

# **“Access to materials stored in Biobanks”**

## **Expert interviews to assess the spectrum of possibilities for the regulation of access, the compensation of biobank owners and priority setting in material allocation**

### **Introduction**

Thank you for agreeing to speak with me/us. As I said in my email, we are currently conducting a research project on „access to materials stored in biobanks“, which is funded by the German Federal Ministry for Research and Education.

Over the next 30 minutes I will be asking you questions around three aspects relating to biobanks: access policies, compensation and prioritization. The interview will be recorded, so I do not have to take notes. And because this is a qualitative study, it is important that a second person can have a look into the data, so that the analysis is more objective. However, the interview will be made anonymous and your name or institution will not be mentioned in any future publications or reports. Do you have any questions before we begin?

I will now start the recorder.

### **1. Regulating access to materials (access policies)**

As you will know, there is currently wide variation in biobank access policies. Some biobanks enable external researchers and institutions access to stored biomaterials while others restrict access to cooperating researchers or internal researchers. The first aim of this interview study is to examine the spectrum of reasons that surround the decision to have broad or narrow access policies. By doing so, we also aim to inform ongoing national and international debates on this topic and assist the development of best-practice standards, thereby explicitly respecting the specific needs and particularities of biobanks.

- I would like to start by asking how often do you/does your biobank receive access requests? Per month/ per year
  - Do you assume that these requests will increase in number in the next years? If yes, what would be the reasons?
- Who is requesting access? Researchers affiliated with your biobank, external partners or other externals? What about requests from industry members?
- Could you briefly outline how such access requests are managed with in your biobank? Why did you choose this procedure? Are you aware of other procedures to manage such requests? What are the advantages and disadvantages of the different procedures?
- Have you ever experienced problems or challenges in deciding on a certain access request? If yes, could you please describe these problems?
- Are there differences in the access procedures for different parts of your collections? Are there gatekeepers in place for certain parts of your collections?
- Do you have any document describing the access procedures?
  - *If yes: is this document publicly available, for instance on your website?*

- *If not: CAREFULLY ASK: What are the reasons to not publish it? What are the main challenges?*
- What are the main challenges in developing access policies? What are the challenges in applying it in daily business?

## 2. Compensation for biobanks and their contributors

Another aim of this project is to examine the spectrum of possibilities concerning compensation for biobanks, contributors and sample owners and the reasons for choosing one of another.

- First of all, there are several different steps in the implementation, maintaining and organization of a biobank, all of which are associated with specific financial costs. While our objective is not to examine all the issues of expenses, we would like to ask whether all of these financial costs involved in running a biobank are fully covered by the funds you receive? Or are there any other expenses you have to pay?
- In your opinion, how should biobanks and the sample owners (for instance contributing physicians) be compensated for their efforts?
- Is the compensation sufficiently covered by the financial means you receive? Or is there a need for financial supplementation or other ways of compensation?
  - Are there differences in compensation with regards to the affiliation of the access requestor? (Internal versus external)
- In your biobank, in the course of collecting, processing and storing the samples, is there any certain kind of finishing or refinement of the samples?
  - If yes, in which way?
  - Besides all technical steps, can there also be something like an intellectual finishing or refinement? Something that other biobanks might not be able to do in the same way?

## 3. Prioritization

The final aim of our project is to examine the issue of prioritization of research projects where the request for samples outstrips the amount possible to supply.

- In your opinion, how do you decide if a sample is of higher or less value? Are there samples of higher value than others?
  - If yes, why?
- Are you sometimes required to prioritize who gets access to samples, for instance in situations where two or more researchers request access to a certain high value samples? Do such situations exist or do you expect these situations in the future? If yes, which criteria should be applied to prioritize access to the „scarce resource“ of biomaterials? Could you give me an example?
  - What is currently the practical impact of prioritization?
    - Do you expect the need for prioritization will increase in the future?
- What are or what would be reasonable and easy applicable criteria for prioritization?
  - What are the practical challenges that you experience with prioritization?

I have now covered all the issues I wanted to. Are there any other important matters with regard to the topic that you think have not been adequately addressed?

Thank you very much for your efforts and the time. If you like, we will update you on any publication on our interviews. If you have any requests, please feel free to contact us at any time.