

# Macmillan-WCISU Partnership: Cancer Data Landscape in Wales

## Third Edition

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Uned Gwybodaeth a  
Gwyliadwriaeth Canser Cymru  
Welsh Cancer Intelligence  
and Surveillance Unit

**MACMILLAN**  
**CANCER SUPPORT**  
**RIGHT THERE WITH YOU**

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## Aims

Macmillan Cancer Support and the Welsh Cancer Intelligence and Surveillance Unit (WCISU) of Public Health Wales have entered into partnership to use data to improve understanding of the impact and costs of cancer and its treatment across the primary, secondary and tertiary care pathways. This partnership commenced in April 2017 and is currently in its second phase. The partnership aims to deliver insightful analysis of Welsh cancer data to support improved design, testing and implementation of better models of care. It also aims to identify gaps and opportunities to deliver world class data collection and analysis for improved outcomes for people living with and beyond cancer. The objectives of the partnership are:

## Partnership objectives

- To identify and access new data sources, improve the use of existing datasets relevant to cancer patients in Wales and deliver insight into the unique characteristics of cancer data in Wales and the opportunities these provide for analysis.
- To identify any gaps in cancer-specific and cancer-relevant data in Wales, particularly in relation to other UK nations.
- To understand the potential to link and analyse data - according to the aims of this partnership - on clinical outcomes and patient experience across primary, secondary and tertiary care in Wales, including data from acute oncology units.
- To develop a two-year data development and analytic work-plan that supports the aims of this partnership, aligns with Macmillan's strategy for Wales (including the promotion of person-centred care and the Framework for Cancer in Primary Care), the Public Health Wales Strategic Plan and statutory duties, and the Macmillan-NCRAS work-plan. The work-plan activities will provide support for the implementation of Welsh Government's Cancer Delivery Plan, including the provision of contextual information to influence the delivery of person-centred care in Wales.
- To assess the feasibility for adapting Macmillan's Routes to Diagnosis approach for Wales or developing a similar, but tailored, set of analysis to map the patient pathway, focusing on cost of cancer journey, patient outcomes and quality of life during survival and living with cancer.
- To influence the commissioning, planning and delivery of cancer services in Wales by delivering relevant, timely and accessible outputs.

## **Introduction**

To inform the work of the partnership and other researchers in Wales this Landscape paper has been produced to summarise the main datasets and publications in relation to cancer data in Wales.

To meet the objectives, the datasets need to be fully documented in terms of what is available currently, what datasets are due to be launched, and what project areas are unlikely during the timeframe of this partnership due to data availability and available resources to analyse and report on the data. The latest partnership period covers 1st April 2019 to 31st March 2021.

## **Policy and Research**

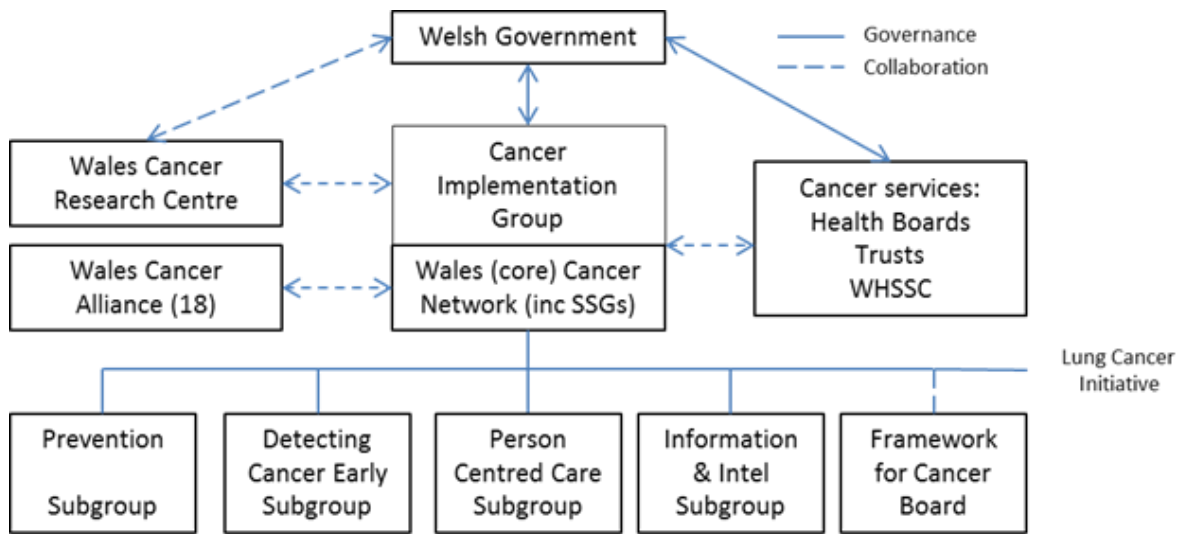
### **Welsh Government**

During May 2011, the National Assembly for Wales gained new powers enabling it to make laws in the 20 areas devolved to Wales, including health services and social welfare. Welsh Government is responsible for developing and implementing policies in devolved areas and also proposing Welsh laws for consideration by the assembly. The structure for health in Wales is through delivery frameworks, which detail the priorities for that period.

On health delivery plans, Welsh Government set out nationally agreed actions and define performance measures and outcomes. These are aimed at improving services with particular attention to: prevention and early diagnosis; integrated and efficient care; better information; more targeted research.

Welsh Government has developed the Cancer Delivery Plan for Wales 2016-2020 alongside the Wales Cancer Network and is responsible for publishing Cancer Waiting times.

Figure 1 – Inter-relation of Cancer policy and delivery mechanisms in Wales.



Source: Welsh Government 2018

A calendar website link for upcoming publications at Welsh Government is available in Appendix 4.

## Cancer Delivery Plan for Wales 2016-2020

Welsh Government, in conjunction with the Wales Cancer Network, published the refreshed Cancer Delivery Plan for Wales 2016-2020 in November 2016. The previous cancer delivery plan was published in 2012 and covered the period up to 2016.

The Cancer Delivery Plan's aim is to close the gap with the best performing European countries by providing everyone with cancer the highest standard of care. This will be demonstrated through improving survival, reducing premature mortality and maintaining high levels of positive patient experience. The Cancer Delivery Plan sets out the vision for the population of Wales and what this means for NHS cancer services. The key areas of focus in the delivery plan are:

- detecting cancer earlier
- delivering fast, effective treatment and care
- meeting the needs of people with cancer
- improving cancer information
- caring for people with cancer at the end of life
- improving cancer information
- targeting cancer research
- Cancer service performance and plan delivery.

The list of measures are available below in Table 1.

Table 1: Specific areas of work and associated service measures

Domain	Measure
Preventing cancer	HPV and Hepatitis B Vaccination rates Smoking cessation rates Public Health Outcomes Framework
Detecting cancer quickly	Stage at diagnosis Emergency presentations Screening uptake
Delivering fast, effective treatment and care	Referral to treatment time Compliance with national quality standards 30-day mortality post treatment
Meeting people's needs	Allocation of key worker Completion of electronic holistic needs assessment Offer of a written care plan
Caring at the end of life	Preferred place of death % advanced care plan in place
Improving information	CPES [longer term PREMs and PROMs] Audit and Peer Review Participation
Targeting research	Number of cancer clinical trials and research studies Patient recruitment to cancer clinical trials and research studies Consent to tissue donation (TBD)

Source: Welsh Government and Wales Cancer Network. *Cancer Delivery Plan for Wales 2016-2020*. Welsh Government and Wales Cancer Network; November 2016

The population outcome measures are:

- Cancer incidence and prevalence
- Short and long-term survival rates
- Premature mortality related to cancer and mortality
- Global Patient Reported Experience Measures (including the Cancer Patient Experience Survey)
- Global Quality of Life measure (to be developed)

The Welsh Government released an Annual Statement on the 23rd November 2017 regarding the progress during 2016/17. Areas of work include: - Early Diagnosis Programme, Single Cancer Pathway and Improvement, Lung cancer, All Wales Cancer Patient Experience Survey, Cancer Information Strategy, Peer reviews of current services and governance and functionality.

Website link to Cancer Delivery Plan for Wales 2016 – 2020 Update

<http://www.walescanet.wales.nhs.uk/sitesplus/documents/1113/171128updateen.pdf>

Website link to Cancer Delivery Plan for Wales 2016 - 2020

<http://gov.wales/docs/dhss/publications/161114cancerplanen.pdf>

## Cancer Implementation Group (CIG)

Cancer services and implementation of the Cancer Delivery Plan in Wales are overseen by a NHS Wales-led Cancer Implementation Group (CIG). There is representation from the Wales Cancer Network, third sector (including Macmillan Cancer Support), primary care, Public Health Wales, health boards, NHS Wales Informatics Service (NWIS) and Welsh Government. The CIG provides the governance for the development of national solutions to common delivery problems and is accountable to the Chief Executive of NHS Wales. The CIG oversees the work of the Wales Cancer Network and the Network team are the delivery arm of the Cancer Implementation Group.

The Welsh Government has provided limited £1 million annual funding for the delivery of the CIG priorities.

Website link to Cancer Annual report 2016

<http://www.walescanet.wales.nhs.uk/sitesplus/documents/1113/170215cancer-annual-report16en.pdf>

The Cancer Information and Intelligence Sub Group is overseeing the implementation of the digital health strategy for cancer published 2017.

Website link to the Cancer Information and Intelligence Framework: A Digital Health Strategy for Cancer in Wales

<http://www.walescanet.wales.nhs.uk/sitesplus/documents/1113/CII%20A%20Digital%20Health%20Strategy%20for%20Cancer%20in%20Wales%202017%20very%20final.pdf>

## Wales Cancer Network (WCN)

A Cancer Information Framework was developed to deliver the information requirements highlighted in the Calman-Hine Report (1995) 'A policy framework for commissioning cancer services', which recommended the restructuring of services to provide equity to high quality care. As a result of this report and the subsequent Cameron report 'Cancer Services in Wales (1996)', three cancer networks were set up (North, South East and South West Wales) with specialist care provided by Multidisciplinary Teams (MDTs).

In April 2014, the Cancer National Specialist Advisory Group (NSAG) joined Public Health Wales to provide support to an executive group and cancer sub groups. In October 2016, the then two cancer networks merged with Cancer National Advisory Group (NSAG) to form one network – WCN.

"The strategic purpose of the WCN is to support Health Boards to:

- Meet the requirements of the Welsh Government's Cancer Delivery Plan, and other national strategic plans and frameworks for cancer
- Improve cancer survival
- Improve the quality of life and experience of those living with the impact of cancer
- Ensure the safety and sustainability of cancer services
- Reduce variation
- Support the principles of prudent healthcare
- Empower patients through co-production of healthcare
- Encourage innovation in order to meet the large increase in predicted demand"

Source: Wales Cancer Network, <http://www.walescanet.wales.nhs.uk/about-us>

Macmillan work in partnership with the Wales Cancer Network under the Macmillan Framework for Cancer in Primary Care and through other strategic initiatives. Together, they aim to improve cancer services for patients by focusing on three areas – early diagnosis, support through treatment and living beyond cancer. Macmillan’s GP Leads in each of the Health Boards and Velindre NHS Trust work with four nurse leads to support primary care providers and their patients.

A memorandum of understanding exists between WCISU and the Wales Cancer Network, with the commitment for a collaborative approach to cancer intelligence focusing on supporting the relevant parts of the CDP and CIIG, including Public Health Wales Integrated Medium Term Plan (IMTP).

Website link to Wales Cancer Network

<http://www.walescanet.wales.nhs.uk/home>

Website link to Macmillan Framework for Cancer in Primary Care

<http://www.walescanet.wales.nhs.uk/sitesplus/documents/1113/Peter%20Gorin%20-%20Presentation%20MacMillan%20F4C%20Cancer%20Conference%20version%20002.pdf>

## **Wales Cancer Alliance**

Wales Cancer Alliance are a third sector organisation comprising a number of voluntary organisations. They work with the Welsh Government and NHS, among others, to promote cancer research and care for people in Wales. The Alliance are campaigning to reduce the variation in cancer incidence and outcomes in Wales by 2021. Their key areas for focus are:

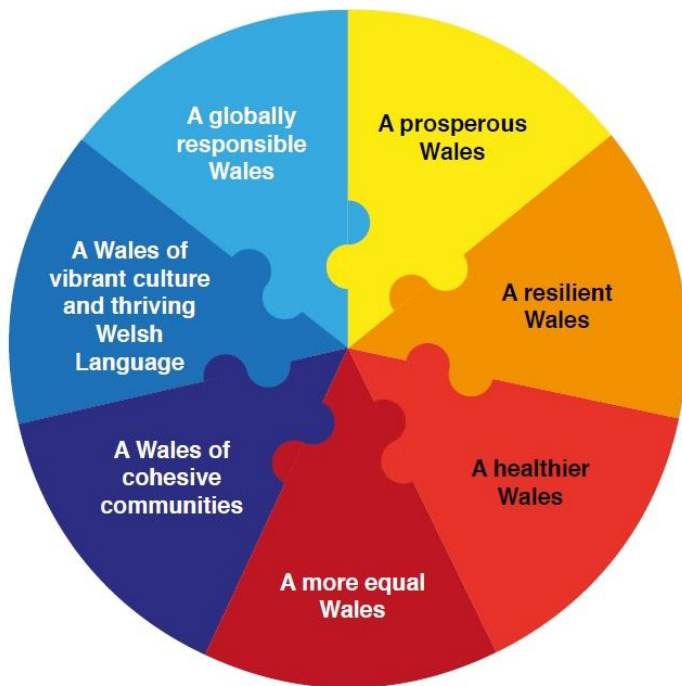
- Preventing cancer
- Earlier diagnosis
- Delivering fast, effective treatment and care
- Meeting people’s needs
- Coordinating care
- Palliative and end of life care
- Improving information
- Children, teenagers and young adults (0-24 years)
- Targeting research

Website link to the Wales Cancer Alliance

<http://www.walescanceralliance.org/>

## **Wellbeing of Future Generations Act (2015)**

The Wellbeing of Future Generations Act has seven new wellbeing goals (see below) which apply to 44 public bodies in Wales (such as local authorities, NHS, Public Health Wales, Fire and Rescue). These public bodies will have to think about the long term, how to stop problems happening in the first place, how they work with others, how they involve people in decisions and how connected our lives are. It became law on the 1<sup>st</sup> April 2016.



Source: Welsh Government. *Well-being of Future Generations (Wales) Act 2015: The Essentials*. Welsh Government; 2015.

Website link to the Well-being of Future Generations (Wales) Act  
<https://futuregenerations.wales/about-us/future-generations-act/>

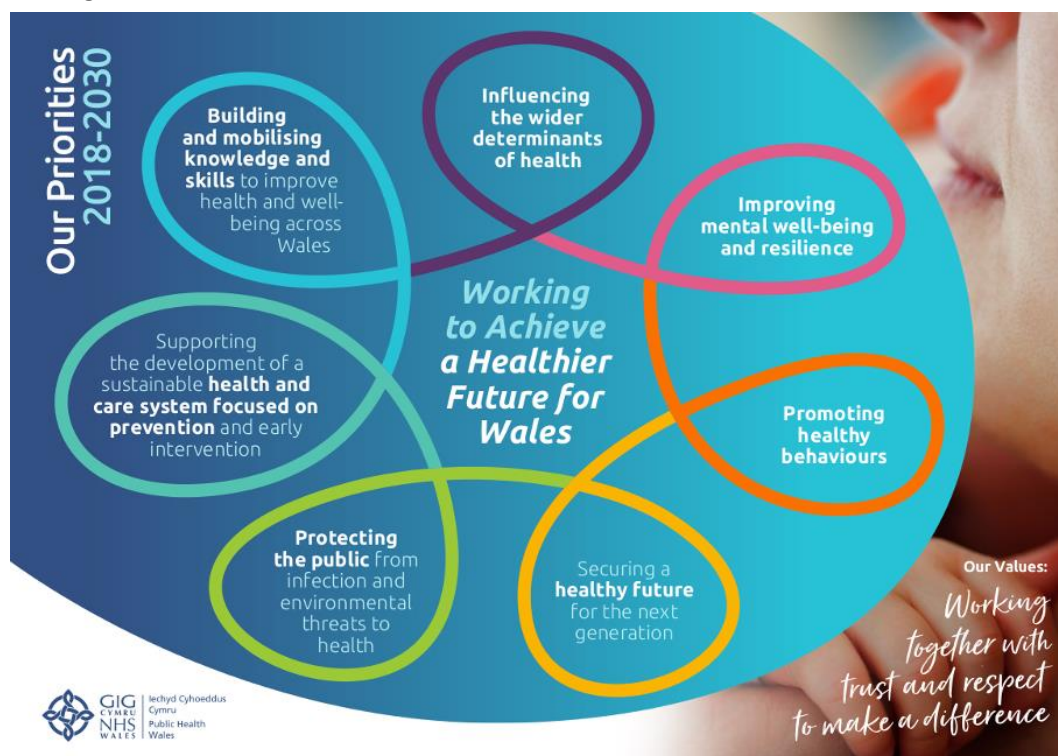
Website link to the Welsh Government information on the Well-being of Future Generations (Wales) Act.  
<http://gov.wales/topics/people-and-communities/people/future-generations-act/?lang=en>

## Public Health Wales

Public Health Wales – Long-term Strategy 2018 - 2030

There are seven strategic priorities in the integrated medium term plan.

Strategic Priorities -



Public Health Wales. *Our priorities 2018-2030*. Cardiff: Public Health Wales NHS Trust; 2018

Strategic Priorities -

1. Influencing the wider determinants of health
2. Improving mental well-being and resilience
3. Promoting healthy behaviours
4. Securing a healthy future for the next generation
5. Protecting the public from infection and environmental threats to health
6. Supporting the development of a sustainable health and care system focused on prevention and early intervention
7. Building and mobilising knowledge and skills to improve health and well-being across Wales

A Public Health Wales Operational plan updated annually supports the strategic priorities in the IMTP.

Website link to the strategic (IMTP): <http://www.wales.nhs.uk/sitesplus/888/page/82750/>

## Macmillan Strategic priorities for Wales

Macmillan have the following five priorities for Wales

1. Engage with the key stakeholder groups of people affected by cancer, volunteers and Macmillan professionals to understand their needs, their perspectives and their expertise in cancer care better to inform our strategy and its implementation.
2. Influence and facilitate, where appropriate, an improved experience for people seeking help for signs and symptoms of cancer so that people are well-supported during pre-diagnosis and early interventions are made to support health and wellbeing to maximise the effectiveness of proposed treatments and care wherever possible.
3. Influence and facilitate the delivery of consistent person-centred care from diagnosis onwards through active treatment.
4. Influence and facilitate consistent delivery of person centred care so that people are able to live well with and beyond cancer.
5. Improve care and support for people with cancer needing palliative care and moving towards the end of life.

## Information available

There are a range of data sources at individual record or aggregated level; some of which are well established and some that are up and coming. Data sources will vary in terms of their completeness and accessibility depending on the years of data required. Any new datasets implemented will not have data from retrospective years. Some datasets are available nationally, while others may be held locally at each health board. A disadvantage of requesting from each health board is that it is time consuming and the data may not be received in the same format, could be received at different times or possibly available only outside the timeframe for a project.

### The Welsh Cancer Registry

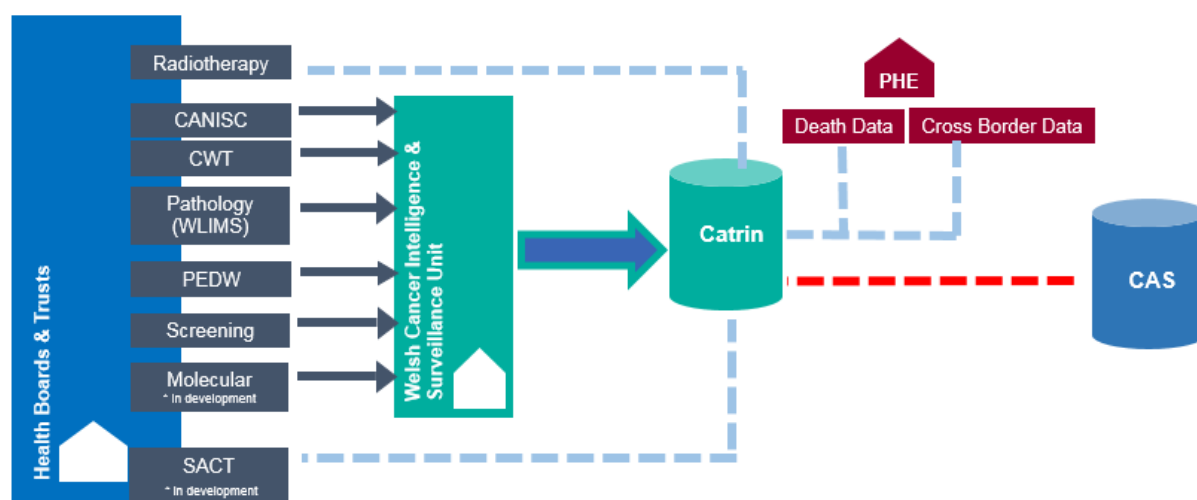
WCISU formed in 1995, collates and maintains the National Cancer Registry for Wales. Its primary role is to record, store and report on all incidence of cancer for the resident population of Wales, wherever they are treated. The cancer registry holds data going back to 1972 and full years from 1974.

Cancer registration is undertaken to agreed national and international standards that involves the interrogation of multiple data sources such as MDT documentation, pathology reports, radiology reports, clinical correspondence, death certificates etc. The registry includes cross border cases where Welsh residents are treated in England. Cancer registration is a dynamic fluid process. There is a time lapse of approximately 9-12 months in the creation of the annual cancer registrations (i.e. cancer registrations for 2015 were complete by December 2016). It is anticipated in some cases some cancer registrations will continue to be created even after this time.

### Cancer registration information system (Catrin)

In April 2017, the Cancer Registry implemented a new cancer information system called CATRIN, which was the enabler to improve the cancer registration processes for efficiency and to allow new additional clinical data to be linked to cancer registrations. As part of this new system, there is a separate reporting platform available now for analytical purposes (Cancer Analysis Service, CAS), which contain monthly refreshes of cancer registration and linked cancer data. Access is granted to CAS based on the level required for specific job roles (e.g. analyst and only for specific offices/locations) for staff working within the NHS. The data set below (Figure 2) shows the data items currently captured for the Cancer Registry data.

**Figure 2: Summary of the data flows that contribute to the Cancer Registration**



\* Systemic Anti-Cancer Therapy (SACT) in development

\* Molecular - In development

## Cancer Network Information System Cymru (Canisc)

Canisc is a cancer specific information system used across Wales. An electronic patient record that allows the recording of clinical data throughout the patient pathway. It allows health professionals to access important clinical information wherever the patient receives specialist care and supports clinicians in the provision of best care to patients. Canisc records outcomes of MDT discussions, clinical and diagnostic investigations and treatments. The coded information is used by the cancer registry.

Website link to All Wales CORE CANCER minimum reporting guidelines

<http://howis.wales.nhs.uk/sites3/Documents/769/All%20Wales%20CCMRRV5.0%20Operational%20Documentation%20Final.pdf>

<http://www.datadictionary.wales.nhs.uk/>

Website link to all cancer sites listed above

<http://howis.wales.nhs.uk/sites3/page.cfm?orgid=769&pid=19419>

The palliative care dataset is part of Canisc. Both statutory and non statutory bodies collect the clinical and activity data on patients referred to palliative care.

Website link to All Wales Specialist Palliative Care Dataset

<http://www.datadictionary.wales.nhs.uk/#!WordDocuments/allwalespecialistpalliativecaredataset.htm>

## **Wales Radiology Information System (WRIS) (Previously known as RADIS2)**

<http://www.wales.nhs.uk/sitesplus/956/page/52551>

Each health board in Wales uses the WRIS to schedule patient appointments for medical imaging, x-rays and MRI scans. The system tracks the patient's progress and records diagnostic reports. This information is available electronically to the patient's GP and is linked into hospital picture archiving, administration and ward viewing systems.

Website link to Shaping the future of radiology in Wales

<http://www.velindre->

[tr.wales.nhs.uk/sitesplus/documents/1137/Radiotherapy%20strategy%20VCC.pdf](http://www.wales.nhs.uk/sitesplus/documents/1137/Radiotherapy%20strategy%20VCC.pdf)

## **Radiotherapy Data Set (RTDS)**

There are three radiotherapy centres in Wales – Velindre Cancer Centre (VCC), South West Wales Cancer Centre (Singleton Hospital, Swansea) and North Wales Cancer Treatment Centre (Glan Clwyd Hospital, St Asaph). A national dataset is agreed and centres are collecting this directly from radiotherapy machines and holding locally. Work began in 2017 to implement systems to enable this data to flow to a national level. It is now available for cancer registration purposes and it is anticipated a national RTDS dataset for Wales will be available later this year (2019).

Website link to RTDS dataset

<http://www.datadictionary.wales.nhs.uk/#!/WordDocuments/datasetstructure7.htm>

## **Office for National Statistics (ONS)**

Death information (general – non specific to cancer), life tables and mid year population estimates are available from ONS. Birth and death data is provided routinely to NHS Wales Informatic Service. With the implementation of the new cancer registration system the death certificate information interfaces from the Mortality and Birth Information System (MBIS) database in Public Health England to CATRIN for cancer registration purposes only.

ONS are the official producers of mortality data for the United Kingdom. This data is provided to WCISU in an aggregated format without any potential identifiers – meaning that the data contains no information which would allow us to identify individuals.

## Cancer screening data (breast, cervical and bowel)

Women aged between 50 and 70 years old are invited for a breast screening mammogram every three years. The service is available for women over 70 years of age on request. The results may indicate that further testing (x-ray, ultrasound or biopsy) is required in some cases.

Women aged between 25 and 64 years old are offered cervical screening through a smear test. Currently, the samples are tested by cytology to identify any abnormalities in the cells. A pilot programme from April 2017 will assess 20% of women for high-risk human papillomavirus (HR-HPV), with a full roll out expected in 2018/19.

Bowel screening in Wales commenced in September 2012. Bowel screening home test kits are sent to men and women aged between 60 and 74 years old. The test is called a faecal occult blood (FOB) test (*guaiac faecal occult blood test (gFOBt)*). This test requires three stool samples within a 10 day period which need to be returned in a special envelope via post. Patients are invited for a colonoscopy if any blood is found in their sample. Faecal immunochemical testing (FIT) was introduced in 2018/19, as it is a more accurate test and easier to carry out at home – with only one stool sample required. SAIL holds individual level data from end of October 2008 onwards. Approximately 280,000 invitations are sent every year and 140,000 tests are recorded. Information regarding the screening category is also recorded – attender, non-attender and lapsed attender.

Website link to Screening in Wales

<http://www.screeningforlife.wales.nhs.uk/screening-in-wales>

Website link detailing screening uptake by GP Cluster

<http://www.breasttestwales.wales.nhs.uk/reports-1>

<http://www.cervicalscreeningwales.wales.nhs.uk/statistical-reports>

<http://www.bowelscreening.wales.nhs.uk/statistical-reports>

## WLIMS – Wales Laboratory Information Management Systems

WLIMS is a clinical IT system used by pathology staff across Wales for storing, recording and exchanging information such as blood test results, pathology samples etc. The systems also link to the machines which conduct the tests and analyse the samples. Around 80% of clinical diagnoses are supported by pathology results. Cancer registration relies on an electronic extract of pathology data from WLIMS.

Web link to WLIMS

<https://nwis.nhs.wales/systems-and-services/secondary-care/welsh-laboratory-information-management-system/>

## Systemic Anti-Cancer Therapy (SACT)

SACT data is available locally at health boards in their e-prescribing systems. Most health boards also record SACT treatments in Canisc and clinical coding departments code some SACT treatment episodes for administrative returns and are available in PEDW.

There is no national SACT dataset currently and this is in development for implementation as an action from the cancer digital strategy anticipated in 2020.

## Potential Sources for Linkage

### NHS Wales Informatics Service (NWIS)

NWIS was formed on 1<sup>st</sup> April 2010 and is responsible for a number of national datasets, including but not limited to:

- Admitted Patient Care Data Set (APC DS)
- Outpatient Data Set (OP DS)
- Outpatient Referral Data Set (OPR DS)
- Critical Care Data Set (CC DS)
- Emergency Department Data Set (EDDS)
- Community Child Health 2000
- Postponed Admitted Procedures Data Set (PAP DS)
- Substance Misuse Data Set (SMDS)
- Radiotherapy Data Set (RTDS)

All above are covered by the NHS Wales Data Dictionary, a user-friendly guide to the definitions, collection and interpretation of nationally agreed data standards adopted by the NHS in Wales. It holds information about the data set structure and format. Datasets are updated with a data set change notice for any amendments or additions. Data can be requested from other sources. NWIS has a request system for linkage to data from sources that they manage. *“Where your request cannot be satisfied through the available data, specific requests for data can be obtained through the NHS Wales Informatics Service bespoke analysis service. This service is provided to the Welsh Assembly Government, NHS Wales and others. For information other than that already available via this website, please contact the Analysis Team at [pdit.requests@wales.nhs.uk](mailto:pdit.requests@wales.nhs.uk) and detail your requirements as fully as possible”.*

Website link to NWIS contact details

<https://nwis.nhs.wales/contact-us/>

Website link to NHS Wales Data Dictionary

<http://www.datadictionary.wales.nhs.uk/>

### Patient Episode Database for Wales (PEDW)

The Patient Episode Database for Wales commenced in 1991 and covers all inpatient and day cases (including maternity admissions) undertaken in Wales. It also covers Welsh residents treated in English NHS Trusts. In 1997 the inpatient and day case dataset was updated to Admitted Patient Care (APC) to allow benchmarking with England. *‘APC contains demographic, clinical and administrative details e.g. age, sex; diagnostic and operative procedures (ICD10 and OPCS – 4). Approximately 100,000 episodes of care are processed each month’.*

The data acquisition team within NWIS collect extracts from each health board in Wales (on the 17<sup>th</sup> of the month) and also from English sites that treat Welsh patients. These extracts are then used to update the Patient Episode Database for Wales. The Business Intelligence Team provides an analysis service and extract data for Welsh Government Publications.

Website link to PEDW

<http://www.infoandstats.wales.nhs.uk/page.cfm?pid=41009&orgid=869>

## Emergency Department Data Set for Wales (EDDS)

The EDDS was implemented from April 2009 to capture attendances at major A&E departments. Attendances at other A&E departments and Minor Injury Units were captured in Situation Reporting Services (SITREPS) prior to April 2012, however from April 2012, health boards have been required to submit EDDS for patients attending all hospital emergency care facilities.

All attendances at a Welsh unit are recorded, however attendances of Welsh residents to emergency departments in England are not included. The data are collected at each hospital and coded data is transferred to NWIS and merged into a main database.

The 2013-2014 NHS Wales delivery framework introduced targets for time spent in emergency care facilities as follows:

- 95% of patients spend less than 4 hours in all hospital emergency care facilities from arrival until admission, transfer or discharge
- Eradication of over 12 hour waits within all hospital emergency care facilities.

Summary reports are produced monthly by the Welsh Government as part of the NHS activity and performance summary.

In March 2017, the Welsh Government announced that a number of statistical releases would be available. The data is published in an online tool detailing:

- demand/activity (e.g. A&E attendances, ambulance calls, referrals)
- performance (e.g. performance against A&E targets, referral to treatment waiting times (RTT))
- context (e.g. median time in A&E, median ambulance response times, median RTT waits).

Website link to accident and emergency waiting times (aggregated)

<https://statswales.gov.wales/Catalogue/Health-and-Social-Care/NHS-Hospital-Waiting-Times/Accident-and-Emergency>

Website link to Information and Statistics for Accident and Emergency

<http://www.infoandstats.wales.nhs.uk/page.cfm?orgid=869&pid=62956>

## Primary Care One (PCOne)

The PCOne website has been set up to promote primary care cluster collaborative working in Wales, and aims to support cluster development at a national level.

Website link to Primary Care One

<http://www.primarycareone.wales.nhs.uk/home>

The Primary Care Population Health Intelligence Support Group (PCPHISG), previously aligned to Public Health Wales intelligence division, has been supported by the Primary Care Hub since January 2017. The group aims to advise on products, appraise new product proposals, allocate new work and align organisational plans. New terms of reference for the group are available and the group can be contacted by email [PrimaryCare.One@wales.nhs.uk](mailto:PrimaryCare.One@wales.nhs.uk). The group have created PCPHISG primary care intelligence products spreadsheet, which includes internal and external data to assist in the

development of practice and cluster plans. (N.B. Some products are restricted to NHS Wales or Primary Care Staff).

Website link to the PCPHISG primary care intelligence products spreadsheet

<http://www.primarycareone.wales.nhs.uk/data-and-health-intelligence>

## SAIL Databank Wales (Secure Anonymised Information Linkage)

*“The SAIL Databank provides you with linkable, anonymised datasets ready for analysis that can be accessed remotely via our unique SAIL Gateway platform, complete with analysis tools.”*

The data sets are split into a demographic and clinical/event part. The demographic part is anonymised and encrypted by NWIS, with each record being given a unique identifier. The datasets are then recombined and can be linked to other datasets within SAIL using the key, or anonymous linking field.

Website link to Sail Databank Wales anonymisation process

<https://saildatabank.com/saildata/data-privacy-security/#anonymisation-process>

The SAIL databank contains individual records that can be linked to answer specific questions. It is split into the core data sets and the core restricted datasets. The core data sets cover the following datasets:

Annual District Birth Extract	Annual District Death Extract	Critical Care Dataset
Diagnostic & Therapy Services Waiting Times	Emergency Department	National Community Child Health Database
Outpatient	Outpatient Referral	Patient Episode Database for Wales
Postponed Procedures	Admitted Primary Care GP (Audit+)	Referral to Treatment Times
UK Health Dimensions	Welsh Demographic Service	

The core restricted datasets require permission from the data providers in addition to the standard application process of IGRP approval (see below) and completion of the safe researcher training:

Active Adult Survey	Bowel Screening Wales	Breast Test Wales
Cervical Screening Wales	Congenital Anomaly Register and Information Service for Wales (CARIS)	Education Attainment
National Survey for Wales	Welsh Cancer Intelligence Surveillance Unit (WCISU)	Welsh Health Survey

There is a two stage application process with an initial application and scoping document to be completed by a SAIL databank analyst and then an application to gain information governance review panel (IGRP) approval. An IGRP application contains an outline of the research rationale for creating the link(s), details of any new datasets that would be accessed, and precisely what variables would be required from the linked datasets. Researchers must indicate in the application that they have

considered the handling of sensitive data in the research design and understand that small numbers could potentially identify individuals. This would require aggregating data or restricting publication below 5 counts per 1000 population. The time for application may take up to 12 weeks, with documents being reviewed.

Website link to application process

<https://saildatabank.com/application-process/two-stage-process/>

Overall website link to SAIL

<https://saildatabank.com/>

### **AUDIT+ Primary Care GP information**

Audit+ is a common software tool that works with the GP's own practice system to maintain an electronic health record for each patient. Details of symptoms, test results, diagnoses, prescribed treatment, referrals for specialist treatment at hospital and social aspects are captured, often using read codes. It aims to support patient healthcare provision in primary and community settings, support population health needs assessments and improve patient safety. The data is held at an individual level and extends from 2000 onwards. From 2010/2011, the money a GP practice receives is linked to the Adjusted Disease Factor (ADPF). Therefore, it is important for the GP practices to ensure that their registers are up to date so that patients are identified and treated appropriately and that the GP practice is reimbursed accurately.

Website link to GP Clinical Systems Strategy

<http://www.wales.nhs.uk/sitesplus/documents/956/GP%20Clinical%20Systems%20Strategy.pdf>

## Other Datasets which may be of interest

### Welsh Health Survey (WHS)

The current Welsh Health Survey commenced in 2003 and collects information about the health of people living in Wales. The survey is commissioned by the Welsh Government. Previous versions of the WHS were conducted in 1995 and 1998. These replaced the 'Health in Wales' survey which was conducted five times between 1985 and 1996. The aims of the WHS is to provide estimates on health status, determinants and health service use, contribute to setting and monitoring targets and indicators, examining differences between population subgroups and local areas, provide a direct measurement of need for health care for NHS resource allocation in Wales, provide local health board and local authority level information for the development of local health, social and wellbeing strategies. The survey is based on a representative sample of adults aged 16 and older living in private households in Wales. Up to two children aged 0-15 are randomly selected from each household assessed. The 2014 questionnaire includes health service use, medicines, illnesses and other health problems, untreated problems or symptoms, health and wellbeing, smoking, alcohol, fruit and vegetables, physical activity, carers and demographics. The information is able to be linked to individual NHS information if the respondent provides consent.

Website link to the survey

<http://gov.wales/docs/statistics/2015/150324-health-survey-2014-questionnaire-adult-jul-dec-en.pdf>

Website link to the 2015 results

<http://gov.wales/statistics-and-research/welsh-health-survey/?lang=en>

Website link for all years

<https://discover.ukdataservice.ac.uk/series/?sn=2000057>

### Life After Prostate Cancer Diagnosis (LAPCD) data set

The Life after Prostate Cancer study is a survey funded by Prostate Cancer UK. For Wales, men diagnosed between December 2012 and June 2014 were identified through cancer registration systems. Approximately 100,000 men, 2591 men in Wales were invited to take part. HRQL (Health related quality of life) and PROMS questions were used in the survey. Telephone interviews were held with men and their partners/spouses. Reporting of the first phase will be Summer 2017. Data is held by the WCISU, but would require approval from the Life After Prostate Cancer study/Prostate Cancer UK for use of the data and only available in an anonymised format.

Website link to LAPCD

<http://www.lifeafterprostatecancerdiagnosis.com/>

## Welsh Cancer Patient Experience Survey (WCPES)

The Welsh Government, NHS Wales and Macmillan launched the the first Welsh Cancer Experience Survey in 2013. A total of 10,945 patients who had received treatment for cancer from seven Health Boards and one Trust were included in the sample for the Cancer Patient Experience Survey. The survey included all patients having treatment for cancer between 1<sup>st</sup> September 2012 and 31<sup>st</sup> March 2013 where this treatment was recorded by Health Boards/Trust as falling within the first diagnosis field. Patients were placed into one of 13 cancer groups using their ICD-10 code and covered both inpatients and day case patients. PROMS (patient reported outcome measures) and PREMS (patient reported experience measures) were assessed. The 2016 survey was published in October 2017 and data linkage will be possible for this data set. Welsh Government hold the data and WCISU have a retrospective copy of the 2013 survey and also the 2016 dataset.

Website link to the 2016 survey report

<https://gov.wales/cancer-patient-experience-survey-2016>

Website link to the 2013 survey

<https://www.quality-health.co.uk/surveys/welsh-cancer-patient-experience-survey>

## Cancer Waiting Times

In Wales, cancer waiting time targets were introduced in 2005. Monthly data has been provided since 2012 but only quarterly data was available previously. The data for Cancer Waiting Times are collected by the health boards and collated by NWIS. The figures are published by the Welsh Government on a monthly basis. The time starts from the date that the decision to treat was confirmed between the MDT (representative) and the patient. If a GP refers a patient via the urgent suspected route the patient should start treatment within 62 days. Patients newly diagnosed with cancer not via the urgent suspected route should start definitive treatment within 31 days of receipt of referral at hospital (or decision to treat).

The statistics include all patients with cancer who have started NHS funded treatment. Patients who receive treatment at a private hospital or outside of Wales are not included. The data relates to patients with a newly diagnosed cancer (i.e. if a recurrence of the original cancer at a secondary site occurs this will not be included in the data collection). If a patient has another primary cancer this will be included. Six out of the seven local healthboards report data as Powys Teaching Health Board does not provide acute services. Patients within Powys will be included in the figures for the health board they are referred to.

Website link to the Quality standards

<http://gov.wales/docs/statistics/2015/150917-nhs-cancer-waiting-times-quality-report-en.pdf>

In November 2017 at the Wales Cancer conference Vaughan Gething announced that the current methods of recording cancer waiting times would be reviewed.

The current targets are: -

Urgent suspected cancers (USC) - At least 95 per cent of patients diagnosed with cancer, via the urgent suspected cancer route will start definitive treatment within 62 days of receipt of referral.

Non urgent suspected cancer (nUSC) - At least 98 per cent of patients newly diagnosed with cancer, not via the urgent route will start definitive treatment within 31 days of diagnosis (regardless of the referral route).

A single treatment route 'The Single Suspected Cancer Pathway (SCP)' and target will measure alongside the current methods from January 2018 and then a review will take place

Website link to the Single Suspected Cancer Pathway

<http://www.walescanet.wales.nhs.uk/sitesplus/documents/1113/Point%20of%20suspicion%20%28SCP%29%20definitions%20-Final.pdf>

## **Electronic prescribing**

Since summer 2009, paper prescriptions issued by doctors in Wales contain a barcode which can be scanned by pharmacies. Pharmacies began to implement the technology required to scan and read the barcodes in 2010. Details about the medications, including dosage and frequency are transferred electronically for each patient, reducing errors that may occur when transcribing information by hand from a paper prescription.

The hospital pharmacy system is used both in the hospital pharmacy and on wards. It downloads details automatically from the hospital's patient administration system (PAS) and records and labels all medication. Medicines Transcribing (MT) and e-Discharge (eD) have also been implemented in hospitals. Medicines Transcribing allows pharmacists to electronically transcribe medications and e-Discharge enables clinicians to record a summary about a patient's hospital stay which can then be sent to their GP electronically.

Website link to Hospital Prescribing Data Extracts

<http://www.primarycareservices.wales.nhs.uk/hospital-prescribing-data-extract>

The General Practice prescribing data extract covers items prescribed in Wales which are then dispensed in the community in Wales or England. The data is presented by GP practice and data is available for the current and two previous complete financial years.

Website link to Community prescriptions

<https://gov.wales/prescriptions-dispensed-community>

## **Welsh Ambulance Services NHS Trust (WAST)**

The Welsh Government monitors the performance of the NHS, including the Welsh Ambulance Services NHS Trust. This is done through measuring against targets in the Operational Framework. Emergency Medical Service (EMS) performance statistics provide information on emergency calls and response times. NHS Direct Wales (NHSDW) statistical outputs are produced by Welsh Government and report on the numbers of calls, online enquiries and visits to the NHS Direct Wales website.

Website link to WAST

<https://www.ambulance.wales.nhs.uk/>

Website link to WAST statistics

[https://gov.wales/statistics-and-research?keywords=ambulance%20services&%20All%20=All&%20All%20=All&%20All%20=All&published\\_after=&published\\_before=](https://gov.wales/statistics-and-research?keywords=ambulance%20services&%20All%20=All&%20All%20=All&%20All%20=All&published_after=&published_before=)

Website link to EMS

<https://statswales.gov.wales/Catalogue/Health-and-Social-Care/NHS-Performance/Ambulance-Services>

Website link to NHSDW

<https://statswales.gov.wales/Catalogue/Health-and-Social-Care/NHS-Primary-and-Community-Activity/NHS-Direct-Wales>

## **Wales Cancer Research Centre (Wales Cancer Partnership)**

The Wales Cancer Research Centre has an all Wales brief and covers all areas from early laboratory research, palliative care and areas of clinical need. Their vision is *“to work with cancer patients and other partners to develop and deliver research excellence which benefits the health and welfare of people in Wales and beyond”*.

The Wales Cancer Partnership is hosted by the Wales Cancer Research Centre and brings together those from a variety of backgrounds involved in cancer research.

Website link to Wales Cancer Research Centre

<http://www.walescancerpartnership.com/wcp/>

## **Wales Cancer Bank**

The Wales Cancer bank aims to collect samples of tumour, normal tissue and blood and store from all patients. *“Researchers based in any country and working in any sector can apply to our cancer tissue biobank for samples and/or data for use in cancer-related research.” “Anonymised samples are supplied to researchers with WCB barcodes and a basic data set of age at diagnosis, gender, histological diagnosis, grade/stage etc. Treatment and follow up data is available on most samples, dependent upon the time since diagnosis. A number of the tissue samples have genetic mutational data available”*. The Wales Cancer Research Centre is working with NHS Wales Information Service to link clinical research information into the SAIL Databank.

Website link to Wales Cancer Research Centre Annual report 2015-2016

<http://www.walescancerpartnership.com/uploads/Research/Final%20Annual%20Report%20Public%20Facing.pdf>

Website link to Wales Cancer Bank

<http://www.walescancerbank.com/>

Website link to Wales Cancer Trials Unit (based in the Centre for Trials Research)

<http://www.cardiff.ac.uk/centre-for-trials-research/research/themes/cancer>

## Datasets for Future Investigation

Mental health data can be obtained from admissions of patients to mental health facilities, psychiatric census, PEDW, Welsh Health Survey, etc.

Website link to admissions to mental health facilities by health board

<https://statswales.gov.wales/Catalogue/Health-and-Social-Care/Mental-Health/Admissions-to-Mental-Health-Facilities/admissionstomentalhealthfacilitiesbylhb>

Adult Dental Health surveys have been carried out every decade since 1968.

Website link to adult dental health survey

[https://data.gov.uk/dataset/adult\\_dental\\_health\\_survey](https://data.gov.uk/dataset/adult_dental_health_survey)

Welsh Oral Health Information Unit

Website link to Welsh oral health information unit

<http://www.cardiff.ac.uk/research/explore/research-units/welsh-oral-health-information-unit>

## Published Reports and Information

### Welsh Cancer and Surveillance Unit (WCISU)

The Welsh Cancer Intelligence and Surveillance Unit (WCISU) is the National Cancer Registry for Wales and its primary role is to record, store and report on all incidence of cancer for the resident population of Wales wherever they are treated. The WCISU publish annual statistics on cancer incidence, mortality and survival via a dashboard which can be filtered by geography (health board and local authority), sex, and single years, three year or five year periods. The unit also conduct data requests for Welsh Government and other organisations and work collaboratively on projects with other organisations. They have produced reports, posters and infographics for specific cancer awareness days.

Website link to WCISU

<http://www.wcisu.wales.nhs.uk>

July 2018, WCISU published project 1 of phase 1 of the partnership, which gave cancer incidence and prevalence statistics for GP cluster networks in Wales, which was filterable by age band, deprivation, rurality, sex and cancer stage at diagnosis. The dashboard is available here:

[GP Cluster Network incidence and prevalence statistics](#)

March 2019, WCISU published the second project of phase 1 of the partnership, which took the original data of project 1 and further analysed the data focusing on 'Comorbidities' using the Charlson Score methodology. The dashboard for project 2 can be found here:

[Cancer patients with other chronic health conditions in Wales: HP Cluster Network incidence, prevalence and all Wales Survival](#)

In addition to the data sources identified above. There are other publications (infographics and reports) which may be useful in understanding cancer data in Wales.

### Public Health Wales Observatory

The Public Health Wales Observatory work on a range of areas (maternal and child health, alcohol, obesity, cardiovascular disease, smoking, inequalities and inequities, physical activity, population estimates and projections, rural health and teenage pregnancy.

Website link to Public Health Wales Observatory

<http://www.publichealthwalesobservatory.wales.nhs.uk/home>

Website links to further data and tools

<http://www.publichealthwalesobservatory.wales.nhs.uk/other-health-datasets>

<http://www.publichealthwalesobservatory.wales.nhs.uk/online-data-tools/>

<http://www.publichealthwalesobservatory.wales.nhs.uk/other-data-sources>

## **Health Maps Wales**

*“Health Maps Wales contains a wide range of Welsh resident data including hospital admissions, mortality and child health. Explore a variety of health indicators by area, map trends in data over time and make comparisons at local and national levels.”*

Website link to Health Maps Wales

<https://www.healthmapswales.wales.nhs.uk/IAS/>

## **Healthwise Wales**

Healthwise Wales is a large study looking into the health and wellbeing of the population. Respondents are asked questions about their lifestyle, health and wellbeing. Respondents consent for access to their NHS records for details about GP visits and hospital visits to be linked. A number of projects may use this data.

Website link to Healthwise Wales

<https://www.healthwisewales.gov.wales/homepage/>

## **International Cancer Benchmarking Partnership (ICBP)**

The ICBP is an international initiative involving 12 jurisdictions in six countries including Wales and the rest of the UK. Previous studies have shown the UK nations often have poorer cancer survival outcomes than comparable countries. This work is about understanding the variations and looks at four cancer sites; lung, breast, ovarian and colorectal.

Website link to ICBP

<https://www.cancerresearchuk.org/health-professional/data-and-statistics/international-cancer-benchmarking-partnership-icbp>

## **European Cancer Registry Based Study on Survival and Care of Cancer Patients (EUROCARE)**

EUROCARE is the widest collaborative research project on cancer survival in Europe with a large number of population based cancer registries participation. The aim of the study are to provide an updated description of cancer survival time trends and differences across European countries, to measure cancer prevalence and the patterns of care of cancer patients.

Website link to EUROCARE

<http://www.eurocare.it/>

# 1.

## Appendix 1 – Index of Terms and Abbreviations

BCHB	Betsi Cadwaladr University Health Board
CANISC	Cancer Network Information System Cymru
CAS	Cancer Analysis System
CIF	Cancer Information Framework
CIG	Cancer Implementation Group
CSCG	Cancer Services Coordinating Group
CVUHB	Cardiff and Vale University Health Board
EnCORE	English National Cancer Online Registration Environment
FIT	Faecal immunochemical testing
FOB	Faecal occult blood test
HRQL	Health related quality of life
IMTP	Integrated medium term plan
NSAG	National Specialist Advisory Group
NWIS	NHS Wales Informatics Service
OG	Operational Group
ONS	Office for National Statistics
PAS	Patient Administration System previously known as Myrddin
PEDW	Patient Episode Database Wales
PHW	Public Health Wales
RTT	Referral to treatment waiting times
SAIL	The Secure Anonymised Information Linkage Databank
SG	Steering Group
WCISU	Welsh Cancer Intelligence and Surveillance Unit
WG	Welsh Government
WLIMS	Welsh Laboratory Information Management System
WRRS	Welsh Results Reports Service
WRIS	Welsh Radiology Information System
WCP	Wales Clinical Portal

## Appendix 2 – Health Boards in Wales

Health Board Name	Health Board (3 digit code)
Betsi Cadwaladr University Health Board (BCUHB) <a href="http://www.bcu.wales.nhs.uk/">http://www.bcu.wales.nhs.uk/</a>	7A1
Hywel Dda University Health Board <a href="http://www.hywelddalhb.wales.nhs.uk/">http://www.hywelddalhb.wales.nhs.uk/</a>	7A2
Abertawe Bro Morgannwg University Health Board (ABMU) <a href="http://www.abm.wales.nhs.uk/">http://www.abm.wales.nhs.uk/</a>	7A3
Cardiff & Vale University Health Board <a href="http://www.cardiffandvaleuhb.wales.nhs.uk/home">http://www.cardiffandvaleuhb.wales.nhs.uk/home</a>	7A4
Cwm Taf University Health Board (CTUHB) <a href="http://cwmtaf.wales/">http://cwmtaf.wales/</a>	7A5
Aneurin Bevan University Health Board <a href="http://www.wales.nhs.uk/sitesplus/866/home">http://www.wales.nhs.uk/sitesplus/866/home</a>	7A6
Powys Teaching Health Board <a href="http://www.powysthb.wales.nhs.uk/">http://www.powysthb.wales.nhs.uk/</a>	7A7
Velindre University Health Trust – includes Velindre Cancer Centre	RQF

## Appendix 3 – Summary of datasets

Data source Name	Brief Description	Owner	Geography level	Start Year	Frequency of updates	Link for more information	Data items available
National Cancer Registry for Wales (WCISU)	A population database; its primary role is to record, store and report on all incidence of cancer for the resident population of Wales wherever they are treated.	Welsh Cancer Intelligence and Surveillance Unit (WCISU) Public Health Wales	Patient level	1972	Dynamic database – annual incidence, survival and mortality reported.	<a href="http://www.wcisu.wales.nhs.uk/">http://www.wcisu.wales.nhs.uk/</a>	Patient demographic Tumour details Diagnosis details Stage of disease Treatments
CANISC	Cancer Clinical System used by NHS Wales. An electronic patient record that collects cancer specific data across the patient pathway.	NWIS	Patient level	2004	Dynamic database		
Cancer Multiple Destination Reporting Requirements	All Wales Minimum Reporting Requirements and a number of site specific Minimum Reporting Requirements, collected within the CANISC system (above)	NWIS	Patient level	2011		<a href="http://www.datadictionary.wales.nhs.uk/#!/WordDocuments/cancermultipledestinationreportingrequirements.htm">http://www.datadictionary.wales.nhs.uk/#!/WordDocuments/cancermultipledestinationreportingrequirements.htm</a>	
Radiotherapy data (RTDS)	Radiotherapy dataset is submitted directly from the radiotherapy treatment machines across Wales.	WCISU/NWIS	Patient level	All three centres from January 2019	Data is submitted to WCISU / NWIS monthly	<a href="http://www.datadictionary.wales.nhs.uk/#!/WordDocuments/cancermultipledestinationreportingrequirements.htm">http://www.datadictionary.wales.nhs.uk/#!/WordDocuments/cancermultipledestinationreportingrequirements.htm</a>	
Patient Episode Database Wales (PEDW)	The Patient Episode Database Wales covers hospital admissions - inpatient and day cases undertaken by NHS Wales plus data on Welsh residents treated in English Trusts	NWIS	Patient level	1991	Data is updated on a monthly basis. Annual data tables published	<a href="http://www.infoandstats.wales.nhs.uk/page.cfm?orgid=869&amp;pid=41010&amp;subjectlist=0&amp;patientcoverlist=0&amp;period=0&amp;keyword=&amp;action=Clear">http://www.infoandstats.wales.nhs.uk/page.cfm?orgid=869&amp;pid=41010&amp;subjectlist=0&amp;patientcoverlist=0&amp;period=0&amp;keyword=&amp;action=Clear</a> <a href="http://www.datadictionary.wales.nhs.uk/#!/WordDocuments/admittedpatientcaredatasetapcds.htm">http://www.datadictionary.wales.nhs.uk/#!/WordDocuments/admittedpatientcaredatasetapcds.htm</a> <a href="http://www.datadictionary.wales.nhs.uk/#!/WordDocuments/outpatientdatasetopds.htm">http://www.datadictionary.wales.nhs.uk/#!/WordDocuments/outpatientdatasetopds.htm</a> <a href="http://www.datadictionary.wales.nhs.uk/#!/WordDocuments/outpatientreferraldatasetoprds.htm">http://www.datadictionary.wales.nhs.uk/#!/WordDocuments/outpatientreferraldatasetoprds.htm</a>	
ONS mortality tables	Mortality tables	ONS	Aggregated data tables			<a href="https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/datasets/deathregistrationsummarytablesenglandandwalesreferencetables">https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/datasets/deathregistrationsummarytablesenglandandwalesreferencetables</a>	

Outpatient Dataset (OPD)	Attendance at outpatient for NHS Wales hospitals	NWIS	Patient level	2004	Monthly	<a href="http://www.datadictionary.wales.nhs.uk/#!/WordDocuments/outpatientdatasetopds.htm">http://www.datadictionary.wales.nhs.uk/#!/WordDocuments/outpatientdatasetopds.htm</a>	
Outpatient Referral Data Set (OPR Ds),	All referrals in Wales including GP, Dental, community dental, A&E departments, self-referrals, walk-ins, emergency patients (accompanied with a GP letter) and consultant to consultant referrals.	NWIS	Patient level	2008	Monthly	<a href="http://www.datadictionary.wales.nhs.uk/#!/WordDocuments/outpatientreferraldatasetoprds.htm">http://www.datadictionary.wales.nhs.uk/#!/WordDocuments/outpatientreferraldatasetoprds.htm</a>	
Postponed Admitted Procedures Data Set (PAP ds),	Collation of information for postponed/cancelled admitted procedures	NWIS	Patient level	2013	Monthly	<a href="http://www.datadictionary.wales.nhs.uk/#!/WordDocuments/postponedadmittedproceduresdatasetpapds.htm">http://www.datadictionary.wales.nhs.uk/#!/WordDocuments/postponedadmittedproceduresdatasetpapds.htm</a>	<a href="http://www.datadictionary.wales.nhs.uk/#!/WordDocuments/datasetstructure5.htm">http://www.datadictionary.wales.nhs.uk/#!/WordDocuments/datasetstructure5.htm</a>
Critical Care Data Set (CC Ds)	Administrative information such as admission and discharge dates from (patient administrative system)	NWIS	Patient level	2006 to present		<a href="http://www.datadictionary.wales.nhs.uk/#!/WordDocuments/criticalcaredatasetccds.htm">http://www.datadictionary.wales.nhs.uk/#!/WordDocuments/criticalcaredatasetccds.htm</a>	<a href="http://www.datadictionary.wales.nhs.uk/#!/WordDocuments/datasetstructure3.htm">http://www.datadictionary.wales.nhs.uk/#!/WordDocuments/datasetstructure3.htm</a>
Substance Misuse Data Set (SMDS)	The Substance Misuse Data Set captures data relating to all individuals (clients), both young persons and adults, presenting for substance misuse treatment in Wales	NWIS	Patient level	2014	Monthly	<a href="http://www.nwisinformationstandards.wales.nhs.uk/sitesplus/documents/299/20140306%20%20Substance%20Misuse%20Data%20Set%20Business%20Definition%20Version%202%200%20Final.pdf">http://www.nwisinformationstandards.wales.nhs.uk/sitesplus/documents/299/20140306%20%20Substance%20Misuse%20Data%20Set%20Business%20Definition%20Version%202%200%20Final.pdf</a>	<a href="http://www.datadictionary.wales.nhs.uk/#!/WordDocuments/datasetstructure6.htm">http://www.datadictionary.wales.nhs.uk/#!/WordDocuments/datasetstructure6.htm</a>
Emergency Department Data Set (EDDS)	All attendances at Welsh Emergency Units are recorded	NWIS	Patient level	Initially in 2009, further data from more units from 2012	Monthly	<a href="https://statswales.gov.wales/Catalogue/Health-and-Social-Care/NHS-Hospital-Waiting-Times/Accident-and-Emergency">https://statswales.gov.wales/Catalogue/Health-and-Social-Care/NHS-Hospital-Waiting-Times/Accident-and-Emergency</a>	<a href="http://www.datadictionary.wales.nhs.uk/#!/WordDocuments/datasetstructure4.htm">http://www.datadictionary.wales.nhs.uk/#!/WordDocuments/datasetstructure4.htm</a>

Data source name	Brief description	Owner	Geography level	Start year	Frequency of updates	Link for more information	Data items available
Child Health system 2000	Births, monitoring of examinations and immunisations	NWIS	Patient level	1987	Quarterly		<a href="http://www.datadictionary.wales.nhs.uk/#!/WordDocuments/communitychildhealth2000.htm">http://www.datadictionary.wales.nhs.uk/#!/WordDocuments/communitychildhealth2000.htm</a>  <a href="http://www.datadictionary.wales.nhs.uk/#!/WordDocuments/childmeasurementprogramdatarequirements.htm">http://www.datadictionary.wales.nhs.uk/#!/WordDocuments/childmeasurementprogramdatarequirements.htm</a>

							<a href="http://www.datadictionary.wales.nhs.uk/#!/WordDocuments/infantfeedingdatarequirements.htm">http://www.datadictionary.wales.nhs.uk/#!/WordDocuments/infantfeedingdatarequirements.htm</a>  <a href="http://www.datadictionary.wales.nhs.uk/#!/WordDocuments/informationrequirements5.htm">http://www.datadictionary.wales.nhs.uk/#!/WordDocuments/informationrequirements5.htm</a>
AUDIT+	Primary Care GP information, GP practices maintain an electronic GP record for each patient	NWIS	Patient level	2000		<a href="http://www.wales.nhs.uk/sitesplus/documents/956/GP%20Clinical%20Systems%20Strategy.pdf">http://www.wales.nhs.uk/sitesplus/documents/956/GP%20Clinical%20Systems%20Strategy.pdf</a>	
SAIL (Secure Anonymised Information Linkage)	SAIL databank is the home of the broadest and most accessible source of anonymised population data	Partnership with NWIS; Funded by Welsh Government and Health and Care Research Wales; Supported by Swansea University	Linkable anonymised datasets	Dates vary depending on the dataset		<a href="https://saildatabank.com/">https://saildatabank.com/</a>	Various
Welsh Health Survey (WHS)	The Welsh Health Survey(WHS), which ran from 1995-1998 and then 2003/04-2015, collected information about the health of people living in Wales, the way they use health services, and things that can affect their health.	UK Data Service funded by Economic and Social Research Council (ESRC)		2003 to present		<a href="https://discover.ukdataservice.ac.uk/series/?sn=2000057">https://discover.ukdataservice.ac.uk/series/?sn=2000057</a>	
National Survey for Wales	From April 2016 health and health related lifestyles are reported on using the National Survey for Wales.			2016 onwards		<a href="https://beta.ukdataservice.ac.uk/datacatalogue/series/series?id=2000035">https://beta.ukdataservice.ac.uk/datacatalogue/series/series?id=2000035</a>	
Life After Prostate Cancer Diagnosis (LAPCD)	The 'Life After Prostate Cancer Diagnosis' study investigated the full range of issues that could affect a man after he has been diagnosed with prostate cancer. Prostate Cancer UK funded the survey in partnership with Movember	Public Health Wales	Anonymised data	2012 – 2014	Survey and resurvey of men diagnosed between 2012 and 2014	<a href="https://lifeafterprostatecancerdiagnosis.com/">https://lifeafterprostatecancerdiagnosis.com/</a>	
Welsh Cancer Patient Experience	This survey monitors national progress of experiences of cancer care.	Welsh Government	Aggregated data	2016/2013	3 years	<a href="https://gov.wales/cancer-patient-experience-survey-2016">https://gov.wales/cancer-patient-experience-survey-2016</a>	

Survey (WCPES)						<a href="http://www.walescanet.wales.nhs.uk/wales-cancer-patient-experience-surveys-1">http://www.walescanet.wales.nhs.uk/wales-cancer-patient-experience-surveys-1</a>	
Cancer Waiting Times	Cancer waiting time targets introduced in 2005	NWIS/Welsh Government	Aggregated data	2005	Monthly/Quarterly	<a href="https://statswales.gov.wales/Catalogue/Health-and-Social-Care/NHS-Hospital-Waiting-Times/Cancer-Waiting-Times">https://statswales.gov.wales/Catalogue/Health-and-Social-Care/NHS-Hospital-Waiting-Times/Cancer-Waiting-Times</a>	
GP Practice Prescribing Data Extract	Quantity and cost of prescriptions by health board and GP practice	NHS Wales Shared Services Partnership	Aggregated data	April 2013	Monthly	<a href="http://www.primarycareservices.wales.nhs.uk/general-practice-prescribing-data-extract">http://www.primarycareservices.wales.nhs.uk/general-practice-prescribing-data-extract</a>	
Hospital Prescribing Data Extract	Quantity and cost of prescriptions by hospital and directorate within	NHS Wales Shared Services Partnership	Aggregated data	April 2013	Monthly	<a href="http://www.primarycareservices.wales.nhs.uk/hospital-prescribing-data-extract">http://www.primarycareservices.wales.nhs.uk/hospital-prescribing-data-extract</a>	
Welsh Ambulance Services NHS Trust (WAST)	Statistics on emergency calls and response times	Welsh Government	Aggregated data	2007	Monthly	<a href="https://gov.wales/statistics-and-research?keywords=Welsh%20Ambulance%20Service&amp;%20All%20=All&amp;%20All%20=All&amp;%20All%20=All&amp;published_after=&amp;published_before=">https://gov.wales/statistics-and-research?keywords=Welsh%20Ambulance%20Service&amp;%20All%20=All&amp;%20All%20=All&amp;%20All%20=All&amp;published_after=&amp;published_before=</a> <a href="https://statswales.gov.wales/Catalogue/Health-and-Social-Care/NHS-Performance/Ambulance-Services">https://statswales.gov.wales/Catalogue/Health-and-Social-Care/NHS-Performance/Ambulance-Services</a>	
2011 Census Data	Census statistics help paint a picture of the nation and how we live. They provide a detailed snapshot of the population and its characteristics, and underpin funding allocation to provide public services		Aggregated data			<a href="https://www.ons.gov.uk/census/2011census">https://www.ons.gov.uk/census/2011census</a>	
Public Health Wales Data	An overview of the main sources of data used in Public Health Wales Observatory Publications	PHW/Others	Aggregated			<a href="http://nww.publichealthwalesobservatory.wales.nhs.uk/phw-data">http://nww.publichealthwalesobservatory.wales.nhs.uk/phw-data</a>	

## Appendix 4 – Platform for publications

Welsh Cancer Intelligence and Surveillance Unit

<http://www.wcisuwales.nhs.uk/>

Public Health Wales Observatory Analytical Team

<http://www.publichealthwalesobservatory.wales.nhs.uk/home>

Welsh Government Statistics and Research

<https://gov.wales/statistics-and-research/welsh-health-care-statistics-mapping-tool/?skip=1&lang=en>

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