

Cancer statistics explained: different data sources and when they should be used

An overview of the cancer statistics produced by Public Health England (PHE) and the Office for National Statistics (ONS), including strengths and limitations, when each should be used, and the differences between them.

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Table of contents

- 1. Introduction
- 2. What are cancer registrations, cancer survival and life tables?
- 3. Understanding which ONS release to use
- 4. Strengths and limitations of the ONS cancer releases
- 5. Information released by Public Health England
- 6. Users of the data
- 7. Data accessibility

1. Introduction

The Office for National Statistics (ONS) and Public Health England (PHE) work in partnership to produce estimates of cancer survival in England. Estimates are produced by PHE while the ONS lead on bulletin production. The cancer registration and net survival data in the various bulletins have been collected and calculated by the National Cancer Registration and Analysis Service (NCRAS) in PHE. The ONS annually publishes official cancer statistics and provides independent commentary purely on data provided. The purpose of this article is to outline the following:

- what is cancer survival?
- the range of cancer releases published by the ONS and the intended use of each release
- the strengths and limitations of these releases
- the range of releases by PHE
- · the users and accessibility of data

2. What are cancer registrations, cancer survival and life tables?

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.

Cancer stage at diagnosis is a measure of how far the primary tumour has grown when the patient first presents in hospital. It is measured and recorded according to <u>internationally agreed standards</u>.

The cancer registrations cover the entire population of England. Our survival estimates are the estimation of the proportion of patients surviving their cancer after 1, 5 or 10 years. Survival estimates are age-standardised wherever possible, to improve the comparability between population groups and over time. From June 2017, age-standardised estimates for adults have been calculated using the International Cancer Survival Standard (ICSS) age weightings. The ICSS weights are used so that results are comparable across all countries in the UK and Ireland.

Net-survival analysis involves comparing the survival of patients with cancer with background mortality (the mortality rate of the general population). Background mortality is derived from population life tables, which are broken down by single year of age (0 to 99 years), sex, quintile of the Index of Multiple Deprivation (IMD) and region. The Office for National Statistics (ONS) has created life tables to use in calculating net cancer survival. Information on the life tables used can be found in The impact of updating cancer survival methodologies for national estimates, 2019.

For more information on cancer, cancer survival and the methods used for these statistics, please refer to our Quality and Methodology Information (QMI) reports for <u>survival</u>, <u>cancer incidence</u> and the <u>index of cancer survival</u>

3. Understanding which ONS release to use

Three of the bulletins relate to cancer survival, while one relates to the number of cancers diagnosed in a given year.

<u>Cancer registration statistics</u>, <u>England</u>: This publication provides data on cancer diagnoses and deaths from cancer.

Cancer survival in England: This publication provides childhood (aged 0 to 14 years) survival and adult (aged 15 to 99 years) cancer survival, split out by cancer site and, where possible, stage at diagnosis. These estimates enable the monitoring of changes in cancer survival over time. Adults' cancer survival estimates, overall and by stage, are created by comparing survival rates for cancer patients with background mortality, to show the effect of a cancer diagnosis on the outcomes for patients. Childhood cancer survival estimates are calculated without comparison to the background mortality, differently to adult survival, because few childhood cancer patients will die from another cause of death while receiving treatment.

Index of cancer survival for Clinical Commissioning Groups in England: This provides an index of all-cancer survival by Cancer Alliance (CA), Sustainability and Transformation Partnership (STP) and Clinical Commissioning Group (CCG). This index should be used to compare survival for all cancers combined (excluding non-melanoma skin cancer and prostate cancer) over time.

Geographic patterns of cancer survival in England: This release provides cancer survival by NHS Region, Cancer Alliance, Sustainability and Transformation Partnership for individual cancer types. The survival estimates here are produced using the same methodology as the adults part of the Cancer survival in England publication. It also provides an annual trend in survival, which is estimated by variance-weighted least-squares regression of the annual survival estimates.

Both this and the <u>Index of cancer survival for Clinical Commissioning Groups in England</u> release provide data for CAs and STPs. Survival estimates for a specific cancer within a CA or STP are provided in the <u>Geographic</u> <u>patterns of cancer survival in England release</u>. Trends in survival estimates for all cancers combined within a CA or STP are provided in the <u>Index of cancer survival for Clinical Commissioning Groups in England</u>.

4. Strengths and limitations of the ONS cancer releases

These Office for National Statistics (ONS) cancer publications have a number of strengths and limitations.

Main strengths

The main strengths of the cancer statistical bulletins include:

- estimates showing the effect of health policy on the survival of cancer patients in England
- they present age-standardised rates wherever possible to enable users to reliably compare results over time and, in the Geographical patterns of cancer survival publication, between areas
- the use of administrative data means that survival estimates are population-based
- these estimates can indicate the potential for improvement in the management of cancer, from early detection through to referral, investigation, treatment and care
- overall survival is considered a reliable estimator of cancer survival in children because, unlike in adults, death within 10 years of diagnosis is almost always due to the cancer
- each publication provides different breakdowns of cancer survival estimates (as outlined in Table 1)

Table 1: Breakdown of estimates provided in each cancer publication

Cancer registration statistics, England	Cancer survival in England	Index of cancer survival for Clinical Commissioning Groups in England	Geographic patterns of cancer survival in England
· sex	• sex	 middle-ages and elderly adults (55 to 64 years and 75 to 99 years) 	• sex
ages at diagnosis	ages at diagnosis	 types of cancer (estimates for breast, colorectal and lung cancer, and all three combined) 	• cancer sites
• cancer sites	• cancer sites	• geographic sites (CA, STP, CCG)	• geographic sites (NHS region, CA, STP)
• geographic sites (region)	stage at diagnosis	• 1-year estimates for CCGs	 1 and 5-year estimates (including an estimates of survival trends)
	• 1, 5 and 10-year estimates by site	 1, 5 and 10-year estimates for CAs and STPs 	
	• 1 and 5-year estimates by stage		

However, there are a few limitations of the cancer survival bulletins, which are detailed further in the following subsection.

Main limitations

The main limitations of the cancer survival statistical bulletins include:

- they do not show overall survival of a patient where they have been newly diagnosed with cancer but die from an unrelated condition
- these statistics are not applicable to an individual, newly diagnosed patient; the survival of a newly diagnosed individual will depend upon many other factors, such as their individual prognosis, their treatment or other diseases, and thus their survival may vary significantly from that reported by the publications
- these statistics cannot be used to infer continued survival time for individuals who have already lived a certain amount of time since being diagnosed
- a recognised staging system is not available for all types of cancer
- in some cases, usually due to small numbers of cases, it is impossible to produce robust estimates of survival for one or more of the age groups, cancer sites, geographies or follow-up periods; all such nonrobust estimates are suppressed
- cancer data files are dynamic and new cases can be registered "late", modified and, more rarely, cancelled

5. Information released by Public Health England

As well as statistics produced by the Office for National Statistics (ONS), Public Health England (PHE) also produces a range of regular and ad hoc publications.

While the ONS publications cover the core registration and survival data, regular cancer statistics from PHE include:

- cancer incidence by stage, which are presented at Clinical Commissioning Group (CCG) level <u>quarterly</u> and <u>annually</u> with a 1-year rolling average that combines the most recent year of data; this provides diagnosis by stage for survival by stage, the ONS <u>Cancer survival in England</u> publication should be referred to
- emergency presentations of cancer, which are published quarterly
- <u>cancer services</u> at General Practitioner (GP) and CCG level

The National Cancer Registration and Analysis Service (NCRAS), in PHE, also publish cancer statistics such as policy documents, methods papers, ad hoc pieces of research and blogs that are not set by a distinct timeframe. They prepare a wide range of reports and information, such as:

- reports: detailed national and subnational reports on aspects of cancer and its treatment, including areas of inequality
- data briefings: short documents highlighting one issue and written for a wider general audience
- guidance documents: documents written to support health services and other users in understanding and using the available information
- peer-reviewed publications: articles published in peer-reviewed journals making use of the National Cancer Analysis System

6. Users of the data

Users of cancer survival estimates include government organisations including the NHS, local bodies responsible for commissioning cancer services, health policy-makers, cancer charities, academics and researchers, cancer registries, the public, and the media.

Population-based statistics may be used to:

- plan services aimed at cancer prevention and treatment
- feed into national cancer plans the Department of Health and Social Care 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 six strategic priorities to
 help improve cancer survival in England, including reducing Clinical Commissioning Group (CCG) variation
 and the ambition to increase 1-year survival to 75% by 2020 for all cancers combined
- inform the NHS Outcomes Framework, which was established to monitor overall changes in performance
 of the NHS and the quality of health outcomes, and includes 1- and 5-year net survival from colorectal,
 breast and lung cancers; the NHS Five Year Forward View 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
- inform cancer research

7. Data accessibility

The latest publications can be found free of charge. Our recommended format for accessible content is a combination of HTML webpages 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.

We have looked at the <u>five different types of user</u> and have worked together with Public Health England (PHE) to make estimates more accessible for each type of user. For instance, text has been simplified and data are available in different formats for data forager users.

To ensure that all information is accessible for our users we welcome feedback on the content, format and relevance of our statistics via email. In Spring 2019, we conducted a short survey to consult with users and this will be followed by a stakeholder event in Summer 2019. The purpose of the survey and the event is to gain insight into which statistical bulletins are used, how the relevant outputs are used, their importance and their quality. We aim to use the stakeholder event to determine future user needs.

If you have any further questions or require any more information, please contact us by email at cancer.newport@ons.gov.uk