

# Cancer registration statistics QMI

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# 1 . Methodology background

<b>National Statistic</b>	
<b>Survey name</b>	Cancer Registration Statistics, England (Series MB1), including the Cancer Registration Statistics, England (First release)
<b>Frequency</b>	
<b>How compiled</b>	
<b>Geographic coverage</b>	England, regions
<b>Sample size</b>	
<b>Last revised</b>	23 February 2016

## 2 . Executive summary

The [Cancer Registration Statistics \(Series MB1\)](#) is an annual publication that presents data on the number of new cancer registrations in England and broken down into English regions. The data tables present the number of cases and rates by sex and age, standardised registration ratios and mortality to incidence ratios for all malignancies. This publication is produced by taking a snapshot of the dynamic cancer database, which is populated with data supplied by the National Cancer Registration Service (NCRS), based within Public Health England.

Following feedback from key users of the statistics we are now providing a first release release of Cancer Registrations Statistics to improve the timeliness of data release. This first release will take the form of reference tables containing the number of newly diagnosed cases of cancer and incidence rates for England. These statistics are produced by using the same snapshot of data, for which the full release of Cancer Registration Statistics (Series MB1) is produced. This first release of data will be equivalent to Table 1 and Table 2 of the Cancer Registration Statistics (Series MB1). The full annual publication of Cancer Registration Statistics will be published later this year.

This document contains the following sections:

- Output quality
- About the output
- How the output is created
- Validation and quality assurance
- Concepts and definitions
- Other information
- Sources for further information and advice

## 3 . Output quality

This document provides a range of information that describes the quality of the output and details any points that should be noted when using both outputs.

We have developed [Guidelines for Measuring Statistical Quality](#); these are based on the five European Statistical System (ESS) dimensions of quality. This document addresses the dimensions of quality and important quality characteristics, which are:

- 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 sections below.

## 4 . About the output

### Relevance

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

The Cancer Registration Statistics (Series MB1) publication provides detailed figures for the number of cases of cancer incidence, incidence rates by sex and age, standardised registration ratios and incidence to mortality ratios for all malignancies in England. In the [ONS Consultation on Statistical Products 2013](#), which sought views on the impact of stopping a number of statistical outputs, including this publication, a wide range of stakeholders reported that the potential cessation of this publication would have a high impact on their work. Since this statistical release is so important to users, we decided to continue to fund and produce this output.

The key users of the data include the [Department of Health](#) and [Public Health England](#) which use the outputs to brief ministers and inform policy making; annual cancer publications also inform progress on NHS Outcomes Framework indicators. Additionally, academics and researchers use these data to engage in the subject and carry out research. Similarly, Public Health England Knowledge and intelligence teams use figures published in the [Cancer Registration Statistics publications](#) to carry out individual and collaborative projects to put the subject knowledge into practice. Charities use the figures to provide reliable and accessible information about cancer to a wide range of audiences, including patients and health professionals, via health awareness campaigns and cancer information leaflets/web pages. Finally, the data used to create the [Cancer Registration Statistics publications](#) are used to answer parliamentary questions on cancer incidence and requests from the media, along with other ad hoc customer requests.

Cancer incidence figures published in the [first release](#) and [ARV](#) prior to 1995 (up to MB1 Series no.27) were for England and Wales. Volume 28 (1995) onwards covered cancer incidence data for England only, since all matters relating to health services in Wales have been devolved to the [Welsh government](#). From 1995 onwards, cancer registrations in Wales have been reported by the [Welsh Cancer Intelligence Surveillance Unit \(WCISU\)](#).

## 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.)

Starting from the 2009 registration year, work has been undertaken to improve the timeliness of these publications. Historically, the National Cancer Registration Service (NCRS) in England was obliged by the Department of Health to provide cancer registration data to ONS within 18 months of the end of the calendar year. For 2009, registries provided the data within 15 months, and for 2010 this was reduced to 12 months to further improve the timeliness of the publications. After cancer registration data have been received by ONS, they are further processed and cleaned using validity and consistency checks (see the “Accuracy” section for more information).

As the cancer registrations are supplied to ONS within 12 months of the end of the registration year, publication dates have become timelier. In order to further increase the timeliness of cancer registrations statistics, in 2016 we have reintroduced the first release of cancer registration data, containing cancer registration counts and incidence rates for the most recent registration year (2014) in England. As a result, 2014 cancer registration statistics at the England level were published in February 2016, just 14 months after the end of the registration year. Further regional breakdowns in the data as well as refreshed time series data are to be published 17 to 18 months after the end of the registration year in Cancer Registration Statistics (series MB1).

Previously, cancer registration data were published 18 months after the end of the registration year. The NCRS and ONS are continually seeking ways to further increase the timeliness of cancer registration statistics. Currently it takes 9 months or more to gather all the information required to confirm a cancer diagnosis, therefore there is a time lag between publication and registration year.

This time lag should be reduced as the processes behind validating and confirming cancer diagnoses evolve.

The publication dates of all cancer statistical bulletins are pre-announced on the [GOV.UK](#) website at least 1 month in advance. Annual publications are published at consistent times each year, plus or minus 1 month. The [GOV.UK](#) website provides 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 [Code of Practice for Official Statistics](#).

## 5 . How the outputs are created

We are responsible for publishing the [National Statistics](#) for cancer incidence in England. Cancer registrations are extracted from the National Cancer Registry at ONS, which is a live and dynamic database, and holds cancer incidence data from 1971 onwards. The NCRS provides ONS with cancer registration data, which they collect, collate, and validate from a variety of sources (for example, pathology laboratories and hospitals). The data we receive are run through further validation checks, which are outlined in the “Validation and quality assurance” section.

Once all the expected records for any incidence year have been received and validated we take a “snapshot” of the dataset, to create the analytical dataset, which allows us to publish the figures for the number of cases of cancer incidence, age specific and age-standardised incidence rates by sex and age, standardised registration ratios and mortality to incidence ratios for all malignancies in England. The snapshot is taken from the year 1995 to the most current registration year. The years prior to 1995 have very few changes to registrations and therefore this data are effectively frozen in the analytical dataset. More information on each of these statistics can be found in the “definition” section of this report.

To calculate age specific and age-standardised cancer incidence rates, our mid-year population estimates from the relevant time period are used as the denominator. To calculate mortality to incidence ratios, the number of deaths in England where the underlying cause was cancer are extracted from the relevant time period from our [annual mortality registration files](#). On our website more information can be found regarding the [mortality data quality and methodology](#).

Age standardised rates are calculated per 100,000 males and females for 5-year age bands and weighted using the 2013 European Standard Population (ESP). All age-standardised cancer incidence rates published by ONS since June 2014 have used the 2013 ESP. More information on the ESP is available in the “Coherence and comparability” section.

After the data are analysed, and commentary is added the statistics are quality assured through peer corroboration and the publication is proofread for accuracy and style before being approved for publication on our [website](#). The figures for numbers and rates of “all cancer” refer to all malignant neoplasms (ICD-10 C00-C97), excluding non melanoma skin cancer (ICD- 10 C44). A [podcast](#) has been produced which provides an overview of the production of ONS Cancer Statistics.

## 6 . Validation and quality assurance

### Accuracy

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

### Cancer registration data

Cancer registrations in England are submitted to ONS by the National Cancer Registration Service (NCRS) in [Public Health England](#). The registration of cancer cases is a dynamic process in the sense that the data files, both at NCRS and at ONS, are always open and changing. Cancer data files are dynamic in a number of ways:

- new cancer cases will be registered: this can include new “late” registrations, where a case is registered after the cancer registry or ONS, or both, have published what were thought at the time to be virtually complete results for a particular year
- cancer records can be amended: for example the site code would be modified should later and more accurate information become available
- cancer records can be cancelled, although this is relatively unusual

Data are submitted to the NCRS from a range of health care providers and other services (for example, pathology laboratories). As the data come from different sources, the quality and accuracy of the data submitted may vary.

The NCRS carefully collate and validate all the data for each patient, before sending a subset of the data, defined as the cancer registration minimum dataset, to the National Cancer Registry at ONS for further validation and processing. Some registrations may be submitted multiple times, whereas others may never be submitted. We resolve issues with duplicate registrations, working with the NCRS to do so. We also check the consistency of the cancer site, sex and associated histology and runs checks on dates, for example to check that the incidence date is not after the date of death. These checks are closely based on those published by the [International Agency for Research on Cancer \(IARC\)](#).

If a record passes all checks, it is given a quality status of 1. If any non-critical checks fail, the record is given a quality status of 2. If a record fails any 1 of a small number of critical validation checks – for example if the date of birth is invalid – the record is given a quality status of 3.

These status 3 records are not reported in the [Cancer Registration Statistics \(series MB1\)](#) and first release publications, or any other subsequent publications, including cancer [survival releases](#), since it is not possible to send these records for verification of vital status such as death or embarkation to the [Health and Social Care Information Centre \(HSC-IC\)](#). For more than 10 years the number of serious errors has consistently been 0.1% or less. All records that fail any of the checks are sent back to the registries to allow them to investigate and submit a correction. A table is included in the [Cancer Registration Statistics \(series MB1\)](#) full publication reporting the quality status of registrations in the cancer registrations database.

Once all the expected cancer records for any registration year have been validated at ONS, a snapshot of the data is taken; these data are then used in all cancer incidence publications, queries and Parliamentary Questions for the next 12 months. A snapshot of cancer registration data is taken to ensure that there is a consistent set of data behind the national statistics for the 12-month period.

In common with cancer registries in other countries, cancer registrations in England can take up to 5 years after the end of a given calendar year to reach 100% completeness, due to the continuing accrual of late registrations. So for example, the figure of 98% is an estimate of completeness based on the figures published for 3 previous years' data (2010 to 2012), compared with the number of late registrations subsequently received for these years and published in 2013. It is therefore the difference between what figures have been published in all our cancer incidence publications within a given reporting year, versus late registrations received after the publication date cut-off and updated in a subsequent year. It is not an estimate of how many cancers never get recorded.

From this snapshot dataset, tables are then published presenting numbers and rates of all types of cancer by age and sex in the first release of [Cancer Registration Statistics \(series MB1\)](#), and additionally by region of residence in the full release of [Cancer Registration Statistics \(series MB1\)](#). We have been advised by expert epidemiologists and members of the former Steering Committee on Cancer Registration that non-melanoma skin cancer (NMSC) is greatly under-registered. Therefore, the published tables present counts and rates for all cancers and for all cancers excluding NMSC (code 173 in ICD-8 and ICD-9, and C44 in ICD-10) to ensure that the reported figures are meaningful.

## **Statistical accuracy**

It is ONS practice to not calculate age-specific cancer incidence rates where there are fewer than 3 cancer registrations in the cell. Furthermore, where there are fewer than 10 cancer registrations age-standardised rates across all age bands are not calculated. In both cases when the rates are based on such low numbers, the rates are susceptible to inaccurate interpretation. ONS practice is also to clearly mark age-standardised rates based on fewer than 20 registrations as potentially unreliable.

Care should be taken when interpreting Standard Registration Ratios (SRR) as it is difficult to separate the effect of variation in levels of ascertainment from genuine differences in incidence. More information on SRRs can be found in the "Concepts and definitions" section of this document.

## Coherence and comparability

(Coherence is the degrees 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.)

When the NCRS submits registrations for the next reporting year, they can also submit “late registrations” for previous years. If any new “late” registrations for earlier years passed all quality checks, they would be included in the subsequent refreshed dataset. This results in small differences in the underlying number of cancer registrations for previous years, although these changes are unlikely to have a meaningful impact on incidence rates.

The first release and full Cancer Registration Statistics (Series MB1) publication presents age- standardised cancer incidence rates calculated using the 2013 European Standard Population (ESP). The ESP is an artificial European population structure used in the weighting of incidence data to produce age-standardised rates.

Using the ESP to produce age-standardised incidence rates allows fair comparison of the average rate of cancer diagnoses across different regions in England and with other countries in Europe, and between different time periods. For this reason, each year, we publish age- standardised cancer incidence rates calculated using the ESP alongside the actual number of cancer diagnoses for each region.

In 2013, the statistical office of the European Union updated the weights used for calculating the age- standardised rate, in order to make the weights more representative of the current population structure of Europe (Eurostat, 2013). We held a public [consultation](#) on how to implement the 2013 European Standard Populations (2013 ESP) and following the results of this consultation, all age-standardised cancer incidence rates published by ONS since June 2014 have used the 2013 ESP. It is important to note that although the 2013 ESP has an upper age band of 95+, currently the official ONS population data required to calculate age- standardised rates is produced with an upper age limit of 90 and older. This will result in cancer incidence rates in ONS National Statistics outputs from June 2014 being based on the 2013 ESP with an upper age band of 90 and older, with the aim of moving to an upper age band of 95 and older when the required population data are available.

The report [The impact of calculating cancer incidence rates using the 2013 European Standard Population](#) analyses the impact of using the 2013 ESP instead of using the previously used 1976 ESP. Wherever possible, we endeavour to present results of the [Cancer Registration Statistics \(series MB1\)](#) in a consistent manner with previous editions to enable comparisons across time periods. However, age-standardised rates calculated using the 2013 ESP are not comparable to rates calculated with the 1976 ESP. Therefore ONS have published a [back series of age-standardised cancer incidence rates](#) in England from 1971 to 2012 using the revised ESP to enable comparisons across time periods.

While we do not hold cancer incidence data in Northern Ireland, Scotland, and Wales, comparable data can be located from the:

- [Northern Ireland Cancer Registry](#)
- [Scottish Cancer Registry](#)
- [Welsh Cancer Intelligence and Surveillance Unit](#)

Cancer incidence figures are published at UK level by [Cancer Research UK \(CRUK\)](#) and the [National Cancer Intelligence Network \(NCIN\)](#), which is part of Public Health England. ONS previously published [UK cancer incidence and mortality statistics](#), however this series was discontinued in 2014, following the outcome of the ONS consultation on statistical products 2013. There may be differences between cancer data published by ONS and NCIN because ONS and NCIN have different quality checks, and as cancer registration is a continuous process, if data extracts are taken at different times for each organisation, this can lead to further differences.

Any future changes in data collection or analysis would be clearly presented within the relevant publication, to allow the user to take this into consideration when making comparisons.

## 7 . Concepts and definitions

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

### Concepts

The [International Statistical Classification of Diseases and Related Health Problems \(ICD\)](#) provides codes to classify diseases. During the period 1971 to 1978, ICD-8 was used to code cancer incidence data. From 1979 to 1994, ICD-9 was used and from 1995 to the present ICD- 10 has been used. The change to ICD-10 in 1995 included the introduction of codes to classify the following conditions: Mesothelioma (C45), Kaposi's sarcoma (C46) and Independent primary multiple sites (C97). The codes in ICD-10 are also more detailed in comparison to ICD- 9, and have improved the precision of coding and extracting cancer incidence data for some cancers.

Cancers are currently coded using the tenth revision of ICD, [ICD-10](#). ICD-10 coding for cancer is based on the nature and anatomical site of the cancer.

### Definitions

Cancer - for the purposes of the national cancer registration scheme the term "cancer" includes all malignant neoplasms (tumours that invade into surrounding tissues), which are conditions listed under site code numbers C00 to C97 of [ICD-10](#). In addition, all in situ neoplasms (D00 to D09), certain benign neoplasms (D32 to D33, D35.2 to D35.4) and neoplasms of uncertain or unknown behaviour (D37 to D48) are registered.

Cancer incidence rate: the number of new cancer registrations in a specific population during a particular time period per 100,000 people.

Incidence rate = (number of cancer registrations/population) x 100,000

A cancer incidence rate can be calculated by specific age groups, this is referred to as an age- specific cancer incidence rate.

Age-standardised cancer incidence rate: a weighted average of the age-specific cancer incidence rates, the weights used are age specific proportions of a standardised population. ONS use the 2013 European Standard Population (ESP). By standardising cancer incidence rates geographical and time comparisons can be made, as the differing age structure of a particular population has been accounted for.

Mortality to incidence ratios: cancer mortality to incidence ratios, are calculated by dividing the number of cancer related deaths by the number of cancer diagnoses for each given cancer site, sex and region. It must be pointed out that the number of cancer related deaths will include people who were diagnosed before 2013; therefore caution should be made when interpreting these statistics.

Standardised Registration Ratio (SRR): a cancer incidence rate (age and sex specific) is taken as a standard rate; we take England as the standard. The standard rate is then applied to another index population of known age structure (for example the South West region of England) to calculate how many registrations would have been expected in this index population had they, at each age group, experienced the standard cancer incidence rate (in this example England). The “expected” incidence is then compared to the observed incidence rate in the index population (in this example the South West), with the ratio being multiplied by 100 to give the standardised registration ratio, in which 100 is the value for the standard rate (in this example England). A SRR of 106 would mean the cancer incidence in the index region (in this example the South West) is 6% higher than the standard rate (England). Conversely, an SRR of 94 would mean the cancer incidence was 6% lower.

## 8 . 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 results of this consultation can be found on our website.

A further consultation to determine future user needs was conducted between 2012 and 2013, results of this consultation can be found on [our website](#). One of the key needs identified as part of this consultation was the need for data on stage at diagnosis, which are being collected by Public Health England. However, these data are not yet of sufficient quality or completeness to be published as National Statistics. We will continue working with Public Health England to ensure that these data items are of sufficient quality for them to be published as National Statistics.

In 2013, we ran a consultation on the future of a wide range of statistical products ( [ONS Consultation on Statistical Products 2013](#)). As a result of this consultation, the [UK cancer incidence and mortality statistical bulletin](#) was discontinued.

We welcome feedback from users on the content, format and relevance of our statistics. Please contact [cancer.newport@ons.gsi.gov.uk](mailto:cancer.newport@ons.gsi.gov.uk).

### 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.)

The latest data on cancer registrations in England can be found free of charge on our website in the form of the [Cancer Registration Statistics \(series MB1\)](#). In addition to this Quality and Methodology Information paper, basic quality information is included in the metadata of the publications.

The [Cancer Registration Statistics \(series MB1\)](#) and the first release of Cancer Registration Statistics are published as web only releases, for both of these releases all charts and tables are available to download from [our website](#).

Our recommended format for accessible content is a combination of HTML web pages for narrative, charts and graphs, with data being provided in usable formats such as CSV and Excel. Our website also offers users the option to download the narrative in PDF format. In some instances other software may be used, or may be available on request. For further information please refer to the contact details at the beginning of this document.

For information regarding conditions of access to data, please refer to the links below:

- [Terms and conditions \(for data on the website\)](#)
- [Copyright and reuse of published data](#)
- [Pre-release access \(including conditions of access\)](#)
- [Accessibility](#)

## 9 . Sources for further information and advice

### Useful links

While we do not hold cancer incidence data in Northern Ireland, Scotland, and Wales, comparable data can be located from the:

[Office for National Statistics cancer registrations](#)

[Office for National Statistics cancer survival statistics](#)

[National Cancer Intelligence Network](#)

[Public Health England](#)

[Welsh Cancer Intelligence and Surveillance Unit](#)

[Scottish Cancer Registry](#)

[Northern Ireland Cancer Network](#)

[Cancer Research UK Cancer Survival Group - London School of Hygiene and Tropical Medicine](#)

[Cancer Research UK](#)

### Contact information

For more information contact the Cancer and End of Life Care team:

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Special extracts and tabulations of cancer incidence data (England) and mortality data (England and Wales) are available to order for a charge (subject to legal frameworks, disclosure control, resources and agreement of costs, where appropriate). Such enquiries should be made to the postal or email address above.

For details of cancer registries in United Kingdom please visit the [UK and Ireland Association of Cancer Registries](#)