Quality Assurance and Supporting Information

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About the output

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, and more recently, the Health Intelligence Division became part of the new Knowledge Directorate within PHW (1st April 2019).

“Cancer survival in Wales, 1995-2016” is a 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, deprivation fifth, stage at diagnosis, 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.

Our statistics are produced to high professional standards set out in the Code of Practice for Official Statistics. They undergo regular quality assurance reviews to ensure that they meet customer needs. They are produced free from any political interference.

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

Methodology

Data are submitted to the WCISU from a range of health care providers and other services (for example, pathology laboratories, multi-disciplinary team meetings, inpatient activity data, radiology, radiotherapy data, death certificates, other cancer registries in the UK). 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.

The snapshot of the cancer registration database is taken for patients diagnosed from the year 1995 to 2016 and followed up until the 31st December 2017.
The data items that are extracted from the database for each cancer patient for analysis are:

- Unique patient identifier
- Unique tumour identifier
- Date of birth
- Date of diagnosis
- Death certificate only flag
- Date of death (if present)
- Exit flag
- Date of exit
- Age at diagnosis
- Sex
- Lower Super Output Area (LSOA01 & LSOA11) at diagnosis
- ICD 10 code
- Stage at diagnosis

A cancer type is assigned based on the following categories:

<table>
<thead>
<tr>
<th>Site name</th>
<th>Site code</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acute lymphoblastic leukaemia</td>
<td>C910</td>
</tr>
<tr>
<td>Acute myeloid leukaemia</td>
<td>C920</td>
</tr>
<tr>
<td>All malignancies excluding NMSC</td>
<td>C00-C97 excluding C44</td>
</tr>
<tr>
<td>Anus</td>
<td>C21</td>
</tr>
<tr>
<td>Bladder</td>
<td>C67</td>
</tr>
<tr>
<td>Bone</td>
<td>C40-C41</td>
</tr>
<tr>
<td>Brain and central nervous system</td>
<td>C70-C72</td>
</tr>
<tr>
<td>Breast</td>
<td>C50</td>
</tr>
<tr>
<td>Cervix</td>
<td>C53</td>
</tr>
<tr>
<td>Cholangiocarcinoma</td>
<td>C221</td>
</tr>
<tr>
<td>Chronic lymphocytic leukaemia</td>
<td>C911</td>
</tr>
<tr>
<td>Chronic myeloid leukaemia</td>
<td>C921</td>
</tr>
<tr>
<td>Colon</td>
<td>C18</td>
</tr>
<tr>
<td>Colorectal</td>
<td>C18-C20</td>
</tr>
<tr>
<td>Head &amp; neck</td>
<td>C00-C14, C30-C32</td>
</tr>
<tr>
<td>Hepatocellular carcinoma</td>
<td>C220</td>
</tr>
<tr>
<td>Hodgkin lymphoma</td>
<td>C81</td>
</tr>
<tr>
<td>Fallopian tube</td>
<td>C570-C577</td>
</tr>
<tr>
<td>Kidney</td>
<td>C64</td>
</tr>
<tr>
<td>Larynx</td>
<td>C32</td>
</tr>
<tr>
<td>Leukaemia</td>
<td>C91-C95</td>
</tr>
<tr>
<td>Liver</td>
<td>C22</td>
</tr>
<tr>
<td>Lung</td>
<td>C33-C34</td>
</tr>
<tr>
<td>Melanoma of the skin</td>
<td>C43</td>
</tr>
<tr>
<td>Mesothelioma</td>
<td>C45</td>
</tr>
<tr>
<td>Myeloma</td>
<td>C90</td>
</tr>
<tr>
<td>Non-Hodgkin lymphoma</td>
<td>C82-C86</td>
</tr>
<tr>
<td>Oesophagus</td>
<td>C15</td>
</tr>
<tr>
<td>Oral &amp; oropharynx</td>
<td>C00-C06, C10</td>
</tr>
<tr>
<td>Ovary</td>
<td>C56</td>
</tr>
<tr>
<td>Pancreas</td>
<td>C25</td>
</tr>
<tr>
<td>Prostate</td>
<td>C61</td>
</tr>
<tr>
<td>Rectum</td>
<td>C19-C20</td>
</tr>
<tr>
<td>Stomach</td>
<td>C16</td>
</tr>
<tr>
<td>Testis</td>
<td>C62</td>
</tr>
<tr>
<td>Thymus &amp; endocrine</td>
<td>C73-C75</td>
</tr>
<tr>
<td>Urinary tract exc bladder</td>
<td>C64-C66, C68</td>
</tr>
<tr>
<td>Uterus</td>
<td>C54</td>
</tr>
</tbody>
</table>

Deprivation fifth was assigned for patients diagnosed between 1999 and 2016 using the income domain of the Welsh Index of Multiple Deprivation (WIMD) based on the 2001 or 2011 Lower Super Output Areas (LSOAs) in Wales. Depending on the year of diagnosis, the following WIMD were used:
<table>
<thead>
<tr>
<th>Year of diagnosis</th>
<th>WIMD</th>
<th>LSOAs used</th>
</tr>
</thead>
<tbody>
<tr>
<td>2008-2010</td>
<td>2014</td>
<td>2001</td>
</tr>
<tr>
<td>2011-2016</td>
<td>2014</td>
<td>2011</td>
</tr>
</tbody>
</table>

The LSOA is also used to assign a health board for residence at time of diagnosis. On the 1st April 2019, Bridgend transferred from Abertawe Bro Morgannwg University health board (renamed Swansea Bay University health board) to Cwm Taf University health board (renamed Cwm Taf Morgannwg University health board). All analysis will use the new boundaries.

The first recorded malignant primary cancer of Welsh cancer patients diagnosed between the ages 15 and 99 years are analysed. Death certificate only cases are excluded.

The official statistics show one and five-year net survival (%) in Wales (along with 95% confidence intervals) by rolling five-year diagnosis periods, by cancer type and sex. The complete approach to estimating survival is applied, including all patients diagnosed between 1995 and 2016. Survival is estimated using the Pohar-Perme (2012) estimator, which provides unbiased estimates of net survival at all ages. Survival is estimated using the publicly available stns algorithm (Clerc-Urmès I et al, 2014) in STATA 14 software.

Where possible, the data are further broken down by health board, deprivation fifth and stage at diagnosis.

Great strides have been made to improve the completeness of staging data and this WCISU report details cancer survival by stage at diagnosis in Wales by cancer type from 2011 to 2016.

One and five-year age standardised net survival (%) in Wales (along with 95% confidence intervals) by rolling five-year diagnosis periods, by cancer type and sex, is also shown for certain cancer types where possible.

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.

Relevance

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

We believe the key users of these data include:
- 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.
- Ministers, Assembly Members and the Members Research Service in the National Assembly for Wales
- Other areas of the Welsh Government to brief Ministers and to inform policy.
decisions
- Other government departments
- 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.
- Media requests regarding cancer related information in Wales
- National Health Service organisations
- Students, academics and universities - to provide valuable reference data for academics and researchers to engage in cancer related research, including WCISU’s direct participation in research collaborations
- Individual citizens and private companies.

We encourage users of the statistics to contact us to let us know how they use the data, please see the Feedback section of this publication for the contact details.

Accuracy

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 if more accurate information becomes available later
- cancer records can be deleted, although this is relatively unusual

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, amendments and deletions.

Wales have implemented a new cancer registration system named CATRIN. This is the same system that is used in Public Health England (called ENCORE). This modernisation programme has improved cross border data sharing in particular. During the data migration process, much attention was focused on duplicate registrations existing in both Wales and England registry databases. A quality assurance and de-duplication exercise was carried out, to rationalise the cancer registrations across the two countries.

All our outputs include information on coverage, timing and geography.

For this output, cancers are coded using ICD-10 from 1st January 1995 to 30th June 2012 and coded using ICD-10v41 thereafter. ICD-10 coding for cancer is based on the nature and anatomical site of the cancer.

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

When the WCISU submits registrations for the next reporting year, they can also submit

1 http://www.who.int/classifications/icd/en/
2 https://www.encr.eu/sites/default/files/A_proposal_on_cancer_data_quality_checks-one_common_procedure_for_European_cancer_registries_1_1.pdf
“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 and survival.

The snapshot of the cancer registration database was taken on the 14th May 2019 for patients diagnosed from the years 1995 to 2016 (snapshot CAS1903).

In the unlikely event of incorrect data being published, revisions would be made and users informed in conjunction with the Code of Practice.

**Timeliness and punctuality**

Historically, the WCISU has routinely published data on new cancer diagnoses (incidence) within 18 months of the end of the calendar year with a survival publication following. The lapse in time is due to the time taken to process and merge all cancer registrations for those patients resident in Wales into one record for each tumour using the data sources provided to WCISU. This publication is delayed further because of the implementation of the new information system CATRIN and the registry moving to use the ICDO3 coding classification.

All outputs adhere to the Code of Practice by pre-announcing the date of publication through the upcoming calendar on the [www.gov.wales](http://www.gov.wales) publication hub. Furthermore, if publication needs to be postponed this will be announced and the reason for the change fully explained, as set out in the Code of Practice.

**Accessibility and clarity**

The statistics will be published in an accessible, orderly, pre-announced manner on the WCISU’s website at 9:30am on the day of publication. We also publicise the outputs on Twitter and Facebook and to our stakeholders via email. All outputs are available to download for free.

The Official Statistics for "Cancer Survival in Wales, 1995-2016" were sent to a number of individual people on the pre-release list five working days prior to the announcement in accordance with the Pre-publication Official Statistics Order Access (Wales) 2009. We aim to use Plain English in our outputs and they adhere to the Public Health Wales’s accessibility policy. Furthermore, all our statistics are published in Welsh and English. Further information regarding the statistics can be obtained by emailing [WCU.stats@wales.nhs.uk](mailto:WCU.stats@wales.nhs.uk).

All cancer statistical publications are web-only releases, available in either HTML or Word formats; data tables are available in Excel format.

**Comparability and coherence**

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](https://www.nicr.nhs.uk/)
- [Scottish Cancer Registry](https://www.cancerregistries.scot.nhs.uk/)
- [Office for National Statistics](https://www.ons.gov.uk)
- [National Cancer Registration and Analysis Service (NCRAS), Public Health England](https://www.nationalcancerregistry.nhs.uk/)
Details of cancer registries in the United Kingdom and Ireland can be found on the UKIACR website.

For comparable survival data the latest international comparisons are available from The Lancet, Volume 391, Issue 10125 (CONCORD-3 Global surveillance of trends in cancer survival 2000-14).

Further information regarding the data completeness and quality of cancer registry data is detailed in the UKIACR performance indicators reports.

Legislation

The WCISU adhere to the ENCR and IARC cancer guidelines for registering cancer diagnoses in Welsh residents.

Under the Data Protection Act, the lawful processing of patient/service user data for purposes other than that necessary for the direct provision of care requires one of the following conditions to be met:

- Explicit patient/service user consent for processing
- Explicit authorisation by statute
- Approval under Section 251 of the NHS Act 2006

Public Health Wales undertakes a number of activities that cannot be classed as direct care, but where the obtaining explicit consent would be impractical or would compromise the integrity of the relevant activity. Examples include:

- Evaluation of screening programmes
- Cancer registration
- Registration of congenital anomalies

So called ‘Section 251’ approval, therefore, remains the most appropriate means of ensuring that Public Health Wales complies with the Data Protection Act when undertaking such processing. Such approval needs to be obtained for new activities and renewed annually for existing activities.

Section 251 was established to provide a secure legal basis for the disclosure and processing of confidential information in the NHS where it is not possible to use anonymised information or to obtain explicit consent. A mechanism was established to enable the Secretary of State for Health to exercise powers of approval under Section 251, advised by the National Information Governance Board (NIGB) and its Ethics and Confidentiality Committee (ECC). The mechanisms operated by NIGB and its ECC also applied to Wales.

The key policy on cancer in Wales is set out in the Welsh Government’s recently refreshed Cancer Delivery Plan 2016-2020.

The Well-being of Future Generations Act 2015 is about improving the social, economic, environmental and cultural well-being of Wales. The Act puts in place seven well-being goals for Wales. These are for a more equal, prosperous, resilient, healthier and globally
responsible Wales, with cohesive communities and a vibrant culture and thriving Welsh language. Under section (10)(1) of the Act, the Welsh Ministers must:

- publish indicators ("national indicators") that must be applied for the purpose of measuring progress towards the achievement of the Well-being goals
- lay a copy of the national indicators before the National Assembly. The 46 national indicators were laid in March 2016

Information on indicators and associated technical information - How do you measure a nation’s progress? - National Indicators.


The statistics included in this release could also provide supporting narrative to the national indicators and be used by public services boards in relation to their local well-being assessments and local well-being plans.

The WCISU adheres to the United Kingdom and Ireland Association of Cancer Registries (UKIACR) small numbers guidance for cancer incidence; i.e. where a cancer incidence count of less than five is observed in any cell with the population at risk being less than 1,000 then the value is suppressed. WCISU also adheres to the Office for National Statistics disclosure control guidance for mortality statistics.

Further details


Feedback

We welcome any feedback on any aspect of these statistics which can be provided by email to WCU.stats@wales.nhs.uk.

Definitions

- **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.

- **Net survival (unstandardised 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 adult cancer patients (aged 15-99 years) 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. Pohar and Perme
Welsh Cancer Intelligence and Surveillance Unit
Uned Gwybodaeth a Gwyliadwriaeth Canser Cymru

(2012) detail the net survival method in further detail for information.

- **Age-standardised net survival estimates** are the estimates that would occur if that population [of cancer patients] had a standard population age structure. Using this allows fair comparison of the rates across different regions in Wales, other countries in UK and Europe, and between different time periods. Five age-group specific survival estimates are weighted by standard weights and summed to give the age-standardised survival estimate (Corazziari et al., 2004). Table 1 details the various weights used for the cancer sites.

<table>
<thead>
<tr>
<th>Age band</th>
<th>ICSS1</th>
<th>ICSS2</th>
<th>ICSS3</th>
</tr>
</thead>
<tbody>
<tr>
<td>15-44 years</td>
<td>7000</td>
<td>28000</td>
<td>60000</td>
</tr>
<tr>
<td>45-54 years</td>
<td>12000</td>
<td>17000</td>
<td>10000</td>
</tr>
<tr>
<td>55-64 years</td>
<td>23000</td>
<td>21000</td>
<td>10000</td>
</tr>
<tr>
<td>65-74 years</td>
<td>29000</td>
<td>21000</td>
<td>10000</td>
</tr>
<tr>
<td>75-99 years</td>
<td>29000</td>
<td>14000</td>
<td>10000</td>
</tr>
</tbody>
</table>

**ICSS1**
Lip, tongue, salivary glands, oral cavity, oropharynx, hypopharynx, head & neck, oesophagus, stomach, small intestine, colon, rectum, liver, biliary tract, pancreas, nasal cavities, larynx, lung, pleura, breast, corpus uteri, ovary, vagina & vulva, penis, bladder, kidney, choroid melanoma, non-Hodgkin lymphomas, multiple myeloma, chronic lymphatic leukaemia, acute myeloid leukaemia, chronic myeloid leukaemia, leukaemia, all cancers

**ICSS2**
Nasopharynx, soft tissues, melanoma, cervix uteri, brain, thyroid gland, bone*

**ICSS3**
Testis, Hodgkins disease, acute lymphatic leukaemia

* For bone cancers, Corazziari et al. (2004) recommend using ages 20+ for survival and so ICSS2 with lower age band 20-44 has been used.

Note that on some occasions the age standardised survival rate for some cancer types and diagnosis periods will be slightly higher or lower for persons compared with men and women individually. This is due to the survival rates by age band and the ICSS weights used to calculate the age standardised rates. It should be noted that the age standardised survival rate for persons will be a better survival estimate compared to men and women individually due to the smaller 95% confidence interval.

- **Complete approach** - Net survival has been calculated using the complete approach. That is, one year and five year survival has been calculated for all diagnosis periods examined irrespective of whether the cohort of patients have one year or five years follow up respectively. For example, all patients diagnosed in 2001-2005 will have one year and five years follow up but not all patients diagnosed in 2012-2016 will have five years follow up. i.e. patients diagnosed in 2013, 2014, 2015 and 2016 will not have been followed up for the full 5 years.

- **A confidence interval** quantifies the level of uncertainty in a measurement or estimate. A 95% confidence interval is the range of values within which we can be 95% sure that the ‘true’ value of a statistical measure for the whole population lies, rather than being a chance finding. Confidence intervals will be wider when there are few numbers of cases.

- **Statistical significance** - If a difference in the survival rates between populations is statistically significant, it means that the difference is unlikely
to have occurred due to chance alone and we can be more confident that we are observing a 'true' difference. In this commentary we use the conventional arbitrary cut-off of less than 5% chance to mean statistically significant, as indicated by 95% confidence intervals that do not overlap. Just because a difference is statistically significant does not necessarily mean that it is large or important – that can depend on our judgement and many other things. Multiple testing occurs when we conduct more than one comparison test for statistical significance. To allow for multiple testing, 99% confidence intervals are sometimes reported. However, multiple testing has not been taken into account in this report and so one in 20 tests will be statistically significant by chance alone.

- **Stage at diagnosis** refers to the size of a tumour and how far it has spread from where it originated. Stage is measured from one to four; stage one indicates that the cancer is small and has not spread anywhere whereas stage four indicates the cancer has spread to at least one other body organ. Stage one and stage two usually refer to early stage whereas stage three and stage four are referred to late stage at diagnosis. Stage grouping in this report refers to overall TNM stage grouping. From 2016, the majority of cancer types are staged in TNM version 7 with one of the exceptions being bowel cancer (colorectal) that remained staged in TNM version 5. Female genital tract also use FIGO staging which can usually be mapped directly to TNM stage.

- Cases of cancer recorded on the cancer registry may have an unknown stage for many reasons. Firstly, not all types of cancers can be staged (a minority). Out of stageable cancer sites then the stage at diagnosis may be unknown for some of the following reasons: cancer registration system limitations; insufficient clinical data received to be able to derive cancer registry stage; exchange of data on cancer patients living in Wales but diagnosed or treated in England often did not include staging data until recently; and patients might be too ill or turn down diagnostic tests to allow clinical staging.

- The **International Statistical Classification of Diseases and Related Health Problems (ICD)** 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**