Official statistics and statutory 2015 data
Quality assurance and support information
Published 28th September 2017

Introduction
The Welsh Cancer Intelligence and Surveillance Unit’s (WCISU) core function is to discharge one of the statutory duties of Public Health Wales:

“To undertake the systematic collection, analysis and dissemination of information about the health of the people of Wales, in particular including cancer incidence, mortality, and survival...”

Critical to this duty is the continuous compilation of the national cancer registry of Wales and the production of legal annual official statistics on cancer incidence and survival, in addition to reporting on cancer mortality in the resident population of Wales.

The national cancer registry of Wales is a live and dynamic database of cancer incidence data from 1972 onwards. WCISU has been responsible for publishing cancer incidence, mortality and survival in Wales since 1997. Prior to this cancer incidence figures were published by the Office for National Statistics for both England and Wales. In 2009, WCISU became part of the Health Intelligence Division of the newly created Public Health Wales.

Cancer survival in Wales is an annual summary that includes the key messages relating to the latest trends in cancer survival in Wales.

The official statistics includes an interactive data tool, available on the website to allow users to customise the survival dashboards to their own requirements; to produce information based on cancer type, geographical area, age band, sex and time period, and to export user-selected reusable data.

This publication is produced by using a snapshot of the dynamic cancer registration database, which is populated with merged, quality assured data supplied by multiple data sources which include NHS Wales health boards and trusts, Public Health England, Office for National Statistics (ONS), and elsewhere within Public Health Wales, such as its Screening Division.

The key users of this data include:

- Welsh Government - to brief Ministers and to inform policy decisions.
- National Assembly for Wales
- Requests from the media on cancer incidence, mortality, prevalence and survival.
- NHS Wales health boards, trusts, and the Wales Cancer Network, as well as other teams in Public Health Wales - to inform progress on NHS Wales outcomes, assist with service planning and population health improvement,
and their evaluation.

- Third sector - to enable charities 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.
- Research and academia - to provide valuable reference data for academics and researchers to engage in cancer related research, including WCISU’s direct participation in research collaborations.

This document provides an overview that describes the quality of the data output and details any points that should be noted in its use.

**About the output**

The snapshot of the cancer registration database is taken for patients diagnosed from the year 1995 to 2014 to calculate one year and five year net survival. The years prior to 1995 have very few changes to registrations and therefore this data remains relatively unchanged year on year.

Net survival is an estimate of survival where the effect on survival of background population mortality rates has been removed. As background population mortality rates, as presented in a life table, are a good approximation to the non-cancer related death rates among cancer patients, the net survival represents the survival of cancer patients if they could only die from cancer-related causes. Net survival is suitable for comparison of survival between different time periods and populations, as the confounding effect of non-cancer death rates is removed.

Age-standardised net survival estimates are the estimates that would occur if that population [of cancer patients] had a standard population age structure. Five age-group specific survival estimates are weighted by standard weights and summed to give the age-standardised survival estimate (Corazziari et al., 2004).

The figures for numbers and rates of “all cancers” refer to all malignant neoplasms (ICD-10 codes C00-C97), excluding non-melanoma skin cancer (NMSC) (ICD-10 code C44).

After the data are analysed, and commentary is added, the statistics are quality assured through peer corroboration and the publication is proof read several times for accuracy and style before publication.

Great strides have been made to improve the timeliness of these publications in recent years. The cancer registrations are now completed within 10 months of the end of the registration year and publication dates have become timelier. Any further reduction in the time between registrations and the publication would risk compromising data completeness and quality, as well as statistical accuracy, as it usually takes 9 months to gather all the information required to confirm and quality assure a cancer diagnosis.

The publication date of ‘Cancer survival in Wales’ statistical release is pre-announced as official statistics on the [GOV.uk](https://www.gov.uk) website at least six months in
advance for the month and year and actual date at least four weeks in advance, and subsequently on the Public Health Wales’ website publication schedule. 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.

The release of official statistics by WCISU is authorised in law by:

The Pre-release Access to Official Statistics (Wales) Order 2009

Official Statistics (Wales) Order 2013 made under section 65(7) of the Statistics and Registration Service Act 2007

Quality assurance

The registration of cancer cases is a dynamic process in the sense that the database is always open and changing. The database is 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 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 deleted, although this is relatively unusual

Data are submitted to the WCISU 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 WCISU collate and validate the data for each patient, defined as the cancer registration minimum dataset. Cancers are currently coded using the tenth revision ICD-10v4¹. ICD-10 coding for cancer is based on the nature and anatomical site of the cancer. A subset of the data is sent onto the ONS for further validation to resolve issues with duplicate registrations that arise between the other UK and Wales registries.

The WCISU checks the data consistency of the cancer site, sex and associated histology and runs validity checks on dates, for example such as, to check invalid combinations for behaviour and site/histology; 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)². Only

---

¹ [http://www.who.int/classifications/icd/en/](http://www.who.int/classifications/icd/en/)

records that pass the critical quality status checks and include vital status i.e. alive or dead will be used for analysis.

Once the expected cancer records for any registration year have been validated, a snapshot of the data is taken to ensure that there is a consistent set of data behind the official statistics for a period of 12 months. Subsequent snapshots of data are taken quarterly and used in further cancer incidence publications, queries and parliamentary questions.

In common with cancer registries in other countries, cancer registrations in Wales can take up to five years after the end of a given calendar year to reach 100% completeness, due to the continuing accrual of late registrations.

When the WCISU 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 reports, although these changes are unlikely to have a meaningful impact on cancer incidence or cancer survival.

Other information

While the WCISU does not hold cancer survival data about residents in Northern Ireland, Scotland, and England, comparable data can be located from the following:

- [Northern Ireland Cancer Registry](#)
- [Scottish Cancer Registry](#)
- [Office for National Statistics (ONS)](#)
- [National Cancer Registration and Analysis Service](#)

Details of cancer registries in the United Kingdom and Ireland can be found on the [UKIACR](#) website.
Glossary of terms

- **Cancer** - for the purposes of cancer registration 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-10v4. 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.

- **Unstandardised cancer survival rate**: the net survival for those patients diagnosed between the ages of 15 years and 99 years.

- **Age-standardised cancer survival rate**: a weighted average of the age-specific cancer survival rates, the weights used are age-specific proportions of a standardised population. WCISU uses the international classification of standard survival (ICSS) weights as defined by Corazziari et al. to produce age-standardised survival rates. Using this allows fair comparison of the rates across different regions in Wales, other countries in UK and Europe, and between different time periods.

- The [International Statistical Classification of Diseases and Related Health Problems (ICD)](https://www.who.int/classifications/icd/en/) provides codes to classify diseases. During the period 1972 to 1995, 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.

References