CANCER SURVIVAL IN WALES, 2002 – 2019

RESIDENTS OF WALES AGED 15-99 YEARS, DIAGNOSED WITH THEIR FIRST PRIMARY CANCER BETWEEN 2002 AND 2019, AND FOLLOWED UP TO 31ST DECEMBER 2021

TECHNICAL GUIDE

This document is part of the Cancer Survival in Wales, 2002 to 2019 Official Statistics publication.

The full publication is available at: http://www.phw.nhs.wales/services-and-teams/welsh-cancer-intelligence-and-surveillance-unit-wcisu/cancer-survival-in-wales-2002-2019

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1.   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 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, with approximately 20,000 patients diagnosed each year in Wales (excluding non-melanoma skin cancer). 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 (PHW), and more recently, became part of the new Public Health Data, Research and Knowledge Directorate within PHW (2nd August 2021).

Historically, official statistics publications by the WCISU have been released in an interactive dashboard, allowing users to make selections based on their requirements. However, in order to release these statistics in a timely manner, this publication will be released in data table format in a Microsoft Excel workbook, only.

This publication is produced by using a snapshot of the dynamic cancer registration database, which is populated and quality assured with data supplied by multiple data providers from NHS Wales Health Boards and Trusts, NHS Wales Informatics Service, Public Health England, 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 of the data collection process, data quality and the methodology applied. It also provides definitions, notes for interpretation, and details of where to find further information on cancer statistics in Wales.

2. Methodology

2.1 Overview

This publication reports on malignant primary neoplasms (cancer tumours) diagnosed between 2002 and 2019 in residents of Wales.

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, and 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 for this publication was taken in May 2022 for patients diagnosed in Wales from the year 2002 to the most current registration year, 2019, and followed up until 31st December 2021.

Only malignant neoplasms (cancers as described by the World Health Organisation (WHO) International Classification of Diseases: ICD-10 codes C00 to C97 excluding C44) that were successfully mapped across from older versions of the ICD have been included in this publication, and only a patient's first malignant primary cancer was used in the analysis.

This publication presents one-year and five-year net survival (%) (along with 95% confidence intervals (CIs)) by five-year rolling periods for men, women and persons aged 15-99 (20-99 for bone cancer patients), diagnosed from 2002 to 2019 for:

- Wales
- Health Boards
- Stage (from 2011 onwards. Staging analysis for leukaemia, brain & central nervous system cancers, Hodgkin lymphoma, Non-Hodgkin lymphoma and Myeloma are not available due to limited information prior to 2016.)

Results are shown for 36 cancer sites where possible. (Please note that bladder cancer is only provided for 2007 onwards due to a coding change.)

Survival was estimated using the Pohar-Perme (2012)[1] estimator, which provides unbiased estimates of net survival at all ages. The publicly available stns algorithm (Clerc-Urmès I et al, 2014)[2] in STATA 14.2 software was used and the complete approach to estimating survival was applied. That is, one-year and five-year survival was calculated for all diagnosis periods examined irrespective of whether the cohort of patients had one year or five years follow up respectively. For example, all patients diagnosed in 2002-2006 had one year and five years follow up but not all patients diagnosed in 2015-2019 had five years follow up (i.e. patients diagnosed in 2017, 2018 and 2019 will not have been followed up for the full five years).

95% CIs for net survival were estimated using a normal approximation on the survival scale (i.e. the plain method), and were capped between 0 and 100.

Population life tables were obtained from the Office for National Statistics (ONS) by age and sex. Each national life table is based on population estimates, births and deaths for a period of three consecutive years. We used the mid-year of each life table for our background mortality as an approximation to the non-cancer related death rates among cancer patients.

The analysis adopted the following post-estimation robustness criteria for each combination of stratifying factors:

- A minimum of 10 patients should be alive at the estimation point being reported (i.e. 10 or more alive one year after diagnosis for one-year survival, 10 or more alive five year after diagnosis for five-year survival)

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[1] Pohar Perme M, Stare J, Estève J. 2012. "On estimation in relative survival." Biometrics 68:113 -20

[2] Clerc-Urmès I, Grzebyk M, Hédelin G, 2014. Net survival estimation with stns. Stata Journal. 2014;14:87-102

- A minimum of two deaths should be observed one year either side of the estimation point (i.e. two or more deaths between zero and two years for one-year survival, two or more deaths between four and six years for five-year survival)
- The standard error at the estimation point should be 20% or less
- The survival estimates should decrease over time (i.e. five-year survival should be less than one-year survival), otherwise censor five-year survival figures
- One-year survival must be present and meet the criteria in order to show five-year survival

If the above criteria was not met, unstandardised net survival was censored for that particular cancer type, period, sex, age group, stage/geography level, and survival estimate point (one-year or five-year).

One-year and five-year age-standardised net survival (along with 95% CIs) were also presented where possible for patients aged 15-99 years by five-year rolling periods, by cancer type and sex at an all-Wales level, using a weighted mean of age-group estimates obtained from the International Cancer Survival Standards (ICSS; Corazziari et al., 2004)[3], Appendix A.

If the robustness criteria mentioned above for unstandardised net survival was not met for each age group, then the two lower age groups (15-44 and 45-54) were combined (15-54, Appendix B) and re-examined. Age-standardised net survival were only provided if every age group met the criteria, and these age specific survival figures were also presented.

A list of the cancer types used in this publication can be found in Appendix C. The list also contains the respective ICD-10 codes and the available breakdowns.

2.2 Reported characteristics

2.2.1 Geographical area

Analysis presented by geographical area, namely health board and at an all-Wales level, is based on an individual's area of residence at time of diagnosis.

There are seven health boards within Wales. As of 1st April 2019, these are: Aneurin Bevan University Health Board, Betsi Cadwaladr University Health Board, Cardiff and Vale University Health Board, Cwm Taf Morgannwg University Health Board, Hywel Dda University Health Board, Powys Teaching Health Board and Swansea Bay University Health Board.

Prior to 1st April 2019, the seven health boards were: Abertawe Bro Morgannwg University Health Board, Aneurin Bevan University Health Board, Betsi Cadwaladr University Health Board, Cardiff and Vale University Health Board, Cwm Taf University Health Board, Hywel Dda University Health Board and Powys Teaching Health Board.

On 1st April 2019 the responsibility for healthcare services in Bridgend County Borough Council area transferred to Cwm Taf University Health Board (now renamed Cwm Taf Morgannwg University Health Board) from Abertawe Bro Morgannwg University Health

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[3] Corazziari I, Quinn M, Capocaccia R, 2004. Standard cancer patient population for age standardising survival ratio. European Journal of Cancer 40: 2307-2316

Board (now renamed Swansea Bay University Health Board), with the health board boundary moving accordingly.

As such, the names of the health boards changed to reflect the new geographical boundaries.

All analysis in this publication are reported using the current health board boundaries, including years prior to 1st April 2019.

2.2.2 Staging

Great strides have been made to improve the completeness of cancer staging data, allowing cancer survival by stage in Wales to be presented from 2011. This publication reports on net survival of cancers diagnosed at stage 1, stage 2, stage 3, stage 4 and unknown stage for 25 cancer types, at an all-Wales level.

Stage at diagnosis refers to the size of a tumour and how far it has spread from where it originated. Stage is measured from 1 to 4; stage 1 indicates that the cancer is small and has not spread anywhere, whereas stage 4 indicates the cancer has spread to at least one other body organ. Stage 1 and stage 2 are usually referred to as early stage, whereas stage 3 and stage 4 are referred to as late stage at diagnosis.

Stage grouping in this report refers to overall TNM[4] stage grouping. From 2018, the majority of cancer types are staged in TNM version 8. Female genital tract also use FIGO staging which can usually be mapped directly to TNM stage. A change in TNM version can result in a noticeable redistribution between stage groups for some tumour sites, for example, TNM version 7 was introduced in 2016 which resulted in an increase in stage 1 cancers and a reduction of stage 2 for prostate cancers.

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). Of those cancer sites that can be staged, then the stage at diagnosis may be unknown for some of the following reasons: patients might be too ill or turn down diagnostic tests to allow clinical staging. In addition, there might be insufficient clinical data received to be able to derive cancer registry stage.

2.3 Reported measures

2.3.1 Net survival (unstandardised net survival)

Net survival (%) is an estimate of survival where the effect of background population mortality rates on survival has been removed. As background population mortality rates, 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 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. However, the analysis is sensitive to differences in background mortality between populations. Please see section 4.1.2 for more information about how life tables affect survival estimates. Pohar and Perme (2012)[5] detail the net survival method further.

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[4] The TNM Classification of Malignant Tumours (TNM) is a globally recognised standard for classifying the extent of spread of cancer. T category describes the primary tumour site and size, N category describes the regional lymph node involvement, M category describes the presence or otherwise of distant metastatic spread

[5] Pohar Perme M, Stare J, Estève J. 2012. "On estimation in relative survival." Biometrics 68:113 -20

2.3.2 Age specific net survival

Age specific net survival (%) is the same as above but presented by age groups, which are used to calculate age-standardised net survival below. The age groupings used can be seen in Appendix A and Appendix B.

2.3.3 Age-standardised net survival

The survival of cancer varies greatly with age. Differences in the age structure of populations between geographical areas or over time therefore need to be controlled to give unbiased comparisons of survival. Age-standardisation allows comparison of rates across different populations while taking account of the different age structures of those populations.

Age-standardised net survival (%) is an estimate that would occur if that population (of cancer patients) had an age structure matching that of the general population. Using this metric allows fair comparison of the rates across different regions in Wales, other countries in UK and Europe, and between different time periods. Survival estimates for five broad age groups are assigned standard weights and summed to give the age-standardised survival estimate (Corazziari et al., 2004)[6]. Appendix A and Appendix B detail the weights used for the different cancer types.

2.3.4 Confidence intervals

Confidence intervals are produced alongside the survival figures.

Confidence intervals are indications of the natural variation that would be expected around an estimate and they should be considered when assessing or interpreting an estimate. The size of the confidence interval is dependent on the number of events occurring and the size of the population from which the events came. Generally, estimates based on small numbers of events and small populations are likely to have wider confidence intervals. Conversely, estimates based on large populations are likely to have narrower confidence intervals.

In this publication, we calculate 95 per cent confidence intervals. This represents a range of values that we can be 95 per cent confident contains the 'true' underlying estimate.

Comparisons are often made between two or more estimates, for example between different areas or time periods (Figure 1). Sometimes in such cases statistical testing is undertaken by comparing the confidence intervals of the estimates to see if they overlap. Non-overlapping confidence intervals are considered as statistically significantly different (Figures 1a & 1b). Whilst it is safe to assume that non-overlapping confidence intervals indicate a statistically significant difference, it is not always the case that overlapping confidence intervals do not (Figure 1c). A more exact approach is to calculate the ratio of the two estimates, or the difference between them, and construct a test or confidence interval based on that statistic. Such methods are not covered in this technical guide, but can be found in a standard textbook.

This publication indicates whether the health board survival figure is significantly different compared to the Wales figure, for cancer type, sex and time period. In this instance, significant difference is indicated by whether the confidence intervals for the particular area overlaps or not with the confidence intervals around the Wales estimate for the cancer type, sex and time period.

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[6] Corazziari I, Quinn M, Capocaccia R, 2004. Standard cancer patient population for age standardising survival ratio. European Journal of Cancer 40: 2307-2316
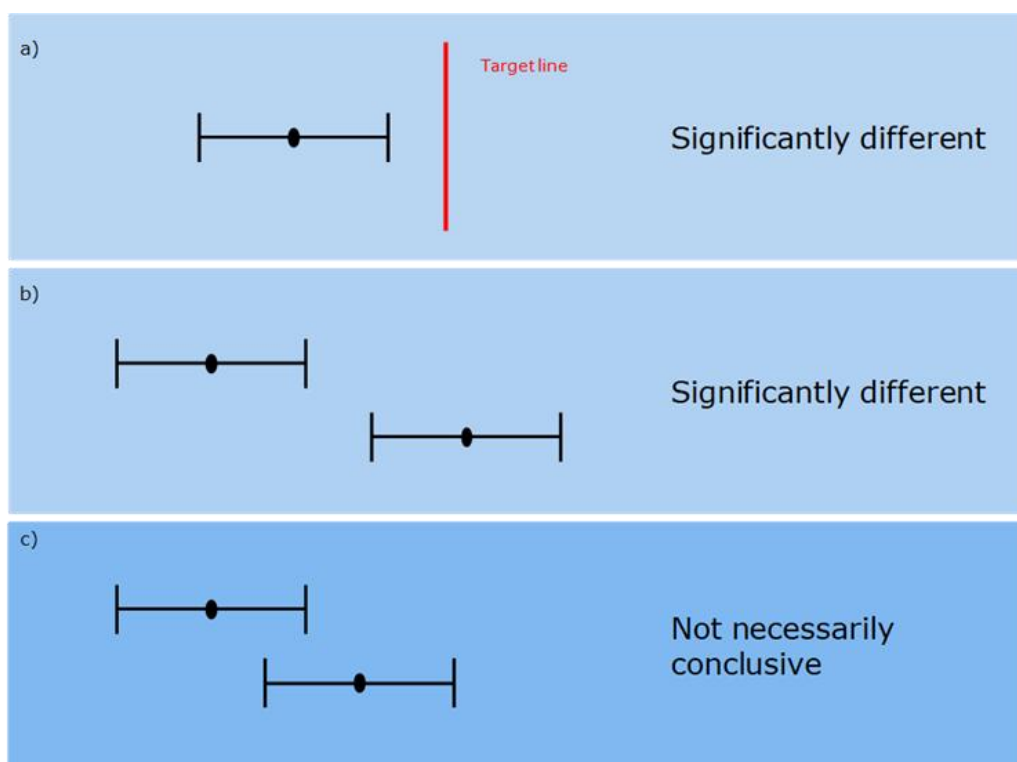
Figure 1. Using confidence intervals for making comparisons
a) & b) Non- overlapping confidence intervals are considered as statistically significant
c) Overlapping confidence intervals do not always indicate a difference that is not statistically significant

3.　Relevance

The release of official statistics by the 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 statistics regarding cancer survival are:

- The public and community groups
- NHS Wales as a whole, and Health Boards, Trusts, and the NHS Wales Cancer Implementation Group and Wales Cancer Network, as well as other teams in Public Health Wales and other national and local public bodies
- Professional bodies, clinicians of all disciplines, and policy makers
- Cabinet secretary, Ministers and their civil servants
- Other government departments
- Senedd Members and the Members Research Service
- Third sector and charities
- Media
- Students, academics and universities - to provide valuable reference data for academics and researchers to engage in cancer related research, including the WCISU's direct participation in research collaborations
- The private sector

We encourage users of the statistics to contact us to let us know how they use the data, please see the contact details on page 1 of this document. Acknowledgement to Public

Health Wales NHS Trust to be stated if reproducing material in this document or accompanying outputs.

4. Accuracy

4.1 Cancer registration

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

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 implemented a new cancer registration system named CATRIN in 2015. This is the same as the ENCORE system used in Public Health England, which has inbuilt registration validations. This modernisation programme has improved cross border data sharing in particular. The data migration process placed a particular emphasis on reducing duplicate registrations existing in both Wales and England registry databases. A quality assurance and de-duplication exercise was undertaken to rationalise the cancer registrations across the two countries. Therefore, this may reflect in a reduction of cancers recorded.

Cancer registrations comply with a quality assurance framework comprising of a suite of quality checks performed at various time points during the registration year e.g. quarterly and end of year checks. These check the data consistency of the cancer site, sex and associated histology as well as validity checks on dates, for example, to check invalid combinations for behaviour and site/histology; check that the incidence date is not after the date of death. These checks align to those published in 2018 by the European Network of Cancer Registries (ENCR)[7].

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

For this output, cancers are coded using ICD-10 from 1st January 2002 to 30th June 2012 and coded using ICD-10v4[8] thereafter. ICD-10 coding for cancer is based on the nature and anatomical site of the cancer. A mapping table is used to convert all cancers to ICD10 using the originally registered site and morphology fields. Only cancers that were successfully converted were used in this publication.

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

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[7] https://www.encr.eu/sites/default/files/inline-files/Cancer%20Data%20Quality%20Checks%20Procedure%20Report%20online.pdf

[8] http://www.who.int/classifications/icd/en/

monthly and can be used in further cancer publications, queries and parliamentary questions.

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 survival.

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

Please use caution when interpreting the trends in survival due to all robust estimates being displayed and some data points have been censored.

4.1.1 ICD-10 coding system changes

ICD-10 coding for cancer is based on the nature and anatomical site of the cancer. Previous official statistics publications mapped to and reported on ICD-10v0 for all diagnosing years. However, this year's publication will report on ICD-10v0 for diagnosing years 2001 to 2012, and ICD-10v4 from 2013 onwards.

There have been changes and revisions regarding the coding of some cancers using ICD-10v4, such as the introduction of new diagnosis codes along with minor changes to some cancer descriptions and naming conventions. There have been some more significant changes related to the coding of blood cancers, mainly non-Hodgkin lymphoma and leukaemia malignancies being coded more precisely. Therefore, caution is advised when examining trends for these sites. The change in reporting of ICD-10 from 2013 onwards should also be taken into consideration when examining data.

4.1.2 Lifetables

Survival analysis estimates the net survival (%) of patients with cancer. These survival figures have been used to produce unstandardised and age-standardised estimates. The model uses population life tables to remove background mortality, and assumes the remaining mortality is due to cancer.

Net survival analysis involves comparing the survival of patients with cancer with background mortality (the survival of the general population). For reasons of practicality, our background mortality data includes cancer deaths. This is unlikely to skew our net survival figures for specific cancer sites, but it would likely have an effect on deaths from all cancers, because cancer accounts for about a quarter of all deaths. For that reason, we have not included survival figures for all cancers combined.

The life tables don't account for known differences in background mortality across different geographies and deprivation fifths. Caution is advised when comparing five-year survival estimates across health boards. However, survival across different deprivation fifths is not reported due to the differences in background mortality.

Please note that patients were followed up until the 31st December 2021 for this analysis. The effect of COVID-19 may be seen for five-year net survival in the following five year diagnosis periods; 2011-2015, 2012-2016, 2013-2017, 2014-2018 and 2015-2019. This analysis uses ONS published life tables which do not fully account for changes in background mortality due to the Covid pandemic. For more information about the limitations of published life tables see ONS lifetable caveats (published 23rd September 2021).

We are currently considering methods to adjust for these issues, and intend to implement these in future analyses.

5.   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 source data being completed and becoming available, 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 the WCISU, according to strict international rules and guidelines of coding, classification and staging.

This particular publication is delayed further by twelve months as both the registration and analysis teams in the WCISU have been further affected by COVID-19 with resources redeployed to support PHW response to the pandemic.

All outputs adhere to the Code of Practice by pre-announcing the date of publication through the upcoming calendar on the Welsh Government Statistics and research page. 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.

6.   Accessibility and clarity

The statistics will be published in an accessible, orderly, pre-announced manner on the Welsh Cancer Intelligence and Surveillance Unit'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 and free to download.

The Official Statistics for "Cancer survival in Wales, 2002-2019" are 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. The individuals on the pre-release list can be found on the publication webpage.

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.

7.   Comparability and coherence

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

- Northern Ireland Cancer Registry
- Scottish Cancer Registry
- Office for National Statistics
- National Disease Registration Service

Details of cancer registries in the United Kingdom and Ireland can be found on the United Kingdom and Ireland Association of Cancer Registries website.

Due to differences in the life tables between different cancer registries, we advise against making direct comparisons between the different UK Jurisdictions. We are working with other registries towards improving comparability. In the interim, the European/world studies is suitable for comparisons between the different UK Jurisdictions as the same methodology was applied, however data for recent periods is not yet available (Eurocare).

The WCISU have recently published their 2020 UKIACR performance indicators. Further information regarding the data completeness and quality of cancer registry data is detailed in the UKIACR performance indicators reports.

8. Legislation

The WCISU adhere to the ENCR 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.

Under General Data Protection Regulation (GDPR), we follow:

Article 6 (1) e - processing is necessary for the performance of a task carried out in the public interest or in the exercise of official authority vested in the controller;

And

Article 9 (2) h - processing is necessary for the purposes of preventive or occupational medicine, for the assessment of the working capacity of the employee, medical diagnosis, the provision of health or social care or treatment or the management of health or social care systems and services on the basis of Union or Member State law or

pursuant to contract with a health professional and subject to the conditions and safeguards referred to in paragraph 3.

The key policy on cancer in Wales is set out in the Welsh Government's "The Quality Statement for Cancer."

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 can be found here - How do you measure a nation's progress? - National Indicators

Further information on the Well-being of Future Generations (Wales) Act 2015.

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.

9.   Further details

Cancer survival is one of three official statistics publications regularly produced by the WCISU, alongside cancer incidence and cancer mortality. All our publications can be found here:

https://phw.nhs.wales/services-and-teams/welsh-cancer-intelligence-and-surveillance-unit-wcisu/

10. Glossary

10.1 Abbreviations

ECC	Ethics and Confidentiality Committee
ENCR	European Network of Cancer Registries
GDPR	General Data Protection Regulation
HB	Health Board
ICD	International Classification of Diseases
ICSS	International Classification of Standard Weights
LSOA	Lower Super Output Area
NIGB	National Information Governance Board
NMSC	Non-Melanoma Skin Cancer
OCAT	Observatory and Cancer Analysis Team
ONS	Office for National Statistics
PHW	Public Health Wales
UKIACR	United Kingdom and Ireland Association of Cancer
WCISU	Welsh Cancer Intelligence and Surveillance Unit
WG	Welsh Government
WHO	World Health Organisation

10.2 Definitions

Age-standardised rate

- Age-standardisation allows comparison of rates across different populations while taking account of the different age structures of those populations. Failure to take account of differing age structures can be very misleading when comparing rates in different populations.

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 but not routinely reported on.

Confidence Intervals

- Confidence intervals are indications of the natural variation that would be expected around an estimate and they should be considered when assessing or interpreting a rate. The size of the confidence interval is dependent on the number of events occurring and the size of the population from which the events came. Generally

speaking, rates based on small numbers of events and small populations are likely to have wider confidence intervals. Conversely, rates based on large populations are likely to have narrower confidence intervals.

Health Board (HB)

- Health Boards are the NHS bodies in Wales responsible for the health of the population within their geographical area. This includes planning, designing, developing and securing the delivery of primary, community, in-hospital care services and specialised services. There are seven health boards.

Lower Super Output Area (LSOA)

- Defined geographical area based on Census output areas with an average of 1500 persons per LSOA. There are 1909 LSOAs in Wales, and the number of LSOAs can vary widely between health boards.

Public Health Wales NHS Trust

- Public Health Wales was established as an NHS Trust on 1 October 2009. The Trust incorporates the functions and services previously provided by the National Public Health Service for Wales, the Wales Centre for Health, the Welsh Cancer Intelligence and Surveillance Unit and Screening Services Wales.

Stage

- Stage at diagnosis refers to the size of a tumour and how far it has spread from where it originated. Stage is measured from 1 to 4; stage 1 indicates that the cancer is small and has not spread anywhere, whereas stage 4 indicates the cancer has spread to at least one other body organ. Stage 1 and stage 2 are usually referred to as early stage, whereas stage 3 and stage 4 are referred to as late stage at diagnosis.

Statistical Significance

- A result may be deemed statistically significant if it is considered unlikely to have occurred by chance alone. The basis for such judgements is a predetermined and arbitrary cut-off, usually taken as 5% or 0.05. In some circumstances this cut–off may be lowered to 1%, for example where there is a greater need for certainty over the safety of a drug or procedure. Statistical significance must not be confused with clinical or other significance. A result may be clinically significant whilst not being statistically significant and vice versa.

Survival

- For the purposes of this publication, the term "survival" relates to net survival and is measured as a percentage. It is an estimate of survival where the effect on survival of background population mortality rates has been removed.

11. Appendices

11.1 Appendix A - International Classification of Standard Weights (ICSS)[9]

Age band	ICSS1	ICSS2	ICSS3	Age band	Prostate
15-44 years	7000	28000	60000	**15-54 years**	19000
45-54 years	12000	17000	10000	**55-64 years**	23000
55-64 years	23000	21000	10000	**65-74 years**	29000
65-74 years	29000	20000	10000	**75-84 years**	23478
75-99 years	29000	14000	10000	**85-99 years**	5522
15-99 years	100000	100000	100000	**15-99 years**	100000

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, Hodgkin lymphoma, 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.

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[9] Corazziari I, Quinn M, Capocaccia R, 2004. Standard cancer patient population for age standardising survival ratio. European Journal of Cancer 40: 2307-2316

11.2 Appendix B - International Classification of Standard Weights (ICSS)[10] combined

Age band	ICSS1	ICSS2	ICSS3	Age band	Prostate
15-54 years	19000	45000	70000	**15-54 years**	19000
55-64 years	23000	21000	10000	**55-64 years**	23000
65-74 years	29000	20000	10000	**65-74 years**	29000
75-99 years	29000	14000	10000	**75-84 years**	23478
				85-99 years	5522
15-99 years	100000	100000	100000	**15-99 years**	100000

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, Hodgkin lymphoma, acute lymphatic leukaemia

* For bone cancers, Corazziari et al. (2004) recommend using ages 20+ for survival and so ICSS2 with lower age band 20-54 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.

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[10] [10] Corazziari I, Quinn M, Capocaccia R, 2004. Standard cancer patient population for age standardising survival ratio. European Journal of Cancer 40: 2307-2316

11.3 Appendix C - Cancer types map

	Cancer type	ICD-10 site code	Wales - Unstandardised	Wales - Age-standardised	Wales - Age-standardised*	Wales - Age specific	Health board - Unstandardised	Stage - Unstandardised (2011 onwards)
1	Acute lymphoblastic leukaemia	C910	✓					
2	Acute myeloid leukaemia	C920	✓					
3	Anus	C21	✓		✓	✓	✓	✓
4	Bladder	C67	✓		✓	✓	✓	✓
5	Bone	C40-C41	✓				✓	✓
6	Brain & central nervous system	C70-C72	✓		✓	✓	✓	
7	Breast	C50	✓	✓		✓	✓	✓
8	Cervix	C53	✓	✓		✓	✓	✓
9	Cholangiocarcinoma	C221	✓					
10	Chronic lymphocytic leukaemia	C911	✓					
11	Chronic myeloid leukaemia	C921	✓					
12	Colon	C18	✓		✓	✓	✓	✓
13	Colorectal	C18-C20	✓		✓	✓	✓	✓
14	Head & neck	C00-C14, C30-C32	✓		✓	✓	✓	✓
15	Hepatocellular carcinoma	C220	✓					
16	Hodgkin lymphoma	C81	✓		✓	✓	✓	
17	Kidney	C64	✓		✓	✓	✓	✓
18	Larynx	C32	✓		✓	✓	✓	✓
19	Leukaemia	C91-C95	✓		✓	✓	✓	
20	Liver	C22	✓		✓	✓	✓	✓
21	Lung	C33-C34	✓		✓	✓	✓	✓
22	Melanoma of the skin	C43	✓		✓	✓	✓	✓
23	Mesothelioma	C45	✓		✓	✓	✓	✓
24	Myeloma	C90	✓		✓	✓	✓	
25	Non-Hodgkin lymphoma	C82-C86	✓		✓	✓	✓	
26	Oesophagus	C15	✓		✓	✓	✓	✓
27	Oral & oropharynx	C00-C06, C10	✓		✓	✓	✓	✓
28	Ovary	C56	✓		✓	✓	✓	✓
29	Pancreas	C25	✓		✓	✓	✓	✓
30	Prostate	C61	✓	✓		✓	✓	✓
31	Rectum	C19-C20	✓		✓	✓	✓	✓
32	Stomach	C16	✓		✓	✓	✓	✓
33	Testis	C62	✓				✓	✓
34	Thyroid & endocrine	C73-C75	✓		✓	✓	✓	✓
35	Urinary tract excluding bladder	C64-C66, C68	✓		✓	✓	✓	✓
36	Uterus	C54	✓		✓	✓	✓	✓

* combined ICSS age groupings used. Please refer to appendices above for further information