

Overview of Available UK-Wide Cancer Prevalence Data
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The following document aims to provide a summary of the available cancer prevalence figures for each individual nation and the UK, including the benefits and limitations of consulting one dataset over another.

When considering cancer prevalence, it's important to stress the difference between complete and observed prevalence data:

- **Current complete, or total, modelled prevalence** represents the total number of people ever diagnosed with cancer who are still alive at a specific time point, also known as the index date. Because cancer registries don't have population-level data for the years prior to their establishment, estimating complete cancer prevalence involves statistical modelling applied to observed prevalence to make up for past missing cancer registrations.

Although complete prevalence figures are impactful in communications, its reliance on statistical modelling, rather than recorded data, means that it is rarely possible to calculate estimates for local areas and rare cancers, whereas it is possible to report on these within observed prevalence.

- **Future predicted complete prevalence** is an estimate of complete prevalence calculated by projecting changes to the prevalent population (estimated through complete prevalence methods) into the future. This can be achieved by modelling future trends for the incidence and survival of cancer types in different age groups¹.
- **Observed, or limited duration, prevalence** refers to the number of people diagnosed with cancer during a specific time period who are still alive on the index date. This limited duration, normally 20 years or more, is dependent on how long a registry has been collecting population-level data on cancer registrations. This makes observed prevalence data a more accurate representation of a population living with cancer over a specific period of time. In addition, it is also possible to report on the observed prevalence for local areas and rare cancer types. For this reason, observed prevalence data is preferable for any statistical work where accurate and granular information are priorities.

Regardless of the cancer prevalence data utilised, it's important not to mix complete and observed prevalence data since this could lead to confusion, unless a clear explanation of the different methodologies is included.

Below are the main complete and observed prevalence data sources for UK-wide cancer prevalence:

Complete prevalence:

- **Macmillan's predicted complete prevalence in 2020, based on Maddams et al's (2012) modelling**

The estimated prevalence data and methods are described here; [macmillan-2020-cancer-prevalence-figures-and-methodology](#)

Benefits:

- Currently, this figure is the most contemporary estimate available for complete cancer prevalence.
- Although it's technically a figure of predicted prevalence, it is closely aligned with observed prevalence statistics
- Widely quoted in Macmillan's communications

Limitations:

- The observed prevalence figures, which form the basis of these calculations, are from 2015 or 2017, as there is a delay in their compilation due to the process of cancer registration and the figures have not been updated with more recent publications.
- These estimates of complete prevalence rely on multiple assumptions, including that the UK growth rates predicted by Maddams et al (2012) are still relevant and apply to each nation equally. The growth estimates are likely to be less accurate for predictions further into the future from the observed prevalence data on which they are based. The Macmillan predicted complete prevalence figures are therefore heavily rounded to acknowledge this.

When to use:

- Macmillan's figure of almost 3 million people for complete cancer prevalence in 2020 is the best estimate available for any nationwide communications related to the number of people currently living with cancer in the UK. The availability of projections of this estimate, based on Maddams *et al* (2012), to 2025, 2030 and 2040 can also be used to demonstrate the estimated growth of the cancer population.

Where to find:

- <https://www.macmillan.org.uk/about-us/what-we-do/research/cancer-prevalence>

- **Macmillan-NCRAS UK Complete Cancer Prevalence in 2013**

In September 2016, the UK Cancer Prevalence Project between Macmillan and NCRAS produced a dataset of complete cancer prevalence for the UK and its nations, for all and the top four cancers, with an index date of 2013. Unlike Macmillan's predicted complete cancer prevalence projections, these calculations aren't projecting future trends in cancer prevalence and are therefore the most accurate figures of UK-wide complete cancer prevalence to date. This project modelled the complete prevalence in the UK in 2013 as 2.27 million.

Benefits:

- As the calculations of complete cancer prevalence are based on observed and modelled prevalence, rather than projections, it is more accurate than the Macmillan prediction for 2020.
- The workbook contains splits of the data by time since diagnosis

Limitations:

- The dataset's index date of 2013 makes it less useful for headline statistics as it is quite old.
- Figures can only be further broken down by the top four cancers, which limits their use in work focused on specific, less common cancer types, as well as health boards and local authorities across the UK. For these more granular analyses, observed prevalence is the best data source.

When to use:

- We recommend the complete cancer prevalence dataset from the UK Cancer Prevalence Project for statistical projects where accuracy of the figures takes priority over being able to quote a more recent index date.

Where to find:

- [UK Complete Cancer Prevalence for 2013 Workbook](#) for UK nations and UK combined.
- [UK Complete Cancer Prevalence for 2013 Technical Report](#) describing the methodology used to calculate complete cancer prevalence estimates.
- [Academic paper](#) describing the work involved in the production of the calculations.

- **Observed prevalence: National releases of observed cancer prevalence**

These datasets provide records of the number of people diagnosed and surviving cancer within an observed number of years, and still alive at a specified index date, for each nation. In contrast to complete prevalence, observed prevalence presents more accuracy with greater granularity, based solely on registrations without modelling, including data on many cancer types, age at diagnosis and time since diagnosis.

However, the available figures are limited by how long the relevant cancer registry has been established. Currently, the most recent dataset of observed cancer prevalence for all England covers a 25-year period, with an index date of 2019. This was produced as a collaboration between the National Disease Registration Service, Health Data Insight CIC and Macmillan, including breakdowns of the data for a number of cancer sites by Cancer Alliances, Sustainability Transformation Partnerships, Clinical Commissioning Groups and Local Authorities across England. It contains totals and rates by age, ethnicity, deprivation, stage at diagnosis, time since diagnosis and index date. Cancer prevalence for Scotland and Northern Ireland has been released by Public Health Scotland and the N. Ireland Cancer Registry (NICR). These examine observed periods of 20 and 25 years with an index date of 2019. For Wales, Macmillan in partnership with the Welsh Cancer Intelligence and Surveillance Unit (WCISU) published 21-year observed prevalence data with an index date of 2015 in the form of an interactive dashboard.

The results from the Macmillan-NCRAS UK Complete Cancer Prevalence Project for 2013 can be used to quantify the difference between observed (limited duration) and complete (total) prevalence figures. Overall, in the UK, this project estimated that 13% of patients had a diagnosis >20 years prior to the index date of 2013. This estimate varied between 12% (England) and 23% (NI) for different nations, and between 1% (prostate) and 18% (all other malignant neoplasms) for different cancer sites.

Benefits:

- Measures of observed cancer prevalence offer the most accurate and up-to-date snapshots of the population living with cancer within each nation over a defined period of time.
- Observed cancer prevalence presents granular information, including breakdowns by several cancer types and age at diagnosis, which are not available for complete prevalence measures.

Limitations:

- In contrast to complete cancer prevalence it only covers periods of data between 20 and 25 years, depending on the national release considered. It therefore misses many people diagnosed with cancer before these dates and surviving to the index date.

When to use:

- When considering cancer types other than the four most common (female breast, prostate, colorectal and lung), observed cancer prevalence datasets are the only sources available for prevalence.
- Where the priority is to quote the most recent figure available, based on actual records, for the number of people living with cancer in a specific nation.

Where to find:

- [England Cancer Prevalence Statistics, 2019.](#)
- [Cancer incidence and prevalence in Scotland to December 2019.](#)
- [Cancer Prevalence for Northern Ireland: 1995-2019.](#)
- [Cancer prevalence \(people living after a diagnosis of cancer\) for Cluster Networks in Wales.](#)

For further more detailed information on prevalence methodologies see the Standard Operating Procedure: Guidelines for calculation of cancer prevalence - <http://www.ukiacr.org/sites/ukiacr/files/file-uploads/publication/2%20UK%20Cancer%20Prevalence%20SOP%20FINAL.pdf>

Table of comparison of available cancer prevalence data for all cancers (excluding non-melanoma skin cancer):

Type of prevalence measure	Duration	Index Date	England	Scotland	N. Ireland	Wales	UK	Cancers	Additional splits in the data	When to use
Complete, predicted ¹		2020	2,400,000	250,000	82,000	140,000	2,900,000	All combined and top 4	Sex, Time since diagnosis (0-5 & 5+ years).	Communications related to the estimated number of people living with cancer in the UK that require the most recent estimates
Complete ²		2013	1,869,300	205,500	69,600	128,800	2,273,200	All combined and top 4		Statistical projects, in which the accuracy of the figures provided would take priority over being able to quote a more recent index date.
Limited Duration ³	25-year	2019	2,198,536	-	-	-	-	All combined and a selection of common sites	Age, Sex, Time since diagnosis, Local health / administrative geographies.	When considering cancer types other than the four most common.
Limited Duration ⁴	20-year	2019	-	202,906	-	-	-			When quoting based on actual records, for the number of people living with cancer in a specific nation.
Limited Duration ⁵	25-year	2019	-	-	68,338	-	-			
Limited Duration ⁶	21-year	2015	-	-	-	115,774	-			

¹ Maddams J, Utley M, Møller H. Projections of cancer prevalence in the United Kingdom, 2010-2040. Br J Cancer 2012; 107: 1195-1202.

¹ Macmillan's complete prevalence projection

² Macmillan-NCRAS UK Complete Cancer Prevalence in 2013

³ NDRS NHS Digital, Health Data Insight CIC and Macmillan Cancer Support

⁴ Public Health Scotland

⁵ Northern Ireland Cancer Registry

⁶ Welsh Cancer Intelligence & Surveillance Unit