

# Stakeholder Management: Perspectives of donors on biobank cooperation with industry



## BACKGROUND

For the purpose of successful stakeholder management in the biobank sector, an understanding of expectations of the various stakeholders is fundamental. Social science methods such as the focus group offer the following appropriate approach:

*"Your primary aim is to try to understand a new area, or investigate people's attitudes, opinions and beliefs, and you will not be able to know what the range of answers will be. You need to avoid forcing people into answering questions in particular ways, for you cannot predict how they will want to answer a particular question."*

(Dawson et al., 1993)

Patient representatives in particular offer valuable expert knowledge. Furthermore they bring along both experience in communication with potential donors and other stakeholders, such as industry representatives and researchers.

## RESEARCH QUESTION

How is cooperation between academic biobanks and industrial partners viewed by patient representatives and patients in the light of their potential role as donors?

## DATA COLLECTION

- **Focus group** with **eight patient representatives** to open up the perspective of potential donors
- **Facilitator and a co-facilitator**
- **Interview guide** for orientation purposes
- Important points were fixed on **moderation cards**

## DATA ANALYSIS

Schreier's steps of **Qualitative Content Analysis (QCA)**

1. **Deciding** on the research question
2. **Selecting** the material
3. **Building a coding frame** from the material by creating categories
4. **Dividing** the material into units of coding
- 5.+6.+7. Trying out, evaluating and **modifying** the coding frame and main analysis
8. **Presenting a systematic and material-reducing** description of the patient representatives points of view using the coding frame

(Vgl. Schreier 2012)

## RESULTS 1: PATIENT REPRESENTATIVES ON INDUSTRIAL COOPERATION – OVERVIEW

### Emic Perspective

Presumed impact of industry cooperation

Hope for purposeful research in the expectation of the patient vs. fear of abuse

Ideal of cooperation between all experts for the benefit of patients

Situation of acceptance of industry cooperation

Acceptance of industry cooperation if it is well thought out

Diversity with regard to patients' opinions on industry cooperation

Need for information and a belief in knowledge on the side of a potential donor.

### Political Consequences – Requirements for Good Cooperation

1 Meet all stakeholders on an equal footing!

2 Discuss the type of data and biosamples provided!

3 Inform the donors adequately!

4 Give comprehensible information as feedback!

5 Create new bodies for information and regulation!

6 Enter into legal obligations!

## RESULTS 2: PATIENT REPRESENTATIVES ON INDUSTRIAL COOPERATION – THEMES DISCUSSED

### 1. Discussion about a Win-win-but-no-business-model

- Industry cooperation requires a "careful weighing of different options for action"
- It is a matter of "ethical" and "sensitive matters"
- "Interests of each partner" should be taken into account
- Evaluation of non-university research should "always be about quality" and Responsibility

### 2. Discussion about anonymisation and various clinical data

- There is a need for talking about different types of data and their meanings for patients
- Explicit talking about data involves negotiating "clear rules" and is again related to educating donors about the possible loss of "rights" to their own data
- "Data sovereignty must lie with the patient"

### 3. Discussion about the need to convince donors and a well thought-out consent form

- Explanation should be "as transparent, as clear and as far-reaching" as possible
- Formulation in "simple language"
- Demand for a joint "process" for drawing up a well thought-out consent document, especially with help of patient representatives

### 4. Discussion about paying in knowledge

- Transfer of knowledge is important for donors
- Biobanks should receive the results of research
- Necessity of simplification of research results for former donors
- Maybe there is a lack of interest in recovery on the part of industry, but research results should "not be made a trade secret"

### 5. Discussion about a clearing house with equal representation

- Establishment of a control body in a biobank law
- E.g. an independent ethics committee, a commission based on the example of an auditing association at banks and a commission consisting of all important stakeholders

### 6. Discussion on legal advice and uniform guidelines

- Prevention of violation
- Creation of "uniform guidelines", "conditions for payment of money" and other contractual regulation, up to a "biobank law"

## OUTLOOK

Academic biobanks should expand cooperation with industry, and the German Biobank Node (GBN) will develop best practice examples eligible for all involved stakeholders. Therefore, these results from the focus group of patient representatives are important for GBN to prepare a successful dialogue between the biobanks and different stakeholder groups. Beside the patient representatives we have conducted qualitative interviews with representatives from pharmaceutical companies. The detailed analysis is expected at the end of 2020 and will provide the second data base for this dialogue. The third group are the biobanks themselves. One workshop has been conducted with biobank partners of the German Biobank Alliance and resulted in a position paper on collaboration with industry (Baber et al.). A workshop is planned for summer 2021 taking the results mentioned above into account and inviting all relevant experts being involved in processes around industry cooperation.

## LITERATURE

- Dawson S, Manderson L, Tallo V L. A Manual for the Use of Focus Groups. INFDC. 1993.
- Schreier M. Qualitative Content Analysis in Practice. Sage. 2012.
- Baber R, Hummel M, Jahns R, von Jagwitz-Biegnitz M, Kirsten R, Klingler C, Nussbeck SY, Specht C. Position Statement from the German Biobank Alliance on the Cooperation Between Academic Biobanks and Industry Partners. In: Biopreservation and Biobanking. 2019. Vol.17, No.4.

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