



WALES CANCER BIOBANK
BIOFANC CANSER CYMRU

Wales Cancer Biobank



Ymchwil Iechyd
a Gofal Cymru
Health and Care
Research Wales



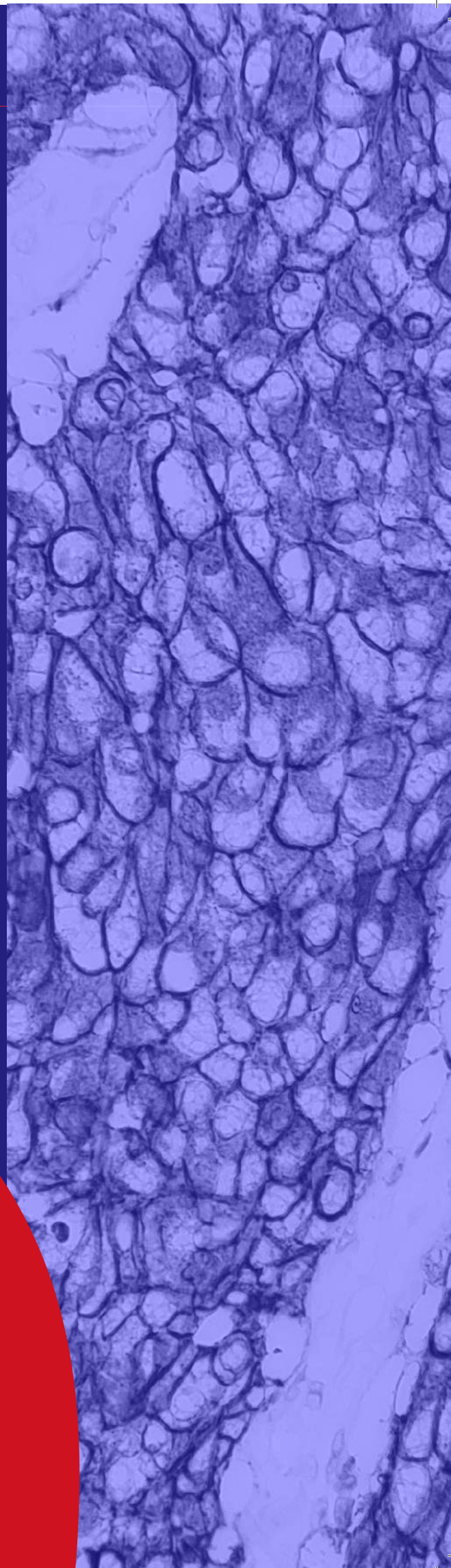
Ariennir gan
Lywodraeth Cymru
Funded by
Welsh Government

2021 - 2022
Annual report



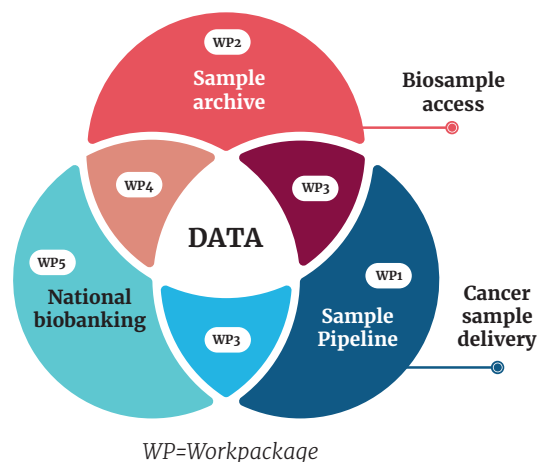
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Foreword

2021/22 has been a year of rebuilding activity and implementing lessons learned from the pandemic and the new ways of working and collaborating that became the new norm.



In our 2020/21 report we stated that we had:

- adopted a collaborative ‘project-focused’ approach with our key research and NHS partners to drive forward new innovations in cancer treatment and diagnosis,

and that our aim for the next 4 years was:

- to engender this collaborative ethos across the cancer research community with patient involvement at its heart.



Our aims for 2021–2022 were to:

- broaden our distribution of samples and data, form new research collaborations focussing on big data and AI,
- influence and enhance the UK biobanking network.

This report outlines our progress in these areas and sets out our vision for the next 12 months. We hope you will enjoy reading the report.

Further details can be found on the Wales Cancer Biobank website (www.walescancerbank.com) and we’d be pleased to welcome you to our Facebook and Twitter ‘family’.



Professor Richard Clarkson
Scientific Director and
Principal Investigator



Dr Alison Parry-Jones
Operations Director



Professor Richard Adams
Clinical Director

Background



The Wales Cancer Biobank (WCB) approaches patients in Wales with known or suspected cancer to ask them to consent to donate biosamples and data for use in future cancer related research.

The Wales Cancer Biobank is a Health and Care Research Wales Infrastructure group, funded by Welsh Government, hosted by Cardiff University, with the grant held within the School of Biosciences. The WCB works closely with a variety of stakeholders to facilitate the supply of biosamples and data from cancer patients in Wales to researchers worldwide. The biobank has been consenting cancer patients around Wales since 2005. The WCB is licensed by the Human Tissue Authority under the UK Human Tissue Act (2004) to store human samples for research and has ethics

approval from Wales Research Ethics Committee 3 as a Research Tissue Bank. WCB collects biosamples and data for use in research projects worldwide to help better understand cancer, how it starts, how it progresses and how it can be treated in new and improved ways for cancer patients in the future.

As one of the UK's largest and longest-established biobanks, with an international reputation for excellence, the Wales Cancer Biobank exemplifies how a centralised infrastructure adds value to the research community. WCB has spent 17 years establishing a core infrastructure and know-how within Wales and in recent years WCB has adopted more efficient procedures to meet the needs of an increasing number of researchers applying for bespoke and archived tissues.



Aims and Objectives

The primary aim of the 2020–2025 Infrastructure award from Health and Care Research Wales is to improve capacity to deliver the Wales Cancer Biobank service to the wider research community, thus increasing both the number and type of projects delivered, helping to develop a host of innovations leading to changes in routine clinical practice.

This is divided into three objectives, each with constituent workpackages:



Objective 1: to increase the number and scope of cancer research projects supported by WCB (Workpackages 1–3)



Objective 2: to embed state-of-art data linkage (Workpackage 4)

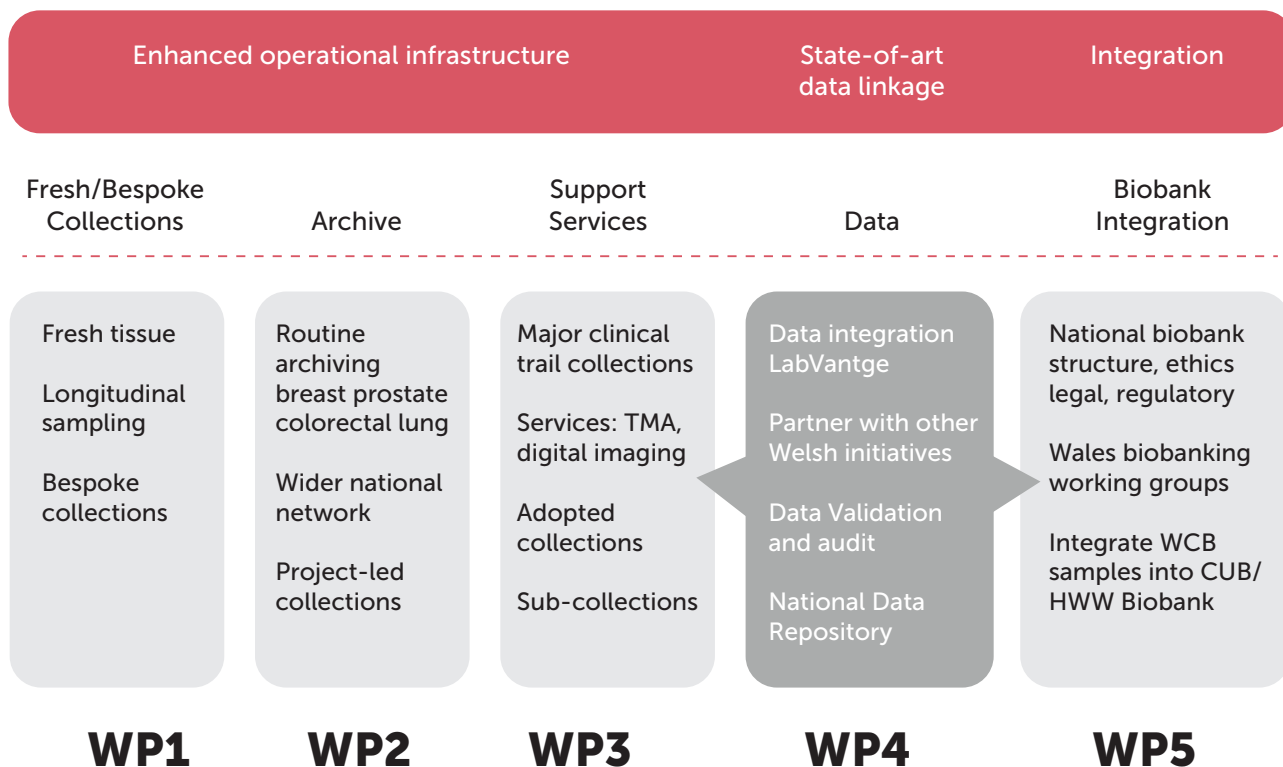


Objective 3: to integrate WCB into a wider biobanking network (Workpackage 5)

Objectives 2 and 3 will be addressed through alignment/integration with key infrastructure partners and relies on the activities of the core infrastructure outlined in Objective 1.



Strategic Objectives



Highlights from 2021/22

- Vaccine study supported by WCB published in Immunology
- WCB staff member first in UK and Europe to pass new biobanking Qualification
- New 'patient-friendly' website and online media content
- New WCB Ethics/Regulatory approval
- First 'big-data' contract with new industry partner
- Participation in new UK and EU biobanking initiatives
- Formed new collaborations to develop IT cancer infrastructure in Wales

Mission Statement



‘To facilitate cancer research through the supply of fit-for-purpose, well annotated biosamples and data.’

Ambition Statement



‘To be an internationally competitive biobank enhancing delivery of translational research to benefit cancer patients globally and bring benefits to Wales.’

Rebrand

In 2021 the Wales Cancer Bank became the Wales Cancer Biobank and a major overhaul of the outward facing media was undertaken to meet our objective to increase engagement with stakeholders by reaching a wider audience. A new logo was launched in October 2021, with updates on the WCB Facebook and Twitter pages, followed by a new website in March 2022.

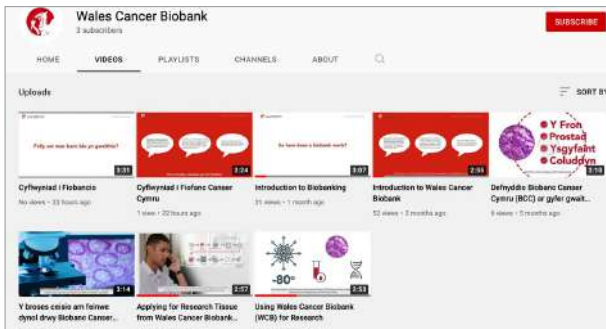
The refreshed website was designed to improve the user experience with a cleaner, less cluttered layout. The new, contemporary design provides contact forms for quick and easy communication with WCB, and the site is optimised for current technologies to ensure compatibility for viewing on different devices. Links to publications arising from research done using WCB samples, newsletters and reports are all available on the 'Blog' page in the 'About Us' section.

Short animations were commissioned to give information in an accessible format about biobanking and how to source samples from WCB.

The four animations are:

- Biobanking – an Introduction
- Introduction to the Wales Cancer Biobank
- Using WCB for Research
- Applying for biosamples from WCB

All four animations are available in English and Welsh and feature on the new website. The WCB also has a YouTube Channel: www.youtube.com/channel/UCtzbTXmr--nsVmB8aOEzz6w



Staff Development and Training

The opportunities for training have been limited during the pandemic but WCB is committed to support staff development, the training of the next generation of researchers and enhancing career options for all. A new online biobanking specific qualification and a bid for an Interdisciplinary Doctoral Training Hub in Cardiff University have been successfully completed during the year.

Qualification in Biorepository Science (QBRS)

WCB Lab Technician becomes the first person in UK and Europe to pass the Qualification in Biorepository Science exam.

Non Williams has worked as a technician in laboratories of the Wales Cancer Biobank since 2019 and in July 2021 she became the first person in Europe to pass the new Qualification in Biorepository Science (QBRS) exam. The qualification was jointly developed by ISBER* and ASCP BOC+ to meet the increasing demand for biobank and biospecimen related education to help to professionalise a biobank's workforce and improve standards. Working together the two organisations developed the qualification which was first offered in 2020 and is open to candidates around the world. Non took the online exam after a period of self-study using the recommended reading resources on the ASCP website.

Non commented that 'it was great to have an exam for individuals to gain recognition for their skills and competencies as biobankers' and that 'the ability to study at home and do the exam online really helped with fitting in around daily work commitments'.



*The International Society for Biological and Environmental Repositories (ISBER) is the leading global society promoting and focusing on Quality in Biobanking, with the mission to 'Advance the expertise and quality of biorepositories and biobanking science worldwide'.

www.isber.org

+The American Society for Clinical Pathology (ASCP) is the world's largest professional membership organisation for pathologists and laboratory professionals. The Board of Certification (ASCP BOC) provides excellence in global medical laboratory professional certification.

www.ascp.org/content/board-of-certification

We are very proud that Non is the first candidate in the UK and Europe to pass the exam. It is very important for WCB to support professional training – hopefully she is the first of many of our staff who will go on to take the qualification. The Wales Cancer Biobank strives to provide a quality service to researchers and well qualified biorepository professionals are central to this aim to support the advancement of biomedicine and biospecimen-based science.

Dr Alison Parry-Jones, Operations Director of WCB

Interdisciplinary Doctoral Training Hub

The Wales Cancer Biobank is a partner in an Engineering and Physical Sciences Research Council (EPSRC) application for funding to create an Interdisciplinary Doctoral Training Hub in Precision oncology: “Unifying biomedical imaging, pathology and genomics”.

The bid is led by Professors Emiliano Spezi and Rachel Errington (Cardiff University). The hub will fund 6–7 PhD studentships and WCB will provide educational input to increase awareness and understanding of the vital role played by biobanks in research. This promotes our aim to ‘Support joint bids to provide infrastructure support for cancer data-linkage projects’ and will link with doctoral training provided via the MRC Partnership bid (if successful) to deliver a cohort of future leaders who will be trained in human sample-based research techniques and the governance landscape of biobanks.

National and International activity

The Wales Cancer Biobank's ongoing contribution to the strategic leadership of biobanking maintains WCB's high profile on the national and international biobanking stage.

National Involvement



CRUK Stratified Medicine Programme

The Wales Cancer Biobank has been a key player in the CRUK Stratified Medicine Programme since 2011, until the conclusion of the programme in September 2021. Over the ten years of the project, WCB acted as the 'Cardiff Clinical Hub' and consented 2,311 patients across South Wales to the programme and contributed samples for testing from 2,052 of those patients.

The first phase of the programme, SMP1, was initiated in 2011 to test the feasibility of running a genetic pre-screening programme within existing NHS infrastructure. The WCB (Cardiff) was one of eight clinical hubs around the UK to consent patients with certain tumour types to use excess tissue and blood samples for genetic testing to identify the prevalence of mutations within the tumour DNA. The programme aim was to collect and analyse 9,000 samples across 6 pilot tumour types (lung, breast, colon, prostate, ovarian cancers and malignant melanoma) within 2 years.

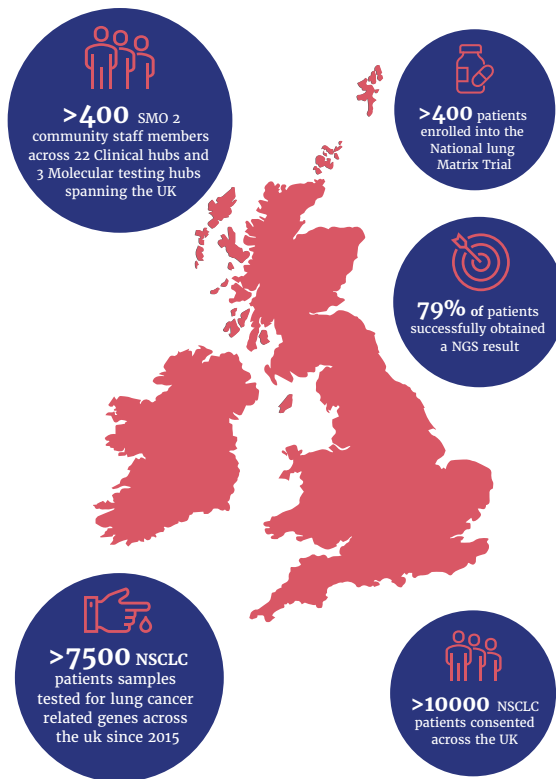
The target for the Cardiff clinical hub was to collect matched blood and tissue samples for a total of 1104 patients over the six tumour types. The hub contributed sets of samples from 1138 patients to the project, achieving 103% of the target. The second phase of the programme (SMP2) switched from individual gene testing to next-generation sequencing (NGS) to be able to test multiple genes at the same time. The focus was on patients with late stage (III/IV) non-small cell lung cancer, that that make up about 78% of all lung cancers diagnosed in England and Wales.



Twenty-two clinical hubs across the UK consented patients with a good-fair performance status who might benefit from specific second-line treatment offered as part of the National Lung Matrix trial. Patients were consented by WCB to allow tumour tissue taken during routine surgery or biopsy to be sent to one of the three designated Technology hubs for testing to determine whether the patient was eligible to enter a treatment arm within the trial.

Following a transition period, phase two started in January 2014. Throughout SMP2 the Cardiff clinical hub target was to submit tissue samples from 920 patients for NGS testing. WCB, as the Cardiff Clinical hub, consented 1,173 patients and successfully contributed samples from 914 of those patients to the project, achieving 99% of the target. WCB had an above average testing success at 81%, compared to the programme average of 79%. The low failure rate was due to the strong link with the Cardiff Technical hub laboratory, which proved invaluable and allowed for a better return of NGS results with little impact to the patient pathway.

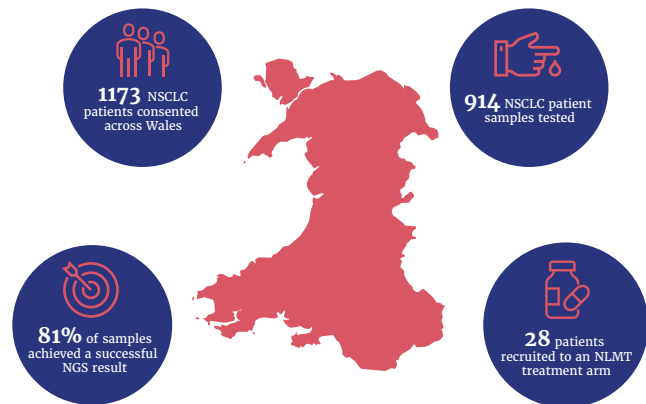
Figure 1 - SMP2 National figures



This work has seen WCB support the recruitment of Welsh patients with lung cancer into world leading clinical trials and has helped establish our reputation as being able to work within an

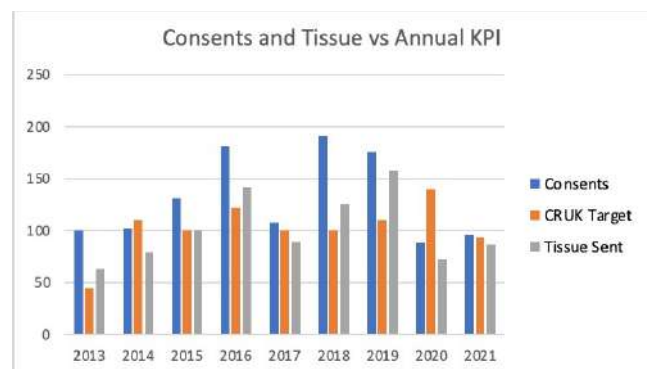
integrated Clinical research and NHS environment, linking state of the art tumour biomolecular analysis in small tumour samples.

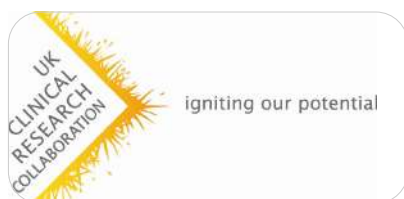
Figure 2 - Cardiff Clinical Hub (WCB) figures



We exceeded CRUK expectations in our delivery by achieving 101% of target over the lifetime of the whole programme (phase 1 and 2 combined) and have been used as a model for other clinical hubs around the UK.

The programme completed at the end of September 2021, and we are using the experience and collaborations acquired throughout the SMP to develop new ventures, specifically supporting the evaluation of plasma based molecular analysis in lung cancer as a disruptive technology to improve personalised treatment approaches, enhance accessibility of clinical trials and improve efficiencies in the diagnostic pathway.





UKCRC Tissue Directory and Co-ordination Centre (TDCC)

The UKCRC TDCC was funded by eight of the members of the UK Clinical Research collaboration to maximise the use, value and impact of the UK's human sample resources in the UK, and beyond. The UKCRC TDCC created a networked biobanking infrastructure and tissue directory to facilitate the discovery and use of the UK's human samples and data.



The development of the UKCRC TDCC was mandated by the UK Clinical Research Collaboration via their Vision for Human Tissue Resources and the TDCC helps researcher to discover samples and data, helps sample resources to improve their data systems for sharing, and works to harmonise policy relating to the discovery and use of samples and data. Along with supporting research in the UK, the TDCC participates in BBMRI-ERIC a European biobanking research infrastructure, as the UK National Node.

The WCB has been active within the UKCRC TDCC since its inception, being listed on the tissue directory, participating in annual Showcase events and as part of the Steering Committee. A group of biobank leads was convened in 2020 to discuss how greater harmonisation across the biobanks in the UK could better facilitate research.

This Biobank Alliance group concentrated on investigating whether (and how) access processes might be harmonised across the constituent biobanks. This would lead to a single point of access to biobanks for researchers and enable in a single application to be valid for multiple biobanks. Funding for the TDCC ended in February 2022 and WCB is part of a consortium bid for funding for 2023-2026 to build on the achievements of the TDCC and expand upon the work started in the Biobank Alliance group.

The new funding would support the establishment of the 'FAIRsamples' network. The main endeavour of the network is to work on bringing FAIR principles to biobanks. The two main strands of work are to develop an open-source sample tracking system and to develop mechanisms that reduce the governance burden on a researcher who is applying for samples from multiple biobanks.



Clinical trial hosting and Sample Adoption

The Wales Cancer Biobank continues to act as a host for sample collections associated with clinical trials. Samples from six actively recruiting trials were received during the year from trials run by the MRC Clinical Trials Unit (CTU) at UCL, the Oxford CTU and the Cardiff Centre for Trials Research. Samples from 8 trials that have closed to recruitment and for which ethics approval has expired were transferred under the WCB HTA licence during the period.

Only samples with consent for future use outside the trial were transferred, and any without appropriate consent were returned to the originating pathology department.

Samples from these trials are now available for use, in line with the conditions of the original consent, via the WCB's application and approval process. Samples from the COIN trial have been used by one researcher and an application for samples from the SUCCINCT trial has been received and WCB is working with the Cardiff Centre for Trials Research to supply samples and trial related data to the researcher.

Trial	COIN	FOCUS 3	FOLFERA	COPERNICUS	SCALOP 1	SUCCINCT	TFRAG	SCOPE1
Tumour type	Colorectal	Colorectal	Colorectal	Rectal	Pancreas	Bladder	Lung	Oesophageal
No. patients	1961	313	91	51	80	44	258	204
Tissue								
FFPE blocks	5068	339	68	0	0	35	13	0
Blood								
Whole blood	0	0	560	211	351	98	459	452
Serum	0	0	0	0	0	0	717	765
Plasma	0	0	883	431	0	172	1017	839

International Involvement



Dr Alison Parry-Jones (WCB Operations Director) was voted in as the incoming President Elect of the International Society of Biological and Environmental Repositories (ISBER) in March 2022. She has been the Director-at-Large for Europe, the Middle East and Africa for the last five years. She co-chaired the Scientific Programme Committee for the ISBER Annual meeting in Toronto in 2017 and received an ISBER Special Service award in 2019 for 'An exceptional contribution towards the goals of the organisation'. She will take up her new role as President Elect at the ISBER annual conference in Atlanta in May 2022.





BBMRI

In June 2021 WCB was invited to participate in a multi-Research Infrastructure (RI) bid for EU HORIZON funding 'HORIZON-INFRA-2021-SERV-01-02: Research Infrastructures services to support research addressing cancer', led by BBMRI ERIC. Cutting edge services and expertise will be provided by the respective RIs and partners across Europe through Trans National and virtual Access (TNA).

Professor Richard Clarkson was the co-lead responsible for developing one of the work packages in the bid and WCB submitted information on available sample cohorts.

The application was successful, and the project will commence in 2022. WCB will be designated a "TNA Service Providing Site" providing tissues and services to the wider EU research community.

The scope and aims of the collaboration are:

- Integrating at EU level and providing access to a wide and inclusive portfolio of complementary research infrastructure services,
- Support the provision of trans-national and/or virtual access,
- Foster cross-fertilisation by offering technologies involved in cancer advanced therapies to research projects targeting other major chronic disease,
- Establish active collaboration with clinical centres to facilitate translation of research results into clinical practice,
- Include infrastructures that can facilitate a rapid transition of research findings to innovations and therefore, to society,
- Include an outreach and engagement plan to actively advertise its services to targeted research communities and, if applicable, to relevant industries, including small to medium size enterprises,
- Include list of services/installations opened by RIs for trans-national or virtual access.

Regulatory

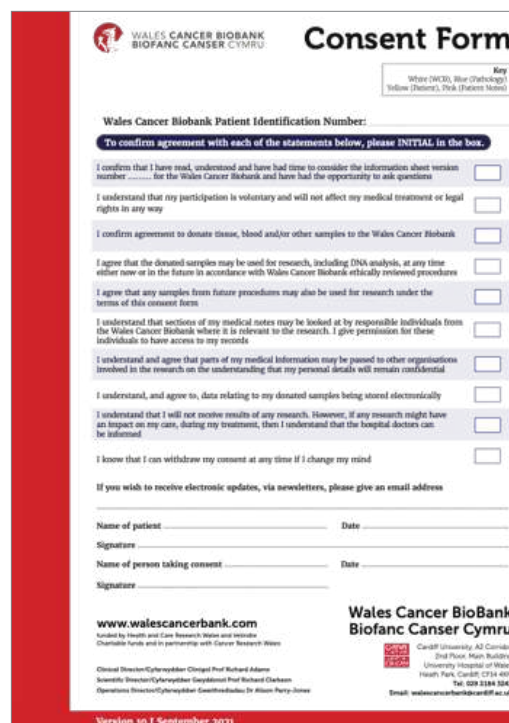
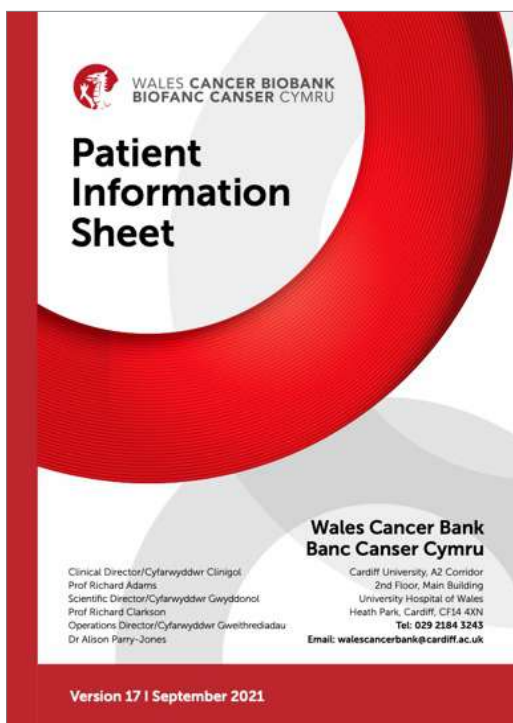
The Wales Cancer Biobank has ethics approval as a Research Tissue Bank from the UK Research Ethics Service (Wales REC3).

The approval runs for five years and was due for renewal in September 2021. At the time of application for renewal, WCB took the opportunity to increase the scope of sample collection to include samples from cancer screening and/or prophylactic procedures (e.g. breast removal if at high genetic risk of breast cancer) and the potential to collect research only biopsies when agreement and support from the local Health Board is in place.

The new approval reference is WA/21/0234 and it expires in September 2026. Information sheets and consent forms were updated with the new logo and a refreshed layout.

WCB submitted a substantial amendment request in March 2022 to be able to collect ethnicity information. Ethnic stratification has been evident during the pandemic and researchers are increasingly requesting ethnicity data to be able to factor this into their research. Patients will be asked to self-identify what best describes their ethnic group or background from a list as per the Office for National Statistics recommended question to gather ethnicity data in Wales.

The largest collections are in breast, colorectal, prostate and lung cancers where tissue and blood are processed and are annotated with pathology data, treatment and outcome data and molecular data. The richness of the data sets and the availability of matched sample sets varies by tumour type.



Data Initiatives

The Wales Cancer Biobank supports the vision of big data and the utilisation of Artificial Intelligence (AI) in cancer research. Working with others in Wales and around the UK, we are an integral part of initiatives to integrate and harmonise data and plan for a more streamlined, secure, and accessible data future.

Images and Artificial Intelligence (AI)

WCB has signed a Material Transfer Agreement/ Service Agreement with a UK based company specialising in AI technologies for the Healthcare Sector. WCB provided images and associated clinical data from our archive of 1,500 breast biopsies to aid development of the company's diagnostics tools.



Sêr Cymru

In line with the Wales Cancer Biobank's mission to supply biosamples with rich curated datasets, WCB previously joined forces with other Health and Care Research Wales funded organisations (Wales Gene Park and the Wales Cancer Research Centre) along with Cardiff University Schools of Medicine and Engineering, the All-Wales Medical Genomics Service, and the Advanced Research Computing @ Cardiff (ARCCA) to develop secure, robust high-performance computing and storage to support data integration across cancer domains.

In June 2020, the partnership had secured £277,865 from the Sêr Cymru Infrastructure Award (Sêr Cymru II – WEFO ERDF Programme 80762; project code CU232) to build a 160-core

compute cluster with a dedicated access node, supported by over 600 terabytes of secure storage replicated across two datacentres. Over the last reporting year, WCB and partners have used Sêr Cymru IT to develop pilot projects (for example, WCB's collaboration with Panakeia) and develop further projects (for example, supporting the recent successful bid to establish an EPSRC Interdisciplinary Doctoral Training Hub for precision oncology, aligning with WCB training ambitions).

Sêr Cymru IT recently secured £25,000 from Genomics Partnership Wales to implement an Information Security Management System (ISMS) as a prelude to ISO 27001 certification of the system to improve security and trust. Sêr Cymru IT is now being used to inform and develop Wales' cancer research digital strategy in line with the Wales Cancer Research Strategy (CRest) strategy and and most recently £554,535 has been successfully secured from commercial partner, Roche, to develop the Cancer Trusted Research Environment (TRE) Project in which WCB will continue to play an active role.

Cancer TRE Project

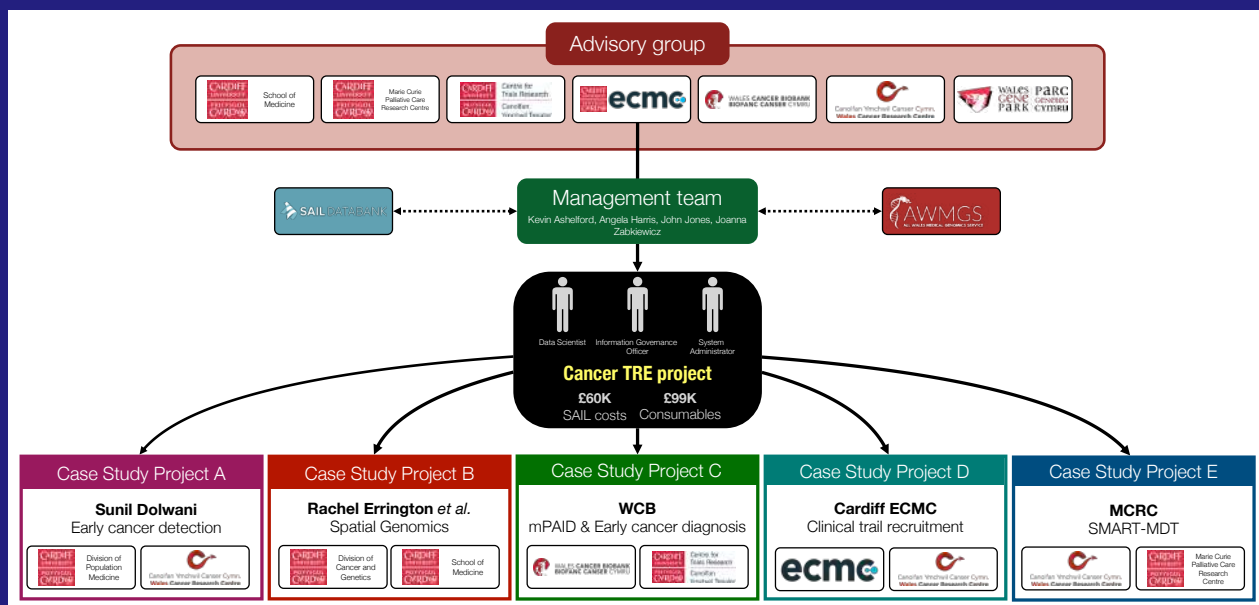
The Cancer TRE Project is a two-year programme, funded by industry, to develop Trusted Research Environment (TRE) capacity for cancer and rare genetic disease research in Wales, working with the SAIL Databank, and informed by the CRSt strategy.

The project aims to align the shared digital ambitions of multiple Health and Care Research Wales funded bodies into a single unified plan around shared digital infrastructure that complements and informs Genomics Partnership Wales' digital strategy for genomic precision medicine. Led by a consortium of Health and Care Research Wales funded organisations (Wales Gene Park, Wales Cancer Research Centre, Wales Cancer Bank, Centre Trials Research) and working closely with other cancer organisations (principally, Cardiff Experimental Cancer Medicine Centre,

ECMC, and the Marie Curie Research Centre, MCRC) the to support selected strategically significant project will work with the SAIL Databank translational cancer projects that illustrate Wales' future cancer TRE requirements.

The project will focus on practical ways of improving secure, safe access to health and care data for cancer and rare genetic disease translational research – academic, clinical, and industrial – with a particular focus on working with the All-Wales Medical Genomics Service, AWMSG, through Genomics Partnership Wales, GPW, to improve the access and use of genomic data for precision medicine benefit.

As such, the project will eventually be based at the new Cardiff Edge development at Coryton as part of the planned GPW relocation of core genomics services.



Programme Update

Throughout the year the WCB Strategy group and Advisory Board have been consulting on the proposed strategic development of WCB over the next three years. WCB plans to align the collection strategy and collaborations with research priority areas highlighted by the Wales Cancer Research Strategy (CReST) and areas of particular strength in Wales to best meet the needs of cancer patients in Wales.

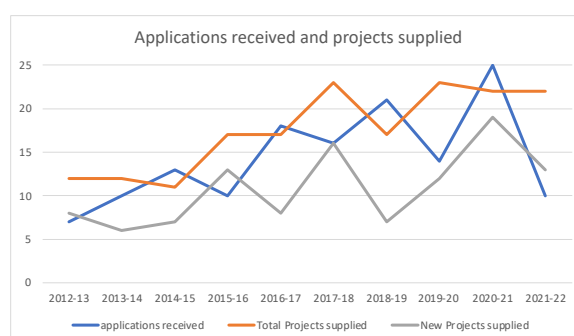
As researchers returned to laboratories following the COVID restrictions of 2020 and into 2021, the impact on WCB supply activity was expected to be reduced but despite this a steady flow of enquiries and supply was achieved. WCB continues to collect samples for approved projects and to add to the archive to be readily available for future projects. Over 16,000 patients in Wales have donated samples for use in future, cancer related research and samples are available from over 20 solid tumour types. The largest collections are in breast, colorectal, prostate and lung cancers where tissue and blood are processed and are annotated with pathology data, treatment and outcome data and molecular data. The richness of the data sets and the availability of matched sample sets varies by tumour type.

Sample Issue

Applications for samples were received from ten research groups between April 2021 and March 2022. Nine were from academic groups and one from a commercial company. One application was withdrawn with the other nine going forward for review.

Nearly three thousand two hundred samples were issued to 22 projects during the year, thirteen new projects (not previously supplied) and nine projects ongoing from previous years. Eighteen of the twenty-two projects receiving samples were based in academia, with the other four projects based in commercial companies. 42% of samples were issued to researchers in Wales and those researchers in Wales accounted for 18 of the 22 projects supplied with samples. Most of the samples issued originated from consents in earlier years, with only 15% (489, issued to 6 projects) coming from consents within the period. Sample supply ranged from 3 samples (ongoing from previous years) to 1519 samples, with a median of 30 (Q1=17, Q3=114). 68% of projects requested and received fewer than 50 samples.

No. samples supplied	No. projects
0-10	3
11-50	12
51-100	1
101-500	5
501-1000	0
1001 -1500	0
>1500	1



Core Metrics

Reporting period: **2021/2022**



Health and Care Research Wales infrastructure award to the group



Direct funding awarded
£464126

Jobs created through direct funding



Grants won during reporting period

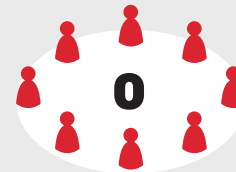
Grants won	Led by group	Group collaborating
Number	1	4
Value	£58587	£7101
Funding to Wales	£58587	£7101
Funding to group	£58587	£7101
Additional jobs created for Wales	1	0
Additional jobs created for group	1	0



Number of publications



Number of public engagement events



Number of public involvement opportunities

Biobanking metrics



Consents



Research requests



Research requests approved



Samples issued to research projects



Projects receiving samples



Publications using samples

At a Glance – New Initiatives



Completion of an inaugural MSc training research project for Cardiff University School of Computer Sciences. Two MSc research projects co-supervised by WCB to apply clinical datasets for the development of an MDT interface for routine practice.



Increase engagement with and support of industry-funded research projects: engagement with WCRC/WGP to collaborate on an ECMC-Roche digital genomics initiative—to provide sample pipeline and consenting for future research collaboration funded by Roche.



Supporting partner in CRUK RadPath, an infrastructure grant application to CRUK RadNet, to establish pathology readouts from radiotherapy samples. Collaboration with ICR, Manchester, Leeds, Oxford, Glasgow. Will be providing samples and infrastructure support for the participating researchers on this grant.



CtDNA R&D project initiated with NHS partners. CtDNA is DNA from patients' tumours that can be picked up in a simple blood test. Our work with the lung cancer community in the NHS in Wales has allowed us to support the development of a new line of work in which we are supporting sample and data collection to evaluate blood tests in patients to expedite cancer diagnosis and speed up the time from diagnosis to the first day a patient commences a treatment targeted to their own tumour.

Public Involvement and Engagement

The continued COVID restrictions and use of virtual media for meetings has curtailed the patient and public involvement and engagement (PPI&E) programme in 2021/22. The focus of the year was to improve the outward facing online content by improving the website and introducing short animations as a new awareness and engagement tool.

The WCB YouTube channel that now houses the animations, will be added to during 2022 to include videos highlighting 'A Day in the Life of ...' to show typical daily activity of various WCB staff. A poster (right) highlighting the changes made in 2020 in the way lay representatives are involved in and interact with the biobank through inclusion in all governance committees, has been accepted for presentation at the 2022 ISBER Annual meeting in Atlanta, Georgia in May 2022.

The WCB is involved in the both the Communications Alliance and Involvement Alliance set up by Health and Care Research Wales. Both groups meet regularly to share information, details on training opportunities, events and provide an important link with the PPI&E research network across Wales.

ENHANCED LAY INVOLVEMENT FOR IMPROVED BIOBANKING
A Parry-Jones
Wales Cancer Biobank
Cardiff University, Cardiff, UK

Background
The Wales Cancer Biobank (WCB) has involved the public and patients since its inception in 2004. Four lay representatives sat on the original Steering committee to define the biobank. These four individuals formed the nucleus of the Lay Liaison and Ethics group who worked with the biobank senior team to draft the patient information sheet, consent form and the application to the ethics board. This group continued to meet as a distinct group for 15 years and although the Chair of the lay group was a member of the Executive group, other lay members had little to no direct input and contact with the wider biobank staff and management. To improve engagement, involvement and governance, a radical rethink and overhaul of lay contribution was needed.

Programme
The UK NIHR National Standards for Public Involvement in Research are the foundation of public involvement in the UK.
The newly integrated programme maps activity onto the standards, alongside a volunteer 'consenting initiative' that was instigated in 2016 where members of the public/lay volunteers are trained to speak to donors to ask for consent for biobanking. The volunteers had no direct experience but had a wealth of transferable skills from previous employment.
A pilot project has been running successfully in Velindre Cancer Centre and until the initiative was suspended due to COVID19, the volunteers accounted for nearly 48% of all consents in the tertiary cancer centre. This model could be rolled out to truly put patients and the public at the centre of research activity.

What did we do?
In 2020 the way the lay group interacted with the biobank changed considerably and members of the lay group were introduced to each of the biobank working committees. In this new structure, two members joined the Operational Management group, and one member joined the Strategy group, whilst retaining the Chair's involvement in both the Executive and Advisory groups.
The group also continues to meet as a distinct committee but the integration into the core groups allows a more informed participation.
Members of the WCB's Lay group are involved in multiple areas of the biobank. They:
• review lay summaries to ensure plain English is used in all applications for use of biomaterials and/or data:
• applications will not be approved until a lay member is satisfied that the lay summary is suitable,
• work with the biobank to consult on new initiatives,
• advise on amendments to ethics and
• give their lived experiences.
As full members of the committees, lay members receive all the papers and reports and are encouraged to participate equally in meetings.

Standards Mapping and Feedback
Feedback from the lay members has been hugely positive and all have reported feeling better informed, more involved and more valued. The members on the operational management group have commented that they had no idea the day-to-day operation was so complex and that the increased knowledge had changed the way they participate and the recommendations they contribute. A lay driven conversation has, for example, initiated the production of two videos aimed at the public to raise awareness and a major refresh of the website.

Conclusions and Outputs
WCB now has its own YouTube channel to host the videos:
https://www.youtube.com/channel/UCt8w...
and a new website
An informed lay voice has greater value to the biobank and gives greater purpose to the volunteer.
Embedding the lay representatives at the heart of all activity speaks to the biobank of improving impact and adding value by not only listening to lay representatives, but truly involving them in governance, impact priorities and future agendas to improve outcomes.

Conclusion and Looking Forward

The Wales Cancer Biobank is looking forward to the supporting the delivery of the new Welsh cancer research strategy, to be launched in 2022 by Health and Care Research Wales. As a key partner in cancer research in Wales and beyond we provide an infrastructure that is developing and adopting new efficient ways of working.

We believe we are uniquely placed to support multiple components of the strategy linking the public, patients, scientists, and clinicians to deliver high quality cancer research focusing on high quality discovery science all the way through to clinical implementation affecting patient here and now.

Thanks go to many, but especially to the **patients** in Wales for their continued support and willingness to donate samples and data to the biobank.



“I consented to WCB to forward research in the area of lung cancer. Also having been affected by different cancers I hope that future generations of my family will benefit from research carried out using my samples”

Quote from donor



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<https://www.youtube.com/channel/UCtzbTXmr--nsVmB8aOEzz6w>

