SCIence outreach: The example of BIObanks in Europe

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General information about biobanks

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SCIBIOEU course lesson

General information about biobanks

- Target group:

  Young/early-stage researchers and university students with limited knowledge about biobanking
    - to improve their own knowledge about biobanks, biobanking process and major biobanking-related topics and
    - to enable them to pass on this information to patients, research participants, citizens, and the public.

- Learning objective:

  As course participant you are able to describe
    - What is a biobank and its role in research
    - An overview of the biobanking process
    - Types of biobanks and generals about data and sample collected in biobanks
    - How to navigate the course to find in-depth information on certain topics

- What awaits you:

  This online course is one part of a series of courses on biobanks and the process of biobanking. This course module is a general introduction to biobanks and biobanking.
  The content of the course takes approximately 20 minutes in total.

- Learning materials
    - Recorded presentation
    - Handout (text document)

General information about biobanks

Biobanks are key infrastructures and resources for biomedical research. They collect, store, and manage a variety of data and samples obtained from patients and research participants, according to national and international quality standards, and according to ethical guidelines and legal instruments. Biobanking can be conceived as a process involving many actors (patients and research participants, experts and professionals in different fields, committees and bodies), and different steps, from data and samples collection, to storage, to use in research.

1. Biobanks as research infrastructures

A biobank is defined as a “facility” [1], “structured resource”, infrastructure” [2] or (part of a) “legal entity” that performs biobanking (ref ISO 20387). Biobanking includes collecting or receiving, processing, storing, retrieving, managing biological samples of high quality, linked to relevant personal data including health data and genetic data for research purposes, and is performed in a standardized and a legally and ethically compliant manner. Therefore, biobanks are resources for medical and health research with reliable and high-quality biological samples and associated data, according to standards of practice and accreditation criteria.

Researchers may collaborate with (or use) biobanks and benefit from biobanks in different ways:
On the one hand, biobanks support researchers in building and storing sample/data collections prospectively. Biobanks can support with study planning and providing pre-analytical knowhow, with

patient/donor recruiting and sample/data collection and processing, they take over sample logistics, storage, retrieval, and management the samples and data.

On the other hand, researchers in need of samples and data may apply for access to the resources of a biobank for research purposes and biobanks may collaborate with other biobanks, with the industry and with relevant governmental structures through a global network system [3].

For researchers, conducting research using biobank's resources guarantees access to high-quality biological samples, along with health and (if available even) genetic data, which can significantly enhance the validity and scope of research studies. Biobanks facilitate interdisciplinary investigations, allowing researchers to utilize a wealth of resources and expertise that can accelerate the discovery of new diagnostics, treatments, and therapies. Additionally, conducting research with data and samples collected by biobanks provides opportunities to engage in large-scale studies, leading to more impactful and translational research outcomes. Through the extensive growth of biobanks resources, the development of high-throughput research methods, like genomics, transcriptomics, metabolomics, and proteomics, supporting better understanding of the pathogenesis of multiple diseases is quite possible [4, 5].

*Read and/or watch the SCIBIOEU Lesson **"Access to biobank samples and data"** to learn more about how researchers can access data and samples for research purposes on https://training.scibioeu.eu.*

2. Types of human biobanks

Biobanks have different backgrounds and goals. Apart from human and animal biobanks serving medical research, there are, for example, biobanks that also archive and conserve species/preserve genetic diversity (e.g., from animals or plants such as livestock biobanks, seed biobanks, or museums biobanks) or virus, microbial or microbiome biobanks. But even human biobanks - which the SCIBIOEU course focuses on - differ greatly and can be classified into various types [6-8].

A general widely-acknowledged categorization by the BBMRI - the European Biobanking Research Infrastructure (https://www.bbmri-eric.eu/) - classifies human biobanks into two main classes:

- **Population-based biobanks**
- **Hospital-based /clinical biobanks**

Hospital-based biobanks collect samples and data from patients visiting a hospital and are thus, generally disease-oriented, while population-based biobanks recruit the general population.

*Learn more about these two types of biobanks and their process of sample/data collection and read and/or watch the SCIBIOEU Course module **"How samples and data get into biobanks"** on https://training.scibioeu.eu.*

Examples of further classifications of biobanks are based on (according to [9]):

- **Sample type** (e.g. tumor and/or other tissues, DNA, RNA, blood, etc.): tissue biobanks, tumor biobanks, DNA biobanks

- **Purpose** (research; i.e. scientific investigation, therapy; i.e. for therapeutic applications like transplantation of stem cells, umbilical material, or stool, etc.): e.g., stem cell biobanks, umbilical cord blood biobanks, or stool biobanks for fecal microbiota transplantation [10]
- **Ownership**: Biobanks operated by universities or other scientific institutions and scientific groups (academic biobanks; publicly-funded biobanks), by clinics, or pharmaceutical or life science companies, networks or associations of biobanks; Some company-owned biobanks are operated as 'commercial biobanks'.

3. Samples and data stored in biobanks

Biobanks collect, store, and manage many different types of samples and data.

A detailed overview on the types of samples and data in biobanks and how the "journey of such samples and data' from the patient/study participant into the biobank and to research & development are provided in another SCIBIOEU Course module:

*Read and/or the SCIBIOEU Course module **"How samples and data get into biobanks"** on https://training.scibioeu.eu to learn more about the types of samples/data and their journey.*

Also Figure 1 below gives an impression of such a journey of samples/data

Data collected in a biobank are generally stored in databases and servers. To ensure the security of data and protection of privacy, many layers of protections are enforced, one of them being sample pseudonymization or anonymization.

Biological samples, such as blood or tissue, are stored in specialized freezers with different characteristics according to the type of sample.
Both the data and samples in a biobank will be stored

a) **in secured locations** where the access is well controlled and continuously monitored.
b) **under well controlled and monitored storage conditions**

The samples must be stored following protocols and requirements of international quality standards (such as ISO standards for pre-analytical sample quality) [11, 12].
Data and samples are usually kept for several years to achieve long term future research.

*Read and/or watch the SCIBIOEU Course lesson **"How samples and data get into biobanks"** to learn about data and samples collection and storage on https://training.scibioeu.eu.*

*Read and/or watch the SCIBIOEU Course lesson **"A need for sample quality"** to learn about sample quality, why is it relevant and how it can be achieved on https://training.scibioeu.eu.*

4. Biobanking as a process

Biobanking is a multistep process and a multitude of actors is involved in all stages of biobanking from participants/patients to trained and specialized professionals (from healthcare, to laboratory and IT professionals) to relevant bodies and committees overseeing biobanking processes (Figure 1 and Table 1).

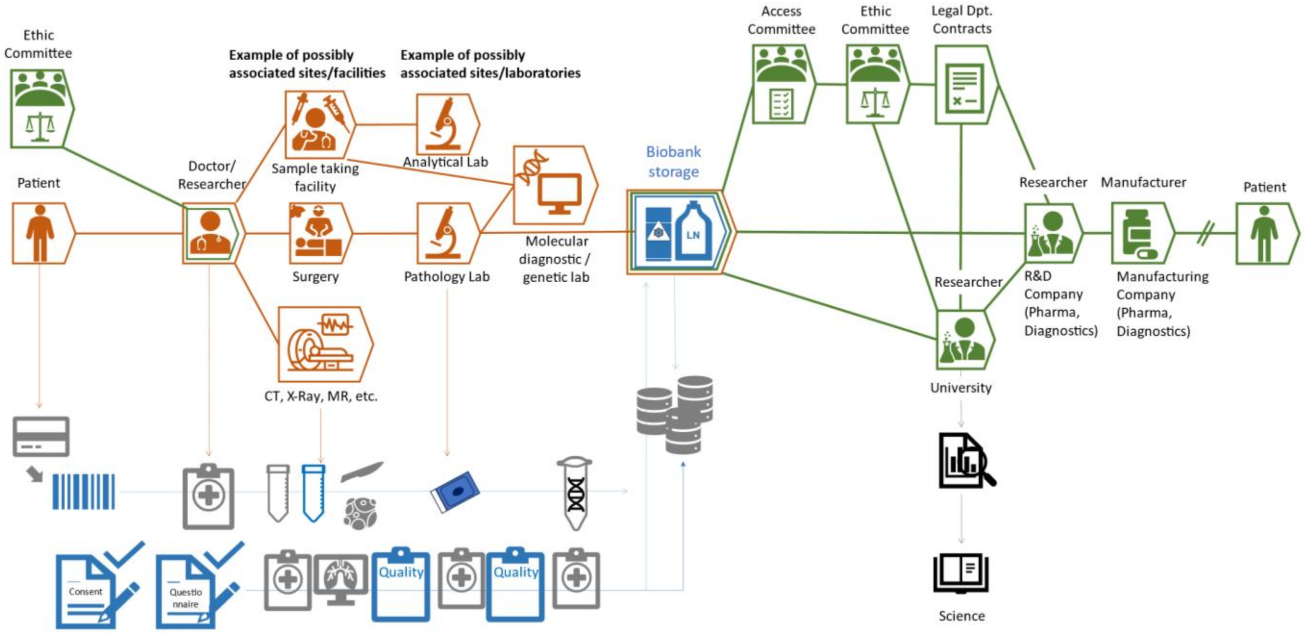

Figure 1. Flowchart depicting an overview of the process of biobanking for hospital-based biobanks (Adapted from SCIBIOEU Lesson "How data and samples get into a biobank").

Study participants or patients
Members of the public
Personnel involved in biobanking
Medical/clinical professionals
Laboratory Technicians
Biobank (Project) Managers and Coordinators
Quality Managers
Data Management and IT Personnel
Administrative Staff
Ethics Committee and ELSI Advisors
Legal Advisors
Public Relations and Outreach Coordinators
Potential Users of a biobank
Researchers

Table 1. Parties involved in biobanking.

Biobanking and biomedical research raise important ethical, legal, and societal issues (ELSI) that must be carefully addressed. For example, ethical concerns include obtaining informed consent from participants and ensuring the responsible use of biological samples.

*Read and/or watch the SCIBIOEU Course lesson **"Informed consent","** to learn about the types of informed consent and participant and patient rights on https://training.scibioeu.eu.*

There are international standards (e.g. International and European quality standards from standardization bodies like ISO and CEN), guidelines (e.g. ethical guidelines such as the Declaration of

Helsinki), and regulations (e.g. biobank laws, General data protection regulation (GDPR)) that must be followed when performing biobanking and/or research with human data and samples. For example, the GDPR governs personal data processing, requiring informed consent, security measures, and strict conditions for personal data sharing.

Read and/or watch the SCIBIOEU Course lesson ***"ELSI – The Regulatory Framework of Biobanks",*** *to learn about types of data, data protection and relevant law and regulation on https://training.scibioeu.eu.*

Our SCIBIOEU Course addresses the various topics related to biobanking and/or research with human data and samples, and provides an insight into these important aspects in several course modules. All these **topics are relevant for medical and other students working or interested in biobanking and research using human samples and data.**

So, dive into the fascinating world of biobanking for research and watch the videos, read the handouts, and perform the quizzes available in the SCIBIOEU Course (Table 2).

"How data and samples get into a biobank"	*to learn about the process of recruitment and data and samples collection*
"Consent and biobanking"	*to learn more about the informed consent process*
"A Need for sample quality"	*to learn about standards of sample quality in biobanking*
"Access to biobank samples and data"	*to learn about the process of access to data and samples for research purposes*
"ELSI – The regulatory framework of Biobanks"	*to learn more about ELSI issues and law and regulations in biobanking*
"Technoethics: Ethical Dilemmas in the Digital Age and Biobanking"	*to learn more about ethics issues in technology and specifically biobanking*
"Introducing biobank communication"	*to learn how biobanks communicate with the public and engage society*

Table 2. All other available lessons in the SCIBIOEU course.

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For further SCIBIOEU Course lessons on biobanking-related topics visit the SCIBIOEU training platform https://training.scibioeu.eu/

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