provision of treatment summary)

The majority of information described in this section will not be available to users outside of the NHS. However, it is important to understand the types of metrics used by commissioners.

Some additional information is available through the **RightCare Commissioning for Value packs**, which were discussed in section 5.

For more information on the metrics used by commissioners, please contact: SECSU.tcstlondon@nhs.net for the Transforming Cancer Services Team for London.

7. Cost of cancer

The [RightCare Commissioning for Value packs](#) include a large amount of information on the cost of cancer treatment. The packs present: the potential savings on elective admissions, non-elective and prescribing; the total spend compared to similar CCGs; and the spend profile of complex patients.

PHE has published a [Spend and Outcome Tool \(SPOT\)](#) which presents the spend on cancer as a z-score. This compares spend in a local region to the national spend or to the spend throughout the region. The cancer related measures are:

- cancer screening coverage - cervical cancer (25-64 yrs, Female)
- mortality from cancer (<75 yrs, Persons)
- mortality from cancer considered preventable (<75 yrs, Persons)
- deaths from lung cancer (Tobacco control)

A recent peer-review publication used the cancer registration data to estimate the cost of care for cancer patients in England ^[12]. This work was completed in collaboration with Macmillan Cancer Support, and further information on their work programme is available [online](#).

In 2016, PHE published [resources](#) on the cost-effective commissioning of colorectal cancer care, including a return on investment tool. These help CCGs, local authorities and Health and Wellbeing Boards to make the case at a local level for investing in earlier diagnosis and intervention to improve patient outcomes, and the release was accompanied with a [blog](#).

8. COSD to understand a trust's activity

The cancer registration data submitted to NCRAS using the COSD framework can be used to understand a trust's activity. **CancerStats** is an online tool that provides information on the COSD submission by each hospital trust.

CancerStats can be accessed using an N3 connection. However, we also have a publicly accessible version with a subset of the information called **CancerData**. COSD on **CancerStats** is split into three levels:

- level 1 summarises whether a trust submitted COSD compliant format data on time
- level 2 provides metrics on the number of cancers diagnosed by various factors
- level 3 provides metrics which summarise the activity of a trust

For every metric in level 2, you can also find out the data completeness. The metrics do need to be considered in conjunction with the data quality metrics, as discussed in Section 4. A trust can conduct comparisons with local, regional and national averages to calculate relative performance. The aim is to improve the quality of data flowing to NCRAS and, ultimately, leading to improvements in patient care and outcomes. The metrics included in Level 3 are currently:

3.1a. Total number of diagnoses

3.1b. Basis of diagnosis: death certificate, clinical, histology or unknown: this specifies what information was used to register a cancer, for example was it due to a histological confirmation from a biopsy

3.1c. Involvement of a clinical nurse specialist around the time of diagnosis

3.1d. Age at diagnosis (5 groupings)

3.1e. Indicator for whether the patient was discussed at a Multidisciplinary Team Meeting

3.1f. Performance status at diagnosis: from patient able to carry out all normal activity without restriction, to completely disabled

3.1g. Final stage group at diagnosis (TNM stage)

3.2. Number of treatments, split by surgery, radiotherapy, chemotherapy, non-active therapy, active therapies

The number of diagnoses is presented by single pathway and also by shared pathway. These counts show patients whose pathway has been partially handled by the trust, but who have also visited other trusts. At the end of the trust summary report for Level 3, there is a breakdown of the trusts that have handled the shared pathway patients. Therefore, this helps to understand the most common pathway for a patient throughout different hospital trusts.

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