

WP4

Societal Engagement with Biobanking Concept for interviews and discussion groups

Deliverable Number 4.1.2

Ulrike Felt, Ingrid Metzler, Lisa-Maria Ferent

July 2020

INDEX

ABOUT THIS DOCUMENT	3
INTRODUCTION	3
1. OBJECTIVES OF WP4: CONTRIBUTING TO A SUSTAINABLE RESEARCH INFRASTRUCTURE	3
2. RESEARCH OBJECTIVES	3
3. FRAMING THE PROJECT	4
4. METHODOLOGICAL APPROACH	7
PART A - INTERVIEWS	9
1. THE ROLE OF QUALITATIVE INTERVIEWING	9
2. TYPES OF INTERVIEWS	10
3. WITH WHOM TO SPEAK – MAPPING OUT THE DIFFERENT RELEVANT ACTORS	11
4. CYCLICAL APPROACH TO INTERVIEWING	12
5. INTERVIEW GUIDES	13
6. PRACTICALITIES	13
PART B – ENGAGING WITH CITIZENS AND DONORS	14
1. PUTTING CITIZEN PARTICIPATION IN CONTEXT	14
2. WHAT DO WE EXPECT THE DISCUSSION METHOD TO ACHIEVE?	14
3. MAIN ELEMENTS OF THE METHOD	15
4. CREATING THE CARDS AND DECIDING THE CHOREOGRAPHY OF THE DISCUSSION STAGES	16
5. VALIDATING THE CARD SETS	17
6. CONDUCTING IMAGINE DISCUSSION GROUPS	17
7. COMPOSITION OF THE GROUPS	18
8. DOCUMENTING THE DISCUSSION PROCESS	18
PART C - DATA ANALYSIS	19
1. GROUNDED THEORY AND SITUATIONAL ANALYSIS	19
2. STEPS IN THE ANALYSIS	19
3. ANALYSIS AND SAMPLING	22
4. INTEGRATION OF CYCLES OF FEEDBACK	22
REFERENCES	23

LIST OF FIGURES

FIGURE 1: BIOBANK AS A SOCIO-TECHNICAL ASSEMBLAGE	4
FIGURE 2: BIOBANKS AS MEDIATORS	6
FIGURE 3: KEY DIMENSIONS OF RESPONSIBLE RESEARCH AND INNOVATION	7
FIGURE 4: INTERVIEWS WITH RELEVANT ACTORS	11
FIGURE 5: CYCLES OF INTERVIEWS AND ANALYSIS	12
FIGURE 6: THREE KINDS OF CARDS TO BE USED IN OUR DISCUSSION GROUPS	16
FIGURE 7: GROUNDED THEORY APPROACH	20
FIGURE 8: EXAMPLE OF A SITUATIONAL MAP WITH RELATIONS IDENTIFIED	21
FIGURE 9: EXAMPLE OF A SOCIAL WORLD/ARENA MAP	21

About this document

In this document we outline our strategy for qualitative interviews and for group discussions as well as our approach in analysing these materials. **Part A** of this document focuses on the role interviews play in achieving the objectives of WP 4 and describes our strategy for **interviews with scientists, bio-medical professionals, and stakeholder, shareholders, policymakers and citizens** in more detail. **Data collected via group discussions with citizens and donors** will provide a complementary body of materials. These will be described in more detail in **part B** of this document. In **part C** we then describe the main lines of doing the analysis; also including the ethnographic fieldnotes from the workshops and from participation in events (e.g. biobank week) as well as documents (e.g. webpages).

Introduction

1. Objectives of WP4: Contributing to a sustainable research infrastructure

Work package 4 (WP4) is integrated into the Austrian node of BBMRI, which is an emerging research infrastructure for biomedical research. **Our mission** is to contribute to responsible research and innovation practices and to the sustainability of this research infrastructure (Felt 2018). We do this by conducting social science research (based on a broad set of qualitative methodologies) and discussing our findings with our partners from the BBMRI.at consortium to get feedback and refine them.

2. Research objectives

We seek to facilitate reflections, dialogues, and mutual learning processes via research, that aims at exploring the broader range of societal questions that accompany the establishment of biobanks. This means asking: who contributes to the successful development of a biobank (from donors to those taking care of the infrastructure), who can get access to samples and data, or who owns data and who benefits from them.

Specifically, WP4 seeks to:

- (1) provide a better understanding of how biobanks are valued by different kinds of actors; engage with different “value systems” and “value generation models” at work; in short: look at **value(s) in and of biobanking**;
- (2) explore how the growing importance of data through data processing and digitisation processes is changing what we know about ourselves and our health, how this knowledge is generated, and how this affects the self-understandings and agency of citizens; in short: we seeking to understand “**bio-data citizenship**”; and
- (3) investigate how the **General Data Protection Regulation (GDPR)** transforms practices of biobanking, the use and sharing of material and data, and the practice of providing material for research.

WP4 integrates findings within BBMRI.at through continuous engagements with the other consortium members, and also makes these findings accessible to the broader biobanking community and the wider public. In this way, we seek to contribute to the building of a scientifically and socially sustainable research infrastructure.

3. Framing the project

As outlined in the project proposal, our work is inspired by the recent debates about **Responsible Research and Innovation (RRI)**. Embracing this framework, we understand the creation and use of a biobank as more than a simple collection of biological material and data on the basis of which research can advance. On the one hand, a biobank is a complex **assemblage** that has to bring together and align diverse actors, technologies, and institutions as well as regulations and values. On the other hand, as any technological realisation, a biobank also **creates new relations; it mediates**, between humans (be they citizens or scientists) and the world.

What does it mean to understand a biobank as an **assemblage** bringing together and aligning diverse actors, technologies, and institutions as well as regulations and values? And why is it important to understand a biobank from this angle?

Understanding a biobank as a sociotechnical assemblage means exploring how a large variety of elements – material and conceptual – have to come together and stabilise to form an infrastructure. The elements forming an assemblage include

- (1) human actors such as donors, citizens at large, researchers, industrial players, policy makers and many more;
- (2) non-human elements such as the samples collected, the data attached to them, the technical devices needed to prepare and store them, tools developed to make them accessible;
- (3) institutional/organisational actors such as universities, ethics committees, or funding agencies;
- (4) practices in research and beyond, as well as relationships pre-existing the biobanks;
- (5) regulations, norms and values, including questions like the use and ownership of samples and data, standards/standardizing procedures, protection of data and privacy issues.

It is key to observe **how all these different elements come together** – how they can assemble – in order to create a whole – the biobank. Therefore, it is essential to not only be able to point to the different elements necessary in the assemblage, but **to understand the multiple relationships between the different elements**. This means looking at explicit strategies for connecting different elements and aligning them in a way that they form an apparently coherent whole – a sociotechnical assemblage. Relationships can be of different strength; some need a lot of work to hold, while others are more robust (e.g. how much work is needed to convince researchers to store their samples in a biobank and thus integrate them into the assemblage). Social scientists developed specific terms to capture what is happening during the creation and stabilisation of such an assemblage. For example, we speak of **“enrolment” and “translation”** to describe the work of transforming actors into new allies (enrolment) by translating their interests to be aligned with the assemblage. At the same time, the assemblage can become fragile and break if an important actor leaves the assemblage and cuts the relationship (e.g. when funding is refused or a legal framework changes substantially).

BIOBANK AS A SOCIO-TECHNICAL ASSEMBLAGE

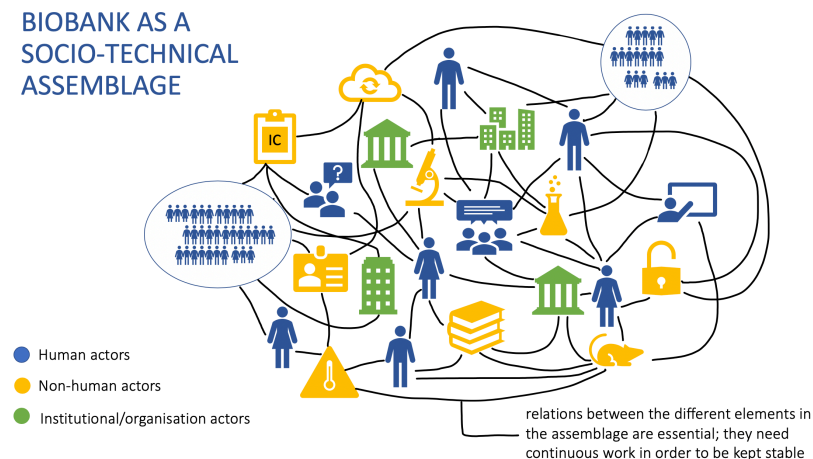


Figure 1: Biobank as a socio-technical assemblage

Assemblages are never fixed but always in-the-making (Law 2004), although they can become temporarily stable. For a biobank this can mean that when a new regulation emerges, such as the GDPR, the relations in the assemblage have to be rearranged in ways to stabilize the biobank again. This means in terms of sustainable biobanking that relations in the assemblage need continuous work in order to remain in place and thus stabilise the whole. Assemblages, despite being always in change, also have to show both **consistency and coherency** (Deleuze and Guattari 1988). While “coherency” refers to the internal order and organisation in an assemblage such as a biobank infrastructure, “consistency” points to the needed capacity to integrate the assemblage into a world of external relations, i.e. a biobank has to fit the broader cultural context but also with what is regarded as adequate in the scientific context.

Understanding a biobank as always in-the-making, explains the lively debates we have been witnessing for more than three decades concerning the past and future role of biobanks, what these assemblages mean for both science and society, what role they will play for the future of health related research and care, about the value they generate but also the values they stand for, who is needed to support them and who is supported by them, and many more. In particular with the entry into force of the EU GDPR in May 2018 also new questions and debates around how biobanks (can) build stable relations to users and donors arise and corresponding adaptations need to be done.

Through our interviews we want to gain a better understanding of how biobanks get assembled, who and where the important actors are, what other elements matter and how the multiple relations are stabilised.

What does it mean when we speak about **mediation between humans and the world** in the context of biobanks? And why is it important to understand a biobank from this angle?

In addition, we have to develop an in-depth understanding of the impact such a biobank has on both how we – as researchers and citizens – understand human/animal bodies, life and health, i.e. how we order and see the world through this infrastructure and, in turn, how this shapes our practices and actions. Over the years, the relation of technological innovation to wider societal developments has been addressed by numerous analysts in the social sciences, and in particular in science and technology studies (STS). They have pointed to the fact that technological innovations are shaped by the values of those developing/designing them (e.g. Winner 1986; Akrich 1992), who **inscribe** their values when designing technologies in specific ways and not others. This demands attending to “history and political culture in ethical reasoning about technological futures” (Jasanoff 2016, 27), i.e. developing a sensitivity to the pre-existing value orders which get incorporated into technological infrastructures.

From their inception, every biobank stands for particular values and expectations, carries visions of potential future developments and contexts of use and contains specific ideas about who has to care for issues of ethics and responsibility. Participants’ consent, for example, is one important element to be cared for. It expresses the values and aims of a biobank, its potential use as well as the rights of donors, assuring a stable relationship between biobank research and society. However, also ways of collecting, standardizing, sharing and using material from biobanks inscribe particular sets of values in research, and how potential problems are anticipated and responsible use is ensured. Current discussions on the fostering of Translational Science is a further domain where values, rights and responsibilities will be negotiated.

In Figure 2. we show that how we understand the world around us, humans/animals and questions of health, is the outcome of relations created through technological means (in our case a biobank and related technologies). Technologies **mediate** the relations between humans and the world.

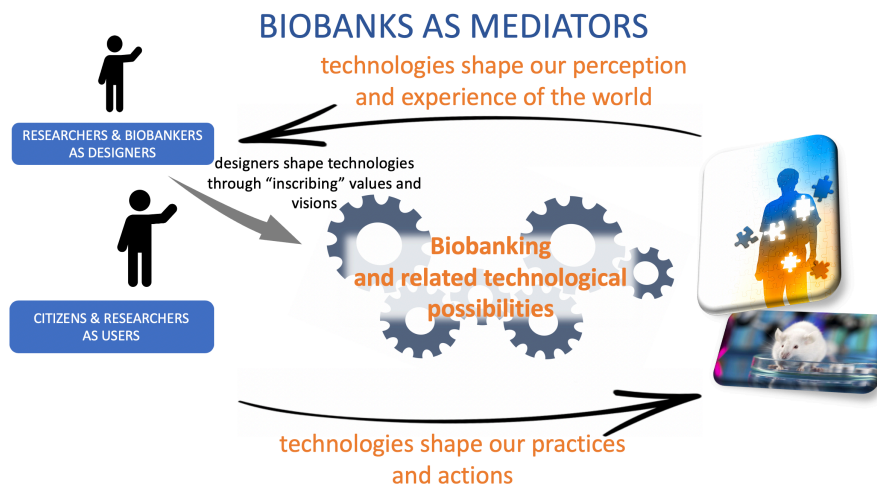


Figure 2: Biobanks as mediators

Biobanks and the related technological possibilities shape how citizens and research actors **perceive and experience** human bodies and learn to understand biological processes. They allow us to make sense of the world in specific ways. This in turn shapes our **practices and actions**, what we do, how we do it and what counts as legitimate action. This is an ongoing cycle that defines our relation to knowledge and perception of the world around us.

Thus, it is important to understand what different actors expect from a biobank infrastructure, where they see the promises for health-related research and care and what future of biobanking they want to contribute to. It is thus crucial to grasp why they find it worth contributing to, using and supporting biobanks. But we also have to engage with potentially shifting understandings and self-understandings of scientists and citizens/patients once a focus on data to understand health related phenomena becomes central. Building and maintaining such a socio-technical assemblage always means engaging with diverse value systems and expectations of potential users and donors, and reflecting corresponding **distributions of responsibilities** (Akrich 1992). For those involved in biobanking — so also for the BBMRI.at consortium members — it is important to know, understand and consider these aspects across sites (locally and globally) and across actor groups.

Finally, what does it mean to investigate biobanks from an angle of Responsible Research and Innovation (RRI)?

Having pointed to the fact that values are inscribed in biobanks and are expressed through them, it seems important to engage with the concept of responsible research and innovation. The basic idea behind this frame was to support “transparent, interactive process[es] by which societal actors and innovators become mutually responsive to each other with a view to the (ethical) acceptability, sustainability and societal desirability of the innovation process” (von Schomberg 2011, 9). Involving citizens and stakeholders into processes of innovation, is described as essential to reflect potential consequences of innovation and for effectively assessing “both outcomes and options in terms of societal needs and moral values” (ibid., 9). RRI can be seen as a response to the awareness that innovations often come with unintended consequences. RRI can thus be understood as the attempt to ensure that both the process and outcome of research and innovation are acceptable and socially desirable.

Focusing our attention to processes of engagement and deliberation with a multitude of actors should allow a more inclusive assessment of the value of an innovation (Felt 2018). This shifts our attention from the (market) value of innovation to the values that are embedded in and realized through innovations (Felt 2017). Thus, not only the question of whether or not something can create harm is of importance, but also looking at the direction of innovations, and the ways in which we imagine and attempt to shape societies (Felt et al. 2007).

To implement RRI as a living concept, Stilgoe and co-authors (2013, 1570) have identified four key dimensions: “anticipation, reflexivity, inclusion and responsiveness”. Thinking along these four RRI dimensions will allow us to better engage with different aspects of a technological realisation (Figure 3.).

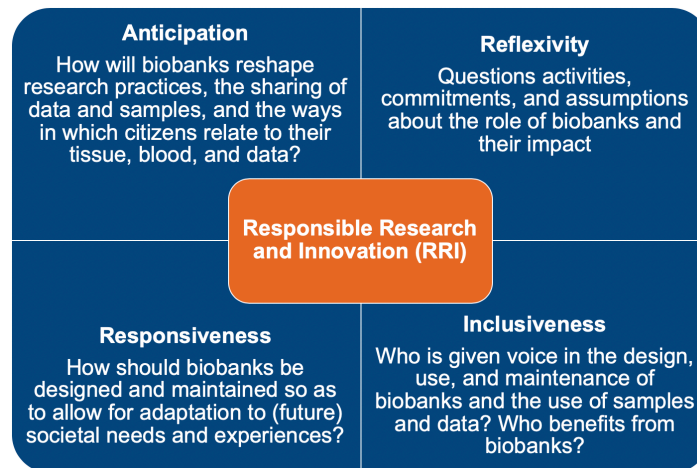


Figure 3: Key dimensions of Responsible Research and Innovation

- **Anticipation** refers to systematically thinking about the many different potential outcomes of innovation. It asks questions such as: who will be involved in defining what a biobank should achieve for whom, or what kind of health-related future is expected to be realised through this infrastructure.
- **Reflexivity** invites us to critically question “one’s own activities, commitments and assumptions, being aware of the limits of knowledge and being mindful that a particular framing of an issue may not be universally held” (ibid., 1571). It calls for considering what imaginations of potential donors and users, but also use contexts, every single actor brings to the design and implementation process. And it pushes us to reflect on absences, i.e. important elements that are getting less attention.
- **Inclusion** draws our attention to questions of power and who is given, or not given, voice in research and innovation. It calls for different forms of user and stakeholder engagement in identifying tacit assumptions in the framing of this domain.
- **Responsiveness** highlights the need to conduct research and innovation in ways that allow rethinking and adjusting “courses of action while recognising the insufficiency of knowledge and control” (ibid., 1572). Needs and values expressed in practice and experiences made by diverse users, can then be integrated into the development and design process.

4. Methodological approach

We use a “grounded theory” (GT) approach in designing our research and analysing the data. GT, to use Charmaz’s (2006, 2) definition, “consist[s] of systematic, yet flexible guidelines for collecting and analyzing qualitative data to construct theories ‘grounded’ in the data themselves”. GT was developed as an alternative to a strongly theory-driven approach, which would presume a clear theoretical framework and works in a deductive logic. While a clear theory-driven approach would mean that we deduce clear-cut hypotheses from theory that we then test empirically, a grounded theory approach leaves the field of inquiry more open and builds on a more inductive or abductive approach. This implies that we approach our research with research problems that we seek to analyse and contribute potential answers through data analysis, i.e. our theorizing is grounded in data. However, this does not mean that we approach our fieldwork “empty headed”. As the previous section 3 shows, we are guided by sensitizing concepts. We aim at contributing to a better understanding of the notion of infrastructure (e.g. Larkin 2013) which is central to BBMRI, we look for the traces of sociotechnical imaginaries (Jasanoff and Kim 2015) in order to better understand

the role of future visions in the making of biobanks, we look for practices as a way to express values and concerns (see Deliverable 4.1.1) and we look at how data and bodies get related through biobanking.

Working with grounded theory starts with data. Thus, it is essential to choose methods that fit the research problem we want to address. How we collect data has effects on what we will be able to see, how, where and when we can gain insights and how we can make sense of them. Therefore we will combine several methods and work ourselves in sequences into the field. This iterative approach will enable us to gradually collect the data needed to answer our research problems; we will in each step decide anew whom to interview and in which contexts we will find what kind of information about our research problem.

In our research in WP4 we will therefore collect, produce and analyse a variety of materials:

- ethnographic fieldnotes from (participatory) observations at events, workshops, and “walkshops;”¹
- qualitative semi-structured interviews with actors involved in biobanking, including researchers, biomedical professionals, policymakers, actors from industry and business, and stakeholders, as well as citizens and providers of samples and data;
- group discussions mainly with citizens and donors;
- and, documents (including information leaflets, informed consents, websites, videos, etc.);

Regular feedback from the members of the consortium to our findings will not only allow us to communicate our findings, but help us sharpen some of the interpretations.

¹ Walkshops will be shortly described in Part A on interviews.

PART A - INTERVIEWS

1. The role of qualitative interviewing

Why use qualitative interviews to address the objectives outlined in WP4?

Understanding what happens in biobanking at large and grasping the perspective of a variety of relevant actors, demands an approach which allows actors to express how they perceive and make sense of biobanks. This entails sharing their experiences, practices, assessments, justifications and visions related to biobanking. We understand interviews not as “fact-finding” enterprises, but as moments where we as researchers can engage with our interviewees and have an in-depth exchange on their specific perspective on biobanking, grasping the different meanings that such a collection of samples can take (Holstein and Gubrium 2008). Interviews will help us to see how different actors conceptualise what a biobank is, what aims it has; or what they find important to mention and what they remember about biobanking, and many more. This will allow us – across the rich material – to better “see” what a biobank is becoming in and through practices, organisation, and other kinds of interventions. Interviews will also help us to learn, what biobanks (as infrastructures) “do” in practice and what differences biobanks make in the ways in which biomedical research is organized and conducted.

Specifically, qualitative interviews with biomedical professionals, shareholders, stakeholder and policymakers will help us to distil and elucidate how biobanks are valued by different kinds of actors. They will also help us develop an understanding of various visions on the purpose(s) of biobanking in the wider biomedical and societal context, and of different understandings of which actions ought to be taken in order to make biobanks into valuable infrastructures (**objective number 1**) and sustain them in this way.

Qualitative interviews will also help us to develop a better understanding of “(bio)data citizenship”, that is ways in which understandings and imaginaries of what “citizenship” is and what it ought to be change in the context of an increasing salience of big data in general and the datafication of biomedicine in particular (**objective number 2**). By interviewing biomedical professionals, stakeholders, and policy-makers we will look at how these understandings and imaginaries of “citizenship” are “made up” (Hacking 2000). Interviews will help us understand how various actors in the field of biobanking “frame” (both discursively and in practice) and “envision” the relationship of (various) groups of individuals to samples and to data. Interviews with citizens and group discussions will help us to complement these perspectives with visions “from below” (see part B).

Qualitative interviews with biomedical professionals will also be key to reach our third research objective, that is to develop an understanding of the ways in which the GDPR, a piece of legislation encoding ideas and cardinal values of data protection, transforms the daily practices of biobanking (**objective number 3**). In interviews with scientists and policymakers we will ask how the GDPR (and its Austrian twin FOG) have been implemented in practice and how their implementations have changed practices and procedures such as collecting, storing, and sharing data and samples. Interviews and discussion groups with citizens and patients will help us to complement this picture, giving us a better understanding of the ways in which the GDPR becomes part of a “narrative infrastructure” (Felt 2017) or “moral repertoires” (Sharon 2018) that citizens use when making sense of their selves and the samples and data that they provide to biobanks (see part B of this deliverable). While the concept of narrative infrastructure sensitizes us to the network of shared narratives “through which meanings and values of [donation and biobanking more generally] and its relation to society can be articulated” (Felt 2017, 56), moral repertoires help us to focus our attention to the “different conceptualizations of the common good [...] that are mobilized by actors” (Sharon 2018, 3) when relating to the GDPR.

These interviews will be moments where we can engage with our interviewees

- grasping the different meanings and understandings of biobanking
- how they assess the importance of this infrastructure
- practices essential in biobanking
- experiences with biobanking

- key-actors to assure sustainability
- key technological achievements
- values that are important & expectations of value generation
- future visions and challenges

2. Types of interviews

We will use semi-structured qualitative interviews for all kinds of actors. As the aim is to find responses to the questions addressed in the beginning, we will design a specific mix of three different kinds of interview techniques.

- **Ethnographic interviews** centre on **practices, experiences and everyday elements of work** (Allen 2017). They combine descriptive and structural questions. Descriptive questions are open and general and allow the interviewee to talk about their experiences, daily activities, value decisions, the objects (samples, data, etc.) of their work, but also of other people that matter in their work. These descriptions provide us with a broader idea of how individual actors see biobanking from their social world. In a second move, more structural questions are used to further explore and deepen responses to descriptive questions. Interviews always begin with more descriptive questions and then continue with structural ones. By using elements from ethnographic interviews, we want to gain a good understanding of the situated perspective of single actors on biobanks and how they perceive their own roles in them. Getting these descriptions will help us to better grasp what other actors are involved, how a specific location matters, which kinds of practices are essential, what goals are followed, which regular activities/routines are essential, how time and resources matter and how they feel about their work.
- **Problem-centred interviews** (Witzel 2000) focus on a set of **specific issues** that are relevant to explore in the context of biobanks. Problem-centred interviews are characterised by their orientation towards identified relevant problems which guide the interview. The interviewer uses the prior knowledge of basic conditions of the examined questions in order to understand the interviewees' explications and to ask questions oriented towards the problem. Parallel to the production of broad and differentiated data material, the interviewer is already working on the interpretation of the subjective view of the interviewed individuals and is sharpening the communication towards the research problem more and more precisely. For example, as we are interested in the impact of the GDPR on biobanking we will explore this issue in more details.
- Finally, our interviews are inspired by basic principles of **narrative interviews** (Czarniawska 2001, 2004). This approach starts from the assumption that **people make sense of the world around them** – in our case of biobanks – by telling and sharing stories. Questions are therefore formulated in a rather open manner to enable the interviewee to develop their personal storyline as uninfluenced as possible, to explain their visions and experiences and share their interpretations. “During an interview”, Czarniawska (2004, 50) underlines, “an interviewee may retell narratives that circulate on a given site of practice, or the interview itself may become a site for a narrative production”. Therefore, the narrative elements in the interviews will allow us to see overlaps between the stories and to identify shared stories, but also to see differences between actors.

While we consider these three types of interviews and combine their respective strengths in our interviews, we also have to keep in mind that most of our interviewees are experts in the field of biobanking. They are experts in the sense that they know a lot about a particular practice or phenomenon **and** they are also involved in shaping this phenomenon in practice (Bogner, Littig, and Menz 2014). **Expert interviews** can be helpful for developing rich materials on specific practices, procedures, and protocols, allowing interviewers to learn from the expert's knowledge, including his/her practical knowledge, and from his/her observation of key events. For the latter, Robert Weiss (1995, 17) invites scholars to approach experts as “privileged witnesses to an event”, such as a practice in the presence in which they participate (e.g., collecting informed consents, or freezing samples for storage), or a process in the past and the present that they (have) witness(ed) (e.g., the transition to broad consent, the closing of a sample

collection). Here, interviewers are asked to invite interviewees to walk the interviewer through the details of events and practices.

The interviews with citizens will be a follow-up from the discussion groups and will aim to deepen some of the aspects which were addressed in the debate. They will be inspired by insights gained from the discussion groups.

In parallel to the interviews, we will also conduct so-called **walkshops**. A walkshop in the context of this project is an accompanied visit to a biobank, where guides explain and also demonstrate steps in, say, sample preparation, or storage, and the challenges confronted during them. Complementing interviews, walkshops allow better than interviews to “address the importance of contextual and embodied dimensions” (Wickson et al. 2015) of biobanking. In short: it is an engaging method, similar to an ethnographic interview where we get explanations and learn as we go. The results of a walkshop are extensive ethnographic field notes and sometimes also visual material which further complement the interviews. Walkshops also serve as visual and textual input to the card-based engagement method which is described in Part B.

3. With whom to speak – mapping out the different relevant actors

We will recruit interviewees from in- and out-side of the BBMRI.at consortium. We will specifically interview members of five groups of actors described in Figure 4. This choice is based on our understanding of biobanking as a socio-technical assemblage. All these different actors will inform us about the various and, most likely, also heterogeneous understandings of the values embedded in and realised through biobanks. The five groups of actors are:

- (1) **Researchers & biobankers**, including actors running and coordinating biobanks, providers of samples and/or data (clinicians); biomedical professionals performing pre-analytic, curation, and/or maintenance work; PIs of collections; and (academic) users of biobanks
- (2) **Institutional actors** such as members of the rectorate of respective universities, research managers, funders
- (3) **Policy makers, regulatory actors and agencies, members of legal departments** dealing with biobanking, and members of **ethics boards** (incl. members of bodies involved in the governance of biobanks)
- (4) **Industry and business** or major users of biobanks outside the academic domain
- (5) **Societal actors**, such as citizens and donors, but also journalists

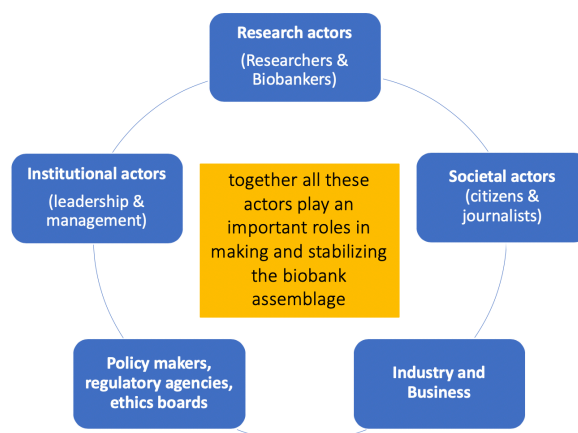


Figure 4: Interviews with relevant actors

In the project application we outlined our plan to do the following number of interviews

- 20 semi-structured interviews with researchers and biobankers from within the BBMRI.at consortium and beyond;
- 15-20 interviews with policy makers, data protection advocacy groups/activists, media representatives, regulators, industrial actors, members of ethics committees;
- 25-30 semi-structured interviews with donors and citizens.

The exact number of interviewees from each group will be decided along the process of interviewing and analysing the interviews. We will start with interviews with members from all groups, except citizens and donors. The interviews with the latter will happen after the discussion groups.

The first round of interviews has a double role. On the one hand, some of them can be seen as “helicopter interviews” (Hajer 2004, 73), because we will choose actors that have an overview of a local biobank, the practices, processes and procedures assembled in a biobank, as well as the specific actors involved in these practices and responsible for the oversight of procedures. These interviews will help us to start making sense of local biobank assemblages. On the other hand, together they will make important connections between the different actor groups visible and point to key-questions to be asked in the following interviews.

This first round of interviews will also help us to identify actors for the next cycle of interviews.

The interviews together should offer us “thick descriptions” (Geertz 1973) of values in practice at the different biobank sites as well as a deeper understanding of key events, as well as of visions and imaginations of the value of biobanking.

4. Cyclical approach to interviewing

We use a “cyclical strategy” for data collection and analysis (Silverman 2011).

This implies that we will already begin to analyse data after a round of first interviews while we still continue to collect data. This allows us to use preliminary insights from data analysis to refine our data collection and rethink our interview strategy. This is in line with the constructivist “grounded theory” approach this project is based on (see Part C of this report), meaning that we alternate between data collection and analysis (see Figure 5.).

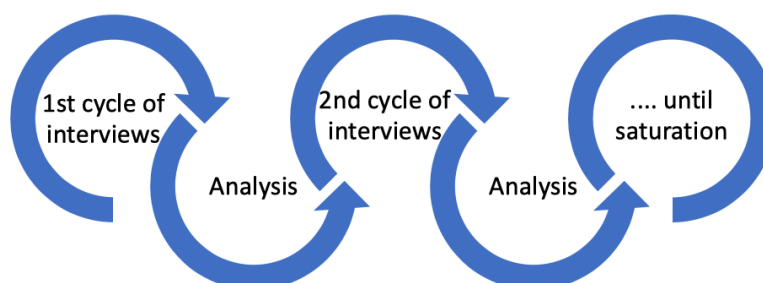


Figure 5: Cycles of interviews and analysis

These iterations continue until “saturation” is reached, which means that additional interviews do not add substantial new insights into the issues at stake. While we have defined the above-mentioned number of interviews in our project proposal, the exact number will be determined in this iterative approach. This might lead to the fact

that in some categories of interview partners we might need more interviews than planned, while in others a slightly lower number might deliver already excellent insights.

5. Interview guides

We will use an interview guide (and not a fully structured questionnaire) with a set of themes and open-ended questions with follow-ups, adapting themes and questions to the specific interview partners. This offers both structure and flexibility, while still making data from interviews comparable. The interview guide contains some question ideas to introduce individual topics and a pre-formulated question to start the interview. Ideally, the guide accompanies the communication process as a kind of background film, which serves as a check on the extent to which its individual elements have been dealt with in the course of the interview. The interview guide is subject to change and will be adapted after conducting the first interviews, as we gain more insights into our research area.

The detailed interview guide will not be shared in full, due to the double role of some interviewees as project partners, but the objectives of the interviews will be discussed in various stages in order to gain valuable feedback and insights.

Our interview guide has mainly **four sections** which cover different perspectives of looking at biobanks.

- The first section opens up the interview and asks the interviewee for his/her personal role in/relation to biobanking. This is then followed by a number of specific back-up questions depending on the interviewee. Even though the interview is making space for personal narratives, these questions serve to assure that all important issues are covered.
- The second section of the interview then addresses the role of biobanks in biomedical research.
- This is followed by a section on the relation of societal actors to biobanks and aims at exploring individual perspectives on how a public understanding of biobanking should/could be achieved.
- The final and last part is then devoted to reflecting on future developments and challenges.

6. Practicalities

The interviews in general will take from 1 to 2 hours. They will be held in person, over phone or a digital platform, depending on the situation (e.g. COVID-19 has led to the fact that some of the first interviews were held virtually).

Interviewees will be informed about the objectives of the project (see Annex 1). They will be asked to give **informed consent** (see Annex 2) to the recording of the interview, the storage of the audio files and a pseudonymized transcript, and the use of the transcripts for research purposes (including data analysis, presentations, and publications).

The interviews will be transcribed verbatim. Pseudonymized transcripts will be used for further analysis.

PART B – Engaging with citizens and donors

1. Putting citizen participation in context

The use of discussion groups as a research method has in recent years become central in the social sciences as they hold the promise of being better adapted to explore and engage with problem formations around technological and scientific developments. Related to the development of concepts such as RRI, diverse forms of discussion and engagement methods have become quintessential to stimulate citizen, patient or stakeholder engagement (Chilvers and Kearnes 2016). In the context of biobanks such a methodological approach seems essential to better grasp how citizens/donors make sense of biobanks.

Bringing citizens together to discuss biobank related issues and exchange with each other, allows us to better grasp:

- how people live in diversified information environments (i.e. they are confronted with a multitude of information sources) and use this in building their own position;
- how the fabric of society (e.g. degree of formal education is rising) matters when reflecting about biobank related developments
- how citizens negotiate with each other the relation of knowledge, values, choices and potential action.

The reasons for the development and performance of such engagement processes are manifold and often a mixture of three elements. Engagement processes can be seen as a means to build public trust in and gain support for scientific institutions, which are fairly distant for most members of society. From a more normative vantage point, engagement is seen as an essential element in contemporary technoscientific democracies. They allow citizens to voice their concerns and express their understandings of developments in science and technology that matter to them. Finally, sometimes the hope is expressed that through including visions and values of various societal groups (e.g. patients, user groups, consumers, concerned citizens) new perspectives might emerge and an infrastructure, like a biobank in our case, would become more socially robust. This is important for biobanks as their sustainability depends, among other, on the continued support by citizen-donors who are willing to contribute with samples and data.

In order to realize these different goals, a range of discussion oriented participatory methods have been developed and applied, varying in structure, group composition and output-orientation. What they all share is the ideal of making the discussion of science related issues and/or decisions more inclusive, empowering and deliberative. In the following, we will explain the design of an engagement method for BBMRI.at#2.

2. What do we expect the discussion method to achieve?

In developing an adequate citizen/donor engagement method for the context of BBMRI.at#2 we can draw on experiences made in a number of prior research projects in which we developed such formats. Concretely we developed and performed engagement exercises in the framework of research projects on nanotechnology (e.g. Felt et al. 2014, 2019), on biomedicine (Felt et al. 2008, 2009; and reports from BBMRI.at#1) and on digital health (Felt et al. 2020).

For BBMRI.at#2 we will also use a specifically developed card-based discussion method inspired by the IMAGINE method (Felt et al. 2014, 2019) – we call it IMAGINE_BIOBANKING. **Four broader considerations** will guide the development of this specific discussion method.

Opening up the complexities of biobanking: As there is no broader public debate on biobanking, citizens have no examples of how relevant societal actors conceptualize and give an account on what is at stake in biobanking; they lack points they could easily refer to when developing their personal position. Therefore, when citizen encounter the concept of a biobank and what it entails for them, it might be challenging for them to develop and unfold their thinking about biobanks beyond vague and general reflections. We, thus, needed to find a way to bring diverse



positions, visions and elements of information (scientific, technological, social, or political) to the table and make them debatable. This will be achieved through preparing different sets of cards, which participants can use as starting points for their reflections when trying to develop a personal position towards biobanks.

Participatory justice: The fact that we will be engaging with people with different backgrounds, agendas, relations to the topic, and knowledge forms (e.g. professional expertise, experiential knowledge of patients) has to be considered when designing form and content of the cards but also the process of discussion. Participants with more experience in discussion settings or with higher education often find it easier to express their position than others who are much less acquainted with such forms of engagement. This will be achieved through making the cards quite easy to read and through designing the discussion process in a way that everybody gets voice and through offering support to express their views openly (even clear minority positions).

Countering the lay-expert divide: We know from many studies of engagement exercises that the inclusion of experts into the discussion may lead to citizens following expert framings (Kerr et al. 2007; Felt and Fochler 2010). This “stakeholder capture” effect (MacLean and Burgess 2010) reproduces pre-existing power relations, and privileges the views of those who have access to technological or scientific knowledge. Therefore, we use the cards to reflect expert statements as an alternative way to bring expert opinions to the table without making the experts physically present. This allows participants to voice critique more easily and openly and to unpack expert assumptions.

Sensing and understanding biobanks: Finally, the aim of the method we develop in BBMRI.at#2 is not only to open up a space of engagement with biobanking. It also aims to guide participants through the world of biobanking, show the many different moments in which decisions are taken, give a better impression of the many ways in which this infrastructure contributes to biomedical research and many more. Such an approach has the aim to contribute to a detailed and balanced debate on biobanking, while simultaneously allowing for a more refined positioning work of participants.

These four considerations led to the development of a card-based discussion method which we will describe in the following.

3. Main elements of the method

We now will briefly describe the central elements of IMAGINE_BIOBANKING. The method follows a multi-stage choreography, which consists of three stages, each shedding light onto biobanking from different perspectives:

- **positions** of different actors towards biobanks,
- **situations** in the process of biobanking (i.e. follow samples through different steps from the moment of donation to the moment where samples get used in research) and
- **values** (e.g. why donate, why use,

Each stage comes with a specific set of cards (more below). The first and the last stage last approximately the same amount of time (approx. 45 minutes). The second stage is the center-piece, which guides participants through the many stages of a biobank (e.g. following a sample from provision for research to use in research), opening up many smaller elements/situations/questions they can engage with (but also learn about). Therefore, this stage takes more time. This choreography provides a clear structure without predefining or restricting what can be discussed, invites to shift perspective and allows some moments of individual reflection when choosing the cards for stages 1 and 3 and more collective moments of exchange. A discussion group will take approximately 3-4 hours (including a break). This length is feasible because the method alternates between more active discussion phases and moments in which the participants read and choose new cards in a silent manner.

The number of participants in each group is relatively low (about 6-8 participants) in order to allow a maximum of time for interactions and the development of positions. A facilitator guides the participants through the process. A short video-clip lays out the topic and its dimensions. This allows the facilitator to not slip into the role of explaining the biobank.

Each participant has a personal board and three piles of cards that are placed flipside up. The participants are asked to pick up one pile at the beginning of each stage. In stage 1 and 3 they are asked to go through the cards and decide on a predetermined number of cards by applying their own rationale for choice (e.g. dislike or agree with a statement, be astonished, find it puzzling, and so on). When every participant has placed the chosen cards on the board in front of her/him, the facilitator can start to inquire about their choices. Stage 2 will function very differently and be more a step by step process of the moderator engaging with the citizens/donors about the different stages in the biobank.

4. Creating the cards and deciding the choreography of the discussion stages

How to create the cards for the different stages?

Exploring and analyzing the issue

In order to come to these decisions, a detailed analysis of the topic to be debated is the starting point (see also Deliverable 4.1.1). A detailed prior research is needed to develop the card material. This includes bringing together elements from qualitative interviews, media and document analysis, ethnographic methods and participant observation. The aim is to identify the spectrum of actors as well as concrete arguments, explanations, regulations, and many more, that together constitute the topic “biobanking”.

Card types

In order to structure the discussion process, we decided to develop three different card types. Each of it addresses a specific angle of the biobank to be explored and their subsequent introduction allows to gradually build a discussion through the three different stages (Figure 6.).



Figure 6: Three kinds of cards to be used in our discussion groups

Position cards: These cards are the first that participants are asked to read and choose from. They contain short statements as expressed by different actors, showing the spectrum of existing positions towards biobanks. Calling them “position cards” should communicate that they are not an enumeration of facts, but are meant to show the multiple ways people understand the potential as well as the problems with biobanking. These statements are not taken literally from our sources, but will need rephrasing and condensation and should be written in a way that they are easily graspable.

Situation cards: The second stage of the debate uses a set of cards to walk our participants through the whole process of biobanking. For this purpose, we structure the discussion of the process of biobanking along a number of concrete “situations”. Each situation describes a specific moment/setting where samples are given, transformed, standardized, stored, given access to. The number of steps and their description will be developed together with our consortium partners and we will use material from interviews, from the literature on biobanks as well as from

walkshops. This type of cards is meant to render participants' positioning work more concrete and detailed. It should allow to elicit a nuanced view on specific moments in biobanking.

This second stage has a clear twofold aim. It should give us more concrete insights on what citizens would expect from a biobank and when and where they express potential concerns. However, at the same time it should give participants more concrete insights into the world of biobanking and thus make their visions and assessments more concrete.

Value cards: We end with a discussion on the key-values that are essential in citizens' views when it comes to biobanking. Experience from previous engagement exercises showed that many value questions already appear in a more latent form in the first two stages. This last stage thus aims to make them more explicit and to also raise awareness for values that are not so evident at first.

How to write these cards

Taking into account previous experiences this means (taken from Felt et al. 2019):

- texts should be easily understandable; if technical terms are to be used at all, they should always be accompanied with an explanation;
- sentences should be short and straight forward;
- a larger font should be preferred to make the reading quick and easy for everybody;
- the number of cards should be adapted to the group composition.

Choreography

As already mentioned before, the first and the last stage last about 45 minutes and always start with each participant selecting a specified number of cards. Once everybody has done this, the facilitator invites everybody to outline why they have chosen a specific set of cards and what has triggered this choice. This is then followed by an open discussion. This procedure allows participants to first make their own choices and to argue them and only in a second step engage with the visions of others.

The middle-part works differently: here the facilitator invites people to go step by step and express their opinion in each of the situations. Here, it is important to also allow participants some time to shortly reflect and only then express their thoughts and concerns.

5. Validating the card sets

A more practical but nevertheless crucial task in creating the cards is to fill them with content that is not only comprehensible for participants coming from diverse backgrounds, but also adequately represents the diversity of positions as well as – for set 2 – the processes in the biobank. At the same time, the number of cards should be limited as participants have to read them all before making a choice. We, thus, will create much more cards at first and then go through a selection and validation process. For this purpose our consortium partners will be cardinal for giving us feedback and vetting the cards.

6. Conducting IMAGINE Discussion Groups

Some practical issues with regard to conducting the IMAGINE_BIOBANKS discussion groups: place/space, facilitation and documentation.

The fact that every participant has a board and several piles of cards that need to be placed in front of them and that they should easily face each other when interacting, demands specific spatial arrangements in form of a round table. They also spend 3-4 hours together, which also means that space is needed to feel at ease.

The facilitator mainly explains the stages and guides the group through each of them. He/she has to take care that participants choose cards and then present and explain their choices. Here, the moderator should make sure that all participants get their turn and encourage quieter participants to contribute. The facilitator only intervenes when the discussion does not take off and generally triggers discussion with open-ended questions and comments meant to stimulate the interaction in the group. However, it is essential, that the facilitator encourages discussion between the participants and not between the facilitator and single participants.

7. Composition of the groups

In the project we plan to do discussion groups with citizens who have not donated to biobanks as well as donors. We are aware that this distinction is not easy to make. From a project on Informed Consent in a hospital context we know that patients sign informed consent sheets without explicitly informing (wanting to inform) themselves what they exactly consent to donate. Therefore, the line between citizens and donors might in reality be quite blurry. However, when using the term 'citizen' we meant people who do not conceptualise themselves as donors, while the other group is made of people who have donated to a biobank.

We will configure groups between 6 and 8 participants. For the time being we plan to keep the two categories – donors and citizens – separated in most of the groups. However, we also plan one or two mixed groups to better see if this makes a difference. To recruit citizens we will use flyers in bulk mail to households and distribute them at places such as popular universities or museums. We aim at heterogeneous mixed gender groups of diverse ages, educational and professional backgrounds because differences between participants “allows one to observe not only how people theorize their own point of view but how they do so in relation to other perspectives and how they put their ideas ‘to work’” (Kitzinger 1994, 113). To recruit donors we will collaborate with those researchers/medical professionals who ask patients to donate.

8. Documenting the discussion process

We plan to audiotape the discussions and transcribe them in a way that includes some details on turn-taking, overlapping speech, pauses and annotation of non-verbal activity. Such a transcription system allows the optimal use of the data.

Participants in the discussion groups will be informed about the objectives of the project. They will be asked to give informed consent to the recording of the discussion groups, the storage of the audio files and a pseudonymized transcript, and the use of the transcripts for research purposes (including data analysis, presentations, and publications).

Furthermore, we will write ethnographic observation protocols after each discussion group tracing observations concerning non-verbal clues such as body language of participants (e.g. approval through nodding).

For the analysis see Part C of this report.

Part C - Data analysis

1. Grounded theory and situational analysis

In designing our research and analysing the data we embrace a “grounded theory” (GT) approach which can be seen as “the gold standard of qualitative data analysis” (Tavory and Timmermans 2014, 28) and offers “systematic, yet flexible guidelines for collecting and analyzing qualitative data to construct theories 'grounded' in the data themselves” (Charmaz 2006, 2) (see also our short methodological summary in the introduction). As already stated, it is an alternative to a strongly theory-driven approach which would presume a clear theoretical frame and works in a deductive logic. While the latter would mean that we deduce clear-cut hypothesis from theories that are then tested empirically through interviews or other means, grounded theory approaches the field of inquiry quite openly. More recently, Tavory and Timmermans (2014) have suggested to use an **abductive approach** to escape the dichotomy between induction and deduction, and to acknowledge that fieldwork and data collection is always informed by some more conceptual and theoretical assumptions. This approach means “recursively moving back and forth between a set of observations and a theoretical generalisation. The act of analyzing data requires that we pitch our observations in relation to other potential cases”. Abduction can thus be described as a “form of reasoning through which we perceive an observation as related to other observations, either in the sense that there is an unknown cause and effect hidden from view or in the sense that the phenomenon is similar to other phenomena” (Tavory and Timmermans 2014, 96-97). Data and their theoretical interpretations are thus in a constant conversation. Using an abductive approach in analysis thus means that we are guided by several sensitizing concepts (see Deliverable 4.1.1), that sharpen the lenses of the analysts, and not a closed framework that (pre)determines data analysis.

Working with grounded theory starts with data. It is key to choose a set of methods that fits the research problem we want to address. How we collect data has effects on what we will be able to see, how, where and when we can gain insights and how we can make sense of them. Therefore, we will use several combined methods and work ourselves in sequences through the field of biobanking. Our data will be rather diverse – as explained in the introduction – ranging from a broad set of interviews to discussion groups. It will also contain ethnographic observations (during the workshops, at conferences) and written documents.

2. Steps in the analysis

Grounded theory allows starting to gain first insights while still being in the phase of data collection. The approach to data, even when framed by sensitizing concepts, remains very open and is always interested in the details of the accounts delivered in many different forms without sacrificing the detail of enacted scenes. Charmaz (2006, 14) compares this to “a camera with many lenses”. While one first gets “a broad sweep of the landscape”, it is then in further steps possible to “change your lens several times to bring scenes closer and closer into view”.

After having gathered the first round of data, **initial coding** is the first step of analysis (for the whole process see Figure 7). We will code and categorize data, using software to organize the coding process. Coding means labelling segments of data (in our case segments of interviews as well as complementary documents and fieldnotes) with labels (or “codes”), so as to enable constant comparison between segments of data (Charmaz 2006; Saldana 2015). When coding data, we will use the elements of biobank assemblages, as well as the guiding questions in relation to our research objectives (values and value of/in biobanking; bio-data citizenship; GDPR) as preliminary categories that sensitize us to specific segments in our data. We will fine-tune these categories in conversation with our data and with theoretical literature (Timmermans and Tavory 2012; Tavory and Timmermans 2014). This leads us to a first list of codes and categories, pointing to key elements that relate to the questions we are aiming to respond to.

Coding is always accompanied by **memo writing**, that is the writing of systematic research notes, which helps to start to interpret and theorize on data segments. Memo writing is essential as memos capture first propositions about connections/relations between categories. Integrating these connections with other groups of categories

gradually allows to generate theoretical insights, moving from the specific to the more abstract. In short: memo writing supports the elaboration of categories, helps specify their properties, defines relationships between categories, and identifies gaps in the data gathered so far.

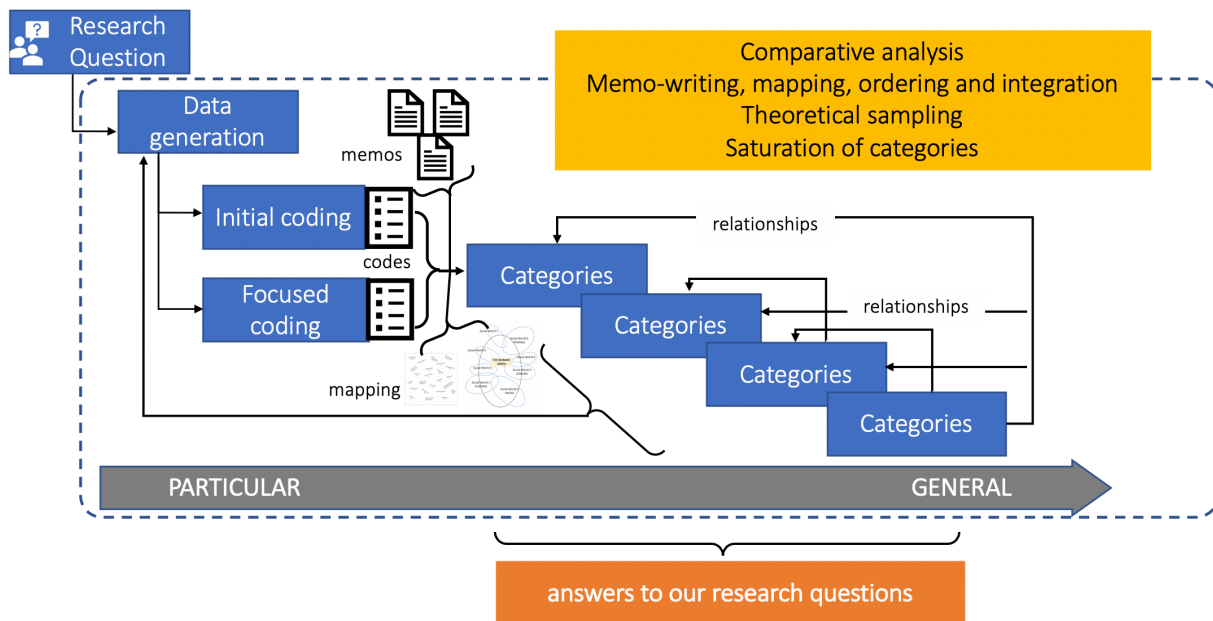


Figure 7: Grounded theory approach

This will be followed by more **focused coding**, digging deeper into specifically significant categories and codes which relate to our research focus. In this step we first put our coded data into bigger categories based on thematic or conceptual similarities and then select what seem to be the most interesting initial codes and test/refine/elaborate them against further data. Throughout the process, we compare sets of data with each other and then data with codes.

Here **comparison** comes to matter, i.e. comparison between different kinds of data (different interviews, but also different documents and fieldnotes), and between different sites and contexts (interviews with biomedical professionals in specific places, or interviews with policymakers as compared to biomedical professionals). This happens all along the process of data generation and interpretation. Comparing, here, is not tied to an effort to “evaluate”, or to “grade”; instead, comparison in the constructivist social sciences is a means to sharpen the analytical lenses of the analyst. It helps us to see the heterogeneity of particular phenomena—such as how providers of data are conceptualized and framed in different situated contexts. Thus, when comparing we are interested in both differences and similarities. Indeed, stabilities and similarities across different contexts will sensitize us to processes of standardization, and emerging stabilities in infrastructures. Similarities direct us to elements of emerging infrastructures that transcend specific locations, while they are materialized through their adaptation in specific locations.

Finally, we will also use and adapt some of the **mapping techniques** proposed by Clarke et al. (2017). They propose three kinds of maps as an analytic exercise to combine different kinds of material into their version of grounded theory analysis. They are meant to complement the coding processes described in classical grounded theory. Maps focus on “the situation of inquiry” – in our case the working of a biobank – which means that they are the unit of analysis. Grasping its elements and their relations is then of key-importance to develop a better understanding of our research questions.

There are three maps which are important:

- **situational maps:** lay out the major human, technological, institutional, discursive and other elements in the situation of inquiry and support the analysis of the relations among them (see Figure 8)
- **social worlds/arenas maps:** focus on relevant groups/actors (e.g. media, institutional actors, universities, ...), key technological elements, and the arena(s) in which major negotiations happen (see Figure 9)
- **positional maps:** identify and lay out major positions taken in relation to specific concerns or controversial issues, and help to spot silences.

We will mainly use situational and social worlds/arenas maps for our analysis.

These maps help to gain an overview and to better identify relevant connections between categories.

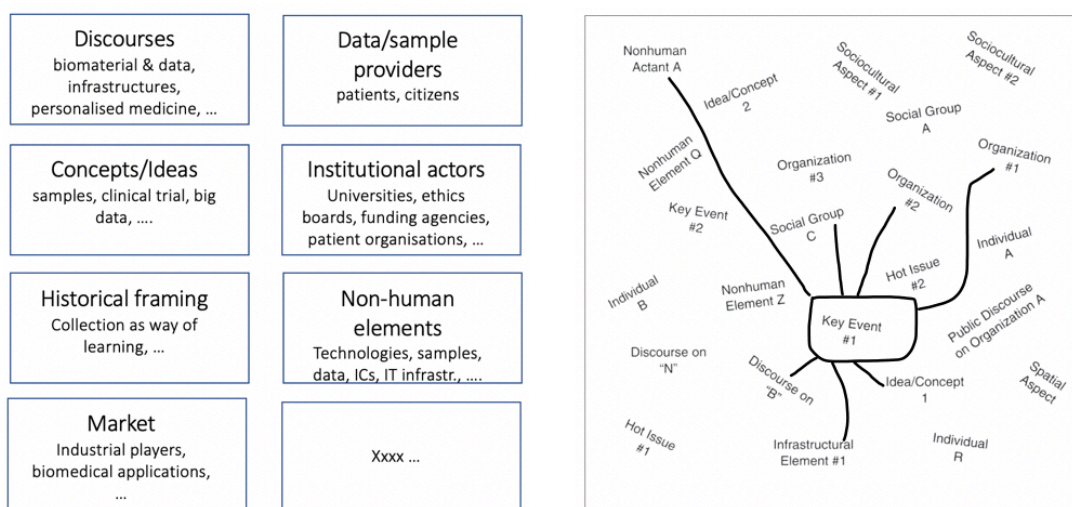


Figure 8: Example of a situational map with relations identified

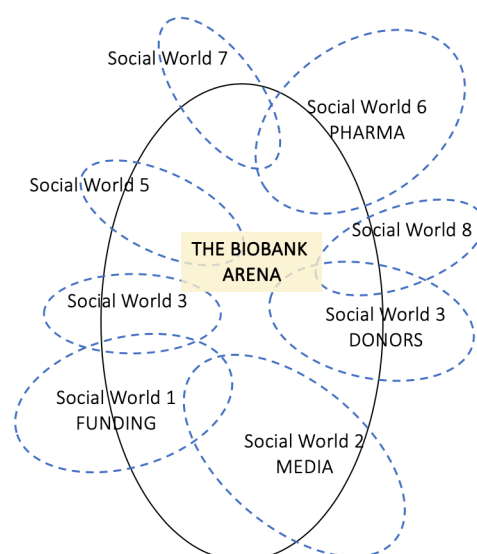


Figure 9: Example of a social world/arena map

3. Analysis and sampling

As already outlined in Part A section 4, the process of interviewing and collecting other relevant material will be cyclical. Once we have conducted a first round of interviews and analysed them, we will decide on the next round of interviews. The choice of interview partners will not necessarily be guided by the idea of interviewees being representative of a specific social group, but be “especially and explicitly [driven] by theoretical concerns that have emerged in the provisional analysis to date” (Clarke 2005, xxxi). We thus predominantly use a “theoretical sampling” approach, which is oriented towards “finding new data sources (persons or things-and not theories) that can best explicitly address specific theoretically interesting facets of the emergent analysis” (ibid., 5).

This process of analysis and producing new data will gradually allow us to move from particular observations to more general explanations. As already outlined above the exact number of interviews for different categories of people will thus be exactly determined by the point in time when we reach saturation, i.e. interviews, workshops, discussion groups do no longer add new insights.

4. Integration of cycles of feedback

Last but not least, a further important tool that will aid data analysis and, in particular, interpretation, will be regular workshops with our colleagues from the consortium, in which we will present preliminary insights from our data interpretation. We think that these will have a double effect:

- feedback will strengthen our interpretation;
- insights while these are still in the making, will be an important tool to facilitate reflections, engagements, and cross-disciplinary dialogues.

References

- Akrich, Madelaine. 1992. "The De-description of Technical Objects." In *Shaping Technology/Building Society - Studies in Sociotechnical Change*, edited by Wiebe Bijker and John Law, 205-224. Cambridge MA: MIT Press.
- Allen, Mike. 2017. "Ethnographic Interview." In: *The SAGE Encyclopedia of Communication Research Methods*. 4 vols. Thousand Oaks, CA: SAGE. doi: 10.4135/9781483381411.
- Bogner, Alexander, Beate Littig, and Wolfgang Menz. 2014. *Interviews mit Experten: Eine praxisorientierte Einführung*. 2014th ed. Wiesbaden: Springer VS.
- Charmaz, Kathie. 2006. *Constructing grounded theory: A practical guide through qualitative analysis*. Los Angeles: SAGE.
- Chilvers, Jason, and Matthew Kearnes, eds. 2016. *Remaking Participation: Science, Environment and Emergent Publics*. London: Routledge.
- Clarke, Adele E. 2005. *Situational Analysis: Grounded Theory After the Postmodern Turn*. New. Thousand Oaks, Calif: SAGE.
- Clarke, Adele E., Carrie E. Friese, and Rachel S. Washburn. 2017. *Situational Analysis: Grounded Theory After the Interpretive Turn*. Los Angeles: SAGE Publications, Inc.
- Czarniawska, Barbara. 2001. "Narrative, Interviews and Organizations." In *Handbook of Interview Research*, by Jaber Gubrium and James Holstein, 732–50. Thousand Oaks: SAGE Publications, Inc. <https://doi.org/10.4135/9781412973588.n42>.
- Czarniawska, Barbara. 2004. *Narratives in Social Science Research*. London: Sage Publications.
- Deleuze, Gilles, and Félix Guattari. 1988. *A Thousand Plateaus: Capitalism and Schizophrenia*. London: Athlone press.
- Felt, Ulrike, Brian Wynne, Michel Callon, Maria Eduarda Gonçalves, Sheila Jasanoff, Maria Jepsen, Pierre-Benoît Joly, Zdenek Konopasek, Stefan May, Claudia Neubauer, Arie Rip, Karen Siune, Andy Stirling, and Mariachiara Tallacchini. 2007. *Taking European Knowledge Society Seriously*. Luxembourg: Office for Official Publications of the European Communities.
- Felt, Ulrike, and Maximilian Fochler. 2008. "The Bottom-up Meanings of the Concept of Public Participation in Science and Technology." *Science and Public Policy* 35 (7):489-499.
- Felt, Ulrike, Maximilian Fochler, Annina Muller, and Michael Strassnig. 2009. "Unruly ethics: on the difficulties of a bottom-up approach to ethics in the field of genomics." *Public Understanding of Science* 18 (3):354-371. doi: 10.1177/0963662507079902.
- Felt, Ulrike, and Maximilian Fochler. 2010. "Machineries for Making Publics: Inscribing and Describing Publics in Public Engagement." *Minerva* 48 (3):219-238. doi: 10.1007/s11024-010-9155-x.
- Felt, Ulrike, Simone Schumann, Claudia G. Schwarz, and Michael Strassnig. 2014. "Technology of imagination: a card-based public engagement method for debating emerging technologies." *Qualitative Research* 14 (2):233-251. doi: 10.1177/1468794112468468.
- Felt, Ulrike. 2017. "'Response-able Practices' or 'New Bureaucracies of Virtue': The Challenges of Making RRI Work in Academic Environments." In *Responsible Innovation 3: A European Agenda?*, edited by Lotte Asveld, Rietje van Dam-Mieras, Tsjalling Swierstra, Saskia Lavrijsen, Kees Linse and Jeroen van den Hoven, 49-68. Cham: Springer International Publishing.
- Felt, Ulrike. 2018. "Responsible Research and Innovation (RRI)." In *Routledge Handbook of Genomics, Health and Society*, edited by Saha Gibbon, Barbara Prainsack, Stephen Hilgartner, and Janelle Lamoreaux, 108–16. London and New York: Routledge. <https://doi.org/10.4324/9781315451695-18>.
- Felt, Ulrike, Simone Schumann, and Claudia Schwarz-Plaschg. 2019. "IMAGINE – A Card-Based Discussion Method." In *Handbook of Research Methods in Health Social Sciences*, edited by Pranee Liampittong, 1167-1182. Singapore: Springer.
- Felt, Ulrike, Susanne Öchsner, and Robin Rae. 2020. "The Making of Digital Health: Between Visions and Realizations." In *Digitaler Humanismus*, edited by J. Fritz and N. Tomaschek. Münster/New York: Waxmann Verlag.
- Geertz, Clifford. 1973. *Interpretation of Cultures*. New York: Basic Books.
- Hacking, Ian. 2000. *The Social Construction of What?* Revised ed. Cambridge, Mass: Harvard University Press.
- Hajer, Maarten. 2004. "Doing Discourse Analysis: Coalitions, Practices, Meaning." In *Words Matter in Policy and Planning: Discourse Theory and Methods in the Social Science*, edited by Margo van den Brink and Tamara

- Metze, 65–74. Utrecht: Knag/Nethur.
- Holstein, James A., and Jaber F Gubrium, eds. 2008. *Handbook of Constructionist Research*. New York: The Guilford Press.
- Jasanoff, Sheila. 2016. *Ethics of Invention. Technology and the Human Future*. New York: W.W. Norton & Company.
- Jasanoff, Sheila, and Sang-Hyun Kim, eds. 2015. *Dreamscapes of Modernity. Sociotechnical Imaginaries and the Fabrication of Power*. Chicago: Chicago University Press.
- Kerr, Anne, Sarah Cunningham-Burley, and Richard Tutton. 2007. "Shifting subject positions: experts and lay people in public dialogue". *Social Studies of Science* 37(3):385–411.
- Kitzinger, Jenny. 1994. "The methodology of Focus Groups: the importance of interaction between research participants. doi:." *Sociology of Health & Illness* 16 (1):103-121. doi: 10.1111/1467-9566.ep11347023.
- Larkin, Brian. 2013. "The Politics and Poetics of Infrastructure." *Annual Review of Anthropology* 42 (1):327-343. doi: 10.1146/annurev-anthro-092412-155522.
- Law, John. 2004. *After Method. Mess in Social Science Research*. London/New York: Routledge.
- MacLean, Samantha, and Michael M. Burgess. 2009. "In the public interest: assessing expert and stakeholder influence in public deliberation about biobanks." *Public Understanding of Science* 19 (4):486-496. doi: 10.1177/0963662509335410.
- Saldana, Johnny. 2015. *The Coding Manual for Qualitative Researchers Third Edition*. 3rd ed. Los Angeles ; London: SAGE Publications Ltd.
- Sharon, Tamar. 2018. "When Digital Health Meets Digital Capitalism, How Many Common Goods Are at Stake?" *Big Data & Society* 5 (2): 2053951718819032. <https://doi.org/10.1177/2053951718819032>.
- Silverman, David. 2011. *Interpreting Qualitative Data*. 4th edition. Los Angeles, London, New Delhi, Singapore, Washington DC: SAGE.
- Stilgoe, Jack, Richard Owen, and Phil Macnaghten. 2013. "Developing a framework for responsible innovation." *Research Policy* 42 (9):1568-1580. doi: 10.1016/j.respol.2013.05.008.
- Tavory, Iddo, and Stefan Timmermans. 2014. *Abductive Analysis: Theorizing Qualitative Research*. Chicago: University of Chicago Press.
- Timmermans, Stefan, and Iddo Tavory. 2012. "Theory Construction in Qualitative Research: From Grounded Theory to Abductive Analysis." *Sociological Theory* 30 (3): 167–86. <https://doi.org/10.1177/0735275112457914>.
- von Schomberg, René, ed. 2011. *Towards Responsible Research and Innovation in the Information and Communication Technologies and Security Technologies Fields*. Brussels: European Commission.
- Weiss, Robert S. 1995. *Learning From Strangers: The Art and Method of Qualitative Interview Studies*. New York: Free Press.
- Wickson, Fern, Roger Strand, and Kamilla Lein Kjolberg. 2015. "The walkshop approach to science and technology ethics." *Science and Engineering Ethics* 21 (1):241-64. doi: 10.1007/s11948-014-9526-z.
- Winner, Langdon. 1986. "Do Artifacts Have Politics?" *Daedalus* 109 (1):121-136.
- Witzel, Andreas. 2000. "The Problem-Centered Interview." *Forum: Qualitative Social Research* 1 (1).