# What is a biobank and why is everyone talking about them?

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Over the last decade, biobanks have become an important infrastructure in research institutes and academic health centers around the world.[1,2] A biobank is defined as "a facility for the collection, preservation, storage and supply of biological specimens and associated data, which follows standardized operating procedures and provides material for scientific and clinical use."[1]

Over the last 15 years, the use of the word "biobank" has increased steadily every year, rising from three papers in 2002 up to 184 papers in 2012[1] and 679 in 2014. According to TIME magazine in 2009, biobanks were one of the ten things that were predicted to change the world that year.[3]

Biobanks are internationally acknowledged and a society exists for them (the International Society for Biological and Environmental Repositories, ISBER).[4] Members of the ISBER community have been exemplary leaders and have developed documents such as "Best Practices for Biobanking".[5] In Canada, other organizations exist to support and guide biobanks such as the Canadian Tissue Repository Network (CTRNet)[6] and, here at the University of British Columbia, the Office of Biobank Education and Research (OBER).[7] As part of recognizing the importance of biobanks, CTRNet has launched a biobank registration and certification program. This program has been taken up in many parts of the world including countries in North America, Europe, and Australia.

Biobanks recruit patients to health research by identifying and consenting potential participants and subsequently collecting, processing, and preserving biospecimens (also referred to as biological specimens, specimens, or samples). Clinical data that may be collected include demographics, diagnoses, and outcome parameters. Researchers may then apply to the biobank requesting biospecimens that fulfill their research criteria. A typical biobank workflow is presented in Figure 1. The biobank process allows for the preservation of highly valuable specimens, which are then available for multidisciplinary, high–quality health research.

Many biobanks are project–driven and are often operated by a single investigator or researcher, resulting in numerous biobanks across a single institute. A situation such as this was present on the Oak Street Campus in Vancouver with researchers recruiting research participants on an as–needed basis and, in some cases, establishing their own informal biobanks. We identified several problems with this approach including: 1) high operating costs for single biobanks hampering access to specimens for researchers with minimal funding or without clinical connections; 2) lack of standardization of methods, making sharing of specimens between researchers problematic; 3) lack of guardianship for specimens resulting in abandoned collections when principal investigators (PIs) retire or leave the campus; and 4) high consent burden for participants resulting in a paternalistic approach whereby clinicians make decisions about which studies "their patients" were allowed to be approached for, leading to less connected researchers, or researchers with limited funding being excluded. To alleviate these issues, we proposed, as others have,[8,9] that consolidation of these individual biobanks into a single biobank has significant benefits. This approach was supported by institutional management as it was deemed that with good governance, a campus–wide biobank would reduce (if not remove) risks such as breaches of privacy or misuse of specimens.[10] As a result, B.C. Children's Hospital now houses B.C.

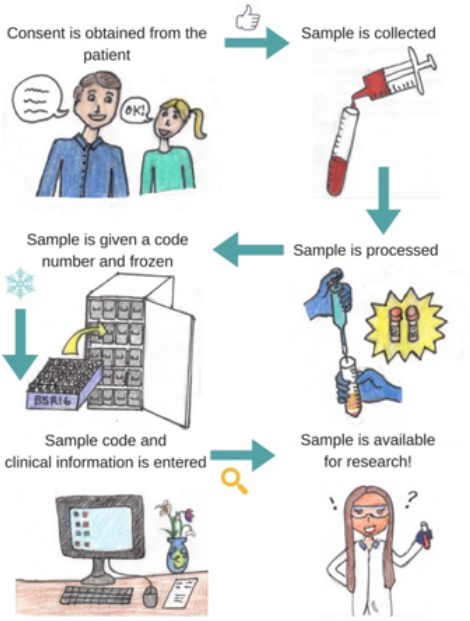


**Figure 1 |** A typical biobank workflow, depicted by grade five students at Queen Mary Elementary School, Vancouver, B.C. A project led by Suzanne Vercauteren, Tamsin Tarling, and Heather Van Tassel.

Children's Hospital BioBank (BCCHB, the first pediatric site–wide biobank in Canada),[11] which is registered and certified under the CTRNet program.

B.C. Children's Hospital BioBank has recruited 1,204 participants from the clinics displayed in Figure 2 for future research and has supported 15 research projects in the areas of immunology, oncology, and rheumatology. In addition, BCCHB is able to provide services for PIs to aid with their projects such as consenting for studies, processing biospecimens, secure storage of biospecimens, or a combination of these. BCCHB currently provides services to more than 50 PIs.

So why are biobanks so important and how are they able to support research?

1. Biospecimens are necessary for translational research (bench–to–bedside). 45% of research uses biospecimens.[12] It is therefore

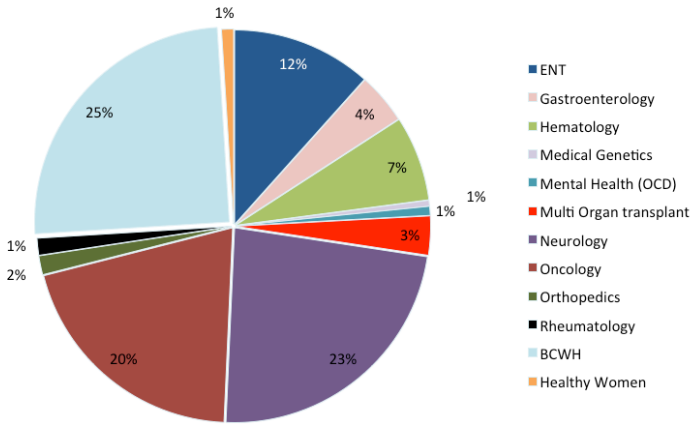


**Figure 2 |** B.C. Children's Hospital BioBank: current clinic representation. ENT: ear, nose, and throat; OCD: obsessive–compulsive disorder; BCWH: B.C. Women's Hospital.

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critical for researchers to have access to biospecimens. However, having sufficient biospecimens to be of statistical significance for a published research project can be an arduous task to manage out of a research laboratory. Biobanks are able to identify eligible patients and recruit them to the biobank with the understanding that their biospecimens will be used for as–yet–undetermined research.

2. Quality of specimens. There are many factors that contribute to the reproducibility of research, the quality of the biospecimens used is just one of them. By following approved standard operating procedures, biobanks have the ability to ensure that specimen quality is high and standardized. At the BCCHB, we record the type of tube the specimen was collected in, the volume, time of collection, time of processing, time of freezing, and the person responsible for each step. This means that if researchers requesting samples have very specific criteria (for example, they are working with a biomarker which is known to degrade within 30 minutes of being at room temperature) we can work with them to identify which specimen which will be eligible for their study and which will not.

3. Facilitation of personalized medicine. Biobanks are able to facilitate personalized medicine, as specimens are collected throughout treatment, including germ line specimens. Annotated clinical data is collected and it is possible to recruit family members in addition to the patient. Due to the methods used, which generate numerous aliquots of the specimen, there is also the ability to request further aliquots of the same specimen for verification or use in other experimental models.

4. One patient specimen may fuel numerous research projects. As mentioned directly above, biobanks generate multiple aliquots of the same specimen and its associated derivatives. This means that a specimen can be used in many different research projects, as dictated by the consent form, as opposed to being designated for one specific project.

5. Secure storage of clinical data and personal information. All specimens and clinical data are securely stored in biobanks. Numerous databases exist that have been designed to store biobank information such as inventory, demographics, diagnosis, clinical annotation, and, where applicable, contact information. Biobank best practices recommend storing samples in freezers that are monitored 24/7 and are in a secure facility with air conditioning and oxygen monitoring.

6. Appropriate governance over the utilization of biospecimens used for research. Transparent governance with robust oversight is key to the success of biobanks[13,14] as it helps to ensure public trust as well as the trust of researchers, as fair access to specimens and data are ensured.

7. Ethical oversight and public engagement. Research Ethics boards ensure that biobanks are established with a governance structure, policies around the return of research findings, policies around re–contacting participants in the future, a fully informed consent process, and assignment of custodianship. Biobanks tend to be established with an ongoing nature so that samples can be collected throughout treatment and patients can be contacted for administrative purposes or future research; this communicative piece gives rise to opportunities for patient engagement and education about healthcare research.

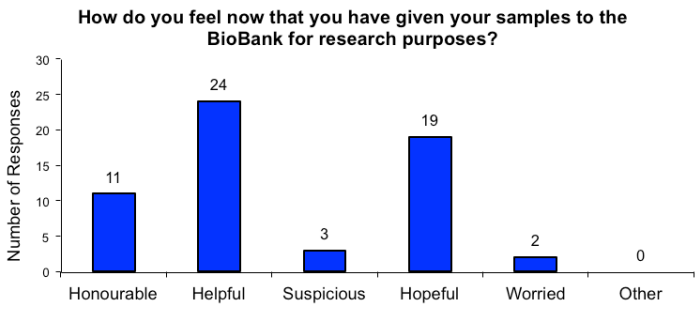


**Figure 3 |** Responses of 30 biobank participants regarding how they felt after donating samples to a biobank.

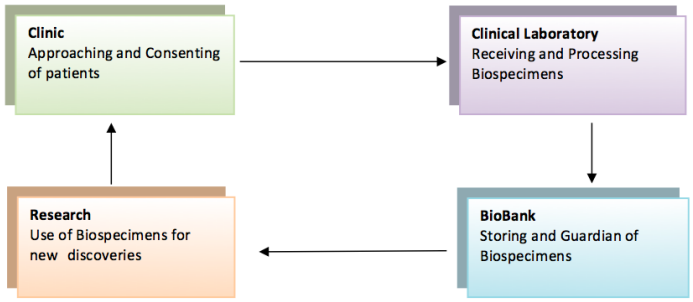


**Figure 4 |** Workflow to demonstrate the integration of biobanks into healthcare and research.

8. Therapeutic effect of biobanking. The BCCHB has carried out surveys with biobank participants. The results of these surveys suggest a therapeutic effect of biobanking that is reinforced by the conversations that BCCHB staff have had with numerous families during the consent interview for BCCHB participation. Patients embrace the concept of being able to give back in some way. In a study of 30 biobank participants, we (BCCHB staff) asked how participants felt now that they had donated to the biobank. Respondents could select as many of the following options as they wished: honorable, helpful, suspicious, hopeful, worried, or other. The vast majority said that they felt either honorable, helpful, or hopeful (Figure 3).[15]

In summary, biobanks have been established to facilitate research and to provide investigators with a high–quality building block (biospecimens) for their research as well as the associated clinical information. Biobankers envisage that specimens collected from patients will be processed, stored, and released for research with the hope that the research conducted will give rise to new treatment and therapies such that it may give back to the clinic in the future (Figure 4).

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