

Frequently Asked Questions (FAQs): Inventory of disease-oriented biobanks for the Biobanking and Biomolecular Resources Research Infrastructure (BBMRI)

The following document refers to clinical biobanks i.e. collections of samples and data from patients (BBMRI WP3). If you are interested in population-based biobanks i.e. collections of samples and data from the general population, please contact gmarguier@p3g.org.

Why will there be an inventory of Europe's biobanks?

To overcome current limitations and to cover the needs of the scientific community BBMRI aims to construct a pan-European resource by linking individual biobanks and networks. Key components of BBMRI are thus comprehensive collections of biological samples from different (sub-) populations of Europe, which should be linked with data on the health status, lifestyle and environmental exposure of the sample donors. A federated network of Europe's most advanced biobanks will be established in European Member States. An inventory on existing biobanks is essential for an actual overview of Europe's biobanking landscape and to identify biobanks that should be part of the BBMRI infrastructure.

Who should participate?

We aim to include institutions, companies, networks or any other organisational forms that are collecting or have collected human biological materials and the associated data for a population or a large subset of a population with information stored in an organised system. In addition, access to external researchers or third parties must be allowed. To be registered in BBMRI, providing the necessary information by filling the BBMRI questionnaire is mandatory.

Confidentiality

The web-based overview catalogue will contain general information on the biobank or the biobank network including contact details, background and objectives, available samples and data and the possibilities for access according to informed consent, etc. All data on costs and financing submitted to BBMRI will be treated confidential and will be used for research purposes only. This information will not be disseminated or published on an individual level.

Structure of the inventory

In the first step **individual biobanks or studies** are asked to complete the BBMRI core questionnaire. **Networks of biobanks or studies** in addition have to fill in the network questionnaire, referring to their individual members, which have to fill in the BBMRI core questionnaire. Since the terms biobank and study are often not used in any systematic way, we use both terms in parallel for this inventory. For examples see Table 1 on the next page. In a second step, additional supplementary questionnaires shall be completed. These supplementary questionnaires are asking for specific details in different areas of biobanking.

The structure of the BBMRI inventory is shown in Figure 1.

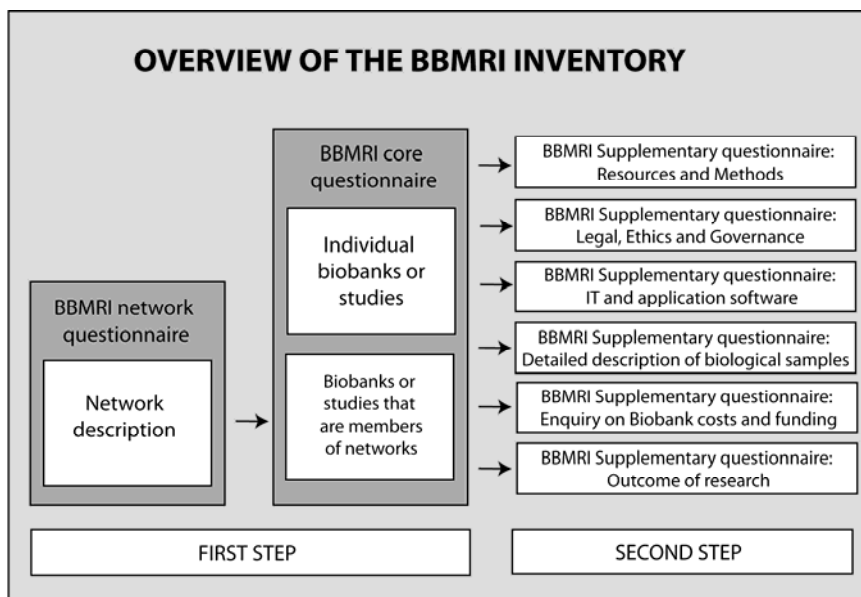


Figure 1: Overview of the BBMRI inventory

BBMRI also aims to collect relevant forms and templates used in your biobank or network for research purposes only. These forms and templates will help inform the design of the platforms, for example the legal platform. None of the requested documents will be disseminated or published or shared with third parties. Any copyrights in the materials will be respected.

What forms do I have to fill in?

For the BBMRI inventory, each individual biobank has to fill in the BBMRI core questionnaire. Filling in the core questionnaire is mandatory to be registered in BBMRI. Networks of biobanks should in addition fill in the network questionnaire, referring to their individual members. For examples see Table 1.

Table1: Examples – What questionnaire(s) should be filled?

EXAMPLE:	QUESTIONNAIRES TO BE COMPLETED:	COMMENT:
EPIC* (European Prospective Investigation into Cancer and Nutrition): http://epic.iarc.fr/	One network questionnaire (the 23 subcohorts of EPIC are mentioned) and one core questionnaire needs to be filled.	EPIC as a whole is a population-based cohort. The individual subcohorts are not described separately.
UDBN (UK DNA Banking Network): www.dna-network.ac.uk	One network questionnaire (listing the 16 individual studies, ordered by “ICD blocks”) and 16 core questionnaires needs to be filled, describing each individual collection.	The individual clinical biobanks are described separately.
National Biobank of Finland: http://www.nationalbiobanks.fi/	One network questionnaire (listing the 10 individual biobanks) and 10 core questionnaires need to be filled, describing each individual collections (e.g. ATBC study).	The individual collections are both population-based and clinical biobanks.
EGP (Estonian Genome Project): www.geenivaramu.ee	One core questionnaire only.	The individual collection is a population-based cohort with mixed design.
GATiB (Genome Austria Tissue Bank): www.univie.ac.at/LSG/gatib/	One core questionnaire only.	Collection of different types of tissues from different diseases. GATiB is considered as one individual biobank.

*For population-based biobanks, please contact gmarguier@p3g.org.

Within the core questionnaire, chapter 4 is asking for specific details of a sample collection including the number of samples, the linked data and the form of consent the donor has given. Large biobanks may contain more than one collection. To describe each of the collections separately, the collection questionnaire should be filled. In this case, the core questionnaire should be used for the first collection only. For all further collections, only the collection questionnaire has to be completed.

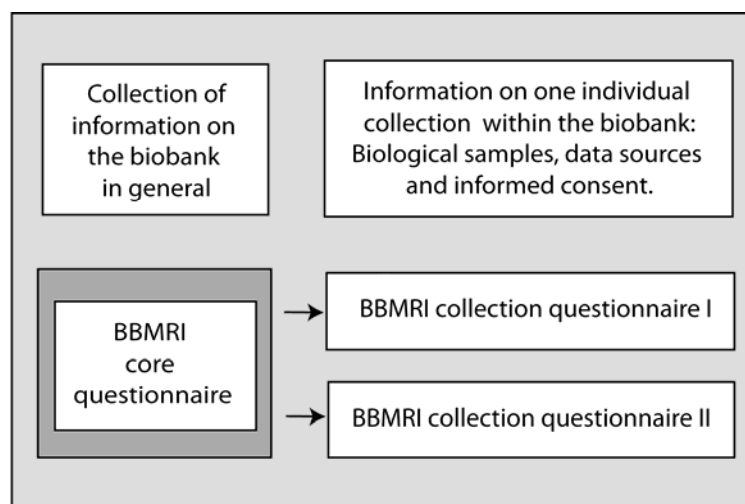


Figure 2: BBMRI core and collection questionnaire

Specific questions that might arise while filling in the Core Questionnaire

Question 1.8: What kind of funding is meant?

This question is about funding obtained in the last three years, including funding on the core of the biobank (i.e. collecting and storing) and funding that enables the biobank to develop further.

Question 1.9: What is a competent authority?

A competent authority is a governmental or otherwise official institution.

Question 4.4: What kind of data should be selected?

Please select all kind of data that you have collected from the donors. Please select no for data that are not readily available but could be traced, for example from the medical records. In this case, please additionally select 'Access to participants medical paper files' under question 4.3.

Question 1.10 and 1.11: Which aspects should be addressed in the Background and which in the Objectives?

The background should describe in general why the biobank has been established, while the objectives should summarize the specific tasks of the biobank. Please note that this information will be displayed on the BBMRI website.

Question 5.5: In case of mixed situations, what labels should be selected?

If different labels are used, please indicate the relative percentages. For example if you are in the process of replacing handwritten numbers by 1D barcodes, please select both and indicate the actual percentages of each labelling system. 'Printed labels' are labels without barcode.

Contact

All questionnaires can be downloaded from our website at: www.biobanks.eu and www.bbmri.eu. Should you have any questions, please contact melanie.kolz@helmholtz-muenchen.de for disease-oriented biobanks. For population-based biobanks, please contact gmarguier@p3g.org.