

## LOCATE

### ***“Find existing collections to obtain previously collected biospecimens”.***

We use the term “LOCATE” to describe the process by which you (as the researcher) try to locate biospecimens for your research that have already been collected and are stored somewhere, for example in a biobank.

*Before we continue, consider this scenario:*

*Dr. Richards is a Professor at the University of British Columbia who has an interest in triple negative breast cancer patients. Dr. Richards would like to obtain 300 cases of fresh-frozen blocks from breast cancer patients at the time of diagnosis within the next 3 months. It is important to Dr. Richards that the biospecimens are of good quality and are standardized for comparison purposes. If his research shows promising results he may wish to obtain more samples from other similar patients in different geographical areas. We will refer to this scenario later in this module.*

Given the objectives we have described so far in regard to biobanks you could expect that a biobank that you locate is a certified or accredited biobank (more details below in “CREATE”) so that you can be confident that the biospecimens and data you obtain will be of known quality.

A common strategy to locating biobanks is to search the scientific literature (e.g. through a database such as PubMed) for published studies that include data bases of cohorts of biospecimens that are similar to the study planned. However, there is no specific indexing of “biospecimen use” in PubMed and there is limited adoption of standards for reporting of data within papers that is relevant to “biospecimen use” that might provide a full understanding of the nature of biospecimens used in most studies. While in some cases papers may provide direction to an established biobank with known standards, in many cases the biospecimens used are of unknown overall quality and are not associated with a sufficiently organized ‘biobank’ structure, consent, or governance that makes it easy to request and obtain them<sup>1</sup>.

Biobanks that have collected and stored biospecimens for future research purposes typically have a database which allows them to inventory, and subsequently locate and draw on, specific subsets of biospecimens and associated data. It is also common for established biobanks to be part of a network and to post details about their collections on biobank locator websites (also known as registries). These ‘locators’ can be displays of simple lists or more complex displays of ‘aggregated’ data and are often combined with query tools. You as a researcher can use biobank locators to find the types of biospecimens you need. This can be a very efficient way for a researcher to obtain the necessary biospecimens in a short period of time and rapidly progress with a research project.

In the early stages of developing a line of research, it can be difficult to justify the high costs and complexity of conducting a specific prospective study with defined inclusion and exclusion criteria to obtain a set of biospecimens and then to wait for a sufficient period of time for

outcomes data to accumulate, before conducting the research analysis. Therefore, acquiring data in support of a line of research by conducting retrospective studies based on biospecimens already collected and stored in a biobank is often an essential step towards justifying and validating findings from more valuable biospecimens collected in prospective studies such as clinical trials.

The 'LOCATE' approach to obtaining biospecimens is often the most efficient in terms of cost and time to obtain materials, it can yield the optimal quality materials when the biobank source has previously adopted a known and relevant quality standard, and this approach may often be the only practical approach in some circumstances, such as when the research question requires biospecimens linked to outcomes data that can only be acquired over many years.

### 7.1.1 Locating a biobank

Finding a relevant biobank can be surprisingly difficult for health researchers. Almost 50% of researchers report that finding biobank collections and sufficient numbers of biospecimens of adequate quality fit for their purposes is a serious barrier to their research<sup>2</sup>. In this BNP platform we link to our own Biospecimen Cohort Locator.

The problem has many facets including:

- difficulty in locating biobanks and lack of registers to facilitate finding them
- inadequate resources for existing biobanks to advertise, respond to enquiries, and make their materials accessible
- absent or restrictive access policies amongst some biobanks
- unrealistic expectations among researchers.

### 7.1.2 Applying to a biobank

Once a potential biobank has been located the next step is determining if the biobank has an approved governance structure and operational capacity that makes it possible to apply for biospecimens. Applications involve some time and effort for both parties, and can be regarded as a barrier introduced by biobanks, but there are several good reasons for an application process such as:

- Collection of biospecimens for research that will occur in the future, means that the research purpose can only be described and considered by a donor in general terms. The broad consent asked of donors means that a biobank needs to introduce adequate mechanisms to provide sufficient assurance that the use will conform to the donors expectations. These expectations include ensuring, to the extent possible, that the biospecimens are used for the best scientific questions, and depending on the mission and stakeholders of the biobank, that there is equitable access. These mechanisms, including scientific review, proof of ethical review and use of agreements to document the transfer of materials (otherwise known as Material Transfer Agreements, (MTA)) enable retrospective research to proceed.

- The application process can benefit the researcher by providing an important opportunity for a researcher to consult with the biobank team, and benefit from input around pathological and clinical selection criteria and biospecimen handling relevant to their specific research study.
- The application process is necessary for the biobank to be able to assess appropriate user fees as part of accepted process of operating all research infrastructures, underline the need for acknowledgement in future papers generated using the biobank, and convey the future capabilities to support additional research studies.

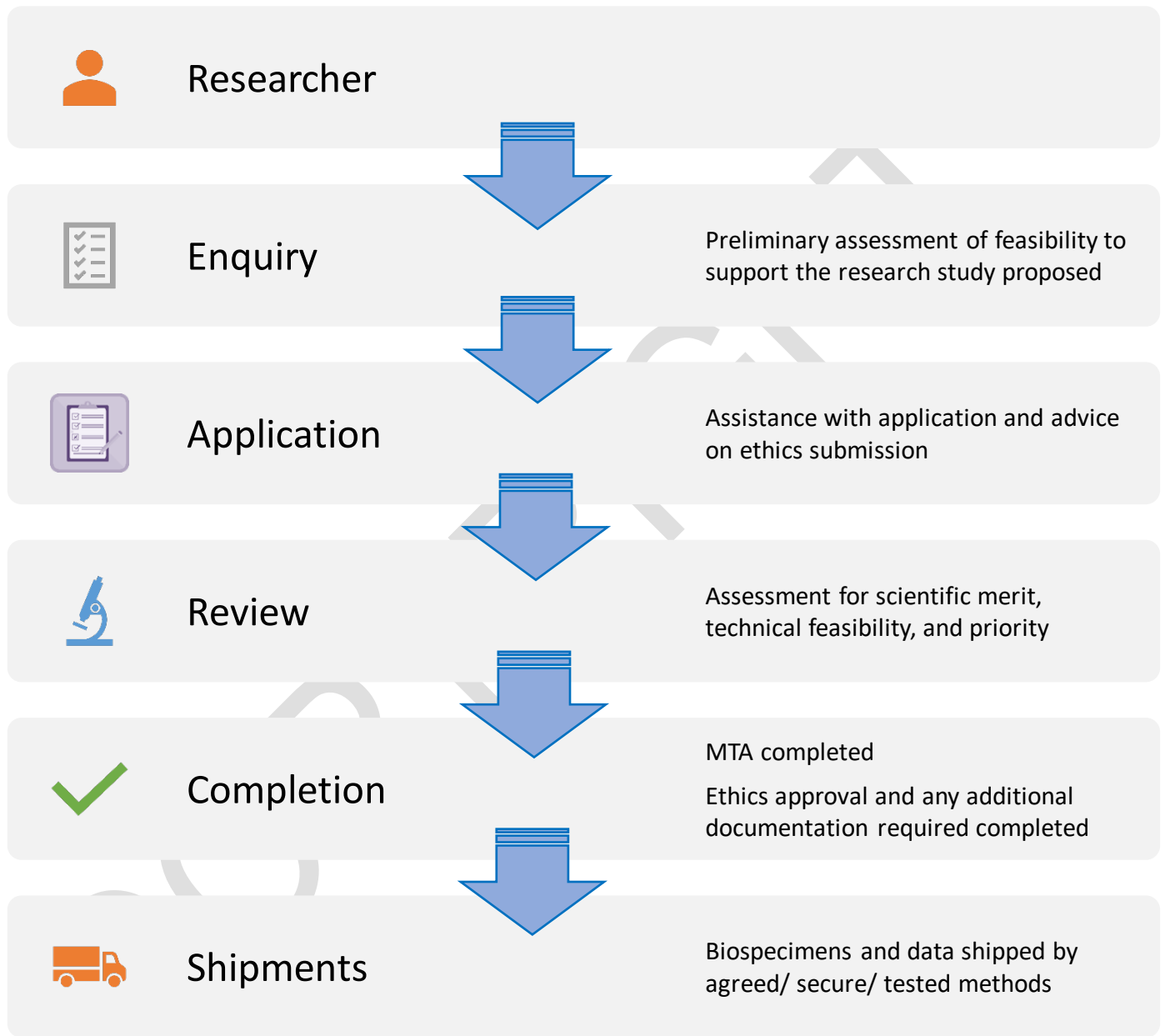
**Table 1: Useful resources to locate biobanks and their collections**

Locators can be found online by using the relevant search terms. A suggested search term strategy is as follows:

(Biobank OR Biorepository) AND Locator  
 (Biobank OR Biorepository) AND Directory  
 (Biobank OR Biorepository) AND (Register OR Registry)  
 (Biobank OR Biorepository) AND (Catalogue OR Directory)

Examples of Biobank locators	URL	Focus	Region
BBMRI-ERIC Directory	<a href="https://directory.bbmri-eric.eu/menu/main/app-molgenis-app-biobank-explorer/biobankexplorer">https://directory.bbmri-eric.eu/menu/main/app-molgenis-app-biobank-explorer/biobankexplorer</a>	All health research	Europe
Biobank Resource Centre Biobank Locator	<a href="https://biobanking.org/">https://biobanking.org/</a>	All health research	International
BioSHaRE-EU	<a href="https://www.maelstrom-research.org/mica/network/bioshare-eu">https://www.maelstrom-research.org/mica/network/bioshare-eu</a>	All health research	Europe
Canadian Tissue Repository Network (CTRNet) Locator	<a href="https://www.ctrnet.ca/">https://www.ctrnet.ca/</a>	Cancer	Canada
ISBER Member Directory	<a href="https://irlocator.isber.org/">https://irlocator.isber.org/</a>	All health and other areas of scientific research	International
NCI Specimen Resource Locator	<a href="https://specimens.cancer.gov/">https://specimens.cancer.gov/</a>	Cancer	US
New South Wales (NSW) Biobank Locator	<a href="https://nsw.biobanking.org/locator">https://nsw.biobanking.org/locator</a>	All health research	Australia
Specimen Central Global Biobank Directory	<a href="https://specimencentral.com/biobank-directory/">https://specimencentral.com/biobank-directory/</a>	All health research	International

**Figure 1: Researchers typically need to complete the following steps and processes when applying to a biobank for biospecimens**



Once a biobank has approved your application for biospecimens you will be required to sign an MTA. The biobank will then be able to ship biospecimens to you. Some biobanks prefer to send a pilot batch of biospecimens to verify that biospecimens will meet your anticipated needs, but also even when this is unnecessary, a pilot batch serves to test that all shipping addresses and

routes and processes are working. It is also then common practice for the biobank to ship larger cohorts in multiple shipments to minimize the impact of a failed shipment.

After ensuring no additional biospecimen samples are required, the data requested will be de-identified and sent along with any other requested materials.

**Table 2: Description of an MTA**

## Description of an MTA

An MTA is a contractual agreement between the biobank and the researcher prior to release of any biospecimens or data:

Biobank should retain MTAs' securely and indefinitely. The MTA may contain information/clauses about the following:

- Clarification about custodianship of the samples.
- Privacy and Confidentiality principles that must be adhered to.
- Statement that the recipient agrees to absolve the biobank for liability from any claims, costs, damages or expenses resulting from usage of the biospecimens provided.
- Restrictions on the use of the tissue, if any.
- Statement on the biohazardous nature of human biospecimens.
- Instructions about return, retention or disposal of unused tissue if applicable.
- Specific conditions for publication of research results, if any (e.g., that the biobank should be acknowledged appropriately in all resulting publications, and that copies of the publications should be returned to the biobank).
- Specific conditions for sharing data, if any.
- Specific conditions for managing intellectual property, if any.
- Specific conditions about user fees assessed and compensation for material transfer.
- That tissue cannot be provided to a third party without the written consent of the biobank (that would require a new, revised MTA).

**Table 3: Aspects of LOCATING**

<b>Aspect</b>	
<b>Time</b>	This option usually allows relatively rapid access to biospecimens. But the Biospecimens you require must already exist in the right preservation format and with the required annotating data
<b>Effort</b>	This option usually involves the lowest effort to obtain the required biospecimens. But this often involves making some compromises such as with respect to the total numbers of biospecimens available and the preferred preservation format. Also the application process can be viewed as a barrier.
<b>Cost</b>	In general this option can involve the lowest cost to obtain biospecimens because the PI does not have to setup and maintain a biobank. Part of the overall costs may be charged and the biobank may be able to amortize the costs incurred in collecting and storing each biospecimen across several research users, or biospecimens may be provided at no cost 'in kind' by the source biobank (in return for example for co authorship on a publication). But competition may exist for biospecimens of interest.
<b>Research study considerations</b>	This option relies on finding existing biospecimens and therefore several pros for study design include the possibility of selecting specific biospecimens on the basis of known biospecimen features and data criteria, such as outcomes data. But an important con is that it can be hard to determine the details of the biospecimen and data quality from locators and publications including biospecimen cohorts.

When obtaining biospecimens by LOCATING to find an existing biobank, you should consider what level of quality is fit for your purpose. Obtaining pre-collected biospecimens from a dedicated biobank that is certified or accredited in an external quality assurance program can be particularly advantageous for many reasons. These are summarized below.

*Consider the scenario we presented of Dr. Richards: LOCATING is advantageous to Dr. Richards as he can acquire his biospecimen in a timely manner with low effort and minimal costs. If his results show promise he can then access more biospecimens in the same manner which will increase his cost effectiveness but he also has the option to tailor his requirements further before acquiring more biospecimens. As long as he looks for an accredited biobank he can be sure that the biospecimens will conform with his requirements of quality and standardization.*

**Table 4: Benefits of LOCATING**

<i>Obtaining biospecimens from an established biobank can be a good option if a) the biobank holds biospecimens that are fit for your purpose and especially if b) the biobank can attest to the following:</i>
<ul style="list-style-type: none"><li><i>• Conforms with known standards, therefore there is a higher impact for the research conducted through translatability and reproducibility</i></li><li><i>• Follows biobanking best practices which include recruitment and consent of participant and maintenance of participants privacy and confidentiality</i></li><li><i>• Undergoes biospecimen and data quality audits to confirm quality</i></li></ul>

#### References

1. Meredith AJ, Simeon-Dubach D, Matzke LA, Cheah S, Watson PH. Biospecimen Data Reporting in the Research Literature. *Biopreserv Biobank*. 2019;17(4):326-333. doi:[10.1089/bio.2018.0143](https://doi.org/10.1089/bio.2018.0143)
2. Massett HA, Atkinson NL, Weber D, et al. Assessing the need for a standardized cancer HUMAN Biobank (caHUB): findings from a national survey with cancer researchers. *J Natl Cancer Inst Monographs*. 2011;2011(42):8-15. doi:[10.1093/jncimonographs/lgr007](https://doi.org/10.1093/jncimonographs/lgr007)