

# A Review of International Biobanks and Networks: Success Factors and Key Benchmarks—A 10-Year Retrospective Review

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## Editor's Introduction

AS ISBER CELEBRATES its 20th anniversary, we should be drawn to critically examine our past biobanking initiatives to assess the merits of their achievement and to learn for our future. A decade ago, Vaught et al.<sup>1</sup> published in *Biopreservation and Biobanking* a review of 16 initiatives in biobanking networks and major national biobank programs. These initiatives represent major biobank efforts from around the world covering the North American, European, and Indo-Pacific regions. A decade on, we asked each of these national biobanking facilities and networks to tell us what their journey has entailed in what has been a shifting and developing environment for biobanks. We sent out an invitation to all 16 initiatives seeking their input to the following questions:

- (1) Is the biobank/network still in operations?
- (2) Has the operations and governance model changed? If so, how?
- (3) Are the access policies the same? If not, what changes have been made?

- (4) Has the funding model been sustained? How has it changed?
- (5) Do you consider this biobank/network as having been successful? Why?

The following responses of experts represent 12 of the 16 initiatives described in the original review.<sup>1</sup> You will read how a few of these biobank networks are now no longer in existence due to funding withdrawal or a shift in operational focus within their regions. Other initiatives are maintaining strong activity having been required to make more subtle changes to their operation models or through diversification of their activities.

These brief reviews provide a snapshot of the changing face of biobanking around the world. These strong biobanking initiatives have been foundational to where we are today, with biobanking now a fundamental activity emerging within our research landscape as well as our medical institutions. Although the future of biobank management is guaranteed to continue to be as capricious as these 12 national biobanks and networks have faced over

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the past decade,<sup>2</sup> one thing remains certain: our biomedical research community will still require the systematic collection and distribution of human tissue specimen from donors to scientists if we are going to continue to build knowledge about human disease and its consequences. The role of the biobanker in this space is advancing, maturing, and becoming far more embedded as a norm. Its initiatives such as these that have been at the frontiers that made this possible.

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## Expert Response: Lisa Devereux on Behalf of the Australian Biospecimen Network

THE AUSTRALIAN BIOSPECIMEN Network-Oncology (ABN-Onc) project<sup>1</sup> was established as a federated biobank in 2005, funded by the Australian National Health and Medical Research Council government instrument through its enabling grant scheme.

Between 2005 and 2014, a total of \$3.7 million AUD supported ABN-Onc in establishing a federated biobank and information hub. Importantly, the funds leveraged a total of >\$8 million AUD of existing support (both cash and in-kind) contributed by the seven member organizations. Each biobank in the federated model retained governance of their respective collections.

Cost recovery fees formed part of the funding model for the majority of member banks; however, fees did not recover the full operational costs, a situation consistent across the Australian biobanking community to date.

Key achievements of ABN-Onc include establishment of the Tissue Specimen Locator<sup>2</sup> (TSL), a web-based tool enabling high-level interrogation of biospecimens available at all participating biobanks. The annual biospecimen collection figures increased year-on-year over the life of the network with the number of samples supplied for research ranging from 62% to 97% of the annual total collected. The dedicated ABN-Onc project manager enhanced communication across the sector including expertise and protocol sharing with emerging biobanks.

Extending from this investment of resources and expertise, the investigator group formed the Australasian Biospecimen

Network Association (ABNA). ABNA was established as an incorporated association in 2009 to ensure continuation of the professional network beyond ABN-Onc funding.

The enabling grant scheme was withdrawn in 2011 and another major infrastructure funding scheme through National Breast Cancer Foundation was withdrawn several years later. When ABN-Onc funding ceased in 2015, operational support at each member biobank was reduced and the project manager role was discontinued.

The ABNA convenes an annual scientific meeting with the 17th meeting held in Cairns Australia in October 2019. The ABNA remains a vital and active organization and will host the TSL on a revised website (under construction in 2019). Six of the seven member banks are still open with a revised operational focus and funded by a range of government schemes and philanthropic organizations.

A formal analysis of comparative rates of research support pre- and post-ABN-Onc is yet to be undertaken. There is a renewed focus on resources linked to specific research questions in the Australian research landscape posing ongoing opportunities and challenges for biobanks.

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## Expert Response: Peter H. Watson and Anne-Marie Mes-Masson on Behalf of the Canadian Tissue Repository Network

THE CANADIAN TISSUE Repository Network (CTRNet) was created in 2004 as an association of leading tumor biobanks and with a charge set by the national cancer research strategy to develop national standards, tools, and resources for biobanking. As such, the network draws on the expertise of member biobanks, but does not control or determine access to them. In the first 10 years, the network was funded by the Canadian Institutes for Health Research (CIHR) to enable contributions to creating standards and assets from across a broad network. Since 2016, CTRNet continues to receive support from the CIHR and also from the Terry Fox Research Institute and has restructured to

concentrate on maintaining and updating its national biobanking standards and associated operating protocols<sup>1</sup> and suite of education courses, and the CTRNet Biobank Certification program<sup>2</sup> hosted by the British Columbia node and the Advanced Tissue Information Management (ATiM) system<sup>3</sup> hosted by the Quebec node.

The success of CTRNet is reflected in (1) increasing enrollment of biobanks (with >300 biobanks) into the CTRNet Biobank Certification program and its adapted versions (including a new certificate program directed at clinical personnel in pathology departments to standardize the approach to providing support for research biobanking)<sup>2</sup> that are accessible nationally and internationally, (2) growing endorsement of the program by research institutions and funders across Canada to increase access to quality biospecimens, (3) implementation of the CTRNet ATiM system<sup>3</sup> and its embedded data standards by >30 research programs and biobanks and adoption as the biobank data standard by large institutions and provincial research initiatives, and (4) expanding memberships in the CTRNet Biobank Resource Center<sup>4</sup> (with >1500 members).

To maintain a fit-for-purpose governance structure and maintain CTRNet's strong partnerships with key Canadian research organizations, a CTRNet College of Advisors (COA) was established, comprising leaders of the charter biobanks and experts in translational cancer research.<sup>4</sup> The COA provides a formal and valuable mechanism to ensure that the national CTRNet standards and the other products and services continue to optimally serve the needs of researchers across the country.

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## Expert Response: Francisco Luna-Crespo on Behalf of the Spanish Biobank Network

**M**ANY THINGS HAVE changed in the Spanish biobanking sector in the past 10 years. First of all, the initial network focused on cancer, promoted and coordinated by the department of molecular pathology at the Spanish Cancer Research Center (CNIO), disappeared, as such, due to the lack of economic support from the promoters. But, its seeds flowered into a wider and more ambitious structure, thanks to the funding and visionary views from the Spanish Research Council, Instituto de Salud Carlos III (ISCIII).

In 2009, biobanking became an important part of the Spanish strategic agenda and funds were released through a competitive call to create the Spanish Biobank Network.<sup>1</sup> The initial project, coordinated by the CNIO Biobank, included 63 members, mainly hospital-based biobanks reminiscent from the tumor bank network, but also population, brain, and other disease-oriented biobanks. The initial funding project has evolved over time based on three strategic pillars: integration, harmonization, and quality-driven public service. The actual Spanish Biobank Network is coordinated by the pulmonary biobank platform, CIBERES, and integrates 39 federated biobanks after the fusion and specialization of many former members.

During these 10 years, the financial crisis hit us hard and had a direct impact on our prospects with the tangible consequence of Spain not taking part in the Pan-European European Strategy Forum on Research Infrastructures: Biobanking and BioMolecular Resource Research Infrastructure-European Research Infrastructure Consortium.

In terms of sustainability, most Spanish biobanks have developed their own cost recovery policies according to their institutions' business models; however, the public funds coming from ISCIII have decreased over time. The access policy remains unchanged as stated in the Spanish legal framework<sup>2</sup> and the basic structure and governance of the Spanish Biobank Network moved to a project-driven model. In that sense, the network contributed in the professionalization of the Spanish biobanking community, incorporating new tools and granting access to quality services to our users.

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### Expert Response: Gerry Thomas on Behalf of the Chernobyl Tissue Bank

**T**HE CHERNOBYL Tissue Bank (CTB) celebrates its 21st anniversary in 2019. It has consented 5226 donors, resident in the contaminated areas of Ukraine and Russia who were aged <19 years at the time of the Chernobyl accident and have developed thyroid cancers or adenomas. It has issued a total of 16,933 biosamples to 37 research projects since 2001.

The project continues to be funded by the National Cancer Institute (NCI) of the USA, and the Sasakawa Foundation of Japan. The European Commission ceased to fund the project in 2012. The governance structure for the project has changed slightly since its inception. The project is now overseen by the steering committee that has membership from the sponsors of the project and Russia and Ukraine. There is a scientific advisory group that supports the project director in the development of strategy for the project. Clinical information on treatment and outcomes, together with information on driver mutations identified by different research projects, is now provided in addition to the information obtained on patient demographics, thyroid dosimetry, and pathology of the specimens collected. A consensus diagnosis is provided by the International Pathology Panel for the CTB. No fee is charged for access to samples: researchers are asked only to cover the costs of shipment from the coordinating center in London.

The project has supported many epidemiological studies into thyroid cancer (e.g., the Ukraine American cohort study sponsored by the U.S. NCI) after the Chernobyl accident, and provided data for many reports by international bodies on the subsequent health effects. Material from 651 cases is currently being put through the Cancer Genome Atlas pipeline in the United States in a unique study to use “omics” technologies to identify potential biomarkers for radiation-induced thyroid cancer. This is the largest study of its type ever to be undertaken.

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### Expert Response: Helen Pitman, Valerie Speirs, and Andrew G. Hall on Behalf of the Confederation of Cancer Biobanks

**T**HE NATIONAL CANCER Research Institute (NCRI) established the Confederation of Cancer Biobanks (CCB) in 2007 to support institutions and organizations based in the

United Kingdom that are involved in the development, management, and use of biobank resources for cancer research.

Over the past 12 years, it has organized a series of well-attended and received meetings centered around topics of interest to the cancer biobanking community, which provide members with an opportunity to network and share best practices. We have also created a confidential sample quality improvement tool<sup>1</sup> that has been downloaded across the world. This tool assesses the standard practice in any given biobank through questions and flagging relevant literature to support the best practice protocols.

In 2017, CCB came under the umbrella of the NCRI Cellular and Molecular Pathology initiative, which promotes the role of pathology and tissue access in precision medicine. This has provided funding until 2021 to continue with cancer biobank activities and expand the membership.

In 2019, we will be reinvigorating CCB with new objectives to enhance the biobanking landscape and facilitate tissue access for research in the United Kingdom. Our vision is for more biobanks to be badged with the CCB name by meeting standards for visibility, accessibility, and quality.

CCB has recently made changes to its memorandum of understanding and its guiding principles setting out its intentions and requirements for biobanks to join the group. These requirements are based on research carried out recently and publicized in the Royal College of Pathologists bulletin.<sup>2</sup>

CCB<sup>3</sup> will also deliver a cost recovery tool, short training guides on important matters for biobanks, as well as continue the annual meetings on exciting topics to bring the community together.

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### Expert Response: Nicole Bollinger on Behalf of the Cooperative Human Tissue Network

THE COOPERATIVE HUMAN Tissue Network (CHTN) was funded in 1987 by the National Cancer Institute (NCI) to prospectively procure, collect, and distribute high-quality biospecimens according to protocols specified by each investigator. The CHTN began its seventh 5-year funding cycle on April 1, 2019. The network, comprising five adult divisions and one pediatric division, provides specimens to investigators at academic, government, and commercial entities.

The operations and governance of the CHTN have not changed over the past 32 years; however, the CHTN works to stay ahead of research trends and strives to forecast researchers' needs based on the most recent scientific developments and trends. The CHTN is governed by a coordinating committee that comprises the principal investigator and division coordinator of each CHTN division and two NCI program directors.

Since the inception of the CHTN, investigators have published >4200 peer-reviewed publications citing the use of CHTN samples and >300 patents have been issued with CHTN attribution. Notably, the CHTN has supported a generation of novel insights resulting in groundbreaking contributions to the understanding of tumorigenesis; helped advance discoveries into clinical applications; supported the generation and testing of targeted monoclonal antibodies for use in diagnostics, therapeutics, and in-patient stratification assays; supported research that defined subtypes and stages of tumor; identified and interrogated interindividual variability in responsiveness and toxicity to widely used chemotherapeutics and novel therapies; and supported the development and validation of revolutionary approaches to diagnosis, including handheld mass spectrometry systems for *in vivo* cancer diagnosis.<sup>1</sup> In addition, the CHTN has demonstrably improved the care of children with cancer in terms of identification of subtypes of childhood cancers as well as identification of markers of prognosis, potential therapeutic failure, and susceptibility to toxicities, which now guide clinical decision-making.

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### Expert Response: Manuel Posada and Hanns Lochmüller on Behalf of the EuroBioBank

THE EUROBIOBANK (EBB) is still in operation. EBB began its activities in 2002 with funding from the fifth frame program of the European Commission. EBB also received funds being part of projects such as TREAT-NMD in the sixth framework program and RD-CONNECT in the seventh frame program. Fondazione Telethon, Italy, also supported part of its infrastructure during recent years. Nowadays, EBB is still working and collaborating in the training pillar of the European Joint Program Rare Diseases, developing an interoperable sample catalogue within the RD-CONNECT community and recently participating in the BMMRI-ERIC.

The current governance consists of a coordinator with secretariat support, an operative committee (acting as a board) and two working groups. We are also integrating services with the aforementioned organizations, BMMRI, EJP RD, and RD-CONNECT community.

Basically, access policies have not changed, since the group's inception, but they are adapting to these larger networks and European biobanking infrastructures, and aligned with the global rare diseases research policies of the International Rare Diseases Research Consortium

The funding model of the EBB has changed because they are not currently supported by specific projects. Activities are now supported depending on their specific aims (e.g., sample catalogue by RD-CONNECT and BMMRI-ERIC; training by the EJP RD, services by BMMRI-ERIC and EBB members).

The EBB has been successful in that it has, for >15 years, distributed thousands of RD samples for research around the world.<sup>1-3</sup>

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### **Expert Response: Heather Thorne on Behalf of the kConFab**

THE KATHLEEN CUNNINGHAM Consortium for Research into Familial Breast Cancer<sup>1,2</sup> (kConFab) is a centralized repository for tissue, blood, and tissue microarrays linked to mutation and treatment data from multicase breast and ovarian cancer families in Australia and New Zealand. This nonprofit biobank is funded by a national cancer foundation and public/advocacy groups and more recently by the supply of biospecimens linked to clinical data to pharmaceutical/industry groups.

kConFab was established in 1997 and is still operational. One of its strengths is the collection of serial biospecimens linked to clinical data with follow-up from participants for a 22-year period, in recent times this collection has incorporated a rapid autopsy program. The operations, governance, and access models that were initially established have proven successful so have not changed. The success of this model can be seen in the 184 active projects of which one-third were approved 15 years ago, thus giving long-term stability to the researcher. There are 390 high-ranking publications that list “kConFab” as an author.<sup>3</sup> Formal feedback from researchers accessing our resource indicates that the formal application is not too onerous and the required Material Transfer Agreements (MTAs) are signed within an acceptable time frame, that is, 3–4 months.

The most difficult issue has been sustainability since the federal government funding for biobanks/cohorts ceased in 2011. This has been successfully countered by introducing a base level cost recovery scheme for all biospecimens and/or data supplied to projects based on a four tier fee system: (1) the principal investigator is at an academic institution in Australia, (2) the principal investigator is an overseas academic investigator with an Australian collaborator, (3) the principal investigator is overseas and does not include any Australian researchers, (4) companies are subject to negotiation. The base fee for all biospecimens and data is reviewed annually and is linked to the Australian Consumer Price Index (CPI).<sup>4</sup>

Owing to the boutique nature of our resource, that is, we only contain familial high-risk cancer cases, we consider it to be a successful operation due to the steady number of active projects for 22 years with 99% of the collected biological specimens and data accessed multiple times. In addition, the follow-up of all participants enables us to support a broad range of research from psychosocial gene discovery through to targets for new treatments.

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### **Expert Response: Chon Boon Eng on Behalf of the Singapore Tissue Network**

THE SINGAPORE TISSUE Network (later renamed as Singapore Biobank [SBB]) was set up in 2002, and after almost a decade of operation was shut down in 2011. Various reasons were cited for the closure, such as underutilization and the presence of alternative institutional biobanking facilities.<sup>1,2</sup> Part of the winding down effort involved sourcing for an alternative biostorage facility. The national grant agencies worked with the National University Hospital Tissue Repository (NUH TR) to ensure that investigators with difficulties housing their specimen were not affected. Also, specimen processing and other biobanking activities continued at the NUH TR. During the transition period from SBB, NUH TR ramped up its institutional biobanking operation to support larger scale national-level biobanking activities.<sup>3</sup> An oversight committee, made up of stakeholders from various institutions, was set up to oversee the governance and accession of the Singapore Biobank’s specimen stored at the NUH TR. In 2018, the Singapore Integrated Network of Biorepositories (SINB)<sup>4</sup> was set up to amalgamate tissue repositories in Singapore as a virtual network of biorepositories. The vision is to better serve the nation’s Health and Biomedical Sciences (HBMS) sector with standardized biobanking best practices (ISBER) and certification program (CTRNet Biobank Certification).

A national catalogue of biospecimens is also being developed for specimen’s availability, linked with biospecimen, clinical, and OMICS data (in compliance with Singapore’s legislation such as Personal Data Protection Act 2012 and Human Biomedical Research Act 2015). For biobanking sustainability, a full cost recovery model was developed and investigators were given a sunrise period to source for

funding before full implementation. The SINB model addresses three main areas of biobanking (1) ownership: stakeholders are involved in specimen accession, (2) biospecimen locator: national catalogue allows for central application and specimen interrogation with enhanced specimen characterization, and (3) financial sustainability: full cost recovery for biobanking activities.

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## Expert Response: Peter H.J. Riegman on Behalf of the TuBaFrost European Human Tumor Frozen Tissue Bank

THE EUROPEAN NETWORK for tumor tissue that later became a cancer sample exchange platform is no longer operational.<sup>1</sup> The main reason is the changed landscape in biobanking networks. It was stopped, because BBMRI-ERIC should now be the facilitator. Introduction of the General Data Protection Regulation (EU) 2016/679 and budget also helped. The governance was not changed, the collecting principal investigator (PI) was always in charge when handling external requests. Access was always reserved to those having an e-mail address showing company/institute involved in cancer research or patient care relations. The network has been very successful to set the stage for biobanking networks. It showed that with only little information and communications technology (ICT) money, an exchange platform can be created and sustained. The costs were not more than an online provider with MySQL facilities and one programmer available for making the needed changes. This way European projects with dedicated users in the exchange platform, such as EuroBoNeT, Euro\_WING, ENCCA, and EEC, were facilitated. Also under the EurocanPlatform and support of the Organization of European Cancer Institutes (OEI), we could optimize the TuBaFrost tumor bank to a sample exchange platform. Consortia could create their own needed exchange environment. Unfortunately, the budget provided from the dedicated users was not enough to sustain the programmer on a yearly basis. Even the cheap solution appeared to be too expensive. Many other TuBaFrost deliverables important for sample exchangeability made a difference,<sup>1,2</sup> including the following.

1. The judicial principle that the country of origin determines what may and may not be done with sample and data.<sup>3</sup>
2. Opt-out system as better alternative for informed consent waiver for residual tissue.<sup>3</sup>
3. Sample quality: standard operating procedure (SOP) for snap freezing (precooled isopentane), SOP for pathology laboratory.
4. Variations in sample quality can influence the test result certainly between institutes, continued in projects such as SPIDIA and SPIDIA-4P.<sup>4</sup>
5. Transparency, access, and governance rules.<sup>1,3</sup>

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## Expert Response: Wayne Ng on Behalf of the Victoria Cancer Biobank

THE VICTORIAN CANCER Biobank (VCB) is still operating as a consortium since it was formed in 2006. Current members include Cancer Council Victoria (CCV), Austin Health, Eastern Health, Melbourne Health, Monash Health, and Peter MacCallum Cancer Centre.

The VCB is still operating as a hub-and-spokes collection model in which the CCV acts as the lead agency and the coordination, centralized biobanking database, project application, and enquiries are managed by the VCB central operations team based at the CCV. The five consortium tissue banks are the custodians of the samples and data they collect. The staff at these tissue banks perform the core biobanking activities that include managing ethics approval, donor consent, specimen collection, processing, and dispatch.

Since 2011, the VCB has changed the operational model from active general collection to a supply-and-demand model based on researcher demand for specific tumor streams. The VCB also provides project-specific collection as part of the service agreement.

The governance model has changed recently. Currently, the strategic advisory group together with the management and operations group (MOG) provides support, input, and guidance to both the strategic and the operational outputs of the VCB. The sample and service provisions of the VCB are

governed by the access committee. The VCB remains as an open-access nonprofit resource that provides services to ethically approved research projects on a cost recovery basis.

The VCB is still funded by the Victorian Government through Victorian Cancer Agency, Department of Health and Human Services. The cost recovery model is also implemented aiming to cover some of the operational cost. VCB does not receive charitable contributions.

The VCB is considered successful for achieving the mission to provide researchers with high-quality biospecimens to facilitate cancer research discoveries and improve clinical outcomes. In the previous reporting year (July 2018–June 2019), VCB has provided services to >70 local and international projects, bringing an impact of 16 high-impact factor publications from some of these projects.

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### Expert Response: Alison Parry-Jones on Behalf of Wales Cancer Biobank

THE WALES CANCER Bank (WCB) continues to consent cancer patients with >15,000 patients in Wales having donated samples—tissue, fluids (blood, urine, saliva, and ascites)—and data in the past 14 years. The original strategy was to collect from all tumor types to provide a representative sample cohort of cancer in Wales. At the height of operation, WCB was collecting samples from 12 hospitals around Wales. A subsequent downturn in core funding gradually reduced that number to four hospitals in 2019.

An internal review<sup>1</sup> of the first 10 years highlighted the need for a revised approach to keep WCB current and well positioned within the market and research community and showed the cost–benefit analyses in terms of sustainability for adopting specific changes to the overall strategy and operational plan. In 2015, this resulted in the adoption of a new strategy of targeting sample collection to four tumor types (breast, prostate, lung, and colorectal) to reflect the

requirements of researchers applying for samples, the cancer burden in Wales,<sup>2</sup> and to work within the funding restraints in the reduced collection sites.

Access<sup>3</sup> remains open to cancer researchers worldwide working in any sector and is subject to a review process and cost recovery fees. Over 100 research projects in 10 countries have sourced ~20,000 samples from WCB and a drive to increase visibility of the biobank has led to inclusion of a number of discovery platforms.

In the past 5 years, new innovations in cancer research have led to a number of new demands for fresh, longitudinal, or matched tissues and liquid biopsies with a requirement for increasingly complex linked clinical or genomics data. The WCB's model has needed to be adaptive to the requirements of researchers while striving for sustainability. WCB's aims for the next 3–5 years are to build capacity within the operational infrastructure to increase sample turnover, enhance visibility of the resource, and improve financial sustainability through a mixed business model, including increased interactions with commercial organizations. Regular reviews of the outputs and key performance indicators have informed the strategic plan and the vision and flexibility to adapt have ensured the continued success of the WCB.

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