

Index of Cancer Survival QMI

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1. Methodology background

National Statistic	
Frequency	Annual
How compiled	Administrative data
Geographic coverage	England
Last revised	27 November 2017

2. Important points

- The index of cancer survival has been designed to provide an all cancer survival estimate over time.
- Due to sparse data, these survival estimates are produced as an index to reduce the effect of random variation in the year-on-year cancer-specific estimates, and data are provided for a 16-year period; interpretation should focus on overall trends rather than on small changes in the survival index in a particular year.
- From November 2017, the index of cancer survival is being published in partnership with Public Health England (PHE).
- The partnership has changed the weights used to adjust for age, sex and cancer type.
- Cancer survival index estimates for Sustainability and Transformation Partnerships (STPs) have been introduced for the first time in the November 2017 bulletin.
- Survival estimates should not be used as the only indicator of a Clinical Commissioning Group's performance in cancer outcomes.
- Further national and sub-national survival estimates are published using a <u>different methodology</u> and are therefore not directly comparable.

3. Overview

Office for National Statistics (ONS) in partnership with Public Health England (PHE) publishes a suite of bulletins on cancer incidence and survival, with accompanying Quality and Methodology Information (QMI) reports for <u>cancer incidence</u> and <u>cancer survival estimates</u>. Survival estimates are produced for the most common cancers in adults (aged 15 to 99 years) by stage and diagnosis and for all cancers combined in children (aged 0 to 14 years).

This report provides details of the methodology used, in partnership between ONS and PHE, to produce the Index of cancer survival for Clinical Commissioning Groups in England National Statistics.

Sustainability and Transformation Partnerships (STPs) are now included to provide a single measure of cancer survival over time at this geography level. Further sub-national survival estimates are produced for the <u>Geographic patterns of cancer survival in England</u> bulletin using a different methodology. The quality information for these estimates can be found in the <u>cancer survival statistical bulletins QMI</u> report.

Cancer is a major cause of death, accounting for around one-quarter of deaths in England. More than one in two people will develop cancer at some point in their life. In July 2015 an Independent Cancer Taskforce published <u>Achieving world-class cancer outcomes: a strategy for England 2015 to 2020</u> (PDF, 4.90MB), which included the aim to improve survival rates for cancer patients. This document sets out how the government plans to improve cancer outcomes (including improving survival rates through reductions in the proportion of patients who are diagnosed with cancer at an advanced stage), screening and treatment standards. These publications of national survival statistics enable the monitoring of changes in cancer survival over time, to assess progress in achieving these aims.

4. Output quality

This report describes the quality of the output and details the points that should be noted when using the output. We have developed <u>Guidelines for measuring statistical quality</u>. These are based upon the five European

Statistical System (ESS) dimensions of quality and several other important quality characteristics:

- relevance
- timeliness and punctuality
- coherence and comparability
- accuracy
- output-quality trade-offs
- · assessment of user needs and perceptions
- accessibility and clarity

More information is provided about these quality dimensions in the following sections.

5. About the output

The <u>Index of cancer survival for Clinical Commissioning Groups</u> publication presents one-year age-(sex-cancer)standardised net cancer survival for tumours diagnosed in England for individual years, followed up for at least one whole calendar year.

The analyses for the bulletin are estimated by use of flexible parametric models to produce survival estimates for adults (aged 15 to 99 years) for breast (women), colorectal and lung cancer separately, these three cancers combined and all cancers (excluding non-melanoma skin cancer and prostate cancer). This includes:

- one-year net cancer survival index for Clinical Commissioning Groups (CCGs) in England
- one-year, five-year and 10-year net cancer survival index for Sustainability and Transformation Partnerships (STPs) in England
- one-year, five-year and 10-year net cancer survival index in England
- separate estimates for the all-cancers combined index and the three-cancers combined index for middleages and elderly adults (55 to 64 years and 75 to 99 years)
- mid-year population estimates and the number of cancer patients included in the analysis

6. Relevance

(The degree to which the statistical outputs meet users' needs.)

Users of cancer survival estimates include Clinical Commissioning Groups (CCG), government organisations, health policy-makers, cancer charities, academics and researchers, cancer registries, the general public, and the media. Population-based cancer survival statistics are used to:

- · plan services aimed at cancer prevention and treatment
- feed into national cancer plans the Department of Health identified cancer as a specific improvement area for preventing people dying prematurely, given that a significant gap remains in survival compared with the European average; the Independent Cancer Task Force set out <u>six strategic priorities</u> to help improve cancer survival in England, including reducing CCG variation and the <u>ambition to increase oneyear survival to 75% by 2020</u> for all cancers combined
- inform the <u>NHS Outcomes Framework</u>, which was established to monitor overall changes in performance
 of the NHS and the quality of health outcomes, and includes one-year and five-year net survival from
 colorectal, breast and lung cancers; the <u>NHS Five Year Forward View</u> (2014) set out: "that improvements
 in outcomes will require action on three fronts: better preventions, swifter access to diagnosis, and better
 treatment and care for all those diagnosed with cancer"
- provide reliable and accessible information about cancer outcomes to a wide range of groups, including patients and health professionals via health awareness campaigns, cancer information leaflets and websites
- to answer Parliamentary Questions on cancer survival in England
- inform cancer research

Survival estimates are used to formulate, monitor and assess health policy and healthcare provision and planning. These estimates feed into the <u>Clinical Commissioning Group (CCG) Indicator Set</u>, which:

"provides clear, comparative information for CCGs, Health and Wellbeing Boards, local authorities, patients and the public about the quality of health services commissioned by CCGs and the associated health outcomes. The indicators are useful for CCGs and Health and Wellbeing Boards in identifying local priorities for quality improvement and to demonstrate progress that local health systems are making on outcomes."

We regularly review our statistical outputs to ensure they continue to meet users' needs. Several changes have been made to the statistical bulletins to make them more relevant for users, including using the most up-to-date geography boundaries. When the NHS organisational boundaries changed in April 2013 (for example, Clinical Commissioning Groups (CCGs) replaced Primary Care Trusts), we updated the boundary sets used in all subnational cancer-related publications from 2013 onwards.

Changes in the coding of cancer occur when a new version of the International Statistical Classification of Diseases (ICD) is implemented. Currently, all malignancies are coded using ICD volume 10 (ICD-10), which replaced ICD-9 in 1995. Coding cancers with the most recent version of the ICD means that coding represents an accurate and up-to-date picture of cancer, so that cancer-related outputs continue to meet users' needs.

Timeliness and punctuality

(Timeliness refers to the lapse of time between publication and the period to which the data refer. Punctuality refers to the gap between planned and actual publication dates.)

Historically, cancer registries in England were obliged by the Department of Health to provide data on all new cancer diagnoses to Office for National Statistics (ONS) within 18 months of the end of the calendar year.

However, with the single National Cancer Registration and Analysis Service (NCRAS) for England within Public Health England (PHE) and the collaboration with ONS, the data are cleaned in-house within the NCRAS and quality assured by colleagues in ONS. The process of data ascertainment and linkage of cancer registrations to death registrations is also substantially reduced due to this ONS and PHE collaboration.

For more details on related releases, the <u>GOV.UK release calendar</u> provides up to 12 months' advance notice of release dates. If there are any changes to the pre-announced release schedule, public attention will be drawn to the change and the reasons for the change will be explained fully at the same time, as set out in the <u>Code of</u> <u>Practice for Official Statistics</u>.

7. How the output is created

General principles of the methodology for this output

The estimates produced in this publication have been produced by the National Cancer Registration and Analysis Service of Public Health England (PHE). These National Statistics implement the <u>UK and Ireland Association of</u> <u>Cancer Registries'</u> ratified Standard Operating Procedure <u>Guidelines on Population Based Cancer Survival</u> <u>Analysis</u>.

From November 2017, cancer survival index estimates have been provided for Sustainability and Transformation Partnerships (STPs) for the first time. There have also been changes to the methodology in the weighting used for age-sex-cancer-standardisation.

Clinical Commissioning Groups (CCGs) are membership bodies in which local General Practitioner (GP) practices are the members. Therefore, the population of a CCG is not entirely based on the geographical population of a defined territory, but on patients who are registered with a GP practice that is a member of that CCG, but who may live in the territory of a different CCG. With this in mind, it is important to note a limitation of these analyses: the cancer patients included in the analyses are those who lived in the territory assigned to that CCG when they were diagnosed, as explained in the article, Dismantling the signposts to public health?

For geographic areas with small populations, like most CCGs, some fluctuation in survival estimates between consecutive years can be expected, as found in the following studies; <u>Cancer survival indicators for Clinical</u>. <u>Commissioning Groups in England</u> and <u>Cancer survival indicators for primary care organisations in England</u>. Fluctuations in cancer survival by CCG can occur due to the small numbers of cancer diagnoses and deaths each year within the population. Therefore, a low survival figure for a single calendar year should not be over-interpreted. However, if the survival estimates in a given CCG are consistently low "outliers" for several years in a row, possible explanations should be considered.

The survival estimates must be interpreted with care. They do not reflect the survival prospects for any individual cancer patient; they represent the survival for all cancer patients in a given area in a given period of time. The survival estimates also should not be compared across geographies.

Survival methodology

Survival is estimated using a publicly available program (stpm2) in <u>Stata 15</u>. The program calculates net survival by the use of flexible parametric models.

Net survival is the probability of survival derived solely from the risk of death from cancer, compensating for the risk of death from other causes (background mortality). For convenience, net survival is expressed as a percentage in the range 0% to 100%. Background mortality is accounted for through life tables of all-cause mortality rates for the general population in England. As background mortality changes with time and varies by sex, age, socio-economic status and region, the life tables used were broken down by single year of age, sex, region and deprivation quintile for each calendar year of death. The life tables used were supplied by the London School of Hygiene and Tropical Medicine's Cancer Survival Group. The life table for 2011 was also used for 2012 onwards.

The survival index is based on survival estimates for cancers of the breast (women), colorectal, lung and all other cancers combined (excluding non-melanoma skin cancer and prostate cancer).

Survival was estimated using flexible parametric survival models, with age and year of diagnosis as main effects and an interaction between age and year of diagnosis. A number of models were fitted to allow up to five degrees of freedom for both the baseline hazard function and time-dependent effects. The best-fitting statistical model was selected by assessing the relative goodness of fit using the Akaike Information Criterion (AIC) and Bayesian Information Criterion (BIC), with scaling tests to check for oversensitivity and a likelihood ratio test to compare the best-fitting models according to AIC and BIC. A separate model was fitted for each CCG, type of cancer and sex.

For each type of cancer, CCG and sex, the fitted models were used to estimate survival for five age groups at diagnosis (15 to 44, 45 to 54, 55 to 64, 65 to 74 and 75 to 99 years) and each diagnosis year. For each CCG and diagnosis year, the all-cancers survival index and the three-cancers survival index were then calculated as weighted averages of the net survival estimates for each type of cancer, sex and age group.

CCG and STP populations can be quite small, meaning that many of the survival estimates are based on fairly small numbers of patients. Even for these very common cancers, it was sometimes impossible to produce robust estimates of survival for one or more of the age groups, most often for patients in the age group 15 to 44 years. In this situation, the missing value was replaced by the equivalent value for the relevant STP or England.

The precision values presented in the bulletin are calculated as the inverse of the variance of each survival estimate. Precision is not presented for England in the reference tables because it is not needed for interpretation of the funnel plots; the survival estimates for the whole of England have very high precision. More information on the models can be found in the following articles:

- flexible parametric models
- further development of flexible parametric models

More information on the AIC and BIC is also available:

- Applications and developments of flexible parametric survival models.
- Using model selection criteria to determine the optimal number of B-spline control points for areal deformation modelling

Adjusting for age, sex and cancer type

Survival estimates are age-standardised, to improve the comparability between population groups and over time. This is because net survival varies with age at diagnosis and the age profile of cancer patients can vary over time and between geographical areas. To produce the all-cancers combined index, the data also need to be standardised by sex and cancer type to allow for comparisons across the different populations.

Estimates were previously weighted with the proportions of cancer patients diagnosed in England and Wales during 1996 to 1999, to account for the differing age, sex and cancer type structure of a particular population. From November 2017, estimates have been calculated using new weights based on the <u>International</u> <u>Classification of Survival Standard (ICSS)</u> for age-standardisation, with additional weighting applied to standardise for sex and cancer type. The weights can be found in Table 1.

The impact of this change in methods is detailed in the <u>Impact of updating cancer survival methodologies for sub-</u><u>national estimates</u> paper. The benefits of incorporating the ICSS age-weights are:

- they are publicly and readily available
- these weights are widely used, for example, in the UK by <u>Northern Ireland and Scotland</u> and internationally by the <u>United States National Cancer Institute</u> and by the <u>International Cancer Benchmark Partnership</u>
- since they are not specific to a certain country or diagnosis period, these weights could be used more widely in other countries wishing to take the same approach for an all-cancer survival index
- the ICSS weights continue to vary by tumour type reflecting age distributions of the different cancers
- the cancer survival in England statistical bulletin was published in June 2017 with changes in methodology, including the use of the ICSS weights; this change to the index of cancer survival for clinical commissioning groups will bring consistency across ONS cancer survival estimates

For both the all-cancers survival index and three-cancers survival index, all values were adjusted using the same set of standard weights. This means that the survival index can be compared over time, because the index is adjusted for any changes in the profile of cancer patients by age, sex or type of cancer. This adjustment is necessary because, without standardisation, changes in survival could result from changes in the profile of cancer patients. For example, overall cancer survival in a given CCG could change simply because of changes in the profile of its cancer patients, even if survival at each age, for each cancer and in each sex did not change.

		International Classification of Survival Standard (ICSS) based weights								
Cancer type	Age group	Male					Female			
		Age weight	Sex weight	Cancer type weight	Final ICSS- based weight	Age weight	Sex weight	Cancer type weight	Final ICSS- based weight	
Breast	15 to 44	-	-	-	-	0.070	1.000	0.167	0.012	
	45 to 54	-	-	-	-	0.120	1.000	0.167	0.020	
	55 to 64	-	-	-	-	0.230	1.000	0.167	0.038	
	65 to 74	-	-	-	-	0.290	1.000	0.167	0.048	
	75 to 99	-	-	-	-	0.290	1.000	0.167	0.048	
Colorectal	15 to 44	0.070	0.500	0.167	0.006	0.070	0.500	0.167	0.006	
	45 to 54	0.120	0.500	0.167	0.010	0.120	0.500	0.167	0.010	
	55 to 64	0.230	0.500	0.167	0.019	0.230	0.500	0.167	0.019	
	65 to 74	0.290	0.500	0.167	0.024	0.290	0.500	0.167	0.024	
	75 to 99	0.290	0.500	0.167	0.024	0.290	0.500	0.167	0.024	
Lung	15 to 44	0.070	0.500	0.167	0.006	0.070	0.500	0.167	0.006	
	45 to 54	0.120	0.500	0.167	0.010	0.120	0.500	0.167	0.010	
	55 to 64	0.230	0.500	0.167	0.019	0.230	0.500	0.167	0.019	
	65 to 74	0.290	0.500	0.167	0.024	0.290	0.500	0.167	0.024	
	75 to 99	0.290	0.500	0.167	0.024	0.290	0.500	0.167	0.024	
Other	15 to 44	0.070	0.500	0.500	0.018	0.070	0.500	0.500	0.018	
	45 to 54	0.120	0.500	0.500	0.030	0.120	0.500	0.500	0.030	
	55 to 64	0.230	0.500	0.500	0.058	0.230	0.500	0.500	0.058	
	65 to 74	0.290	0.500	0.500	0.073	0.290	0.500	0.500	0.073	
	75 to 99	0.290	0.500	0.500	0.073	0.290	0.500	0.500	0.073	

Source: Office for National Statistics

Inclusions and exclusion criteria

The following <u>criteria</u> are used to identify the patients that are eligible to be included in the analysis:

- patients should have a unique identifier
- patients should have a complete date of birth and be aged between 15 and 99 years at diagnosis
- patients who have died should have a complete registered date of death
- patients should have a complete date of cancer diagnosis
- patients should have a known sex
- patients should have a known date of being recorded as alive or dead
- patients should be resident in England and have a valid postcode for usual place of residence
- tumours should be malignant, newly diagnosed in the studied cohort and a primary tumour
- cancers of the blood (lymphomas, leukaemia and myelomas) should not occur in a solid tumour
- patients are included even if they have further new cancer diagnoses later in the period of interest; for each patient, survival time is counted from the earliest diagnosis in each period of interest
- patients are excluded if they have had a primary tumour of the same site diagnosed before the period of interest
- patients are included even if they have a primary tumour of another site diagnosed at any time; for each site, patients are included in survival analyses where the earliest diagnosis of a tumour from that site occurred within the period of interest
- tumours should not be Death Certificate Only (DCO) registrations, where the only confirmed record of the tumour is recorded on the death certificate
- the sequence of dates should be valid (for example, a patient should not be diagnosed before they are born)

Other criteria applied include:

- excluded if the patient could not be attributed to a CCG of residence at diagnosis
- records for multiple primary tumours were excluded when estimating the all-cancers combined survival index
- where a patient dies on the date of diagnosis but is not a DCO registration, then these patients should be included in the survival analyses but should have one day added to the recorded date of death to accommodate limitations in <u>Stata's stset command</u>
- when two or more tumours of the same type are diagnosed on the same day for a patient, the one with the worst prognosis is chosen for inclusion
- coding the cancers with reference to the <u>International Statistical Classification of Diseases 10th Revision</u> (ICD-10); the details of the coding applied are: breast, female (C50), lung (C33 to C34), colorectal (C18 to C20, C21.8) and other cancers (C00 to C97) excluding female breast, lung, colorectal, non-melanoma skin cancer (C44) and prostate cancer (C61)

In the survival analyses, for age groups where the estimates do not meet the following quality criteria, the result is suppressed for that particular age group of the specific cancer site:

- for one-year survival, a minimum of three patients within the age, sex, cancer type, geography and diagnosis year sub-group and/or cumulative survival for those within the sub-group of at least one person-year
- for five-year survival, a minimum of five patients within the age, sex, cancer type, geography and diagnosis year sub-group and/or cumulative survival for those within the sub-group of at least five person-years
- for 10-year survival, a minimum of five patients within the age, sex, cancer type, geography and diagnosis year sub-group and/or cumulative survival for those within the sub-group of at least 10 person-years

Normally, to age-standardise survival estimates for cancer of the breast (women) and age-sex-standardise for colorectal and lung cancers, a weighted average of all the survival estimates of the five age groups is used. Even for these very common cancers, it was sometimes impossible to produce robust estimates of survival for one or more of the age groups, most often for patients in the age group 15 to 44 years. If one of the age groups fails to meet the previously mentioned quality criteria, the missing value is supplied by the equivalent value for the relevant STP or England.

The all-cancers combined index also requires age-sex-cancer standardisation and this relies on having an estimate of survival for each combination of age, sex and cancer, for each calendar year and for each CCG. In some CCGs, the populations are quite small. As with the individual cancer estimates, CCG and STP populations can be quite small, meaning that many of the combined index survival estimates are based on fairly small numbers of patients. It was sometimes impossible to produce estimates of survival for one or more of the age groups, most often for patients in the age group 15 to 44 years. For the combined index, the missing value was again replaced by the equivalent value for the relevant STP or England.

Structured Query Language (SQL) is used to extract data from the NCRAS' Cancer Analysis System and Stata code is used for preparing the data and calculating these estimates. To aid transparency and allow replication of the estimates produced in this bulletin, annotated copies of the SQL and Stata code can be provided on request. Please email any requests to NCRASenquiries@phe.gov.uk.

8. Validation and quality assurance

Accuracy

(The degree of closeness between an estimate and the true value.)

Cancer survival releases are produced using the most robust methods available for population-based cancer survival estimation. All bulletins published on cancer survival use the same underlying data files, which are prepared for analysis by using the same documented quality assurance procedures.

Each year, almost 300,000 patients are newly diagnosed with cancer in England. Cancer incidence data for England are collected by the regional offices of the National Cancer Registration and Analysis Service (NCRAS), which is part of <u>Public Health England</u> (PHE). Data are submitted to the NCRAS from a range of healthcare providers and other services (for example, pathology laboratories). The quality and accuracy of the data submitted by different sources may vary. The regional offices of the NCRAS collate all the data for each patient, including checks for internal consistency of the sequence of dates, as well as the cancer site, sex, morphology and duplicate registrations. These checks are closely based on those published by the <u>International Agency for Research on Cancer (IARC)</u> and are reported on by the <u>United Kingdom and Ireland Association of Cancer Registrations (UKIACR) series of performance indicators</u>.

If a record fails any critical validation check – for example, if the date of birth is invalid – the records are not reported in Cancer Registration Statistics, nor in any other Office for National Statistics (ONS) publication, including survival releases, since it is not possible to send these records to <u>NHS Digital</u> for verification of the patient's vital status. If a record passes all critical validation checks, or fails one or more minor quality controls, these records are sent to NHS Digital for verification of vital status.

<u>NHS Digital</u> routinely updates these individual cancer records with information on each patient's vital status (alive, emigrated, dead or not traced). Typically, at the time that data are extracted for the most recent statistical bulletins, less than 0.3% of patients diagnosed could not be traced during the relevant period.

Further checks are required for survival analysis; these are carried out in two stages. The first stage involves checking the eligibility of a record based on its completeness, the patient's usual residence, tumour behaviour and morphology. Patients with an invasive, primary, malignant tumour are eligible for analysis (see the "How the output was created" section, which lists the full criteria). Ineligible patients include those whose tumour is benign (not malignant) or in situ (malignant, but not invasive) or of uncertain behaviour, or for which the organ of origin is unknown.

The second stage involves checking the patient's age (15 to 99 years for adults), vital status, that the patient's sex is compatible with the cancer site, the dates are valid, and the patients' tumour was not registered solely from a death certificate.

Patients diagnosed with malignancy of the skin other than melanoma were excluded. Cancer of the prostate was also excluded from the index, because the widespread introduction of prostate-specific antigen (PSA) testing since the early 1990s has led to difficulty in the interpretation of survival trends, as explained in <u>the article</u>. Excess cases of prostate cancer and estimated overdiagnosis associated with PSA testing in East Anglia.

Since 2001, cancer registrations for each year have been estimated to be between 96% and 99% complete at the time of extraction, with completeness improving over time. However, it is important to note that the cancer registration database is dynamic.

In common with cancer registries in other countries, cancer incidence in England can take up to five years after the end of a given calendar year to reach 100% completeness and stability, because of late registrations, corrections and deletions. The estimate of completeness for a diagnosis year is based on the figures published for the three previous years, compared with the number of late registrations subsequently received for these years. It is therefore the difference between the figures published in <u>Cancer Registration Statistics</u> (and all subsequent ONS cancer incidence publications within that reporting year) and late registrations received after the publication date cut-off. It is not an estimate of the number of cancers that are never recorded.

Previously, data from Office for National Statistics (ONS) historic cancer registrations were used, but it has now been agreed that data provided by PHE will act as the only sources of cancer registrations for England and ONS will archive its registry.

It is important to note that the checks and quality measures undertaken in the PHE National Cancer Registration and Analysis Service are similar to the checks that the ONS Cancer Registry historically applied to the National Cancer Registration database.

Coherence and comparability

(Coherence is the degree to which data that are derived from different sources or methods, but refer to the same topic, are similar. Comparability is the degree to which data can be compared over time and domain, for example, geographic level.)

Survival is estimated using the most <u>up-to-date Clinical Commissioning Group (CCG) boundaries</u>

In 2013, we published an all-cancers survival index for the 211 Clinical Commissioning Groups (CCGs) in England for the first time (Cancer survival index for Clinical Commissioning Groups, adults diagnosed 1996 to 2011 and followed up to 2012). CCGs were created in 2013, replacing NHS Primary Care Trusts. To provide a baseline time series, the index was created for each CCG for each of the 16 years (from 1996 to 2011) to assess progress over time. Interpretation should focus on overall trends and the relative position of each CCG in the funnel plots throughout the years, rather than on small changes in the survival index in a particular year. Since 2013, we have regularly updated the number of CCGs included in the analysis in line with changes to the geography boundaries.

Estimates for England and STPs are published in both the <u>Index of cancer survival by Clinical Commissioning</u> <u>Groups in England</u> bulletin and the <u>Geographic patterns of cancer survival in England</u> bulletin. Care should be taken when comparing these estimates for one-year and five-year site specific cancer survival estimates as there can be differences. The specific cancer sites presented in both publications are breast (women) and lung, with colorectal (C18 to C20, C21.8) being included in the cancer survival index whilst cancer of the colon (C18) is presented in the survival estimates. This is because of the different methodology applied to calculate net survival. Further details of the other methodology can be found in the <u>Cancer survival statistical bulletins Quality and</u> <u>Methodology Information report</u>.

Cancer survival estimates are published at England level by various organisations and they will not all be directly comparable. Raw data may be taken from different sources and differences in quality assurance procedures will influence final estimates.

<u>Cancer Research UK</u> publishes relative cancer survival estimates by geography, deprivation level, cancer site, age at diagnosis and sex.

The <u>Northern Ireland</u>, <u>Scottish</u> and <u>Welsh</u> registries publish national figures for their respective countries. The period for which most recent data are available may differ between countries.

9. Concepts and definitions

(Concepts and definitions describe the legislation governing the output, and a description of the classifications used in the output.)

Definitions

Cancer

For adults, cancers are coded using the <u>International Statistical Classification of Diseases 10th Revision (ICD-10)</u>. ICD-10 coding for cancer is based on the nature and anatomical site of the cancer.

For the purposes of adult cancer registration, the term "cancer" includes all neoplasms that are both invasive and malignant (tumours that invade into surrounding tissues), which are conditions listed under site code numbers C00 to C97 in ICD-10. In addition, all in situ (malignant but not invasive) neoplasms (D00 to D09), certain benign (not malignant) neoplasms (D32 to D33, D35.2 to D35.4), and neoplasms of uncertain or unknown behaviour (uncertain whether benign or malignant, D37 to D48) are registered.

Morphology and behaviour codes used can be found in the International Classification of Diseases for Oncology, Second Edition (ICD-O-2).

Primary cancer

A primary cancer is the tumour that first develops in an identifiable part of the body, for example, the stomach, and usually gives the name to the type of cancer with which a patient is diagnosed.

Metastatic or secondary cancer

A metastatic or secondary cancer is a cancer that has spread from the first primary cancer, which may be located within the same site as the first primary cancer (local metastasis) or spread beyond the site of the first primary cancer (distant metastasis). The metastatic cancer should have the same underlying cell biology and morphology as the first primary cancer. A spread of primary tumour cells within the system of lymph nodes is not usually considered to be metastases of the primary tumour.

Health geographies

Sustainability and Transformation Partnerships (STP)

The NHS and local councils have come together in 44 areas covering all of England to develop proposals to improve health and care. They have formed new partnerships – known as <u>sustainability and transformation</u> <u>partnerships</u> – to plan jointly for the next few years. They are built around the needs of the local population across whole areas, not just those of the individual organisations involved.

Clinical Commissioning Groups (CCG)

<u>Clinical Commissioning Groups (CCGs)</u> commission most of the hospital and community NHS services in the local areas for which they are responsible. Commissioning involves deciding what services are needed for diverse local populations and ensuring that they are provided. All GP practices now belong to a CCG, but CCGs also include other health professionals, such as nurses.

Survival methods

Relative survival

An estimate of the probability of survival from the cancer alone excluding other potential causes of death. Estimates in all ONS adult cancer survival bulletins released before publication year 2011 to 2012 are based on relative survival.

Net survival

The survival of cancer patients compared with the background mortality that patients would have experienced if they had not had cancer. Background mortality is accounted for through <u>life tables</u> of all-cause mortality rates for the general population in England. For convenience, net survival is expressed as a percentage in the range 0% to 100%. Net survival is an unbiased estimator that accounts for "informative censoring" bias. "Informative censoring" refers to the fact that some groups of patients are less likely to be observed for the full duration of follow-up than others, independently of their cancer prognosis.

Details of alternative survival analysis approaches can be found in the <u>Cancer survival statistical bulletins Quality</u> and <u>Methodology Information report</u>.

Follow-up

A measure of the patient's time at risk. For example, the time from when a patient is diagnosed with cancer, until their date of death or embarkation (out of the NHS system).

Age-standardisation

A technique used to enable metrics derived for different populations to be robustly compared even when the populations are different in terms of their age profiles. Age-standardised rates also allow for more robust comparisons between males and females, years, and geographical areas.

95% confidence interval

A measure of the uncertainty around an estimate. Confidence intervals provide a range of values that are likely to contain the underlying population parameter with a given level of certainty. If the underlying rate of cancer survival remained the same and 100 cohorts were sampled over time and 95% confidence intervals were constructed for each of these cohorts, then 95 of the confidence intervals are expected to contain that underlying rate.

Funnel plots

Funnel plots show how much a particular survival index deviates from the overall survival index for that year in England (the horizontal line in each plot), given the statistical precision of the index for each CCG. The precision is the inverse of the variance of the survival index. Funnel plots of the one-year survival index for all cancers combined are presented for all adult patients (aged 15 to 99 years). Each data point represents one CCG.

The two "control limits", in the shape of a funnel around the horizontal line, represent approximately two (95% control limits) and three (99.8% control limits) standard deviations, respectively, above or below the national average. Data points that lie inside the control limits may be considered as within the range of geographical variation that could be expected by chance.

Flexible parametric survival models

Flexible parametric models are a form of excess hazard model, in which the all-cause mortality is modelled as the sum of the excess (cancer-related) mortality hazard and the expected (or background) mortality.

Scaling test

A likelihood ratio test comparing the selected model to the same model with one extra degree of freedom. This is used to check for oversensitivity in the model selection process.

Legislation

The Statistics and Registration Service Act 2007 permits the Registrar General to provide to the UK Statistics Authority, to carry out any of its functions, both information that is kept under the Births and Deaths Registration Act 1953 and any other information received by the Registrar General in relation to any birth or death. The Health Service (Control of Patient Information) Regulations 2002 Statutory Instrument No. 1438, Regulation 2, permits confidential patient information relating to patients referred for the diagnosis or treatment of cancer to be processed for the following purposes:

- the surveillance and analysis of health and disease
- the monitoring and audit of health and health-related care provision and outcomes where such provision has been made
- the planning and administration of the provision made for health and health-related care
- medical research approved by research ethics committees for the provision of information about individuals who have suffered from a particular disease or condition where: that information supports an analysis of the risk of developing that disease or condition, and it is required for the counselling and support of a person who is concerned about the risk of developing that disease or condition

This regulation was made under Section 60 of the Health and Social Care Act 2001 and continues to have effect under Section 251 of the NHS Act 2006.

Office for National Statistics (ONS) processes and stores cancer registration data in accordance with the requirements of:

- the Data Protection Act 1998
- the Code of Practice for Official Statistics
- the International Association of Cancer Registries (IACR) and their Guidelines on Confidentiality in Cancer Registries (1992)
- the European Network of Cancer Registries (ENCR) Guidelines on Confidentiality (2002)
- the UK Association of Cancer Registries (UKACR) Guidelines on Confidentiality 2012
- the NHS Act 2006
- the Statistics and Registration Service Act 2007

Public Health England (PHE) processes and stores cancer registration data in accordance with the requirements of:

- the Data Protection Act 1998
- the Health Service (Control of Patient Information) Regulations 2002
- the Caldicott Report 1997
- Information: To share or not to share? The Information Governance Review March 2013
- the Freedom of Information Act 2000
- Section 251 of the NHS Act 2006 (originally enacted under Section 60 of the Health and Social Care Act 2001)
- Confidentiality: NHS Code of Practice 2003
- NHS Records Management Code of Practice (Part 1, 2006 and Part 2, 2009)
- the Health and Social Care Act 2012
- the NHS Information Security Management Code of Practice 2007
- the Computer Misuse Act 1990
- the Human Rights Act 1998

10. Other information

Assessment of user needs and perceptions

(The processes for finding out about uses and users, and their views on the statistical products.)

A stakeholder review of all our cancer publications was conducted in 2010. Stakeholders were asked for their views about how they use the relevant outputs, their importance and their quality. Comments were also sought on any changes respondents would like to see in terms of content and presentation of the outputs and of our cancer web pages. The <u>results of this consultation</u> are available.

A <u>stakeholder consultation of all our cancer publications</u> was undertaken in 2012 to determine future user needs. The results of this consultation are available. One of the important needs identified as part of this consultation was for data on stage at cancer diagnosis, which are collected under the National Cancer Registration Scheme and collated by Public Health England (PHE). Due to improvements made by PHE in the collection of stage information as part of cancer registration, PHE in partnership with Office for National Statistics (ONS) are now able to publish estimates of survival by stage diagnosis of cancer in the form of Experimental Statistics. ONS will continue working with PHE to ensure that such survival estimates will be published as National Statistics in the future.

To promote ongoing feedback and to accommodate user's needs, a workshop was held on 20 March 2017, to discuss what aspects they felt would be more useful and what they would like to see in future releases. The workshop included participants from the Department of Health, NHS Digital, Public Health England, Office for National Statistics, Cancer Research UK, Macmillan, Cancer Vanguard and UCL Great Ormond Street Institute of Child Health.

We welcome feedback from users on the content, format and relevance of our statistics. Please contact <u>cancer</u>. <u>newport@ons.gov.uk</u>.

11. Sources for further information or advice

Accessibility and clarity

(Accessibility is the ease with which users are able to access the data, also reflecting the format in which the data are available and the availability of supporting information. Clarity refers to the quality and sufficiency of the release details, illustrations and accompanying advice.)

For information regarding conditions of access to outputs, please refer to:

- Terms and conditions (for data on the website)
- <u>Accessibility</u>

In addition to this Quality and Methodology Information report, quality information relevant to each release is available in the quality and methodology section of each of the statistical bulletins and in the metadata contained within the downloadable tables.

All cancer survival statistical bulletins are web-only releases, available in either HTML or PDF formats; data tables are available in Excel format. For further information about cancer survival bulletins, please contact the Cancer Analysis Team via email at <u>cancer.newport@ons.gov.uk</u> or by telephone on +44 (0)1633 456508.

Useful links

More information about cancer survival and registration is available via the <u>United Kingdom and Ireland</u> <u>Association of Cancer Registries</u> and the <u>National Cancer Registration and Analysis Service</u>.

12. References

- Royston P, Parmar MK. 2002. <u>Flexible parametric proportional-hazards and proportional-odds models for censored survival data, with application to prognostic modelling and estimation of treatment effects</u>. Stat Med. 21(15): pp 2175 to 2197.
- 2. Lambert PC, Royston P. 2009. <u>Further development of flexible parametric models for survival analysis</u>. Stata Journal. 9: pp 265 to 90.
- 3. Corazziari I, Quinn M, Capocaccia R. 2004. <u>Standard cancer patient population for age standardising</u> <u>survival ratios</u>. European Journal of Cancer. 40: pp 2,307 to 2,316