SCIence outreach: The example of BIObanks in Europe

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How Samples and Data 'Get' Into a Biobank

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Image: modified ChatGPT

SCIBIOEU course lesson

How Samples and Data ‘Get Into’ a Biobank

- Target group:

  Young/early-stage researchers and PhD students with limited knowledge about biobanking
    - to improve their own knowledge about biobanks, biobanking processes 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
    - How samples and data get into biobanks / Where biobank samples and data come from
    - How this happens in different types of biobanks
    - Which types of samples and/or data can enter and be handled by a biobank for research purposes
    - In which situation citizens may come into (direct or indirect) contact with a biobank

- What awaits you:

  This online course lesson is one part of a series of SCIBIOEU course lessons on biobanks and the process of biobanking. This course lesson teaches how, which and when samples and data of patients/research study participants can enter a biobank.
  The content is explained using information texts and videos and is lightened up with an online quiz.
  The text and video content of the course takes approx. 20 minutes reading time for the text and 5 minutes for the recorded presentation (video). Extra time should be allowed for the quiz and the links to films in the text below.

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

How and when do samples and data from patients or research study participants ‘get into’ a biobank?

The route by which different types of samples and data from a person (a patient or a participant in a research study) get into a biobank depends on the type of biobank and its collection strategy.

Such samples can, for example, be blood, urine, saliva, buccal swabs, stool or tissue from biopsies and surgical therapeutic interventions; Data can be about the person, such as demographics, medical data (medication, therapies, diagnosis from health records, medical images, etc.) or life-style (smoking, dietary habits, physical activities etc.) as well as data describing the sample (for example information about type and processing of the sample).

In all cases, however, providing samples and data to biobanks for research purposes is voluntary. Only after detailed information has been given to potential patients/research study participants and their explicit agreement has been obtained are their samples and data transferred to a biobank. It will not negatively influence the quality of diagnosis or treatment of a patient if they do not want their samples and data to get into the biobank and be used for research.

Below, find out about the major types of biobanks, the types of samples and data that can be delivered to a biobank, and the typical processes of sample and data collection.

1. What are the major types of biobanks?

In order to understand how samples and data get into biobanks it is important to know what a biobank is and which major types of biobanks exist, as the "journey of samples and data" into these biobanks slightly differs and also how patients can come into contact with biobanks.

Human biobanks are facilities which collect, process, store, and manage high-quality human biological samples and accompanying data to be used for medical research (1, 2). Although many different classifications of biobanks exist (7), they can be broadly classified into the following two major types or formats:

- **Disease-oriented which are often hospital-based (clinical) biobanks**

  These biobanks collect, process and/or store samples and data from hospital patients in the context of medical diagnosis and treatment. Together with clinicians and medical researchers they establish cohorts for which research interests exist. (6) This can be done through a
  - 'diagnostic/therapeutic' workflow (samples are taken for a diagnostic (e.g. blood for a blood test) or therapeutic purpose (e.g. surgical removal of a tumor) and afterwards samples and data also used for research)

  or a
  - 'research study-oriented' workflow (patients are recruited and their samples and associated data are collected and used for a specific research study but not necessarily for the diagnosis or treatment of a disease)

  Aim: These biobanks were created to promote and support the study of human disease pathogenesis to identify possible therapeutic strategies (1).
  Examples of hospital-based (clinical) biobanks are Biobank Graz at Medical University of Graz (AT) and Auria Biobank at the Turku University Hospital (FI).

- **Population-based biobanks**

  They typically collect, process and store samples and data from thousands of volunteering individuals from the general population representative for a certain country or region who might or might not have a specific disease (3, 8).

  The aim of many population-based biobanks is to examine the role of individual genetic susceptibility and exposure to external factors (e.g., life-style habits) on the general health status and the development of specific diseases. (1)' Therefore, these biobanks typically collect samples and data over a longer time (called longitudinal) during several visits of the same individuals.
  Centralized population-based biobanks and population-based (biobank) cohorts have been established in several countries. (8)

  Examples of population-based biobanks are the UK Biobank (UK), Danish National Biobank and Estonia Biobank; examples of population-based cohorts at biobanks are the Paracelsus Medical

Cohort Salzburg, Austria (AT)[1], the Cooperative Health Research in South Tyrol (CHRIS) Study[2] or the German National Cohort (NAKO-Gesundheitsstudie, NAKO).

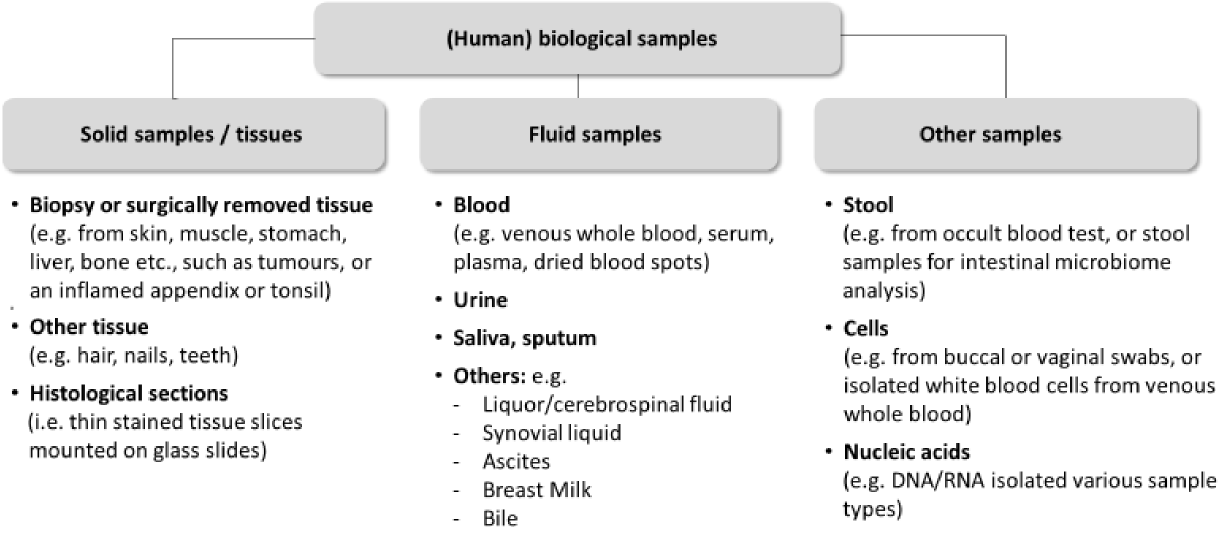
For more details on biobanks see SCIBIOEU course lesson on "General information about biobanks" on https://training.scibioeu.eu

2. Which types of samples and data can 'get into' the biobank?

Several different types of human material (called 'samples') and associated information (called 'data') can be stored in a biobank and are of high relevance for research (4, 5, 9).

Samples

Samples can be almost everything removed from the human body for diagnostics, therapy or special research studies. The three major categories of samples are solid, liquid and other samples although the differentiation is sometimes difficult. Examples are listed in Figure 1.



(Human) biological samples

Solid samples / tissues

- **Biopsy or surgically removed tissue** (e.g. from skin, muscle, stomach, liver, bone etc., such as tumours, or an inflamed appendix or tonsil)
- **Other tissue** (e.g. hair, nails, teeth)
- **Histological sections** (i.e. thin stained tissue slices mounted on glass slides)

Fluid samples

- **Blood** (e.g. venous whole blood, serum, plasma, dried blood spots)
- **Urine**
- **Saliva, sputum**
- **Others:** e.g.
  - Liquor/cerebrospinal fluid
  - Synovial liquid
  - Ascites
  - Breast Milk
  - Bile

Other samples

- **Stool** (e.g. from occult blood test, or stool samples for intestinal microbiome analysis)
- **Cells** (e.g. from buccal or vaginal swabs, or isolated white blood cells from venous whole blood)
- **Nucleic acids** (e.g. DNA/RNA isolated various sample types)

Figure 1: Examples of human samples in a biobank

Data

Data that accompany the human samples and that are stored directly in a **hospital-based biobank** are usually mainly those required to identify and manage samples for research (for example sample number (ID, code), health or disease status and medication of the patient/study participant, origin of the sample (e.g. organ), sample type (e.g., tissue, plasma), storage place and storage condition of the sample, entry and exit dates of a sample etc.).

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[1] https://bbmri.at/for-researchers/biobank-cohorts/

[2] CHRIS study portal (for researchers)>; CHRIS study website (for participants)>

Further data, e.g., clinically relevant data, are often stored in the patient's health record in the hospital and retrieved only when needed (e.g., detailed diagnosis, laboratory data, associated imaging data like images from x-ray or computed tomography investigations, therapies received and responses to a therapy, etc.).

Personal data about the patient, like the patient name, date of birth or social security number remain with the hospital information system and database and are in the hands of the attending medical staff at the clinics.

In population-based biobanks usually all **data** are stored directly in the biobank as these biobanks have direct contact to persons volunteering to be(come) study participants and recruit such persons themselves, gain information about them in form of questionnaires, collect, process and analyse the samples in the biobank.

These can be basic data about the individual (name, age, sex, weight, height, life-style data, health status, clinical data (such as ECG), data derived from the biological samples (e.g., biochemical parameters, such as blood values like cholesterol level), or molecular data like genetic data). Data in biobanks include also about the sample (sample type, information about sample collection, processing and quality, test results, relevant data about the sample and data that are specific to the research question that will be addressed.

Examples of data that can be associated with human biobank samples are listed in Figure 2.

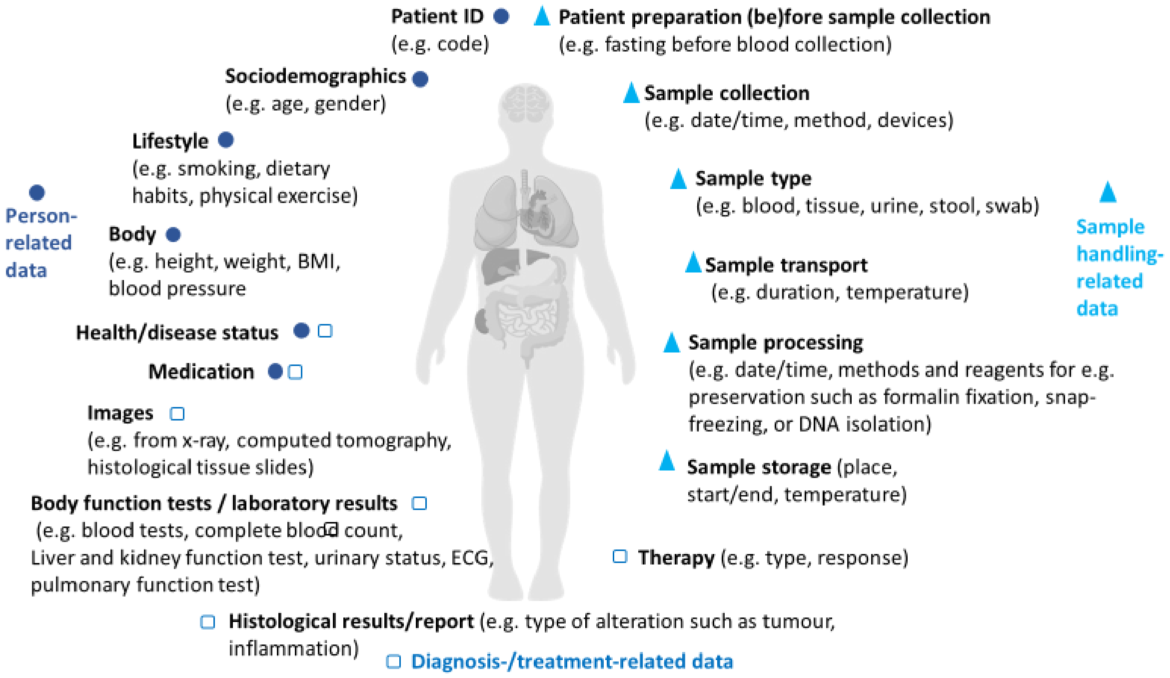

Figure 2: Examples of data that can be associated with human samples and of relevance for research

3. What is required before samples and data can get into a biobank?

Before samples and associated medical data may be transferred into a biobank for research, potential patients/research study participants must **receive detailed information in written form about the research purpose** for which samples and data will be used (albeit often only in general terms, since future use cannot be precisely specified at the time of donation).

Also, **any risks and advantages for the patients/research study participants** have to be described. Such risks may include bodily risks, risks to privacy and others.

Information on **how data and privacy are protected** must be provided. The person's option to change opinion and withdraw the agreement for transferring the samples and data to the biobank must be explained.

This written patient/research study participant information may be accompanied by a discussion with medical staff and/or general videos about biobanking (as an example see patient information video of BBMRI.at partner Biobank Graz). If the potential patients/research study participants agree that their samples and data are transferred to a biobank for research, they **sign a so-called informed consent**. *For more details on biobanks see the SCIBIOEU course lesson on "Consent and biobanking" on https://training.scibioeu.eu*

Patients/study participants may withdraw their consent at any time and without giving a reason. If samples and data have already been collected, the biobank must destroy all samples and delete all data related to these persons. (This may not always be possible if the person's identity cannot be reconstructed, which may be the case if data are fully anonymized).

Both biobanks and researchers must have a patient/study participant information which is used during the informed consenting process approved by an Ethics Board. Moreover, any research study that will be performed with the samples and data must be approved by the Ethics Board. For research studies this patient/research study participant information must be specific, describing the research performed and the analysis methods applied.

More information on ethical and legal issues is provided in the SCIBIOEU course lesson "Associated ELSI topics" on https://training.scibioeu.eu

4. How do samples and data 'get' into a biobank?

Depending on the type of biobank and the collection strategy of a biobank there are different routes for samples and associated data to enter biobanks. Typical routes and processes are described below for the two major types of biobanks or biobanking activities covered in this course lesson: a) hospital-based (clinical)[3] and b) population-based biobanks or biobanking.

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[3] https://bbmri.at/news-articles/samples-data-and-their-mobility-in-biobanking/

- **Hospital-based (clinical) biobanks**

  Hospital-based (clinical) biobanks typically obtain samples and data from patients during or after diagnosis and/or treatment of diseases.

  The steps are explained below.

  - **Admission to a hospital for diagnosis or treatment** - either as an outpatient (not staying overnight) or inpatient (staying overnight) - always involves as a **first step an anamnesis in a physician-patient conversation.** There, the medical history of the patient, current complaints, (chronic) disorders and illnesses, and medication, together with other facts that may be relevant for diagnosis or treatment are gathered. In some cases, family anamnesis (i.e., whether a certain disease has already occurred in the family) may be collected. Often patients are already informed at this stage about biobanking and educated about the informed consent. This information about the patient's medical demographics, medical history or life-style represents 'data associated with the sample'.

  - **To diagnose a potential disease**, **examinations and investigations are performed.** Sometimes photographic or radiological images, such as from x-rays, computed tomography, magnetic resonance, or ultrasound may be taken. These images are also data that may accompany samples in a biobank, and support their later use in research.

  - **Often samples may be taken for diagnoses, for example blood, urine and other body fluids** (see sample types in chapter 2, above). This might need a special preparation of the patient before sample collection (e.g. no food intake for 10-12 hours before blood collection).

  - **If a patient has signed an informed consent, additional body fluid may be collected** in a separate vial (Figure 3) for the biobank. (For example, one more blood vial during the blood withdrawal performed for diagnostics. Venepuncture is performed only once and several tubes of blood can be collected without a separate venepuncture). Sometimes, also residual samples not required any longer for diagnosis can be stored in the biobank.

  - **Both the diagnostic and the biobank samples are processed in clinical laboratories and/or in the biobank to preserve them in the appropriate format**. For example, blood is centrifuged, serum or plasma collected and aliquots are frozen. Or white blood cells may be isolated and frozen. Urine, saliva and stools sample are aliquoted (i.e., transferred into several smaller tubes for storage). It is important to know that the way samples are processed can have a dramatic impact on the quality of the samples. Therefore, it is important to document this so called pre-analytical information in a database. The pre-analytical phase comprises all the steps that happen before the analysis/the laboratory test.

    Learn more about the pre-analytical phase and why it is so relevant in the SCIBIOEU course lesson "A need for sample quality & quality management in biobanks" on https://training.scibioeu.eu

  - **Some diagnoses require that tissue** is removed from the body, e.g., a biopsy is taken, where a small piece of tissue is collected with a thin needle. The biopsy allows diagnosis of a disease, e.g., to decide if a suspect area in the breast is a cyst or a cancerous node. Since biopsies are usually quite small, often no material remains for biobanking. Unlike with body fluids, usually no additional biopsies may be taken for biobanking, since there is a greater risk associated with taking them.

- **During treatment,** it may be necessary to **remove tissue by surgery**, such as parts of an organ containing a tumour. Such surgical tissue samples are primarily used for diagnosis, but they are often large enough that tissue remains for biobanking.

  This tissue can then be either frozen (for storage in liquid nitrogen) or formalin-fixed and paraffin-embedded (FFPE) (for storage of FFPE tissue blocks at room temperature) (Figure 3).

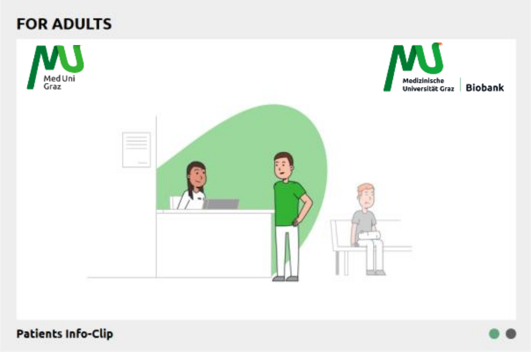
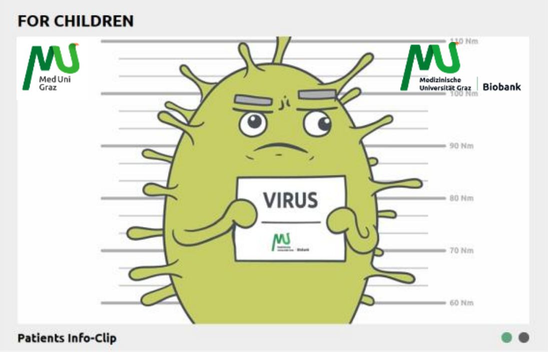
  In addition to the tissue, also histological tissue sections (stained and mounted onto glass slides), which allow for microscopic evaluation and/or generation of digital (whole slide) images, are sample types often stored in biobanks and used for research. Research using histological slides increasingly includes the development of algorithms for artificial intelligence analysis tools which aims to support diagnosis making in pathology (Figure 3).


Blood samples
Frozen tissue
FFPE tissue blocks
Histological tissue sections
Isolated DNA

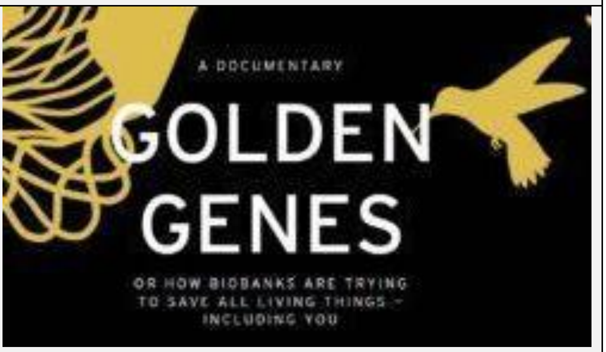
Figure 3: Images of different human sample types

OPTIONAL:
To learn more about biobanking in a hospital-based biobank and to have material for scientific outreach to citizens, watch the following:

Three animated videos from BBMRI.at - the Austria Biobanking Infrastructure – and from the BBMRI.at Partner 'Biobank Graz': ● Video for **researchers** (by BBMRi.at, GBN, SBP) ● Video for **adult** patients/study participants ● Video for **child** patients	>Unveiling Biobank Power: A Film by the Austrian, German, and Swiss BBMRI Nodes **>LinkedIn BBMRI.at**
	

>Biobanking explained to adults (video from Biobank Graz/Med Uni Graz; in English)	>Biobanking explained to children (Video from Biobank Graz/Med Uni Graz; in German)
	

For more advanced content about the setup and use of biobanks view the following videos. These are also suitable for showing to the (interested) general public:

>"European researchers tackle cancer with biobanks" (video EuroNewsTV; in English)	>"Golden Genes" Documentary movie on biobanks; in English)
	

Biobanking is very expensive and also requires a lot of resources in terms of experienced personnel, processing and storage facilities Therefore, not every sample and not all data from every patient and for every disease diagnosed or treated in a hospital can be stored in a biobank. A typical **biobanking strategy** is **to collect samples and data** of specific diseases of special interest for research. Such biobanks are often called disease-oriented biobanks.

For special research studies, patients in the hospital may be enrolled if they match the criteria for participation (e.g., for certain diseases like COVID-19: acutely infected people or people suffering from long-COVID for special COVID-19 related studies). Alternatively, healthy and/or diseased citizens can be directly recruited (e.g., by announcements in newspapers), to participate on a voluntary basis.

Biobank samples are used for research: Many researchers collaborate with biobanks who support them with sample logistics, processing and storage, documentation of sample processing as well as management of samples and data. Samples and data that are no longer used for that special research study may remain in the biobank for further research studies.

- **Population-based biobanks**

In population-based biobanks (or in other biobanks building a population-based sample cohort) **samples and data from thousands of individuals across whole populations are collected** – usually directly by the biobank. Typically, research study participants represent the general population of a certain country or region.

Typical steps during include:

- **The biobanks recruit individuals** and invite them to participate on a voluntary basis through a tailored communication and engagement strategy and suitable media. Depending on the research questions, study participants can be selected to be representative for a certain country or region. The potential study participants might have a disease but are not selected for this criterion.
- **The citizens volunteering to take part in this study are asked to provide samples and data**. Participating individuals have to complete a questionnaire and provide data/information on e.g. demographics (e.g., gender, ethnicity, socioeconomic status), life-style (e.g. smoking, dietary habits, alcohol intake, physical exercise, etc.), health / disease status (e.g. allergies, migraine, depression, diabetes, etc.), medication, etc. Data collected by population biobanks are shown in part 2, and in Figure 2).
- **The biobanks collect different types of samples and data from the same study participants over a long time** and often during several visits. Possible sample types are those listed above (in part 2 and Figure 1) and can be for example blood, saliva, buccal or nasal swabs, urine, and/or stool, hair, fingernails. From healthy persons, tissue is usually not collected in population-based biobanks, since the associated risks do not justify this – an Ethics Board would not give permission.
- **These biobanks often perform several types of measurements and examinations**, like measuring height, weight, or blood pressure, or imaging analysis (e.g. magnetic resonance imaging (MRI) or computed tomography) in collaboration with other centres or hospitals (8, 9). Very often sequencing such as whole-exome and whole-genome DNA sequencing is performed using samples like blood, or analysis of the microbiome composition in stool.

The samples and data are stored in and managed by the biobank, and are used by researchers in researcher studies.

OPTIONAL:
Get an impression how a population-based biobank can work in a video about UK biobank

5. How may citizens come into contact with biobanks?

There are two major ways citizens may come into contact with biobanks:

- As patients or research study participants
- Through public activities or events organized by many biobanks

Biobanking fundamentally depends on the willingness of citizens—whether as patients or research study participants—to provide their samples and data, collected in the context of diagnosis and/or treatment in a hospital setting, or through participation in specific research studies or population-based biobanking activities. This contribution enables the use of these samples and data for research purposes. In doing so, citizens play an essential role in advancing medical research and healthcare.

Overall, biobanking relies on the agreement of citizen - whether being patients or research study participants - **to provide their samples and data** gathered in the context of diagnosis and/or therapy in a hospital setting or on participation of volunteers in specific research studies and in population-based biobanking activities and allow the use for research purposes. In this way citizens contribute to the advancement of medicine and healthcare.

- **Contact with biobanks as patients or research study participants**

  Anyone may be asked at some point to volunteer and provide samples and data to a biobank—either during clinical care (e.g., diagnosis or treatment in a hospital) or through participation in a specific research study in a hospital- or population-based biobanking initiative. Participation in all cases is voluntary, and refusal to participate has no negative consequences.

  Biobanks handle patient samples and data with the utmost care, ensuring both privacy protection and high sample quality. Their mission is to support internal and external research partners in compliance with all ethical and legal requirements.

  Biobanking for medical research depends on the consent of individuals to provide their samples and data and to allow their use for research purposes. Every year, millions of people give their consent for their samples and data to be stored in biobanks and used in research. In doing so, they make a significant contribution to scientific progress and medical advancement.

- **Contact with biobanks through public biobank activities/events**

  Many biobanks—and members of the BBMRI biobanking research infrastructure—actively engage with the public and offer communication and outreach activities. It is important that citizens are already familiar with biobanks before being asked to provide their samples and data for research. They should be informed in advance about the existence, purpose, and value of biobanks and the research that uses biobanked samples.

  The more citizens understand the setup, processes, roles, and benefits of biobanking, the better equipped they are to make informed decisions about contributing their samples and data.

  Biobanks offer a wide range of public outreach activities and events, such as guided tours of the biobank during events like the Long Night of Research or open house days. They also offer hands-on workshops for various age groups, from children to adults. Examples include:

- BBMRI.at (in Austria): Activities for citizens>; Long Night of Research>, Kids University Courses on Biobanking & Pathology>, TV reports and vidoes about the biobank as well as animated videos for adults and children (see above).
- BBMRI.cy's (Cyprus) public activities: European Researchers' Night>

Learn more about biobank communication and engagement in the SCIBIOEU course lesson "Engagement of biobanks with patients/research participants and other stakeholders" on https://training.scibioeu.eu

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