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Out of body, out of mind?

People's understandings of their contribution to biobanks and the role of informed consent therein

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Berit Doreen Wolff, B.Sc.

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List of Abbreviations

Abbreviation	Written Out
ANT	Actor-Network-Theory
BBMRI.at	Biobanking and BioMolecular Resources Research Infrastructure Austria
BBMRI-ERIC	Biobanking and BioMolecular Resources Research Infrastructure - European Research Infrastructure Consortium
CGT / GT	(Constructivist) Grounded Theory
FOG	Forschungsorganisationsgesetz
GDPR	General Data Protection Regulation
OPP	Obligatory Passage Point
STS	Science & Technology Studies

1. Introduction

In 1951, Henrietta Lacks was at Johns Hopkins Hospital, Baltimore, for treatment of her cervical cancer, when two samples were taken from her cervix for research purposes; one from healthy cells and the other from cancer cells. This happened without her knowledge, a common practice back then. Henrietta died a few months after the diagnosis, but her cells went on to live, up until today, and potentially forever. This is the often-told story of the HeLa cells, which helped develop the polio vaccine, went to space, were used in Nobel-Prize-winning research, and are still used, e.g., for studying viruses and cancer as well as for developing drugs. The cells have been cultured in such vast amounts that the estimated weight of all HeLa cells ever grown amounts to over 50 million tons (Skloot, 2010). Henrietta Lacks never knew about the use let alone the impact of her cells on the biomedical field and the world as we know it today; her family only found out over 20 years after her death and was shocked. The fact that Henrietta Lacks was a Black woman adds another dimension to her fate given the history of medical racism and exploitation of marginalised groups for research. Even today, the legitimacy of the samples' collection is discussed, and the consistent debate around this case has had major ramifications for bioethical practices (e.g., Beskow, 2016).

If we turn our gaze to biomedical research in Austria today, the situation looks different. Firstly, samples obtained in the context of medical care may only be used for research if the patient has given their informed consent. And secondly, for research, only the residues of what is taken anyway for the patient's treatment or diagnosis are used (and possibly an additional small amount of blood), so that no additional medical interventions are necessary. Neither of these aspects was fulfilled in Henrietta's case. In contrast to Henrietta, people receive information and are asked before something is collected for research. What interests me in these instances is how people think about their contribution to biomedical research, how it affects them, and what role informed consent plays in their participation, as it is the context in which they are asked and made aware of a contribution. This is the point of departure for my master's thesis.

When talking about the collection and use of samples for biomedical research, there is one essential infrastructure: biobanks. They enable the collection, storage, and provision of large collections of samples like bodily fluids and tissue and therefore advance and facilitate research. These samples are then used for researching diseases and treatments, leading to improvements in therapeutic and diagnostic procedures (Neururer & Landmann, 2021). It is argued that only with high numbers of samples and standardised processes, significant results can be found, which is easier to achieve when biobanks cooperate closely. In Austria, the national node of BBMRI-ERIC (Biobanking and BioMolecular Resources Research Infrastructure - European Research Infrastructure Consortium), BBMRI.at, aims at facilitating research by deepening collaborations among the different partners and

by establishing shared quality standards, making it easier to share and use the over 22 million samples that are in total stored by BBRMI.at partners (*BBMRI.at*, n.d.).

The samples gain their worth by linking them to additional information like age, gender, and the patient's medical history (Asslaber & Zatloukal, 2007), which are also stored by the biobank. Therefore, it only makes sense to consider them together, especially since samples become datafied for further research. Alongside the fact that when samples and data are collected for biobanking it is usually not yet known what they will be used for in the future, many ethical and societal questions arise, for example concerning privacy, ownership, access, and usage. The current biobanking practices addressing these issues, such as informed consent, have certain values and beliefs inscribed in them and envision participants in certain ways, leading to the mediation and co-construction of peoples' perceptions and experiences through biobanks. Not surprisingly then, it has been argued that "biobanks play a key role in delineating collective identities" (Gottweis, 2008, p.33) and have the power to change what citizenship means, e.g., as it can shape the view on what rights and obligations come with being part of a community as well as what constitutes the formation of identity and relationships (e.g., Faulks, 2003; Felt et al.,2020). In particular, because of their contribution to a biobank and research, data and samples might affect how people understand themselves, their bodies, and others. To zoom in on how citizens perceive this themselves, I focussed on a specific biobank practice, namely informed consent, which is a mandatory process prior to one's participation, hence constituting an obligatory passage point (Callon, 1984) for those who partake in biobank research.

In this way, new insights into how people relate to biobanks and are impacted by their participation will be gained; a topic of high interest from a Science and Technology Studies (STS) perspective. Also, little is known about the Austrian context, despite having one of Europe's largest and most innovative biobanks, the Biobank Graz (Huppertz et al., 2016). Understanding how participants think of biobanks, relate to them, and are affected by their contribution will help create sustainable biobanking practices since it can point to ways in which public support and interest can be secured. This is essential for biobanks, as they rely on citizens' voluntary participation.

1.1. Structure

Before diving into the thesis, I will give a short outlook on the structure. In Chapter 2, I present existing literature that is relevant for addressing my research interest. The chapter is divided into three sections, starting with insights into participation in biobanking, such as how it is conceptualised, what motivations and underlying attitudes participants have and how (national) contexts matter for participation. In the second subchapter, I explore the role of informed consent. The function of informed consent is outlined as well as the challenges encountered in practice. The last subchapter dives deeper

into the positionality of the participant by looking at how they relate to the material they have contributed, their embeddedness in society and the possible impact that information based on their contribution could have. Following from the presented literature, I formulate my research questions in Chapter 3 with the main one being "How do people understand their contribution of samples and data in the context of biobank consent processes?". Afterwards, in Chapter 4, I lay out the conceptual framework for my work. For this, I chose are Actor-Network-Theory and Citizenship, which provide a lens for examining the entanglements of humans with actors around them, human and non-human. Building upon ANT, I discuss how both Obligatory Passage Points and Boundary Objects (Star & Griesemer, 1989) can be insightful when looking at informed consent. In the subchapter on Citizenship, particularly two dimensions are in focus: data citizenship and biological citizenship, which are merged into the notion of (bio)data-citizenship. In Chapter 5, the methodological approach of my work is presented, including a description of the case and the material. As a means of inquiry, I chose qualitative interviews that are supported by a visual aid to facilitate the conversation about the rather abstract and remote topic of biobanking. I interviewed 8 people who had previously contributed biological material to a biobank in Austria, all in the context of participating in a study. The transcripts of the interviews were analysed using Constructivist Grounded Theory. Chapter 5 contains the empirical part. In four subchapters, I lay out my findings. The first examines how people understand their contribution in the first place, focusing specifically on the motivations and reasons for participation, and the costs and concerns on the other side, which are weighed against each other, defining one's willingness to participate. Afterwards, people's perceptions of informed consent are outlined: how was it understood, what is taken away from it and what consequences does it have. From there, I am moving on to how people relate to what they have contributed e.g., in terms of ownership, and what impact their contribution can have, for example when receiving feedback. The fourth subchapter discusses how the participants see themselves in relation to other people, uncovering both inclusive and exclusive narratives. Subsequently, in Chapter 7, I present three main findings: participation is an effortless side product, a *collateral good*; informed consent and how it is understood acts as a mediator in how people think about their contribution; and people no longer (actively) think about their participation afterwards, it basically has no lasting impact on them, therefore, the title 'out of body, out of mind'. Simultaneously, I discuss these insights along further literature and my chosen concepts. In the final Chapter, I synthesise the findings and their implications while also reflecting on the limitations of this work and possible future research.

2. State of the Art

In this chapter, different strands of literature that relate to my research interest are connected. First, I will delineate the role of citizens in biobanking, beginning with the language that is used in discussions revolving around participation, then continuing with the publics' and participants' attitudes towards biobanking and factors that impact it as well as pointing out the need for context sensitivity. Next, I will elaborate on one central and in most cases mandatory interaction in the process of contributing to a biobank: informed consent. I will look at how it takes place, what people think about it, and what limitations and implications it has. The chapter is rounded off by examining different aspects of people's self-understanding, for example how people relate to what they contribute, what role their embeddedness in society has and how biomedical knowledge can affect them. Together, the different parts illuminate the social processes that are active in the context of contributing to a biobank.

2.1. Participation in Biobanking

Without people that are willing to give blood, tissue, and medical data to biobanks, biobanks would not exist. The way biobanks are organised presupposes the participation of citizens and considers them a resource (Mitchell & Waldby, 2010). Yet, describing people as a resource is a "technoscientific objectification of bodies" (Ruckenstein & Schüll, 2017, p.264) and puts them in a passive position. However, the participants are more than mere providers of biomaterial (Bühler et al., 2019), which has political and ethical implications. There are several deliberations on which role participants take or should take in biobanking as well as how contributions of biomaterial should be framed. As a basis for further discussions, I will thematise the language used in the context of biobank participation.

2.1.1. Conceptualising Contribution to Biomedical Research

The probably most prevalent term for the contribution to a biobank is 'donor' (and 'donation'), we can also find it on the websites of the biobanks in Graz and Innsbruck (*Einverständniserklärung*, n.d.; Neururer & Landmann, 2021). However, there are arguments in favour of avoiding these terms due to their connotations of altruism and the implication of gifting something, hence being morally laden. Altruism and gift might not always be appropriate descriptions, e.g., in cases where someone is giving blood or tissue for the mere reason that it does not mean anything to them (Tutton, 2007). The discussion is made more complex by the somewhat conflicting definitions of gift and their relation to altruism: on the one hand, a gift is giving something of a certain value to someone without expecting anything back, a free gift, so an altruistic act. On the other hand, gifts are often seen as a means to create and deepen social relationships. As such it is not entirely altruistic since one expects something in return; in the context of biobanks not immediately and not necessarily for oneself, and it could also be the case that

people have already received or expect something, e.g., clinical care, and with their participation, they want to give something in return (Hoeyer, 2010), so there is a bidirectional exchange. In a similar vein but moving even further away from the notion of a gift, Locock and Boylan (2016) argue that framing donation as altruistic ignores the reciprocity and expectations people have. Their study showed that people conceptualise a contribution as giving something but rarely as a gift since it requires neither effort nor costs for them and entails no continuous obligations. What they are giving is of low value to them and considered 'waste', so it does not match a gift's connotation of being of worth (Locock & Boylan, 2016). Thus, not only is the use of gift problematic because of its multiple meanings but also in practice it is rarely used by participants, being reserved rather for more meaningful occasions.

Referring to altruism and other morally laden terms like solidarity is often used to engage people by appealing to their duties as citizens and their connection to others, presenting biobank research as a contribution to the common good (Petersen & Lupton, 2000). Generally, participation is regularly framed as a matter of citizenship (e.g., Árnason, 2009; Tutton, 2007), evoking a sense of belonging and being a member of a community given the chance to give something back to it by contributing biomaterial, which is one of the reasons I will refer to citizenship as a sensitising concept. In doing so, I will also mention a particular instance of citizenship, bio(data)-citizenship, which is a central concept in the project, in the framework of which my master's thesis is undertaken (Felt et al., 2020)

Instead of considering people a mere source for data and samples, passive research subjects, or donors, it is a relatively recent development in biomedical research to construct the role of citizens more and more as participants, and at times even as partners or co-decision makers (Corrigan & Tutton, 2006; Tutton, 2007). In this way, a more active role is assigned, which suits the idea of an empowered citizen that we can find in many other contemporary health-related accounts (e.g., Prainsack, 2017). Though an active role might be considered worthwhile, it might not actually be desired by the partaking people themselves (e.g., Hoeyer 2003; 2004a). Yet, while no term is perfect and all have certain connotations, 'participant' is a more nuanced term than donor, which can acknowledge the different levels of engagement when contributing, from active to passive, and helps us to not just think in terms of donors and non-donors (Tutton, 2007). It avoids the moral pitfalls of donation and captures the varying relationships between participants and biobanks (Hoeyer, 2010). In this work, I will thus mainly use participants (and contributors)[1] and pay attention to how my interviewees describe themselves as it tells

[1] The biobanks to which I refer in this work are university clinics associated ones, so 'patient' is also a descriptively well-fitting term and used on the websites of Austrian biobanks, since in most cases, people are patients in a hospital when they are being asked to contribute. Those patients are residing at a hospital for a medical examination where tissue or blood are collected for diagnostic purposes or treatment anyway, so as mentioned in the introduction, there is no additional medical intervention needed for the collection of samples, and hence there is no extra risk for physical harm. The notion of patient is an important cue as it reminds us that the different parts in a care relationships are not equal. However, I will not use patients to refer to my interviewees since their

us about how they understand themselves and their contribution. To further approach this, I will now discuss how participants and the general public think about biobanking.

2.1.2. Motivations & Attitudes

The prior paragraphs might already give a hint that it is difficult to generalise the relations between participants and biobanks. The context for a contribution can differ, e.g., reason for hospitalisation, type of tissue collected, and type of population (Lipworth et al., 2011), and similarly, there are a variety of reasons for contributing to a biobank: altruism, sense of duty, contributing to research and thus the common good (Domaradzki & Pawlikowski, 2019; Hoeyer, 2003), making use of otherwise wasted material (Lewis et al., 2013) and the hope to acquire more knowledge about one's medical condition, though this is usually not given. Another reason could be the relations of care the participants are part of: they might feel gratitude for their treatment and care and want to reciprocate something or think that denying one's participation is more effortful and might lead to tension with the caregiver (Hoeyer & Lynöe, 2006). This points to the fact that the context of the contribution, including the interpersonal relations, needs to be considered (Hoeyer, 2008, 2010; Lipworth et al., 2011), an aspect we will encounter again (and again) in the course of this work. Besides, we see that people have various and complex reasons for participating. In a quantitative and qualitative study with 800 Australians, Critchley and colleagues (2017) identified two groups concerning their priorities regarding biobanking: one group prioritised respectful behaviour towards the participant, while the other regarded advances in science as more important. Overall, the study participants valued the protection of privacy and ethical practices above the maximisation of health care benefits, which, in turn, was prioritised over data sharing. Monetary compensation was considered the least important priority, and many people dismissed it entirely (Critchley et al., 2017). People often express their aversion to the use of their data for commercial gains, since such usage of data and samples is not in accordance with their values and deviates from their idea of biobanks' purpose to serve the public good. Not surprisingly then, people are more willing to donate to public institutions like hospitals than to the pharma industry (Kaufmann et al., 2009). Worth mentioning is, however, that people who have actually participated do not think about their participation a lot and made mostly vague statements in interviews (Hoeyer, 2004b) and not seldomly, people do not even remember having donated (Hoeyer et al., 2005).

Generally, people know very little about biobanking and about two-thirds of Europeans had never heard of a biobank (e.g., Domaradzki & Pawlikowski, 2019; Gaskell et al., 2013). Despite not being familiar with biobanking, many participants in studies have an optimistic and positive attitude towards

participation in a study was more pivotal to their contribution to a biobank than the medical care they received such as a booster vaccination against COVID-19.

biobanking (Lipworth et al., 2011) and are largely willing to donate, but the willingness varies from country to country (Domaradzki & Pawlikowski, 2019). However, the actual participation is higher than the results from surveys, so there appears to be a difference between attitude and acting (Johnson et al., 2010).

Willingness is impacted by several factors: knowledge, values, experiences, trust (in experts, institutions, research etc.), perception of risks and benefits, concerns about security, and demographics (Domaradzki & Pawlikowski, 2019). Typical concerns are the commercialisation of biobanking and commodification of human material (e.g., Hoeyer, 2002; 2008) as well as an impact on privacy, e.g., the responsible handling of data and samples but also stigmatisation and discrimination based on findings are feared (Critchley et al., 2017). In general, there are many discussions around the impact of biobank practices on fairness and autonomy. As a way to address and potentially resolve these issues and insecurities, obtaining informed consent from the participants prior to their contribution is often considered a solution and has become a requirement in many countries when collecting and storing tissue and data (Hoeyer, 2008). The efficacy and practicability of informed consent are contested, as I will elaborate on in below in 2.2.4. For now, I conclude that attitudes towards biobanks and especially reasons for contributing are complex, multiple, and conditional; hence, they are not fixed and need to be seen in context, as the next subchapter points out in more detail.

2.1.3. (National) Context

National differences concerning the attitude towards biobanks are considerable. In Northern Europe, a higher approval of biobanking and willingness to donate can be found (Gaskell et al., 2013), and many of the Nordic states have population biobanks or registries (Tupasela et al., 2010), whereby participation becomes framed as a matter of citizenship. Countries like Norway and Sweden are welfare states, which might be an additional factor to see contributing to society as a more common deed (e.g., Hoeyer & Lynöe, 2006; Ursin & Solberg, 2009), even a duty for being part of the community and to give something back.[2] In Austria, only about 35% of those surveyed could imagine providing information to a biobank, compared to 93% in Iceland, making Austria the most sceptical European country alongside Greece (Gaskell et al., 2013). These results have been attributed to a general scepticism towards technological innovation in Austria and negative experiences with experimental medical research during World War II (Gaskell et al., 2013; Gottweis, 2011). These national differences show

[2] In Norway, the concept of *dugnad* has a special tradition, which is unpaid and voluntary work. In pre-industrial times this could mean helping each other to build one's farm, but it is still present today. It is expected by others to do the same, so we see that it is not purely based on altruism, but rather on solidarity and reciprocity. When taking part in a dugnad, people are part of a community, so belonging is a motivation as well. There is a civic duty, but people can still decide freely if they want to participate. Contributing to a biobank has been described as a "health dugnad" (Ursin & Solberg, 2009).

that there is no united European attitude toward biobanking which poses challenges to the harmonisation of biobanking practices across Europe and is a caution not to mindlessly transfer the empirical findings from one country to another.

Conducting qualitative interviews helps to reveal the rationales behind the quantitative data from the past and explore individuals' perceptions in the Austrian context. The national context also impacts the health care and research system with which the biobanks are entangled. In addition to that, context sensitivity is also important on a more personal level as the care relationship and the patient's experiences and understandings inform how they relate to contributing to biobank research (e.g., Hoeyer 2003; 2010). This aspect will be discussed over the course of the next chapter on informed consent.

2.2. Informed Consent

In this chapter, I will discuss the role of informed consent in biobanking and explain its purpose as well as delineate the criticisms and caveats that have been raised, which question the relevance and adequacy of the current consent processes in biobanks and hinder the ideal execution of informed consent in practice.

2.2.1. Why Informed Consent?

In Austria, biobanks are required to obtain informed consent from the participants in order to collect and use samples for research (*Einverständniserklärung*, n.d.; Neururer & Landmann, 2021). Informed consent means the participants need to (1) be fully informed about all aspects and (2) voluntarily give their consent, usually in written form (Neururer & Landmann, 2021). For example, it outlines very broadly how the samples will be used (while the specific use remains unknown) and by whom (e.g., academic and non-academic institutions), that the sample will be stored for an indefinite amount of time, that the ownership is transferred to the biobank or the medical university to which the biobank belongs, and how the withdrawal works (*Einverständniserklärung*, n.d).

It allows people to make their own informed and free decision about whether they want to participate, so it has the ethical purpose to empower and protect autonomy as well as the legal purpose to secure the rightfulness of the researchers' acts, to navigate the handling of potentially sensitive material, and to transfer the rights of ownership. As informed consent is mandatory, everyone who has contributed to a biobank has (or at least should have) experienced an informed consent process, hence rendering it a point that everybody passes, in STS terms an obligatory passage point. [3] As such, informed consent

[3] Yet, at the same time it is not entirely true that informed consent is always obligatory, at least for data, as stated in the Austrian *Forschungsorganisationsgesetz* (FOG) in accordance with the GDPR the secondary use of data

is a valuable tool since it is a common denominator for different participants, whereas it might differ who asked them for consent and in which context.

Another aspect that links informed consent to my research is that it carries values and intentions of the biobank and the use of samples as well as envisions how a citizen should be and what they should do (Felt et al., 2020). This becomes clearer when looking at the purposes that have been ascribed to informed consent, for example protecting and respecting patients' rights, preventing exploitation, promoting autonomy and well-being, providing information, securing trust, and enabling engagement (Ursin, 2008), but also to give the researchers using the samples a legal basis (Hoeyer, 2008). It is an attempt to find a balance between respecting the participant and their interests while facilitating and advancing research for the common good (Critchley et al., 2017). Moreover, informed consent navigates aspects like uncertainty, accountability, and ownership. In this way, informed consent is a top-down influence by inscribing roles, thereby shaping identities and the relation between biobank and citizens. Oonagh Corrigan (2004) describes the informed consent process "as a process that in effect constructs subjects as 'biological citizens' who have rights to be informed about biomedical research, and who simultaneously have obligations to make informed, reflective choices" (p.84), so the individual is being responsibilised. However, she also points out that the expectations of active or participatory citizenship behind this can burden the participant, who might prefer a passive role and as little engagement as possible. This is why consent processes in practice cannot always fulfil the ideal "of an autonomous, rational, free thinking moral being" (Corrigan, 2004, p.85). Instead, people have their own approaches to informed consent and co-shape informed consent processes, so that it is not entirely top-down. Hence, it is interesting to investigate how informed consent is understood and how it impacts the contribution and the relation to that contribution.

Another reason why informed consent is valuable to look at is that it provides an access point to broader discussions about biobanking. For example, in a previous BBRMI.at project discussions about informed consent often led to general discussions, in which biobanking practices were related to more general issues revolving around datafication and big data in our society, such as protection and privacy (Felt et al., 2018). How people think about these topics plays a role in how they perceive biobanks and themselves. Besides, by talking about informed consent people can refer to a personal experience, which makes it easier to access abstract ideas like autonomy and citizenship.

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without informed consent is possible (Gesamte Rechtsvorschrift Für Forschungsorganisationsgesetz, 2018). In BBRMI-ERIC informed consent is part of the guideline, but the implementation differs from country to country. In this study, only people who have passed an informed consent process will be interviewed.

2.2.2. Critiques & Caveats

Consent is one of the most discussed topics in the context of biobanking and probably the most discussed ethical topic (Budimir et al., 2011). While there are several ongoing discussions surrounding informed consent, I will only briefly touch upon the aspects most relevant to my research interest, such as which form of consent is the most adequate for biobanking needs and the discrepancy between the bioethical ideal of informed consent and its relevance in practice.

First, as the future use of samples is usually not yet known when collecting them it is not possible to provide participants with specific information about the use. Therefore, they are asked to give broad consent (sometimes also called blanket consent), which just informs them very generally about how samples are used in research.[4] However, it is contested whether broad consent can be counted as informed consent since it does not grant specific information, thus participants do not know what they are eventually agreeing to. They lack information for a fully informed decision, which can be seen as a violation of their autonomy (Caulfield & Kaye, 2009). With broad consent, people only have control over whether they donate, but not for what exact research purposes their donation will be used, which is why it has been argued that for the sake of research, people give up their self-determination. Generally, there is no consensus on what the best way to obtain consent is. Nevertheless, despite its contentious nature, broad consent is the most common choice, mainly justified for practical reasons since it only needs to be collected once and comes with relatively low costs, but also because the contribution serves the common good and has minimal risks. Yet, it is often considered ethical provided that data is handled responsibly, a right to withdraw exists, and ethics committees are involved in which research is allowed to use the data and samples (Simon et al., 2011). Besides, other forms of consent are argued to be impractical (Caulfield & Kaye, 2009); for example, specific consent restricts research possibilities and requires getting re-consent for each study, thus costing time and money. Presumed consent, on the other hand, is often discarded for ethical reasons since it impairs people's self-determination and is seen as paternalistic and disempowering towards participants. Proponents often justify it on the grounds that it would accelerate medical progress and has basically no risks (Stjernschantz Forsberg et al., 2009). There are a myriad of works contemplating what consent form is the best; the best for research, the best for the public, the best for the individual, and to each counterargument you will find another argument. Plenty of questions remain: does more information equal a more ethical outcome? Is broad consent a violation of autonomy and is autonomy violation immediately unethical? (When) Is general information too little information? I will not (and frankly cannot) answer these normative and epistemological questions; there will be ongoing discussions, with

[4] While it might sound as if there are no restrictions at all on how it can be used, this is not the case: studies making use of the biobank material have to get the approval of an ethics committee.

or without me putting in my two cents. While bioethical discourses are important and informed consent has the power to mediate experiences and actions because of the values and the morality that are inscribed in it, we must not forget that things are likely to look different in practice, where many of the theoretical considerations might become irrelevant or overshadowed by other issues.

2.2.3. People's Attitudes Regarding Consent

More interesting than the theoretical considerations might be how (potential) contributors think about it. Not surprisingly, like their general attitudes towards biobanks, their attitudes towards informed consent in biobanking are also heterogenous and complex, reflecting the bioethical discourse. Which type of consent is preferred varies from study to study. In one study from the US around two-thirds preferred broad consent over specific consent (Simon et al., 2011). Another study, also from the US, reported that about half of the participants preferred being asked one time (and the use of samples being approved by oversight mechanisms such as an ethics committee) (Murphy et al., 2009). At the same time, around 40% would prefer to be asked for each study, but the survey also only offered three options to choose from, with categorical consent being the third one with a preference of 10% (Murphy et al. 2009). While some want to be contacted again when their sample is used, others considered re-consent annoying and bureaucratic. In a third US study approximately the same number of participants disapproved of specific consent (43%) and broad consent (44%) equally (De Vries et al., 2016). This differs from the study by Richter and colleagues (2019), conducted in Germany, where over 90% were willing to give broad consent, and three-quarters were even willing to waive consent altogether. In Sweden, the preference for broad consent was found to be around 72% (Kettis-Lindblad et al., 2009). These results are not as heterogenous as they might appear at first sight: in the evaluation of the results of these studies, it must be taken into consideration what options were given and what questions were. For example, it makes a difference whether people are asked for their acceptance or preference for an option: when presented with other choices aside from broad consent, those were often preferred, but that does not mean that they do not also accept broad consent. Broad consent is rather a compromise than an ideal solution. Also, the results of one study imply that the willingness to donate does not rely on the type of consent: when given a depiction of broad consent, 76% expressed their willingness to participate as well as 74% of those receiving a different version with study-specific consent (Ewing et al., 2015). The same study found that what impacts the willingness and preference for a consent model is demographics and concerns about privacy and handling of genetic information. Also, the national context of the study plays a role, as there seems to be a correlation between trust in government and acceptance of broad consent, meaning that people who have a high trust are more likely to agree (Gaskell et al., 2013).

Moreover, there is a discrepancy in how different stakeholders relate to consent, e.g., what they consider important in the informed consent process (Beskow et al., 2010). Klaus Hoeyer (2002) observed that policymakers care more about informed consent than the participants, who are not as concerned with being informed but rather care about the broader implications of the research. Participants often do not engage with the informed consent, have no memory of consenting or are not aware that material has been removed and stored in a biobank. Informed consent fails to achieve its goal of informing people, which again raises the question of whether it actually is an *informed* consent.

The participants' lack of interest leads to arguments for making consent processes as easy as possible (Lipworth et al., 2011), for example by presuming consent and offering an opt-out option[5] instead of having to opt-in, or by letting ethics committees make decisions on behalf of the patients (Hoeyer et al., 2004). It is argued that since only about one out of 700 patients does not provide consent when being asked to donate and only one in 19000 withdraws their consent, an informed consent process where each individual needs to be informed and asked is disproportionate with regards to the resources it requires (Johnsson et al., 2008).[6] However, it should be kept in mind that just because it is practical it does mean that it is ethical. Besides, approval is not unconditional but contingent, hence there need to be measures that maintain and secure trust, e.g., by transparent communication and offering options for withdrawal (Gaskell et al., 2013).

2.2.4. Informed Consent in Practice

After already teasing it, I will now discuss in more detail how informed consent procedures take shape in practice and especially how they differ from the bioethical ideal of *informed* consent. Those differences that occur can often be explained by including the social setting (Corrigan, 2004) which impacts the decision-making of the participants. Empirical research that has taken the context into consideration has drawn a more complex picture of informed consent than depicted in theory, with the

[5] Worth mentioning is that organ donation in Austria happens by default, meaning that everyone is an organ donor unless they explicitly declined (*Organe*, 2020). However, not all Austrians are aware of this opt-out system.

[6] These are numbers from a study in Sweden so they should be taken with a grain of salt since the willingness to participate is generally higher in Northern European countries (Gaskell et al., 2013). Interesting about these numbers is that less than one per cent of the patients declined their consent, so the percentage of actual participants among patients is way higher than the number of potential participants among average citizens, as in Swedish surveys 'only' around 80% said that they could imagine contributing to a biobank (Gaskell et al., 2013; Johnsson et al., 2008). This discrepancy between behaviour and attitude could be due to the obligation a patient might feel as being part of a care relationship, which makes it more challenging to decline, or it could also be linked to reciprocation, a sense of duty and trust. Fittingly, the authors write that though the "results tell us what patients do, they may indicate little of what they think" (Johnsson et al., 2008, p. 3). This again emphasises that participation needs to be regarded in context. Also in Austria, the participation is supposed to be well above 90% (personal communication, 28/29.11.2022), while in studies only 35% indicated their willingness to contribute something to a biobank (Gaskell et al., 2013).

side-effect of questioning the relevance, adequacy, efficiency, and necessity of informed consent (Hoeyer, 2003; 2004a).

On the issue of whether people actually want to be informed, several studies have observed that though people want to be asked and want to choose for themselves, the information provided in the consent processes was not essential for their decision-making (Cho et al., 2015; Lipworth et al., 2011). Some patients do not really think about or pay attention to the information that is given to them. One explanation for this offered by Klaus Hoeyer (2004a) is that by not reading the informed consent sheet, the content cannot cause anxiety and people can escape the sense of responsibility they would feel if they had known about the details. Thus, while informed consent is originally supposed to reduce anxiety and uncertainty, it can produce it since it makes one aware of potential risks, which people have not thought about before. With knowledge comes responsibility, and this is something people resist by not reading the provided information (Hoeyer, 2004a); they are "refusing the information paradigm" (Felt et al., 2009, p.87). Yet they are "still fulfilling their sense of duty" (Hoeyer, 2003, p.240) by consenting and contributing material, while also staying ignorant on purpose (see Michael, 1996).

Besides, in the context of medical care, patients often express the desire to let their doctor decide for them and not make decisions themselves (Ducourneau & Cambon-Thomsen, 2009). This delegation is not just a way to transfer responsibility but also expresses trust in the caregiver, which can be seen as another explanation for the ignorance: patients are trusting the healthcare providers, the care system and the broader framework in which biobanks are embedded. Trust plays a more prominent role in their participation than the information, or, in other words, the participation does not necessarily depend on knowledge (e.g., Felt et al., 2009; Hoeyer, 2003; Hoeyer & Lynöe, 2006; Kasperbauer et al., 2022).

In a qualitative study on informed consent processes in the context of breast tissue donation (Felt et al., 2009), patients consented as they could not think of reasons that would speak against it and simultaneously did not want to produce any tensions in their relation to their caregivers by declining the clinician's request to donate (Bister, 2010). It again shows that saying yes is not a decision based on information but in this case, an assessment of effort and outcome, as it is easier to say yes and in their personal interest to not say no to someone who is taking care of them (Bister, 2010). Another aspect of being entangled in a care relationship is that the patients might want to reciprocate something for being taken care of by relinquishing bodily material and giving back to the system. Several arguments for participation come together, namely, the desire to meet other people's requests (thereby avoiding tensions), to help someone's work, and to give something back; resulting in regarding a contribution to research as an uncontroversial topic and a matter of course (Bister, 2010).

That social entanglements are of great importance is even more apparent in a study by Dixon-Woods et al. (2006) who report that in an informed consent process concerning surgical interventions, women

“rarely do anything other than obey professionals' requests for a signature” since they are “enmeshed in the hospital structure of tacit, socially imposed rules of conduct” (p.2747). They argue that in these situations the capacity to act freely is limited, so patients might agree even if they actually do not want to. This is even the case in the context of an operation, which is a much more incisive and severe situation than contributing to a biobank, where they do not have to fear bodily harm or consequences. As part of a care relationship, the patients are subjected to power asymmetries, which prestrucure the leeway of their choices.

In a similar vein, but less drastically, it has been argued that patients in a hospital, the main context of origin for samples, are in a constant state of being approached by others in order to give or receive information; they are in *Ansprechbereitschaft*, and in this state, people are unlikely to decline their consent (Bister, 2010), as they are attuned to be cooperative. The informed consent for biobank research is not differing from other things they must sign. This indicates a “routinisation of informed consent” (Ploug & Holm, 2013, p.215), which leads participants to always agree when asked to consent. This is not desirable as it impugns the autonomy of the patient, and they might be acting against their actual interest. So far, such a routinisation has been found in the context of online services where people accept terms and conditions without reading, also in relation to health data (Ploug & Holm, 2013).

To summarise this section, there is “a profound gap between participants and a procedure that is intended to empower them to act as informed and autonomous subjects” (Ducourneau & Cambon-Thomsen, 2009, p.41). The decision-making in the consent process is not as informed and autonomous as desired, thus not meeting the ethical standards it sets for itself and rather turns into a mere legal safeguard on the biobank’s side. Therefore, the “decision to donate must be viewed as something other than an information-based, intentional act” (Hoeyer & Lynöe, 2006, p.16). Instead, giving informed consent and contributing to a biobank needs to be seen in its societal embedding as well as the context of the contributor’s past experiences and beliefs (Felt et al., 2009; Hoeyer, 2003; 2010), since the decision they make does not depend merely on the knowledge they receive but also on personal reasons and entanglements. We have to take the broader context into consideration, beyond information and autonomy of the individual as the guiding principles since participants are not individuals in isolation but entangled with others. Contribution to a biobank always occurs in a social setting (Corrigan, 2004).

After discussing all these aspects of how informed consent is not as relevant, not cared about and insufficient, you might be wondering, why devote so much time to it? It is still given a lot of attention by researchers as, because of its insufficiency, it is a point of tension, one that every participant passes and therefore, a good entry point for research. Besides, it has the potential to mediate how participants understand themselves and the world around them as it has certain beliefs inscribed. This is why, in this work, I want to investigate if informed consent does affect the participants and if so how, regardless of whether informed consent is equipped to do what it is supposed to do.

It is also worth looking at what role informed consent plays, because, with advances in information and communication technologies, new possibilities for acquiring consent emerge, with the hope to have a type of consent that satisfies everyone's desires. A frequently discussed model is dynamic consent, where over a digital interface, often referred to as a donor portal, participants can choose for themselves which type of consent they would like to give and can easily change it (Kaye et al., 2015). Giving broad consent would still be possible, but if desired participants could also opt for a study-specific consent or determine categories, depending on the affordances of a donor portal. Besides, with such an infrastructure, continuous communication between researchers and participants can be enabled, and engagement can be strengthened, e.g., by further data sharing or receiving feedback. These portals are believed to improve patients' rights and increase participation, transparency, trust, and control (Kaye et al., 2015). On the other hand, it is likely to be more effortful, for example, because of navigating the interface and not just having to decide if one wants to participate but also how one wants to participate.

2.3. (Self-)Understanding

Biobanks, being research infrastructures, are part of the biomedical progress that is continuously taking place and affecting our lives: "Developments in biotechnology frequently destabilise and reconstitute naturalized relations between bodies, bodily fragments, human identities and social systems" (Waldby, 2002, p. 308). Through technological and medical advances new insights into body and health are gained, shifting what is possible, on a collective as well as on individual level. How we understand ourselves and the world around us changes, therefore affecting our relations with ourselves and others. Yet, biobanks differ from other results of the biomedicalisation of society and thus might have a different degree of impact in comparison to e.g., commercial health technologies. In this subchapter, I will first examine a constitutive part of this discussion: the body, which is inseparable from the self. When participating people contribute something that was previously part of their body, and the value that they attach to the samples and data shapes what, if any, impact their contribution has on them. Therefore, a question that comes up in this context is: what role do the participants assign to the biological material, e.g., is it still part of them? And does the participation preserve, enact, or transform the identity (of the sample and the self)? Afterwards, I will discuss a more global body, the society, and look into how our surroundings and the entanglements to others, not just to clinical staff, shape our thinking and acting. Towards the end, I will discuss the impact of knowledge, in particular the impact of medical feedback that people receive. Another relevant strand of literature that relates to this will be introduced in the theoretical framework of my thesis below: in the context of citizenship, I will discuss further how data and biomedical research can re-configure our ways of thinking and living. It follows a short conclusion that draws the different parts of the state of the art together.

2.3.1. Relation to Body – How Matter Matters

In our daily lives we use our bodies to express ourselves – the things we do, the way we dress, hiding or showing our feelings. Also, the contribution of biomaterial can be seen as a site of embodiment. The body becomes instrumentalised in order to achieve something; to do something good and to contribute to science; to conform, to feel altruistic, and/or to fulfil a sense of responsibility, or in other words, "with their donations people enact values" (Hoeyer, 2009, p. 250).

How we act towards and with our bodies, e.g., if one participates and for what reasons, depends on how we relate to it. There is no heterogenous answer to how people relate to the contributed samples and data. Instead, we have to deal with ambiguities. On one hand, people have difficulties differentiating between data and samples (Felt et al., 2018). On the other hand, the meaning ascribed to data versus bodily material differs among people. In a Swedish study, it was found that sharing medical records is often met with more reluctance and concerns than giving away tissue or blood (Hoeyer et al., 2004), indicating that the data might be considered more valuable and personal despite its less material form. The samples do not seem to be valuable in itself, but rather the information that is drawn from the sample when it is used in research (Locock & Boylan, 2016). In a sense, the biomaterial then changes from worthless to valuable, when it arrives in the hand of a researcher who can extract information from it (Bister, 2010), so (bio)value is produced. While the participants give the matter away since they do not consider it valuable, the researcher wants it because it is useful to them and gains value.[7] They act according to the meaning that they ascribe to the samples (see Blumer, 1986) and in this way, two complementary attitudes converge. Participants are even surprised that there is a demand for their tissue (Bister, 2010). This indicates the ambivalent and dynamic status of samples, which have also been attributed to data (Lupton, 2020). The strong ambiguity towards samples is reflected in the ways they are described: waste, leftover material, a gift, a proxy for a person (e.g., Felt et al., 2009; Hoeyer, 2004), moving between ascriptions of useless waste products and high value. How people relate to the biological matter depends on the context (e.g., tissue type or the health condition of the donor) (Hoeyer, 2008), for example, cancer patients feel no attachment to the cancerous tissue and want it to be gone; it is not part of their identity (Felt et al., 2009). In contrast, in the context of donating blood, people have shown a (more) conflicting relationship: giving away blood is not considered meaningful, it's a "mere thing", but at the same time the blood is seen as a part of their body, as something intimate (Hoeyer, 2004a, p. 99). Some people expressed concerns about the use of their blood for cloning or gene

[7] Furthermore, also policymakers think differently about data and blood (Hoeyer, 2002) and have other concerns than patients.

modifications, which they oppose as it attacks their idea of personhood and the essence of what makes one human, therefore questioning their own sense of identity (Hoeyer, 2004a).

It has also been observed that people are more willing to give material that can be collected without an invasive operation, such as blood and saliva. In biobanking material that would be taken anyway is collected (aside from minimal amounts of additional blood), and often people have no close relation to it, as they do not see it as part of themselves, e.g., as in the case of cancerous tissue. In contrast, there is a low willingness for donating reproductive tissue, e.g., eggs left over from in vitro fertilisation (Lewis et al., 2013). Those are considered more intimate: the closer a body part is coupled to identity, the greater the reluctance to giving it away (Wagner, 2010). In the case of a biobank contribution, people typically do not feel a strong personal connection or sense of ownership over these samples and do not consider them as part of themselves (Lipworth et al., 2011), while data about their health is more valuable and revealing to them.

Additionally, one person can have multiple interpretations of the sample; perceiving the sample as "both human and non-human, both living person and dead object" (Hoeyer, 2004b, p. 67) and these understandings are not fixed.

Though few consider it part of them, there is, viewed from an external perspective, still a certain connection through the previous relation to it, it becomes an extension of their body. But as described above, the connection is often perceived as relatively weak or non-existent, yet it differs and the boundaries between body and biomaterial are not fixed. Hence, to understand the impact of one's contribution in the context of biobanking, it is important to explore how participants personally perceive it, how they relate to the material and the data they have provided and the significance of informed consent therein. Besides, how people understand their contribution does not end with physical matter but extends to more abstract levels: their environment and the society they live in.

2.3.2. Individuals in (a) Society – "No one is an island"[8]

In the context of informed consent processes, it has already become obvious how interpersonal relations affect decision-making. However, the participants are not only in entanglements with their caretakers, but their relations with friends and family and, on a more abstract level, the society as a whole, including the state and other institutions, affect them in who they are and how they understand themselves. Earlier I mentioned that the meaning that people ascribe to objects, here samples and data, impact their behaviour, and this meaning is "derived from, or arises, out of the social interaction that one has with

[8] Adapted version of the line "No man is an island" (Donne, 2007, p. 108) from John Donne's 1624 prose work *Devotions upon Emergent Occasions.*

one's fellows" (Blumer, 1986, p. 2). People grow up with a certain socioeconomic, political, and historical background, and they are never in isolation but always in one way or the other intertwined with others. Hence, it is not possible to disentangle individuals and collectives, as "the self always implies the presence of others" (Jenkins, 2014, p. 63). The fact that people are often regarded as separate individuals is not appropriate since humans cannot exist outside of social relations, and their interaction with their environment, human and non-human, shapes and co-creates their interests and identities (e.g., Jenkins, 2014; Prainsack & Buyx, 2017).

Drawing on political theory, we can conceptualize this relational understanding of personhood as being a citizen, where people have rights and obligations due to being part of a society. The notion of "citizenship" will reappear in this work as a sensitising concept for the analysis, therefore I will save a more thorough discussion for the concept section. Here, I will only pre-empt how citizenship and contribution to a biobank relate to each other. At the outset, I already described how participation is regularly framed as a matter of citizenship. This framing is not gratuitous but due to the strong relations between health and the state that can be found in many European countries, e.g., in the form of mandatory health insurance.[9] Since the participants are usually approached during a stay in the hospital, which is to the most extent covered by their health insurance, they are in embedded in the health care system, and consequently "the donation of bodily substances can be understood only within the larger context of how people perceive the State and its health system and their roles and duties within it" (Felt et al., 2009, p. 89). As discussed, this situation in which one is being cared for might make it less likely that patients are going to decline when asked to contribute something. Besides, not consenting would go against the principles of the health care system that is based on solidarity and mutual obligations. There is a co-dependence between the individuals, others, and the system, which comes with certain expectations. Whether these also influence someone's contribution to a biobank will be part of my investigation, so if for instance through the participation (a certain idea of) citizenship is enacted and if it can be seen as an active participation in society.

Our environment is not just filled with other humans and institutions, but also with non-humans like infrastructures, streets, syringes, hospitals. To each of them, people have attributed different meanings depending on their experiences, and they are all, more or less, involved in a contribution to a biobank. Essential to the contribution is informed consent, which legitimises the contribution by obtaining participants' written consent and transferring the rights of the samples while simultaneously informing them. Hence, the informed consent process is a place where ideas about one's relation to the contribution can rise (Hoeyer, 2004a), mediating how the contribution is understood. Whether this

[9] 99,9% of the Austrian population is part of the mandatory health care system, which is not exclusive to Austrian nationality (*Informationen zur Krankenversicherung in Österreich*, 2023).

actually happens in practice is uncertain because, as we know, people are not always engaging with the informed consent, for a variety of reasons (trust, indifference, purposeful ignorance...), which is why I would like to investigate this aspect with this work. Another important aspect is knowledge, here not in the form of information provided in the informed consent process, but the potential knowledge one can gain in the biomedical context, e.g., test results, which might also give insights into people's understanding of their biobank contribution.

2.3.3. The Impact of Knowledge on the Self

There is limited literature on how donors understand themselves and their relations to samples and data, but when we look at other areas using healthcare-related data, we can gain a glimpse of what impact it can have, for example how genetic information or data from self-tracking can change how we understand ourselves (e.g., Lupton, 2020; Rose & Novas, 2005; Tutton & Prainsack, 2011). This impact on one's self-understanding has consequences, as "individuals *will act on information* and (…) the information *will have an impact on their lives*, the magnitude of which will depend on the nature of the information and the value the individual places on that information" (Dressler, 2009, p. 95, emphasis in original). Biobanking differs from using self-tracking devices for health purposes or commercial services like 23andme which offer genetic tests. These are instances where people actively seek information about themselves. It exemplifies people's desire to know more about themselves; whether it is how many steps they take or where their ancestors are from, which adds information that they can integrate into their sense of self and can be adapted into one's behaviour, e.g., increasing one's daily steps. With new knowledge new ways of seeing and knowing oneself are created that were previously not accessible. Such information can be both empowering and anxiety-inducing, yet it is not a purely top-down process, as people's experiences and perceptions shape how this information is taken up and what is made of it.

In (Austrian) public biobanking, it is not envisaged that people receive feedback concerning the use and the results of their samples in research, for lack of resources as well as technical and ethical reasons, thus differing from 23andme and similar services. People do not directly profit from their contribution but only as part of the collective that benefits from advances in biomedical research such as the development of new drugs. Biobank research focuses on producing generalisable knowledge and not individual results. While the findings from commercial digital health technologies are not adaptable to biobanking due to the purposes and nature of business, they might nevertheless give insights into how people's self-understanding is affected when contributing data and receiving something in return. Besides, people have often expressed interest to receive results of the research (e.g., Hoeyer, 2010).

2.4. Conclusion

To conclude, in this chapter my aim has been to provide a basic understanding of biobank participation and a variety of facets relevant to my research interest. I looked at motivations and attitudes surrounding participation, various factors that weigh in, and the social and material context surrounding it, including the role of informed consent and its limitations. Informed consent is of special interest as it delineates the relation between the self, society, and the body by providing information about the contribution and what it entails. It is a place where ideas about oneself, responsibilities, and rights can emerge (Hoeyer, 2004a). How individuals perceive their bodies and consequently the material they contribute plays a role in their decision to participate, and looking at this in practice helps us to grasp their understanding of their contribution with informed consent as the place where their contribution is formalised. In addition, we must not overlook the fact that this process takes place within a social context and that the contribution itself is used again within another social context; the sample is a "socially efficacious remainder" (Bister, 2010, p. 167). A recurring notion throughout the literature was citizenship, often used as a way to frame contribution and embed it in a wider societal context. Before delving deeper into citizenship in Chapter 4, in the context of my theoretical framing, and demonstrate how data and biomedical progress change the way we think and live on a more conceptual level, I will outline my research questions.

3. Research Questions

Following from the different strands of literature presented in the State of the Art, my overarching research topic is how participants understand the contribution of samples and data to a biobank in regard to how they make their decision to participate and what affective impact their contribution has on them, with informed consent as my point of departure. By investigating this, I hope to add yet another perspective to the heterogeneous findings. Broadly speaking, my main research question asks: "How do people understand their contribution of samples and data in the context of biobank consent processes?". I will buttress my main research question with several subquestions. The first one, "How do people assess their contribution to a biobank?", aims at exploring the reasons for participating to understand the context of their contribution and disclose their concerns. This gives an insight into their underlying motivations, values, and beliefs. In order to reveal the relevance and role of informed consent, my second subquestion asks: "How is the informed consent process perceived?". This thematises the tension between the idea of informed consent and its practical relevance, and it can help to figure out the context of consenting and what the participants take away from it. In relation to that, I will ask thirdly: "How do people relate to the data and samples they contributed (and how is this affected by informed consent)?". Giving away bodily material and data might re-configure how they bear relation to it in a sense of ownership and agency, while also taking into account what was given away, in which context as well as how samples and data are understood and what effect it has or could have on their understanding of themselves and their body. Lastly, I am interested in how the participants position themselves and their contribution in relation to others. By asking "What is the situatedness of the individual to others and within society in the context of a biobank contribution?", I hope to gain insights into how people refer to others and what they think their contribution means to society, such as whether it is a civic duty, an act of solidarity or a reciprocation. This then relates back to how they perceive their contribution and how they are affected by it. To summarise, the main research question (MQ) and subquestions (SQ) that I aim to answer with this project are:

MQ: How do people understand their contribution of samples and data in the context of biobank consent processes?

SQ1: How do people assess their contribution to a biobank?

SQ2: How is the informed consent process perceived?

SQ3: How do people relate to the data and samples they contributed (and how is this affected by informed consent)?

SQ4: What is the situatedness of the individual to others and within society in the context of a biobank contribution?

4. Sensitising Concepts & Theoretical Framing

In the following chapter, I will introduce the theoretical framework that I consider valuable for making sense of how people understand their contribution and how they relate to data, samples, informed consent and biobanking generally. First, in order to explore the various relations between humans and non-humans that play a role when contributing to a biobank, I will discuss Actor-Network-Theory and in particular the notion of obligatory passage points, before linking those to boundary objects. In the second part of the chapter, I will elaborate on the concept of citizenship and regard it in more detail in the context of datafication and biomedicine, concluding with (bio)data-citizenship. This enables a closer look at the role of participants and how they are impacted by technoscience in their lives.

4.1. Actor-Network-Theory

Having already referred to informed consent as an obligatory passage point (OPP), it might not come as a surprise that I will employ actor-network-theory (ANT) as one of my theoretical points of departure (e.g., Latour, 2005). ANT provides a useful vocabulary when looking at sociotechnical assemblages like biobanks where a variety of different actors, non-human and human (e.g., researchers, clinicians, patients, samples, data, technical equipment, informed consent) come together. It sensitises regarding the agency of non-human actors and in this way pays attention to the effects that samples, data, values, infrastructures, standards, and the like can have. It is thus a material-semiotic approach and does not just focus on humans as the sole actors but on the entanglements between humans and non-humans, which form relational, heterogeneous associations that can be mapped as networks. Biobanks are such networks: they are not single or isolated entities but contain a heterogeneity of actors and their relations. Observing biobanks from the perspective of ANT, we can see how there are not just technological aspects but social ones, too and we cannot completely differentiate between them.

In my work, informed consent will take a central role as the OPP which patients ideally need to pass when contributing to a biobank, at least when contributing for the first time. Relevant in this context is the process of translation (Callon, 1984), which describes the transformation of identities and interests of actors that can take place at an OPP. Translation and OPP will be further examined in the next section, but I will pre-empt that they allow us to see that identity is never given nor fixed but dynamic and shaped by its relations to other actors in the network. Mike Michael (2017) writes that “any specific human individual or collective, any given technological artefact or system, has resulted from the configurations of associations that draw in both human and nonhuman” (p. 41). Hence, identity is relational since it is always emerging through interactions in the network with other human and non-human actors; it is an effect of the network. This relates back to the relationality of the self as discussed above in 2.3., showing that people are always entangled with others. This is also important to keep in

mind when thinking in terms of citizenship, which I will introduce as a second sensitising concept. Michael (1996) furthermore emphasises, aside from the non-human impact on the construction of identity, the historical, local, and political conditions at play: the emergence of identities needs to be seen in their context. He argues that "social practices constitute givens which have consequences" (Michael, 1996, p. 5), pointing out that institutions and their practices, like consent procedures, contribute to the constitution of identities. With biobanks and the contexts in which they are situated, new ways to structure and imagine our lives occur, yet it also always needs to be considered that things could be different (Michael, 1996), e.g., when practices change. Informed consent for example is an active non-human entity to which certain functions have been delegated, which then provoke actions from other actors (Sayes, 2014). If the practice is altered, the actions and effects it induces change accordingly.

ANT has repeatedly been criticised for its apparent ignorance towards the existing differences between the capabilities of humans and non-humans and for depicting them as equal (e.g., Jasanoff, 2015), whereas non-humans do not have the same cognitive capabilities as humans and only come to matter in interaction with humans. However, being impartial (principle of generalised agnosticism), not making any a priori distinctions (principle of free association), and using the same terms to describe humans and non-humans (principle of generalised symmetry) do not imply that they have the same agency, only that it is distributed among them (Callon, 1984; Latour, 2005; Michael, 2017). Yet, it remains a weakness in that ANT neglects existing power structures due to its principles (e.g., Star, 1990). Furthermore, the principles of symmetry and agnosticism pose some challenges in practice as the non-human entities cannot be interviewed but simply observed. This marks a distinction between the different actors; only the perspective of the human actors can be captured by conducting interviews. Moreover, by choosing interviewees, some roles are assigned a priori.

Despite its limitations, ANT remains a valuable theoretical framework as it pays close attention to the role of non-humans and materiality more generally in our society as well as how humans and non-humans mutually construct each other. This helps to follow the interviewees' associations with other actors (samples, data, consent, clinicians…), gaining insights into these relations and how the participants make sense of them, and emphasising how realities are multiple, enacted, contingent and always in the making (e.g., Law 2004; Michael, 2017). This is of relevance as I want to find out how the participants understand their contribution to a biobank, mediated through the informed consent process. As Mike Michael (2017) has said, "ANT reconfigures our understandings of the processes that shape the social world" (p. 6) and helps to see its complexity.

4.1.1. Obligatory Passage Points

Now it is time to discuss the already several times mentioned ominous obligatory passage point in more detail. An OPP can maybe be best imagined if we think about it as a bottleneck or a gatekeeper, which all actors need to pass. For example, in the times of the COVID-19 pandemic, it was required to show a COVID-19 certificate in order to be allowed to enter certain venues like theatres or restaurants. At this passage point, people were forced to comply or otherwise, they could not pass. In a sense, an agreement is achieved, or rather created, between the different actors with different interests, which converge at the OPP. OPPs are essential for forming a network as they establish and (re-)configure relations between different actors, e.g., in a biobank informed consent is a way to negotiate the relationship between participant and biobank in written form prior to the research. It mediates and structures the interaction between the different actors, as through informed consent responsibility, agency, and ownership are clarified; it is a "single locus that could shape and mobilise the local network" (Law & Callon, 1992, p. 31). The OPP is usually a central part of a translation process (Callon, 1984), where certain actors' interests influence other actors so that their interests and identities are redefined in order to align with the rest of the network. When the interests are successfully translated, the actors have been 'enrolled' and are fulfilling their, by the other actors, assigned role to act in accordance with the network (Michael, 2017). The informed consent process initiates the circulation of data and samples by transferring them from the person to the biobank, leading to a reconfiguration of the relation between participants and the contributed material.

Essentially, an OPP shapes the interactions in the network and is essential for building a network and its orientation. In the case of biobanks, informed consent is a way to secure and legitimise participation on the biobank's side, yet it also establishes a hurdle as it potentially could discourage people.[10] It is a point at which the various stakeholders negotiate and align their interests to ensure that the network continues to function, because without consent there are no samples and without samples there is no research. Through the alignment of the different entities, the network becomes more stable and durable. Using the concept of obligatory passage points from which to view informed consent helps provide insights into how much people are affected by it and what different interests are aligned.

4.1.2. Boundary Objects

However, there are several issues with using obligatory passage points as a concept, generally, but also in particular for my study. As abovementioned in 2.2.4., informed consent is often not acknowledged

[10] Yet, this could also be regarded as part of the purpose of informed consent since people are meant to be able to make informed decisions and freely decide if they want to participate.

by the participants in practice, raising the question if a translation is necessary in order for them to become enrolled. As people are already willing to contribute, basically no interests need to be aligned, at least not in the moment of the informed consent. This would mean that I need to nuance the use of the notion of obligatory passage point, towards a mere passing point. Star and Griesemer (1989) developed the concept of boundary objects, which is more flexible than OPP, as it recognises that several processes of translation can occur simultaneously at different places with different actors. These passage points do not have a single dominant perspective, whereas 'classic' ANT scholars like Callon, Law, and Latour look at the OPP originating from a specific actor, who acts upon others (Star & Griesemer, 1989). Furthermore, the different passage points do not need to be passed by all actors but are passed by different sets of actors, e.g., for example in the case of people who have been in the hospital before and from whom no further consent must be obtained. Though the informed consent remains obligatory in a legal sense, in practice it might go unnoticed or take different forms depending on the context, therefore a boundary object might better reflect the characteristics of informed consent. What exactly boundary objects are, is best described in the work of its genesis:

> *[It] is an analytic concept of those scientific objects which both inhabit several intersecting social worlds (…) and satisfy the informational requirements of each of them. Boundary objects are objects which are both plastic enough to adapt to local needs and the constraints of the several parties employing them, yet robust enough to maintain a common identity across sites. They are weakly structured in common use, and become strongly structured in individual-site use. These objects may be abstract or concrete. They have different meanings in different social worlds but their structure is common enough to more than one world to make them recognizable, a means of translation. The creation and management of boundary objects is a key process in developing and maintaining coherence across intersecting social worlds. (Star & Griesemer, 1989, p. 393)*

So, a boundary object is and does many things; it can bring different actors with different interests together and integrate these interests, mediating between the different actors, like an informed consent which informs and transmits rights. It can be the minimal shared denominator, upon which the involved social worlds agree, and which allows for collaboration. It is a shared object that enhances the communication between the different sides and their autonomy and "makes new kinds of joint endeavour possible" (Star & Griesemer, 1989, p. 413). It matters where different social worlds meet; it is a common ground; an object in which both sides have an interest as it helps to achieve their goals by appropriating the object and deriving the benefits they need from it due to its interpretive flexibility. There are different meanings for different actor groups, but this is usually understood by all parties

involved. [11] Hence, at a boundary object, we come upon a more balanced relationship than at an obligatory passage point, where rather a one-way street can be found due to being set up by central actors for others. Stark and Griesemer still look at the materiality of things but do not ascribe them as much agency as Latour, Callon, and Law do (Trompette & Vinck, 2009).

Furthermore, four different types of boundary objects are delineated, one of them being standardised forms. Informed consent processes can be counted among them since they are "methods of common communication across dispersed work groups" through which, ideally, "uncertainties are deleted" (Star & Griesemer, 1989, p. 411). As a boundary object, informed consent helps to create and stabilise the network by connecting and assembling researchers, clinicians, and research participants.

Using boundary objects as an analytical tool offers many advantages compared to OPPs since it is better at capturing multiplicity and does not have a single passage point but several. As such, data and samples could also be considered boundary objects. Besides, boundary objects acknowledge ambiguity and the co-existence of cooperation and heterogeneity and are less agonistic (Michael, 2017) in contrast to the forceful alignment of interests by a central actor in the case of an OPP. Yet, my interviewees might regard informed consent as a rigid, hierarchical and single passage point rather than as a boundary object. Therefore, both OPP and boundary objects are used as analytical lenses, and it will be observed how they come to matter in practice.

4.2. Citizenship

In addition to ANT, which is particular helpful for discussing informed consent and other non-human actors, I will employ citizenship as a theoretical lens in my work to conceptualise the positionality of the participants. Citizenship is a political concept referring to a relationship between a person and a state, which is often equalised with the membership of a certain nationality (Faulks, 2003).[12] However, though the focus of my research is on Austrian biobanks and participants, citizenship, in this case, is not meant to be understood in a national sense but rather as "a framework for the interactions between individuals within civil society" (Faulks, 2006, p. 107), which is more encompassing: it is concerned with processes of identity formation; with the rights, duties and responsibilities one has as a citizen and

[11] The influence of symbolic interactionism on boundary objects is obvious: humans act according to the meaning that they ascribe to things (Blumer, 1986).

[12] Often in discussions about citizenship, the national context is in focus. For example, in German, 'citizenship' is usually translated with 'Staatsbürgerschaft' or 'Staatsangehörigkeit', showing the strong national association of the term. However, Faulks (2003) argues that citizenship is not limited to national contexts. He wants to liberate it from being associated with nation states, as "the nation is not an appropriate foundation for citizenship" (Faulks, 2003, p. 30), because, for example, national borders lose their importance with increasing globalisation. For example, I also interviewed two people who are not originally from Austria but live and work here and are part of the civil society; they are included in the idea of citizenship that is described here.

as part of a collective; and with the conflicts that arise through these entanglements. Citizenship also points to the interdependence in our lives because of our manifold connections to other people and institutions (Faulks, 2003). As broached earlier, living is always relational, and identity formation does not take part in isolation but within communities and collectives; it is co-shaped by actors around us, including non-humans (Michael, 1996). Following this interdependence, citizenship is dynamic and contingent and needs to be understood in context (Faulks, 2003).

Furthermore, citizenship is concerned with granting autonomy to individuals and recognising them as contributors to society and seeing them as political agents that can make decisions and judgements on their own (Faulks, 2003). Practices such as informed consent are examples of recognizing and enacting these rights while, at the same time, a particular idea of what a citizen should be like are upheld and imposed, thus co-constructing identities (Bühler et al., 2019). Another important characteristic of citizenship that matters in the context of biobanking is an ethic of participation: in order to have a functioning society and a good life, individuals need to participate actively in the societal and political spheres (Faulks, 2003). There are passive and active conceptions of citizenship, and in many Western societies, citizens are rather passive receivers of rights, but active engagement is sometimes needed and encouraged (Hintz et al., 2019). To strengthen the ethic of participation, Faulks (2003) argues for making voting obligatory, like military and jury duty in some countries. Also surrounding biobanking there have been discussions about whether participation should be obligatory, however, it has only been considered a moral duty and not a legal one (Schaefer et al., 2009). It has been argued that certain rights are accompanied by certain obligations, e.g., the right to health, with which biobanks are associated by the circumstance that sample collection takes place in the hospital. Rights do not exist in a vacuum, and there are discussions on whether therefore a "participatory imperative" (Petersen and Lupton, 2000, p.147) exists. In fact, donating to research has implicitly been regarded by patients as part of one's duties as a citizen and as a solidary contribution to (future) society (Felt et al., 2009). So, by contributing to biobanks, the participants potentially enact a certain idea of what it means to be a citizen.

The concept of citizenship reminds us that we are never looking at individuals in isolation but at interdependent and relational agents. Relating this back to ANT, citizens are not just interacting with other citizens but also non-human entities, and society can be regarded as a heterogenous network (Law, 1992). Basically, all aspects of our lives are mediated through objects; we live in houses, move forward with machines, and communicate through technologies (Law, 1992). The material resources one may or may not have enable or restrict one's possibility of exercising citizenship (Faulks, 2003). Through the lens of ANT, this material basis of citizenship can be expanded to the inclusion of laws, infrastructures, data, biomaterial etc.

Citizenship matters in biobanking as giving away biomaterial for research purposes is often framed as a contribution to the future improvement of public health and thus the common good, leading to a

negotiation between individual rights and public interest, as we can also find it in discussions surrounding compulsory vaccinations or quarantining. Regarding participants as citizens recognises as well as respects their rights and responsibilities. Besides, looking through the lens of citizenship helps to keep the broader context of society in mind such as the nationality or the (neo)liberal developments in politics in the past decades, where the individual and their rights and freedom are often prioritised over societal obligations and communal sense, thus also requiring more self-governance and self-responsibility from citizens (Faulks, 2003; Peterson & Lupton, 2000), including being informed and making their own decisions.

Furthermore, with advances in technology and science, new dimensions of citizenship co-emerge since they mediate how citizens experience the world, how they can act in it and what they know about the world and themselves (e.g., Hintz et al., 2019; Lupton, 2020). Simultaneously, citizens co-shape technology and science. Thus, looking at citizenship also tells us something about biobanking, since it is co-produced by individuals and collectives.

In the following, I will present two different aspects that have re-configured ways of thinking and living, including the notion of citizenship, and which become entangled in the case of biobanking; namely datafication, in particularly in the context of health data, and the advances in biomedicine, which have led to the concept of biological citizenship. I conclude the chapter by introducing the concept of (bio)data-citizenship which merges these two aspects.

4.2.1. … in the Context of (Health) Data

While there is little literature on how participants relate to the samples and data they give to a biobank, existing literature on datafication provides insights on how data affects people. In her book *Data Selves*, Deborah Lupton (2020) writes "the emergence of novel ways of generating digital data (…) has facilitated new understandings about how people learn about & conceptualise their bodies and selves" (p. 5f.) to describe the impacts of self-tracking devices and other digital media, which have become ubiquitous in the daily lives of many. People and data are now inextricably entangled in assemblages; they "emerge together" and "make each other" (Lupton, 2020, p. 121). The importance of these devices and services as well as the data they generate continues to grow as more and more aspects of our lives become digitalised. Though citizenship is not explicitly thematised in her book, Lupton recognises that individuals are relational entities, constantly interacting with others and being embedded in societies. Data and being surrounded by technology are constitutive of who we are nowadays; it affects what it means to be human and blurs boundaries (Lupton, 2020). New insights into health and body and the capacity to act on them lead to new forms of selfhood and embodiment. Particularly in the context of health, datafication has overhauled many practices and influenced what health means in the first place (Ruckenstein & Schüll, 2017). With new technologies the production and consumption of medically

relevant information has changed, having epistemological and ontological effects on what can be known and how to act on that knowledge. For example, with the (self-)collection of data, new ways of dealing with illnesses and health issues arise, from tracking steps and cycling over menstrual cycle tracking to insulin monitoring, datafying bodies and health and hence mediating how we experience and understand them both. Since biobanking, unlike self-tracking, does not return data to the individual, these insights are not easily transferable. The data is not directly of use to the individual contributing it, but they are involved in the production of knowledge: through an accumulation of data sets, advances in medicine are enabled on a bigger scale, which may also benefit the contributor.

Similarly, but with an explicit focus on citizenship, Arne Hintz and colleagues (2019) thematise what it means to live in datafied societies and how "a broader set of technological, political and social transformations" (p. 4) has changed our lives. They use the terms data citizen and digital citizenship to capture the possibilities and latitudes that arise through digitisation but also include the risks and problematic aspects like the collection and analysis of personal data. Nowadays, many facets of our lives are datafied and affect our interactions and constitute what citizenship means, since for example, new orders, new ways of participation and decision making, and new identities emerge. As a side effect, the collection of data has become a normalised aspect of many citizens' daily lives. Due to the ubiquitous nature of data and digital technologies in our lives, it might not be surprising then, that when talking about biobanking, citizens have in the past often drawn on common narratives around data, e.g., concerning data protection and privacy (Felt et al., 2018). This helps them to make sense of biobanks and shows that biobanking needs to be seen in the context of big data. But these interactions with data and technology interwoven in our daily lives differ from peoples' encounters with biobank: the biobank does not directly provide a service to them unlike digital services like Facebook, Google, or self-tracking devices, where it could be argued that people receive something in exchange for providing their data, so here we are facing different kinds of relationships. Furthermore, the samples in biobanks are not self-generated and the process of giving them away is not happening on a daily basis.

Nevertheless, many issues of datafication also come to matter in the case of contributing to a biobank; people are concerned about privacy, commodification, exploitation and about how the data is used (Ruckenstein & Schüll, 2017). While the perspectives on data on these issues are insightful, they are not sufficient to address the facets of biobanking, therefore I will now discuss the biological dimension of citizenship.

4.2.2. … in the Context of Biomedicine

With advances in biomedicine and related fields, like whole genome sequencing, new possibilities and knowledge have emerged and continuously challenge and change what it means to be human. To conceptualise this impact of biological knowledge on our (collective) identities, Rose and Novas have

established the notion of "biological citizenship" (2005). According to them, biological citizenship describes "all those citizenship projects that have linked their conceptions of citizens to beliefs about the biological existence of human beings, as individuals, as families and lineages, as communities, as population and races, and as a species" (Rose & Novas, 2005, p. 2). With citizen projects, Rose and Novas mean the ways in which citizens are imagined by institutions, governments etc., the actions that are implemented to achieve this, e.g., by determining who is allowed to participate, and how this reconfigures identities. Nevertheless, biological citizenship should not be understood as a purely top-down endeavour, since citizens have leeway in how they make sense of these pre-settings and how they construct themselves. For example, patient organisations and activist groups have co-shaped what citizenship means by successfully stepping up and becoming involved in governing processes and decision-making, e.g., concerning how drug research is conducted (Epstein, 1995) or by recruiting donors as well as financing and sustaining biobanks for myopathy research (Mayrhofer, 2008).

Rose and Novas (2005) delineate hope for future treatments and cures as the main driver for becoming actively involved. In that sense, contributing to a biobank could be seen as a way to invest into the future; one's own and that of others. Hence, biological citizenship takes place within a "political economy of hope": there is hope for treatments, and that is why life becomes capitalised and oriented towards these treatments (Rose & Novas, 2005). This produces "a public arena in which responsibility for the cure is not merely attributed to scientists and doctors" (Rose & Novas, 2005, p. 26) but to those impacted by illnesses and those that could be, or broadly speaking it extends to the public. As such, the expectations and commitments of citizens, which they have for themselves, their families and broader communities, become intertwined with their biology. With increased (potential) knowledge about health, illness and genetics, "aspects of life once placed on the side of fate become subjects of deliberation and decision" (Rose & Novas, 2005, p. 36). This impacts citizens' rights and duties, for example, the responsibilisation of the individual due to the available knowledge. As such, biological citizenship is individualising as well as collectivising (Rose & Novas, 2005), affecting the individual through biological knowledge and collective movements like patient organisations.

In the future, through the investments and acts in the present, biomedical research will further evolve together with advances in e.g., machine learning, which affordances augur personalised medicine, and information technologies, such as interfaces for dynamic consent, which could potentially facilitate the consent process and the return of results. What we know about our bodies and ourselves is likely to be continuously expanded and reconfigured, emanating from a close entanglement of biomedicine and datafication.

4.2.3. (Bio)data-Citizenship

The term (bio)data-citizenship was coined by Ulrike Felt et al. (2020) in order to jointly account for the impact of biomedical progress and the increasing datafication of our lives, including the production, collection and analysis of health data, as this constitutes the context in which biobanks have to be understood in. The concept draws attention to the changes surrounding citizenship through the rise of big data in various areas of society, one of them being biomedicine. With datafication, new practices and relations emerge that enable unprecedented forms of engagement with our bodies and health, and due to the knowledge, that is gained, one's body and health are perceived differently. In other words, data mediates how we see our health and body, and thus how we act in relation to them (Felt et al., 2020). Also, biobanks can be regarded as mediators in that sense, since they influence how the world is understood and affect how we relate to our bodies, health, and others.

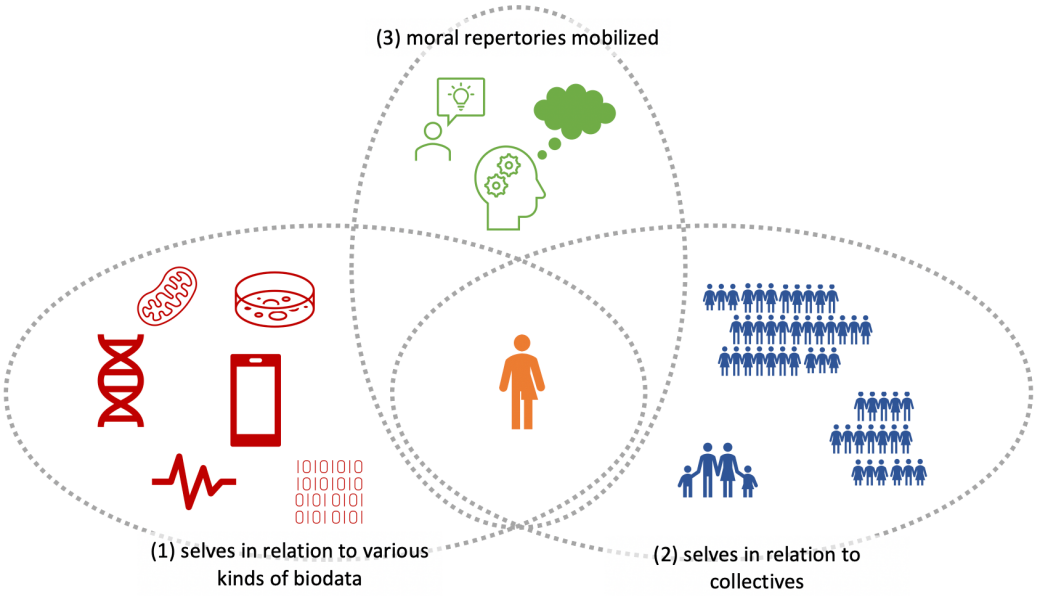

Figure 1: Dimensions of bio(data)-citizenship (Felt et al., 2020, p. 46)

Felt et al. (2020) depict several dimensions of (bio)data-citizenship, of which the first *(selves in relation to various kinds of biodata)* has the strongest link to my research interest on the self-understanding of participants, but it is, as indicated by Figure 1, overlapping with the other dimensions, *selves in relation to collectives* and *moral repertoires mobilized,* such as values and norms, that are playing a role when talking and thinking of the relations to biobanks, data, others and the self. All dimensions come to matter in the formation of identity, or rather the construction of identity (Michael, 1996), as it is impacted in a top-down manner by expectations, rights and duties that are imagined by others e.g., through the informed consent process. In this way, multiple imaginations of citizenship are produced. In addition, how people relate to biobanks is formed by their history and former experiences with the state and

institutions like the health care system and how they perceive their role in the context (e.g., Hoeyer, 2003; Hoeyer & Lynöe, 2006). At the same time, through their participation, citizens shape biobanks and help to reinforce their legitimation, hence citizens and biobanks are co-producing each other (Bühler et al., 2019; Tupasela et al., 2015). With (bio)data-citizenship, we have an encompassing notion that takes the different aspects constituting the climate of biobanking into consideration and thus helps us to illuminate how citizens are affected by their participation and the many questions that emerge in the context: How do they relate to the contributed biomaterial? To whom does material belong? What are the reasons for their participation? What are the imagined ideas of citizenship and what do they look like in practice?

5. Methods & Material

In this chapter, I describe my approach to answering the research questions, starting in the beginning with a description of the case background, then continuing with the preparation, conduct, and analysis of the qualitative interviews along my chosen methodology, Constructivist Grounded Theory. I conclude with some ethical considerations and constraints.

5.1. Case Study

The work on my master's thesis began in parallel to the start of my job as a research assistant for the BBMRI.at#2 project at the Department of Science and Technology Studies, alongside Ulrike Felt and Lisa-Maria Ferent, who have already been working on the project. BBRMI.at is the Austrian Biobank network and one of the over twenty national nodes of BBRMI-ERIC, the European Biobank Research Infrastructure (BBMRI.at, 2023). Currently, BBMRI.at is in its second funding period (December 2018 – November 2023), therefore called BBMRI.at#2. It encompasses 6 different biobanks connected to medical universities and consists of seven work packages, with the University of Vienna contributing one. The objective of our work package is to look into the societal dimensions of biobanking in Austria, with a focus on (1) how the different actors involved in biobanking (researchers, clinicians, citizens, etc.) value the infrastructure and which values are at play in biobanking and (2) how people relate to and are impacted by samples and data, for which the abovementioned notion of "(bio)data-citizenship" was developed by Felt et al. (2020). I was mainly responsible for the part of the work package that focussed on citizens and participants of biobanks. My tasks, in collaboration with other project members, included the recruitment of and contact with potential interview partners, the development of the interview methodology and conducting the interviews, as well as analysing data, drafting reports, and contributing to other work package-related tasks.

Like many of the people I eventually interviewed, I initially knew little about biobanks, which is why I was lucky to draw from the resources that were collected in the previous BBMRI.at projects and to attend meetings of the Austrian biobank partners that gave me insights into biobanking practices. Working on the project gave me the opportunity to conceptualise my research interest around the topics we were looking at and to make use of the data we collected. Early on I decided to focus on the aspect of how participants are relating to their data and samples because of my personal interests in the impact of technoscience and being more familiar with the literature in the field of data and citizenship. Therefore, I looked more deeply into how citizens are affected by their contribution and, based on the literature, identified the informed consent process as a crucial moment in the citizen-biobank relationship since it is at this moment that ideas are materialised in written form and roles are delegated. As I have discussed though, these forms are not necessarily always read, thus rendering it an interesting

point of tension between how informed consent is imagined and how it proceeds in practice and what this means for how people perceive their contribution. The research question that I worked out from this interest and the literature are described in Chapter 3.

5.2. Empirical Material

After having depicted the context of my study, I want to outline how the collection and analysis of the data proceeded. Overall, my methodology is based on a version of Grounded Theory as developed by Kathy Charmaz, Constructivist Grounded Theory (CGT). After introducing CGT, the data collection by means of semi-structured qualitative interviews as well as the data analysis will be discussed, both oriented towards CGT.

5.2.1. Constructivist Grounded Theory

"We do not see things as they are, we see them as we are" – Anaïs Nin (1974, p. 578)

Grounded Theory (GT) was first introduced by Barney Glaser and Anselm Strauss in 1967, with the objective to develop theories out of empirical evidence, so that the theory is grounded in data (Glaser & Strauss, 1967). Since then, it has been further expanded, separately by Glaser and Strauss, as well as by others including Kathy Charmaz (e.g., Charmaz, 2006; Glaser, 1978; Strauss & Corbin, 1996). Charmaz developed a Constructivist Grounded Theory, in which she adopts and adapts some of the predecessors' characteristics.

A Grounded Theory approach is of value for my project for several reasons. First, it is inductive and exploratory, thus very open to the data, and through its qualitative methods, it can capture complex social realities (Strauss & Corbin, 1996) since it gives access to the inner and usually hidden feelings and thoughts of the interviewees and explores social worlds from their perspective. Developing categories uncovers the main aspects, and we gain insights into how the interviewees make sense of the world around them. By going back and forth between data acquisition and analysis until theoretical saturation is reached, meaning that no new insights arise through new interviews (Charmaz, 2006), an encompassing picture of the issue can be painted.

I decided to use Constructivist Grounded Theory (Charmaz, 2006) as it not only provides a rich tool kit for the research process but also pays close attention to the role of the researcher, through which it sets itself apart from classical GT where the main focus is on the data and not the surrounding conditions. Other advantages of CGT are its endorsement of literature reviews, the use of abductive reasoning on top of an inductive basis and its demarcation to positivism, by acknowledging that there is not just one reality (Charmaz, 2006). Theories and more generally any empirical findings do not just emerge from

the data but are constructed through the interaction of the researcher with it (Charmaz, 2006). Hence, researchers are always involved in the constitution of the research context and the resulting data, and the methods they employ are not just tools for describing social realities but constitute reality (Law, 2004). As an interviewer who asks certain questions and predetermines the structure of the interview, I play a direct role in what answers are given. By taking a constructivist stance, I acknowledge that each interview and consequently the resulting data are products co-constructed by the interaction of the interviewee and the interviewer and that they are never objective nor given (Charmaz, 2006; Silvermann, 2006). This is amplified during the analysis, as the codes and categories do not simply emerge from the data but are constructed by me (Charmaz, 2006). I am myself part of networks and co-constitute them, so I affect other actors as much as they affect me.

Constructivist GT comes to matter throughout the research process. For example, it influences how data are collected, using theoretical sampling: the iteration between data collection and analysis that allows for adjustments, e.g., of the interview questions, based on intermediate findings, therefore helping to remain flexible and open. Also, for the data analysis, CGT provides useful tools such as memo writing, coding, and comparison methods (Charmaz, 2006), which I will present later.

5.2.2. Recruitment of Participants

Before being able to start with the interviews, the biggest challenge was recruiting interviewees. As we were particularly looking for people who had already contributed to a biobank, the question was how to obtain access to the participants' contact information in the first place. For this, we cooperated with the biobank in Graz, which is affiliated with the Medical University of Graz and one of the partners in the BBRMI.at project. The principal investigators of several biobank collections were approached, yet some declined, e.g., in order to not put any additional burden on their patients. In the end, we got the allowance to contact three collections that featured healthy participants and were supported in establishing contact to them, but the process was prolonged because of the submission of a required ethics application to the Medical University of Graz and the approval by the ethics committee. Eventually, people were invited to our study by contacting them via mail or during their visits to the hospital from September onwards. If they were interested, they could contact us, and an interview was arranged.

For the interviews, one person was recruited personally, who had participated in a COVID-19 booster vaccine study. From the collections, 7 people reacted to our invitation, 6 of them coming from the same study, which was a different booster vaccine study, while the seventh person is participating in a longitudinal biomarker study. Consequently, I conducted 8 semi-structured interviews between September 2022 and April 2023 for my master's thesis with people who had previously contributed to a biobank. One half of the interviews were conducted in person and the other half over Zoom. In both

online and in-person situations, I obtained informed consent in written form and explained our method and project prior to the interviews,[13] giving them a chance to ask any questions before starting the interview and the audio device that recorded the interview. The interviews lasted between 27 and 95 minutes, with an average duration of 65 minutes. In some cases, an informal conservation continued afterwards. The gender distribution was equal, with 4:4 The ages varied between 25 and 72 years, with a mean of approximately 40 years. All of them had at least graduated high school (*Matura*) with most having further professional or academic education. Except for one person, everyone was a native German speaker. The parts of the German interview transcripts presented in this thesis were translated into English.

For the project, also 23 non-donors were interviewed and though the content of these interviews certainly informed my general understanding of the matter and my analysis, I decided to focus only on interviews with the biobank contributors. In this way, I could collect accounts of how people experienced contributing and the informed consent process first-hand, and the interview set of participants was sufficient in that the data offered diverse views, while also having a robust set of themes.

5.2.3. Means of Data Collection

Initially, the plan was to conduct card-based group discussions. For several reasons, e.g., an ongoing pandemic and the increased difficulties in organising on-site meetings with several people, we decided to switch to qualitative, semi-structured interviews as the more pragmatic and sensible method for the inquiry. Besides, in contrast to previous studies within BBMRI.at, which involved citizen-expert panels (Felt et al., 2018), the use of semi-structured individual interviews helps provide deeper insights into the themes that emerged in these earlier discussions and delve more thoroughly into how individuals that have contributed something construct meaning. Through semi-structured guidelines and open-ended questions, the individual perceptions, attitudes, and experiences of the participants become accessible which otherwise would not have been observable. It also allows the researcher to react to the interviewees' statements and ask follow-up questions, which can broaden or deepen the conversation (Charmaz, 2006; Jensen & Laurie, 2016). Thus, the interviews took slightly diverging paths or had other foci, yet they were all based on the same interview framework, which facilitated working out similarities and differences in attitudes and experiences across the different interviews.

[13] The irony of following a procedure that I have criticised earlier for its lack of practical relevance is not lost on me, but it remains the best available procedure and to which there is no alternative. As I am aware that people might not read the sheet, I went through the information verbally as well.

The initial questionnaire was developed together with the other people on the project, including Laura Bomm, who temporarily supported us with the conceptualisation of the interview material (see Figure 2). The aim was to cover the most important aspects of our research interests (including mine), thus pre-structuring the course of the interview and its topics while also remaining flexible (Jensen & Laurie, 2016). I revised the interview guide after each interview, adding new aspects or removing questions that did not work out in practice, and included the participants' contexts of donation.

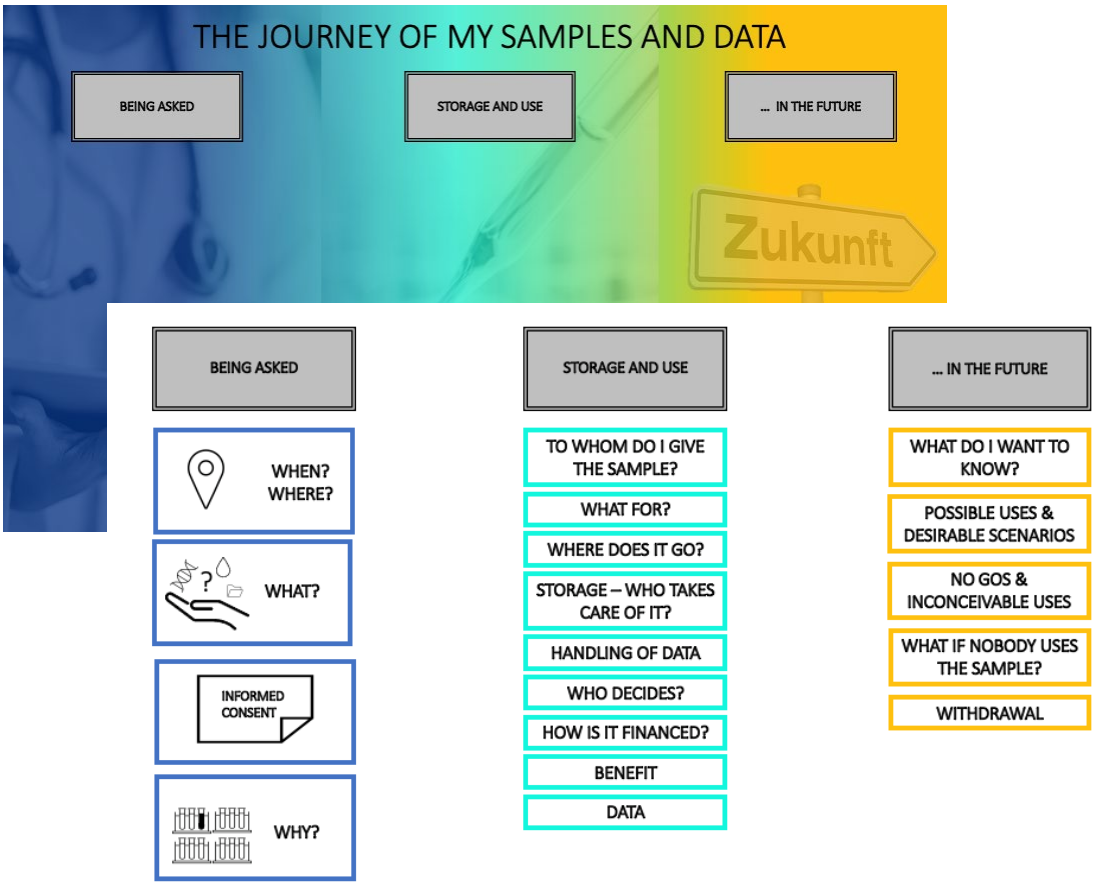

Figure 2: English version of interview poster and cue words

The interviews were supported with visual input material in the form of a poster (Figure 2). For the conceptualisation of the poster, the questions from the guideline were divided into three blocks, each depicting a main facet of the biobanking process and signifying the journey of data and samples: the context of being asked and contributing, the storage and usage of the data and samples, as well as future perspectives. Specific key terms belong to each area, which could be provided as add-ons to the poster, such as "When? Where?", "Informed Consent", and "Who decides?", depending on the course of the interview. The intention behind using the visual material was that it might aid to make this topic, to which people usually do not devote many thoughts (Hoeyer et al., 2004), less abstract and to facilitate the conversation by providing an overview and point of references, to which they can come back to

throughout the interview (see Glegg, 2019). By visualising the different practices in biobanking we furthermore circumnavigated the usage of certain words which might lead to pre-conceptions and certain images, because, as mentioned, terms like donation, donor etc. imply the act of gifting something and are morally laden. Language, like technology, enables and restricts its users to act and think in certain ways. Hence, with this visual aid, we attempted to avoid a predetermination of the language and let the interviewees conceptualise it themselves.

As the overarching research project also focuses on other aspects beyond the topic of this master's thesis, the interviews only partially addressed my research question. Particularly relevant was the block about the context of being asked, where the informed consent was discussed. Yet, the other parts of the interviews were still relevant and insightful with regard to the conceptualisation of data and samples in relation to oneself and offered contextualisation.

5.2.4. Data Analysis

The data analysis took place after the verbatim transcription and pseudonymisation of the interview data and was facilitated through Atlas.ti, a software for qualitative analysis. The goal of the data analysis is to find patterns and themes in the available data in regard to the research questions (Jensen & Laurie, 2016). Through coding the data, a thorough grasp of how participants understand their contribution, how they relate to biobanks and research and what motivates their actions can be formed. For this, the transcribed interviews were first initially coded, followed by focused coding (Charmaz, 2006). During the initial coding, I tried to stay close to the data while also being open to all possibilities, following abductive logic (Charmaz, 2006). I coded both line by line as well as paragraphs to break up the data. Next followed focused coding, based on the initial codes. For this, I subsumed and selected relevant codes. From the focused codes, categories were constructed, which I then tried to put in relation to each other. In all phases, constant comparison of codes and categories with and among each other is crucial, as this reveals differences and similarities that lead to the construction of new categories. This is also important for theoretical sampling as it informs whether further data collection is required. I supported these processes by writing memos, which contain notes on the codes, their connections, and existing gaps as well as other thoughts and reflections on the research process, providing transparency and a way to trace trains of thought. The memos also lay a basis for the writing process and simultaneously help to put thoughts into writing and thus sorting and advancing these thoughts. As such, writing becomes part of the analysis and cannot be separated from it.

5.3. Ethical Considerations & Challenges

As mentioned earlier, the recruitment of the participants for the study was approved by the ethics committee of the Medical University of Graz. For our study, informed consent from the participants in written form was obtained prior to each interview, where they were informed e.g., about the objective of the study and that the data, with regard to storage and access, is handled according to the GDPR. The interviews were only recorded if the participants permitted it. Furthermore, they had the possibility to end the interview at any point as well as to withdraw their consent, also in the future. In order to protect our participants and to provide confidentiality, the data has been pseudonymised and is only accessible to the people working within the work package, and the interviewees could decide if their statements can be cited in presentations and publications. Yet, it remains a possibility that people who know them can identify them based on their statements. Also, to consider is that in the context of biobanking, it is likely that someone's medical history comes up, which can be a potentially sensitive matter and therefore needs to be handled with care.

The participants were compensated with 20€ for their time and efforts. In that way, it was hopefully possible to avoid a bias of only having people willing to bear the costs for their participation. At the same time, the monetary compensation is not so high that it would be a sufficient reason for people to participate. Because this is a convenience sample (and not a representative sample), as is usually the case in qualitative research, self-selection bias is expected to persist. The sample consists of people who are willing to participate, thus we are not assembling a neutral group of people, but likely one with a positive bias towards research. Another caveat of the methodological approach is that with interviews the focus is on studying other people's perceptions and not their behaviour (Silverman, 2006), meaning that we have to rely on their accounts, whereas what people say is not necessarily how they act (see Johnsson et al., 2010). Nevertheless, through interviews, I get an insight into the participants' sense-making and their justificatory practices.

An additional challenge is that between the objects of my interest, the informed consent and the contribution to the biobank, and the interview with the participants more than a year had passed. Relying on memory is generally a difficulty but in the case of biobanking it is an added hurdle since, as discussed in the state of the art, people who have contributed do not think about their contribution a lot and make mostly broad statements in interviews (Hoeyer, 2004b), sometimes they do not even remember having participated. Yet, this also makes it interesting to see which aspects they remembered and what matters to them in the context of the interview. Through the interview, they are in a situation where they are propelled to think about things they have not considered before (see Hoeyer, 2004a), and more attention than usual is generated for the topic. This relates back to CGT: their accounts are mediated through the

interview situations, and the data is co-constructed in interaction of me with the interviewee and the interview material, which might already lead to changes in how they think about certain aspects.

Due to external circumstances, namely the low response rate to our recruiting efforts and the time horizon of the project and the desired finishing date of my master's thesis, the number of interviews was restricted. Therefore, I could only conduct 8 interviews with biobank contributors. Still, already among these interviews, many themes re-emerged, while at the same time also depicting diverse views within the context of (healthy) study participants' experiences with informed consent in Austrian biobanking.

A particularity of the sample was that all interviewees were participants in medical studies, which means that they first decided to participate in a study and then upon consenting to the study they also agreed to contribute something to a biobank. This is noteworthy since it acts as a confounding factor: reasons for participation in the study might differ or at least are more specific in comparison to a biobank contribution (e.g., receiving feedback on their results as part of the study). As these two contributions were taking place at the same time and one of them led to the other, it is often difficult to disentangle them and analyse them separately. When looking at the data, it is thus important to keep in mind that all participants also, or rather initially, participated in a study, and in addition to it agreed to have samples taken for a biobank.

An additional particularity of the sample was that a majority of the participants were working in a health-related job or at least within the context of a medical university. This was caused by one of the studies being connected to a COVID-19 booster vaccination being offered to people who were employed by the medical university. Yet, the interviews showed that those participants did not necessarily know more about biobanks, still, their situatedness played a role in their sense-making.

6. Analysis

The following chapter, which consists of the presentation and analysis of my empirical findings, is structured into 4 parts, oriented along my different research questions. In the first part, I examine the factors that shape individuals' decisions to participate in biobanking efforts. This includes the role of the context as well as the common concerns that individuals may have in regard to biobanking, where I concludingly argue that participants weigh the benefits against potential risks and costs, thus turning the decision to participate into a cost-benefit analysis. Section 6.2. focuses on the informed consent process and how the participants perceived it. I explore the different ways in which individuals understand and remember the informed consent process, and how the process impacts their understanding of their contribution. Following this, I look at the participants' relationships to their data and samples that they contributed in section 6.3., discussing aspects like ownership and agency. In section 6.4., I focus on the relationality of the biobanking process, meaning that I will look at how participants think about others and are connected to them in the context of biobanking, which can take including and excluding forms. The different findings will be drawn together in Chapter 7, trying to answer my main research question, which asks how people relate to their contribution of biodata in the context of biobank informed consent processes while simultaneously discussing the findings along further literature and my chosen concepts.

As the data is the product of eight interviews, one will find the numbers 1-8 behind the quotes that I use, in connection with the year in which the interview was conducted, helping me and the reader to trace the statements of the individuals. Before continuing, I want to make a short remark on language, like I did in the beginning of the State of the Art, where I talked about how the words chosen in the context of biobanking can have an impact. For this reason, I tried to avoid the term donation and its derivations in the interviews, however, in practice, it was more difficult than expected to use alternatives, as both the interviewees and I often reverted to using donation etc. I will continue to mainly use the terms contribution and participation. However, in comparison to previous parts of this thesis, I will use also donation and the like more frequently, attuning to the diction of my interviewees.

6.1. Making Sense of Their Contribution

With regard to my first subquestion, “How do people assess their contribution to a biobank?”, I discuss several aspects that contribute to that assessment, like contextualisation, the different factors that shape their decision to participate, and how they interact.

6.1.1. Context, Convenience & Other Contingencies – Factors for Contribution

When participants talked about motivations for and the context of their contribution, several factors came up which seem to shape their willingness to contribute, already indicating the complexity of the matter at hand. While I cannot offer an exhaustive list of all the different factors, I will present the most prominent ones that I constructed from the data: personal context, convenience, receiving benefits, contributing to the common good, reciprocity, and an imagined value hierarchy of biomaterials as well as trust and the lack of concerns. The different factors interact, making participation conditional in multiple ways.

Context – "I took part in the study"

The most prominent factor for the contribution, at least for the specific group of people that I interviewed, was the context of the study they participated in. Having already mentioned it before, it is not possible to disentangle the contribution to the biobank from the study, since one preceded the other. This also means that people had already decided to participate in the study when they were asked to give material to a biobank. As one person pointed out, someone who would say 'no' to a biobank might not be someone who would take part in a study in the first place (2023_8), or if we turn it around: if you have already said 'yes' to the study, you won't say 'no' to the biobank. These people are willing to contribute to scientific purposes and their motivation is already high enough to participate in a specific study, so why would they not also contribute something more generally? To deny their consent to the biobank would be regarded as inconsistent with their previous behaviour.

In this context, it is not about biobanking primarily but about the study. And for most of the participants, the study itself was embedded in a particular context, as they asked if they wanted to participate in the context of receiving a booster vaccination against the Coronavirus. The attitude of 'why not' could be observed frequently, as if there simply was a lack of reason against the contribution to a biobank if one is already there for the study and the vaccination, respectively. The only thing that they had to do in order to extend their participation to a biobank contribution, was to sign a separate biobank consent form in addition to the study-specific consent, after being asked if they wanted to contribute something to a biobank. No material other than what was collected for the study was taken (except for some additional amount of blood).

The study contextualises the request for a biobank contribution, so to say it builds the frame for it, it is the foreground within which the non-specific biobank contribution takes place, thus it is not surprising that people recall more things about the study, and that their accounts often reflected more their attitudes towards the study. This shows that how they think about biobanking is determined by the context in which it takes place. Besides, other context factors were involved in how they felt about donating, like

their profession and who their employer is (2022_5, 2022_6), medical condition (2022_1), or age (2023_8).

Some participants also stated that it was not even clear that they were donating something to a biobank and only through the invitation to our interviews were they made aware of this (2022_7, 2023_8). This has several implications: not knowing that one's samples are used in biobanking makes it void to have any thoughts and concerns about it and they are only generated when being made aware of it. This attitude of 'what I don't know won't hurt me' and 'what the eye does not see, the heart does not grieve over' is often reflected in the attitudes of the participants. Secondly, it shows the generative power of the interviews: by inviting them and asking questions, we made them think about issues that they had previously not thought about. The co-constructive role I play as an interviewer becomes apparent. For many of them, it was the first time they grappled with the topic more intensively, as they also stated that they did not further discuss the participation with anyone, only aspects of the study, and did not think much about what would happen to their biomaterial once it had left their bodies (which does not mean that it does not interest them though). For them, thinking about the topic was triggered through the interview situation and was nothing they otherwise did on their own.

We see that biobank participation does not play a big role, neither at the point of the contribution nor in the aftermath, as it is always overshadowed by the context in which it takes place. The context matters, as the contribution to the biobank cannot be seen separately from it. The contribution is always part of another process, here the participation in a study, but in other cases, it is most usually embedded in clinical care.

Convenience – "I am already here"

The overshadowing of something else also offers the explanation for one of the most prominent factors for their willingness: it does not require any effort from the participant, as they were already there for the vaccination and for the study, respectively. They had to sign papers anyway, their participation in the biobank does not change anything about the procedure (except for the additional informed consent, which was sometimes not even remembered) and they do not have to do anything for it. This lack of effort was very present throughout all interviews, being the code that I used the most in the analysis. As being asked to contribute something to a biobank is always part of another occasion, be it participation in a study or clinical care in the hospital. one participant fittingly described it as a "side effect" (2023_8). The study was foregrounded for the participants, as it offered an incentive (e.g., antibody titer or information about health status) and a specific purpose, both aspects a biobank cannot offer. The strengths of a biobank, so to speak, lie elsewhere: all participants mentioned the simplicity of the process, the fact that it did not take much time, and the convenience of being able to participate while being at the clinic or during working hours. All these aspects suggest that having a convenient and

efficient process for participation can positively shape participants' willingness to contribute to biobanks, which is illustrated by this quote:

> *I don't recall it taking much more time. So, I think for me that was what was convenient about it. While you were there, they're like, "Can we take some extra blood for this or some extra samples?" and I was like, "Sure, I'm already here". (2022_5)*

Being a partial aspect of something else enables effortlessness. The same person adds that if it were a standalone donation of a sample, she probably wouldn't do it, also because she does not know what it is used for, pointing at the unspecificity of biobanking as a weakness. Interaction of the different factors is at play: if it is convenient for them, then it is also alright not to know what the samples are used for, but as a singular instance it would not be attractive. Biobanking is dependent on being a side product to other situations, be it clinical care or studies. Within a given context, it becomes 'natural', which we can see for example by the statement of the person above, saying "Sure, I'm already here". Within this context, it means no additional effort, while consciously opting for it and going somewhere would. With additional effort, people become more reluctant, pointing out its contingency and how the willingness can shift depending on the context.

On top of that, most of the participants work in close proximity to the study's facility, so they had a short distance, no costs for getting there, and could do it within their work time.

> *(...) I thought it was not such a big time commitment. Because it was just over at the clinic, it is only taking blood and saliva samples and if it is only such small things, then I think to myself, I am happy to be a participant in the study, because it is often difficult to find enough participants anyway, I think to myself. (2022_3)*

Though this participant rather referred to the study participation than the biobank, this applies to the biobank as well. We can already see a lot of different factors coming together, aside from the proximity, also the little time commitment and the low effort of only giving saliva and blood were mentioned. On top of that, this participant was also impacted by thinking that it is a challenge to recruit participants and thus was happy to help. Only for two interviewees the context differed, in one case it was as part of a medical appointment that also included a study, and in the other case, the participant has been part of a longitudinal study for many years, which offers him benefits in form of health screening so that the time he invested "was worth it" (2023_8). This indicates that the personal situation and embeddedness matter: it needs to be compatible with their daily lives, e.g., it needs to be approved by the employer (2022_3, 2022_4, 2022) and not take up considerable space or time, or if it does, it needs to make up the time commitment through what they receive in return. They are not willing to go the extra mile for their participation, in the quite literal sense. It should be as little disruptive as possible, especially if you do not get a lot in return. When they get something back, the potential costs that they are willing to bear

increase (2022_2, 2022_6), hence becoming a cost-benefit consideration that is grounded in pragmatic reasoning.

Receiving Benefits – "Kind of a win-win"

Not only was it not an expense but the participants of the studies also received something for their participation, which is why several times, people talked of a "win-win" situation (2023_8):

> *Basically, to just once participate in the study, so to speak, to help a little bit or to make it possible. It was not really an additional effort for me, on the contrary, I then even got an antibody test. That was kind of a win-win for me. (2022_6)*

The participants could support research and help others, while also receiving benefits for themselves, therefore both sides benefited. Of course, benefits like the antibody titer in the case of the COVID-19 studies, insights into one's state of health in the longitudinal study or receiving an earlier medical appointment, are not part of the biobank, but as they were asked to contribute to the biobank in the context of the study, this was frequently mentioned as a reason for why they participated. It is again emphasising that the contribution to the biobank is strongly entangled with the participation in the study: while the feedback they received is part of the study, it is also affecting their contribution to the biobank. One participant (2022_4) also admitted that the antibody detection was the main reason for participating in the study because they got it for free and would otherwise need to pay for it. During the time of the study, which was Winter 2021/2022, this knowledge was quite valuable, enabling an assessment of one's vaccination protection. Similarly, another interviewee described getting the antibody titer for free as the "biggest perk" (2022_5) of the participation, and another one said that as he was curious about the antibody titer test it was a quick decision for him to participate in the study (2022_6), else he might have had to think about it longer, but believes that he would have come to the same result and participate.[14] A participant of another study uttered "it wasn't that I gave away biosamples for public benefit reasons, but that I just expected from this project (...) I get very good feedback about my health condition at regular intervals" (2023_08). If it would not pay off for him, he would not be interested in the study in the first place. This makes sense following a cost-benefit analysis, as in his case, the participation in the study was more effortful since it entailed biannual health checks that took several hours. Thus, the benefits must be higher to counteract the costs than those of the vaccination study participants, whose visits did not last longer than 15 minutes, according to them.

[14] As such, contributing is not simply a yes or no decision, but it is nuanced, as how fast one decides to participate can be affected by different factors and the interplay of them like the benefit (2022_3, 2022_6).

While in the context of donations for medical or scientific research including biobanking, altruism is often a buzzword (e.g., Locock & Boylan, 2016; Tutton, 2007), we see that it differs for the study participation in these cases. Even if there are altruistic tendencies, it is definitively not the sole reason. Since the studies constitute the context of the biobanking contribution, it is heavily affected by it. Helping research alone is not a sufficient condition for their contribution but needs to be complemented by convenience or personal benefits, otherwise, some would not have agreed to participate in the study in the first place. And if they had rejected the study participation, they would not have gotten into the position of being asked to contribute something to a biobank.

On the other hand, people also said they would have contributed something without receiving feedback, it just made their decision to take part in the study easier and was an additional incentive. They also don't expect money in return, but it "is not a disadvantage if you get something" (2022_2). Some people think that it "would have been nice" (2022_3) to receive something but given the low effort, this is neither necessary nor expected. Many interviewees expressed interest in receiving information about how their samples will be used and what results will be obtained from them. So generally, it is appreciated to receive some form of benefit or compensation for their participation in the study, even if it is not monetary.

The Common Good – "Being able to help a greater cause"

The other part of the win-win I mentioned earlier is that one contributes to research and the common good by providing samples and data. It is a more general motivation that spans across the participation in the study and the biobank. People want to do something good and like to feel helpful to research, researchers, and the general public. It reveals a multi-layered valuation, from contributing to the common good to more concrete forms, e.g., helping researchers or finding cures for specific diseases, which was connected with the personal background of individuals (2022_1, 2022_5). The more personal connection they had to research and medicine, the more specific the cause for their contribution was. For people with less personal relations and intersections to this field, the 'doing something good' remained rather abstract most of the time and research was not specified. However, it was always emphasised that the outcome of research should be positive and give some new insights (2022_6), so resulting in something productive somehow. These accounts were not further specified, showing that people lack imaginations when talking about biobanking. Participation is more understood as an abstract contribution to science, which is probably a consequence of not knowing what the samples are used for in the end. That the results of research could help individual patients was not at the forefront of their thinking, so the intermediate goal for helping people, namely the biomedical research needed for that, was more present. They do it for the potential benefit of future research and the general public, as these two quotes show in an exemplary way:

I don't know if I find advantages for myself but I think it's more about doing something good. I think it's really the same as when I was donating blood back home; I didn't really get anything out of it, but it was just like voluntary work, right? So, it's the idea of doing something that is selfless, I guess, and just being able to help a greater cause. (…) So for me, that was I guess a win, this idea of being able to do something that was helpful. (2022_5)

I do it for the science ((laughs)). So I think, I don't know if there is any advantage for somebody themselves, I think one would have to think more about the general public, for later on, for the future, for the research simply. (2022_3)

This suggests a broader view of the potential impact of biobanking and research beyond individual benefits, but as we have seen this altruistic attitude is not the whole story. The narrative of contributing to the common good is pervasive, rarely questioned, and an enabling factor for participation. Yet, contributing to research and the common good also relates back to themselves and becomes a personal motivation. For example, in the case of a participant who suffered from an autoimmune disease and was talking about research in that area, that person said that "if you somehow get the feeling that you can contribute to the research, then you are also happy for yourself" (2022_1). But also 'healthy' participants voiced similar sentiments when asked about the significance and value of the participation:

B: I actually felt it was very cool to participate in something like that, in a study like that, and somehow make a contribution. ***I: Cool for yourself or cool for others that you did it?***
B: Well, more for others, but if it's cool for others, I'm just happy too. (2022_6).

People acknowledge that when the common good profits from it, it is also good for them. While the first person is happy as she is a potentially direct profiteer if there is research about her disease, the second statement reflects a rather second-order benefit: he derives joy from helping others, it is, again, a win-win. It also shows that they believe to contribute to a meaningful and eventually effective endeavour, which is rewarding in itself. The desire to help others intermingles with the personal satisfaction one gains from it. Though there is an altruistic character, it is minimised through the participation being convenient, thus the motivations are diverse and overlapping and other people or concepts are playing a role, indicating the relationality of the self to others.

Related to this is the concept of reciprocity, so to say a mutual exchange, in the sense that you give something because you also have received something, or that, in a pre-emptive way, you cannot expect to receive something if you do not also give something yourself (2022_4). Reciprocity can also take more specific forms:

I think it's just being in research, I work in basic science, so we're usually doing work with mice and my university in [my home country], I always had this idea of wanting to give back that way, I guess. So, I know, I hear it because I don't do clinical work, but I hear it from colleagues how difficult it is to recruit and to get participants, and then I guess I was always heightened and looking for advertisements that I would fit the criteria. (2022_5)

Her desire to give something back to the field in which she works and where she makes use of certain resources makes her readily available for a contribution to research. This is also influenced by her familiarity with the field, knowing how difficult it can be to get the right samples.

Imagined Value Hierarchy of Biomaterial

Another factor of relevance for willingness is how people value the specimen they give away. Participants have an imagined hierarchy of the value of samples, in the sense of what they mean to them and what can be done with them analytically, e.g., if the material can be used for cloning (2022_7).

So, blood, I think to myself, not much can happen, what should they do with that, but if, I don't know whether I would donate something like that at all, oocytes or something, then I would have to know exactly for what or that I just give that away now, probably not. In that case I would rather engage myself with this matter. Or want to know exactly what happens then. (2022_4).

The reason for this person to give something away is the lack of risk she sees connected to blood and because she believes that not a lot can be done with it, so she does not see the potential value it could have to others. The available knowledge affects one's relation to biomaterial and therefore the willingness to give it away. In contrast, other tissues such as oocytes are regarded as more valuable, and there was concern that they offer more possibilities for practices the participants would not approve of, as an oocyte theoretically could be "somehow fertilised or something" (2022_4). Therefore, the threshold for giving them away increases, for example, they would want to receive specific information about the sample to amortise the additional 'costs'. Other had similar value hierarchies with blood at the lower end, but for different reasons:

I think I can sacrifice a vial [of blood]. It's not going to kill me and I know that my body replenishes it. (…) It's going to come back. I think it would be so much different if you're asking me to donate my kidney, something that I'm not going to get back, and then it could have further consequences in the future if I have only one kidney. Then it's more complicated. But for blood, I think I don't even bat an eye. (2022_5)

I don't know if I see it as waste, but I mean, (…) I am not losing anything. (2022_1)

Here, though blood is not worthless to them, it is not a loss since it is replenishable, and hence, since it is *just* blood, they don't have to think twice about providing it. Also, no risks or negative side effects were attributed to blood contribution. On the other hand, giving away something that is finite and allows more analytical insights according to them, like oocytes or an organ, which are arguably more personal or more constitutive of oneself in comparison to blood or saliva (Wagner, 2010). Several participants stated that they would have to think more about it before contributing it. Similarly, if extra costs are required from their side, e.g., in the form of an extra surgery, they are more hesitant or not willing to participate and would require more justifications like what the material would be used for, indicating a trade-off. Thinking back to the convenience factor earlier, this does not come as a surprise. However, these considerations of surgery etc. are somewhat void in the case of biobanking, as no extra incisions ever take place, yet it was something that people contemplated and nonetheless the treatment or reason for hospitalisation may impact individuals' willingness to participate in biobanking. It has to fit the context, meaning what is contributed has to be appropriate to the situation of the patient and also the value of the material can shift, e.g., through sickness. So once again it is not a fixed factor, and it shows that matter matters for the willingness.

This hierarchy of samples did not apply to all participants: “That would not be a problem [to give away something other than blood], so if that comes off in passing then I see no reason not to make it available. It's all anonymised anyway, right?” (2022_7), which instead indicates another condition for participation: anonymisation, which I will discuss among other things in the next section on concerns.

6.1.2. Concerns & the Lack Thereof

When talking about factors that shape willingness to contribute, we should not forget possible risks and concerns. If we consider the concerns one can have as a spectrum from none to many, all participants would be placed on the lower end of the scale. Though there were differences, as I will present in this section, no one had considerable concerns, otherwise, they would probably not have participated in the first place. I will first discuss those who had no concerns before discussing what potential risks the others saw and how they were mitigated, particularly through trust.

Absent Risks and Acceptable Risks

Apparent was that there is a lack of imaginations of what possible risks are and what could possibly go wrong. Participants could not think of exemplary aspects that they would not agree with in the context of biobanking, as it is in the research area and the data and samples are ‘anonymised’ (2022_4, 2022_7). The first contingency will be examined later when looking at trust. The second one, anonymisation, is quite fragile because of the fact that the samples and data are not actually anonymised but only pseudonymised within the biobank (e.g., in order to enable the withdrawal of consent). Hence, there is

a misconception that influences people's sense of safety and how they feel about their contribution. They don't see how their contribution could cause any harm, for themselves or for others, and can't imagine what would have to happen for them to disagree or withdraw their consent, making them not hesitant about the contribution (2022_1, 2022_5). Therefore, with their participation, nothing is at stake for them.

The lack of concern is also reflected in the accounts of two participants which resembled the infamous 'nothing to hide' argument often used in discussions about surveillance and privacy (Solove, 2014). Even if something were to happen, like a data leak or cyber-attack, it would not bother them, as they deem the information that would be revealed not as a secret, therefore missing the point that it would still be a violation of their privacy and also not seeing the negative impact it could potentially have on them:

> *Even in the newspapers, if there was really my name mentioned because they used my sample, well, I don't have anything to hide there actually. (2022_4)*
>
> *But I wouldn't care either because I, so like I said, it's not a bad or secretive thing or something. (2022_1, see also 2022_2)*

On the other hand, a majority of the participants saw possible risks, yet they were not too concerned or attributed these concerns to other people while not having these concerns themselves, as they deemed them neglectable due to the surrounding factors. Though people talked of concerns and risks, those often remained unspecified, as if it was not imaginable to them what could happen, only that something could happen. But this 'something' is regarded as being accepted if one agrees to the participation, so these risks are simply part of it, and that generally "something can happen anywhere" (2022_6), so risks are not unique to biobanking. Some participants insinuated that risks are part of our society and our daily lives. The sociologist's brain immediately shouts "risk society", a term coined by Ulrich Beck (1986), which states that as a part of our modern societies with their strong orientation towards the future, where we are surrounded and constituted by a variety of complex technologies and their impacts, technological hazards that are self-produced by society are becoming part of our lives as well. Risks and threats are so to say a "consequence of modernity" (Giddens, 1990). Hence, the feeling arises that something can always happen with your data (and the samples), like commercial use, which for some was a major concern as it conflicts with the idea of a voluntary contribution. So, it is not reason enough for them to not contribute; it's a risk they are willing to take for the greater good (2022_5), and one they accept when they decide to contribute. Another concern that often came up was privacy and data protection issues, which were connected to broader societal ideas and beliefs about these aspects. Above, I mentioned how people have no concerns or fewer worries due to their understanding of how data and samples are handled, but some saw the potential to draw conclusions about their health and

personal information based on possible de-pseudonymisation of the data as critical, therefore contrasting the ‘nothing to hide’ attitude of other participants. Providing data was often compared to the use of social media and other digital services, where the collection of data has become ubiquitous, and where together with metadata information can be inferred from the users. So, while it is a fear, it is not one that is unknown to these people, and therefore also does not deter them from contributing to a biobank but instead is seen as a more general part of our lives and a risk they are willing to take (2022_5):

> *It's a certain risk that you take. But I think I take that risk with the first doctor's visit I make; I take that risk. With the first insurance I take out, I take that kind of risk, etc., etc. (2023_8)*

> *Well, actually, when I handed it in, I already decided anyway that maybe something can happen with it, if something happens to it, yes, okay. (2022_6)*

The risks that are seen in the context of biobanking are already present anyway and are considered as becoming steadily bigger with an increasing accumulation and concatenation of data, as one person pointed out (2023_8). Nevertheless, his concerns were limited despite his non-existent trust in data protection, which he thinks is only ever a temporary thing and dependent on political circumstances. Because of his advanced age, he was not too concerned with what could happen to his data, which he would see differently if he were younger, showing that concerns are also changing under certain circumstances. There is simply an uncertainty that we do not know what will be tomorrow, with which we have to live if we want research and other aspects of our lives to progress. With the belief that the benefits will eventually outweigh the risks, the latter are accepted.

We see from the varying degrees of concerns and their origins that concerns are shifting and contingent, e.g., on anonymisation or personal living conditions. Due to the not fixed nature of the concerns one aspect that is part of the informed consent gains in importance: the option for withdrawal. So, if something would happen, although people could not imagine what that could be, they could still make use of it and withdraw their consent.

Though people might agree in the present, this should not be regarded as immutable, even if they think that they will never make use of it, it is important to them to have this possibility to change their opinion: “You can get out at any time. That's actually completely logical to me. If it wasn't possible, I would never have started” (2023_8). For many, this option is a precondition for the contribution, because otherwise it is perceived as too much commitment to something that is undetermined in the moment of their contribution and would bereave them of a free choice. With this back door open they are more comfortable to agree to an unknown use of their samples, as they can still leave. Despite not thinking

that they would use it, it would be seen as problematic if this option were not there (2022_1). Therefore, the option mitigates existing concerns.

Trust – "If it is for science, why not?"

As another kind of risk mitigator acts trust: a majority of the participants revealed that they trust that everything goes the right way and regard research, biobanks, or the European legal framework as renowned and trustworthy instances (2022_2). Their idea of how data and samples are handled in these contexts leads them to have fewer concerns, perceive fewer risks, and are not questioning biobanks, which makes them more available for contributing. Where this trust is coming from was not always traceable but seemed to be connected to the prevalent narrative of research and its related (public) institutions being inherently good: "If it is for science, why not?" (2022_6). As one person also pointed out "it's quite strange, because somehow you have a trust that they definitely don't do anything stupid" (2022_1), indicating that the trust is institutionalised and hence not scrutinised a lot. At the same time, trust might also be a way to encounter the lack of control one has over one's sample and data in these situations since the decision-making concerning samples and data has been devolved to the biobank and its ethical committee: "But at the same time, I have confidence, as I said, that there's an ethical review institution, as to what's going on, I have confidence that it makes sense for the biobank to exist" (2022_1). This participant believes that the existence of biobanks is justified because if there would not be a reason for their existence, they would not exist, so she has no considerable worries which are further alleviated through the ethical review institution. Yet, this raison d'être has to be earned; trust is not unconditional. Though it might seem inherent, it can change if the circumstances change: participants often linked their conformance with biobanking to certain conditions it needs to fulfil, e.g., they have little concerns about contributing as long as it is for research and the public good, as long as not personal rights are harmed and the samples and data are handled in a protected area, and as long as it remains in Europe (e.g., 2022_2, 2022_4, 2022_7). These conditions reflect certain values and again show that concerns and trust are connected to broader societal debates and not just limited to biobanking, but data protection laws, personal rights, and what good research is. Therefore, as long as the context remains according to their expectations and imaginations, they are willing to contribute.

Trust can also be grounded in knowledge, as one person, who is not worried about her data she has contributed because she knows "that there's systems in place to make sure that's protected" (2022_5). The person is a researcher herself in the biomedical field, it is not trust that matters but rather her knowledge about safety measures that then creates the trust, showing that with more insights into the proceedings, the willingness might increase.

6.1.3. A Cost-Benefit Analysis

The previous sections have presented a variety of aspects that shape people's willingness to donate, while simultaneously indicating how they think about their contribution and biobanking. This should by no means be regarded as an exhaustive list but as a rendition of the aspects that stood out in the analysis. Yet, these illustrate that several factors interact, rendering the decision to contribute a complex matter. We cannot simply add up the different factors, as individuals attach importance to different things: "I think it always depends on what it is, what exactly I have to give away, what the effort for it is, what I have to do, what it costs me in terms of time, yes" (2022_3). For example, in this case, the participant mentions the context, type of material, and efforts including time commitment as factors that determine her willingness to participate. It is a prime example that reasons for contributing are complex, multiple, and conditional, hence they are not fixed. Besides, while seeing research as something good and/or wanting to contribute to the common good seems to be a necessary condition for one's contribution, in the sense that it is the basic requirement in order to be willing to contribute, it is not sufficient, if the participation comes with considerable costs, like taking up time or causing harm. As long as the costs are not too high, it also does not matter that there are few benefits for oneself, and as long as there are not more disadvantages than advantages, people decide to contribute. We can see that a cost-benefit-analysis is going on, so as there are few benefits for themselves in the case of biobanking, the costs have to be low as well in order to not make a 'loss', therefore the absence of any substantial harm, effort, and risks are crucial. This is possible because the biobank contribution is effortless due to being connected to another situation, a study, in which participation was also a cost-benefit-analysis whereas when they would have the biobank contribution as a standalone procedure, they would not do it. This turns their participation into something that is a positive side effect of something else. The fact that they are supporting research and the common good with their biobank contributions is collateral because they are not primarily doing it for those reasons, but because they are already doing something else to which it is conveniently bound; therefore, I refer to this as a *collateral good*.[15]

In order to illustrate the cost-benefit analysis and how the assessment of a contribution can shift, I will give an example in regard to how participants felt about commercial use of their samples. In their eyes, when company makes money from their samples, their contribution no longer serves the common good but is commercialised. As a consequence, the cost-benefit-calculation shifts, since they are not willing to give something for free when someone else profits financially from it, and their view on compensation changes: while in the case of biobanking, they don't need compensation, in this case,

[15] In the context of clinical care, other factors shaping the willingness are likely to be more prominent, e.g., being part of a doctor-patient-relationship.

they want to receive something back, as it otherwise does not appear to be a fair trade for them if the profits based on their freely given samples are concentrated on one actor (2022_2, 2022_6). So, the motivations behind the participation shift, in order to still have a righteous situation they agree with and in which they do not make a loss while others profit. In other words, the purpose for which the samples and data are used needs to be appropriate to the context in which they were given. If they give it for free, and then it is exploited for commercial purposes (or used for solving criminal cases), the intent of contribution does not match with the intent of the use.

6.2. Making Sense of Informed Consent

In this subchapter I will discuss how the informed consent process was perceived by the participants, looking at what they remember from it and how they value it, including what functions they attribute to it and how this impacts their understanding of their contribution. Towards the end, I will discuss how alternatives to the current broad consent were taken up in order to evaluate if there are viable alternatives to broad consent.

6.2.1. Remembering Informed Consent

An overarching observation across all interviews was the lack of memory of the informed consent process. A pair of people could not even remember that they had agreed to the biobank informed consent and were only made aware of it through our study, as we can see here:

> *I have probably never read through the printout of this consent form very carefully, as it happens so often, and now I have just had an occasion to read through it very carefully. And noticed that I had signed it for years anyway and never thought anything of it. (2023_8)*

With the occasion he means the invitation to the interview, admitting that prior to it he had not had a thorough look at the informed consent, which seems to be a usual behaviour according to him, and thus only now becoming aware of his contribution to biobanking, despite having been in the study in which context he signed the biobank consent for several years. In a similar case, one participant who frequently takes part in studies said,

> *It's like, honestly, I didn't even know that my samples were given to the biobank. I guess that was cleared up on the side with a second sheet. That's not really clear in any study. (2022_7)*

Furthermore, he remarked that the information talks are basically exclusively about the studies. What was presented as a strength earlier; being a side effect of another context, the study, which makes it

effortless and increases the willingness, is becoming a weakness here: because of being in the background, the information about it is not as present and there is a lack of clear information provided to study participants regarding the use of their biological samples and the extent of the informed consent, so there is a need for more transparency and communication around the biobank participation. Justifiably, there was then some questioning from the side of the participants if all those that say yes are actually aware of it, also by relating it back to the practice of accepting cookies on the internet:

> *Maybe of those 90% who say yes, maybe 20% know what they are really doing and the others do it automatically. Who reads the fine print? I sign, just by going on the Internet, so many consent forms every day that I just click away, not knowing what I'm really doing. (2023_8)*

> *And all, most of the people who are actually in the clinic actually give their samples away for the biobank without actually, I think, consciously knowing what's behind it. (2022_4)*

These indicate, just like Klaus Hoeyer has pointed out in his work (e.g., Hoeyer, 2008; Hoeyer et al., 2005), that informed consent is not necessarily an adequate measure to inform patients but rather a formality that is discounted as a legal requirement (2022_3, 2022_4) and that often remains unread in practice. In order to really be an *informed* consent, more clarification is needed, however, this might not actually be taken up or be desired by the participants, as there are people who purposefully do not read the informed consent (2022_2).

Though most interviewees still remembered the process and knew that they had been informed, in most cases they did not recall where they stored the informed consent sheet, what they were informed about and could only give a few specific accounts:

> *So if there had been anything in it that I didn't agree with, I would have said, no, I'm not going to participate, or yes, if there had been anything specifically unclear or that I didn't comprehend, but it's so vague or written in such a general way that you don't really have any questions, or you don't have many questions, I think. So that's how it went for me. I read through it a bit and then I thought to myself, yes, they are simply using my data and I can object at any time anyway, but that was all that stuck with me. (2022_4)*

What is important to them is more easily remembered, but the participant also points out that due to the nature of the informed consent which is very broad, not a lot of questions arise, because it means all and nothing at the same time. It is sufficient to know at the moment of consent that there was nothing they were opposed to, but beyond the participation, most information does not stick with them, even if they have read it. Yet, one piece of information that often remained prominently was the option for

withdrawal, which gave them the feeling of ongoing control over their contribution. About the consent conservation itself, one person recalled:

> *I certainly got a general explanation at the beginning also with the biobanks, but of course I forgot that again. Because somehow, when you think, I'm going to participate because I want to support this, then it's not so relevant what, let's say, everything is in there. You read it through, you take note of it, but it's not something that you fully store away if you just think to yourself, you want to support, yes. (2022_3)*

Similar to the previous quote, she made explicit what was also implicit in many other interviews: the information is not as relevant if you have already made the decision to contribute something, which leads them to let the informed consent and its content through on the nod. So, it is read but not lastingly taken up, "of course", as the person in the quote said, once again signifying that negligent behaviour towards informed consent is considered normal. If the decision is already made and the information that one is taking in fits with one's ideas, these papers are signed without much contemplation. Only later on if something disruptive happens, like here in the interview situation but also imaginable in the case of negative headlines about biobanks, people begin to think about it again.

While it is not possible to say that the informed consent does not play any role in the decision-making, since it might confirm their decision to participate but also because people that declined are not included in our sample, those participants who I asked about it decided to participate before having the full information and did not reconsider during the informed consent. One participant even admitted that he purposefully did not read the informed consent and signed it blindly because of the trust he has (2022_2).

The fact that not a lot is remembered about the consent procedure is not surprising, given that these procedures date back about a year at the time of the interviews and were only part of a bigger informed consent procedure of the study that overshadowed it. Only when being asked about the informed consent, some memories are brought back to light, which is apparent in this quote:

> *It was a pretty good explanatory talk, I just remembered, and it was conducted by a doctor. That's right, he actually explained to me where the material goes and what happens to it, but I don't really remember that anymore. (2022_6)*

However, he could not recall any details about what he was informed, only that he was informed. This quote shows again the construction of the given accounts through the interview situation, which also was already observable above where participants only became aware of their contribution to a biobank because of the interview inquiry (2022_7, 2023_8).

While it was remarked that the informed consent sheet could be shorter, people were generally satisfied with the process, had no suggestions for improvement, and felt that there were no uncertainties (despite several misconceptions and not remembering it). This is in line with other findings that have shown that informed consent is not often read or fully comprehended, yet people do not feel like they are lacking information (Hoeyer, 2003). It was remarked that it was nice to have the consent procedure in person, being given the possibility to ask questions if necessary and generally having a better feeling about it when it is not anonymous (2022_1, 2023_8). In particular, it was emphasised that they were asked without any pressure (2022_1):

> *I remember them being really good about it. The way that they asked, they were not pushy at all. I was very willing. So, for me, it was not like I'm not sure. I didn't have a lot of questions. I was mostly like, "Yeah, sure, why not, I'm here." But I do remember the way I was asked was very inviting and very encouraging as opposed to like "We're going to do this, sign here". So, it didn't feel forcible at all. (2022_5)*

Here, the already existing willingness of the participant and the inviting consent process make it a smooth endeavour and a positive experience, whereas a pushy manner could be off-putting and discouraging. Being presented with a choice and consequently having a feeling of agency is important for feeling good about it.

However, despite its ostensibly little impact on memory and decision-making, people still value the informed consent process, and it is important to them that they are being asked for their consent, indicating that they want to have a free choice and highlighting the importance of respectful and clear communication in biobanking. Informed consent is an essential part of this, and though it does not always fulfil its purpose of informing people successfully, it is a big aspect of creating a welcoming and comfortable environment that encourages participation without being coercive.

Yet, it was often remarked that receiving information is more important than the actual act of consenting, which is why not everyone considered the informed consent process necessary. As long as they can always withdraw, it is a continuous free choice for them. Still, this is not a sufficient reason for them to change the procedure, as the way it is now is deemed appropriate and widely accepted. I will look at alternative ways of informed consent and how they are taken up later, but first I will discuss the impact of informed consent on their understandings.

6.2.2. Mediating Understanding, Relations & Perceptions

The informed consent process provides the participants with information and distributes rights and responsibilities among them and the biobank. How those aspects are remembered, whether correctly or not, as well as what functions are attributed to the informed consent shape people's relation to their contribution, including a sense of security and control. For example, they expected certain things to be mentioned in the informed consent like who will use the sample, how long it will be stored, e.g., "In the informed consent it says up to 10 years or so. Can this be?" (2022_7), or what happens with the samples and data after one's death. After being told that the information is not in there, they suggested that it should be put down in the informed consent, "listed as a point [what should happen with the samples after one's death], so again with, do I agree or disagree. And that people can then still decide it during their lifetime" (2022_3). Concerning use of the samples for industrial purposes the same person wished "that such an informed consent should also include the fact that you agree to this" (2022_3), which I understood in a way that she does not currently think this is the case, though it is not ruled out by the informed consent, a belief that was also implicitly present in other interviews. Also, when being asked how she felt about other things, e.g., how long it should be stored or to whom the samples belong, her initial response was always that this is certainly mentioned in the informed consent. How she felt about and related to her contribution was shaped by the informed consent, or rather, her idea of it. So, her idea of what was stated in the informed consent without those things necessarily being part of the informed consent sheet or not being like she remembered them influenced how she thought about those things. Instead of relying on her personal view, she delegated how she is supposed to feel and think about it to the informed consent. Also others banked on practices being regulated in the informed consent. And, the other way round, if something is not taken care of by the informed consent and not part of it, then people are against it being practised, e.g., one participant would not want to receive information about incidental findings, as this is something he did not agree to when signing the informed consent. On the same basis, he also ruled out the use of his samples for criminal cases. Therefore, he says "some people want to know, some don't want to know. And I think something like that should then be clear from the beginning" (2022_7), indicating that if people consent to it, it becomes legitimised. However, the informed consent is formulated in a very general way, so many things are inconspicuously included or not explicitly excluded, like cooperation with industry ("non-academic use"). Therefore, some aspects might go unnoticed and will not become part of the mental representation of the informed consent.

We see that not only correctly remembered content from the informed consent process can influence people's understanding but also what they believe to have been part of the informed consent. One major misconception concerns anonymisation: many participants referred to it as the reason why they are not worried about bad consequences or misuse; they think it would not be related back to them. However, samples and data are only pseudonymised most of the time, and also with anonymisation complete

safety cannot be guaranteed, therefore it is a double misconception, yet not completely spurious as de-pseudonymisation would require a lot of effort and ill intentions.

A second instance where we can observe misconceptions mediating the participants' relationship with the sample and data is the option for withdrawal. Withdrawal is an important part of informed consent, as already discussed, it is essential for risk mitigation, providing a way out of the participation and is, therefore, a prerequisite for some people. So, due to the possibility of withdrawal, the perceived relation to the data and samples is deviating from what the informed consent states. It still takes the role of legitimising the use, however, the participants do not consider it the transmission of ownership, as it is the case, but with signing the consent, they only allow the biobank to use the samples and data while they still remain 'theirs':

> *So it is part of me, but yes, they can work with it. So that's what I gave my consent for. (2022_4)*

> *As long as there is this possibility to withdraw this sample and also to withdraw the data, it is a part of the respective proband, I feel. (2022_7)*

Though with signing the informed consent the ownership of the samples is in fact transferred to the hospital or medical university the biobank belongs to (*Einverständniserklärung*, n.d.), participants seem to have the general understanding that the samples still belong to them and only have been loaned to the biobank to use in research until revoked; they are "just making it available" (2022_2). To them, the option for withdrawal, or rather the way they understand it, implicates a property situation that is not actually there. Furthermore, being able to revoke their consent gives people a sense of agency and control over their contribution. This is connected to another misconception, namely the assumption that the sample and data would be destroyed if revoked, which is not the case in practice as it is only no longer made available for research (*Einverständniserklärung*, n.d.) when consent is withdrawn.[16]The understanding of both anonymisation and withdrawal is also important in regard to the general willingness and attitude towards biobanking because as we have seen above, both are reducing the perceived risks for the participants, independently from whether they actually reduce risks.

There are also people who no longer think of the data and samples as theirs because with consenting they give up their rights. This will be discussed below in 6.3.2, but it already shows that people who

[16] In most cases individual samples and data are not destroyed or deleted when the people withdraw their consent. and it would be necessary for participants to explicitly and of their own accord state that they want this to be done (personal communication, 29.03.2023). However, this is not mentioned in the informed consent, and participants in our interviews (donors and non-donors) assumed that it would be deleted if they withdrew their consent, which is why they probably would not emphasise specifically that they want it deleted if they ever withdrew their consent.

had the same informed consent take different information and understandings from it. The content of the informed consent process is not void, despite often being forgotten and misremembered; however, it is very selectively integrated. There are instances where we see the impact on understanding, but in theory, this impact appears bigger than in practice: as pointed out by Klaus Hoeyer (2008), informed consent seems to be overvalued in ethical and sociological research, since in practice people care little about it beyond their participation (e.g., due to trust in the system or other reasons). Informed consent is one of many attributes that is shaping their participation and not the mere definitive aspect, which is why we need to focus on the wider assemblage.

Still, borrowing another term from ANT, the informed consent process acts (or can act) as a mediator, as it is not just a passive object but an active participant in the network that shapes one's contribution to a biobank and materialises practices. Its role is to inform and facilitate the interaction of different actors in the network, such as the transfer of samples from participant to the biobank, and therefore negotiates and assigns roles to the different actors and shapes their behaviour and relations as well as the outcomes of the network. However, the foreseen roles inscribed in informed consent are not always taken up correctly, as we have seen in the case of ownership; its goal to inform people does not always succeed. This is because the informed consent process "creates what it translates as well as entities between which it plays the mediating role" (Latour, 1993, p. 78). The meanings that are supposed to be transported are reconfigured as they pass along, complicating the intended relation (Michael, 2017). Not just the informed consent sheet itself and its vague clarifications cause this, but the entire process matters since the context and other social factors shape how and if the sheet is properly understood.

6.2.3. Discussing Alternatives to Broad Consent

In this section, I want to examine what differences a different consent procedure would make in comparison to broad consent as it is now. Though the informed consent procedure in its current form is (obviously) accepted and regarded as appropriate by the participants since they see the practical value of it for research and themselves, some people personally preferred an opt-out system or less formal consenting. But I will start with discussing an alternative to broad consent, which no one preferred: re-consenting each time.

No one wanted to give specific consent, so being asked to consent for each study again, since it was considered too much effort and unnecessary bureaucracy for all involved parties, which is in line with the effortlessness aspect I discussed in 6.1.1. Participation should be as easy as possible, and being contacted again and again and having to sign it again would be annoying and even deterrent, especially since participants believe that they would say 'yes' each time anyway (2022_5, 2022_6). People said that they still have the option to withdraw if they no longer want to participate (2022_1, 2022_6). Similarly, dynamic consent was deemed unnecessary, because of the option for withdrawal (2022_1).

At times it was discussed to have additional options in the initial consent process, e.g., to determine for which types of research their biodata could be used or if they allow transfer to non-academic or commercial actors, or at least be given examples of what it could be used for (2022_4), thus increasing the information obtained and the ability to make free choices. However, given that the information in the informed consent was not always (correctly) taken up, it raises the question of how these changes would actually make a difference, as how the information is eventually taken up by the participants is not in the hand of the biobanks. Yet, the feeling of security is important to participants, and this can be enhanced by offering information and being transparent about the study's procedures and goals.

Although participants did not want to have to consent each time, some people would be interested to be contacted when their sample is used (which is not foreseen and rather difficult to implement).

> *Maybe not necessarily again that you have to sign something, because you already have done that at the beginning, but just the information that you get, it is now used for this and that, yes (2022_3)*

> *As I said, I would find it cool if I could just then quasi see that this is now being used for this or so. (2022_6)*

While being informed and being asked about contributing something to a biobank was generally important to basically all participants, for some just being informed would have been enough already and the consent form itself did not make a difference to them:

> *So if I hadn't signed it, I would have done it anyway. So it was not important to me now that I have this consent form in my hand. (2022_4)*

> *So whether I would have signed it or not probably wouldn't have made any difference at that moment, because I would have been curious anyway. (2022_6)*

In the second quote, the speaker refers to the antibody level that they received for participating in the study, which indicates that it is yet again context dependent. In both cases above the informed consent then becomes a mere formality, which does not make a difference for them in the end. Still, they want to be at least informed if something is taken (2022_6) and it is important to be asked (2022_4), as this induces a feeling of being able to decide freely, so for them being informed is valued higher than the actual act of consenting. Being repeatedly asked to consent is not desired, though it would offer the ultimate freedom of choice, which shows that there is a trade-off between having as little effort as possible and still being able to choose freely. Through the option for withdrawal, their participation remains a free decision as there is still space for agency if needed. This is also the reason why some people would agree with an even less restrictive alternative to broad consent:

An opt-out system (also called presumed consent), as in the case of organ donation in Austria, entails that everyone is a donor by default unless they say explicitly no, which is then listed in the opting-out registry (*Widerspruchsregister*). Some were supportive of such a design since they considered it an asset to research due to making it easier to collect samples. They argued that they would still have the option to say 'no' and the effort for this would be on them, so people would not thoughtlessly say opt out. However, as a prerequisite, everybody should be informed about this, which is what some people saw as a critical aspect of it, as it could leave a bad taste as this person points out:

> *I think that's really important because if you don't know and you find out later, then it can have a negative consequence or negative reaction as opposed to like you're doing something good, you're helping. You should be aware of it and be able to say yes or no. (2022_5)*

Only if people are aware of it, it is still a free choice, otherwise, it is something that happens behind their backs and that people might not be thrilled about if they find out later. Being informed (and being asked) is therefore good for increasing trust and gaining long-term support. This particular interviewee also recalled a conversation with a friend whose mother was upset when she found that she was automatically registered as an organ donor without ever having explicitly agreed to it. Hence, there is some potential for conflict if the communication is not clear enough. This is why, though the participant likes the idea and thinks it is good if the responsibility would be on the person to say no, she thinks it is generally important to be asked even if it is not important for her personally (2022_5). Also, others shared this view: they would prefer such a system but take into account that other people might dislike this solution and that it would require comprehensive information (2022_4, 2022_6). So, while it would personally be an option for them, it was not deemed to be widely accepted. It has a better character and is more trustworthy if people are explicitly asked and can actively decide for themselves.

In contrast to these rather liberal attitudes towards the opt-out system, one participant was strictly against it:

> *Well, then we can spare ourselves everything anyway, if everyone has to give everything automatically and hand it in without consent. Then we might as well have a communist system ((laughs)). The point is that everyone has the free will to give their consent or not. And if that is not the case, then I would not feel good about that. And organ donation is something else. There you don't have the opportunity to consent when you die. (2022_7)*

To him, the opt-out system equals no longer having a free choice and therefore he does not approve of it. He jokingly associates the idea that everyone is automatically available for a contribution with communism, which is linked to a certain form of government and idea of citizenship that he opposes, thus affirming the claim "different models of consent imply different visions of the citizen" (Árnason,

2009, p. 131). Yet, he finds such a system appropriate in the case of organs, and he was not the only one to point out that an organ donation is a different situation (e.g., 2022_1). When you are dead, you can no longer be asked and the immediacy is different, as an organ can directly save someone else's life, while a sample might be stored without ever being used. We see once again that the circumstances matter, so what is taken, when, and for what purposes.

To conclude the section on informed consent, we see that, unlike broad consent, which was widely accepted, the other alternatives have certain weaknesses and are either considered too effortful or limiting one's free will, whereas broad consent seems to strike a balance between these two. It is also a compromise in the sense that informed consent, as it is now, is a place where the biobank and the participants meet in the middle, reducing the effort for both sides while maintaining information and free choice, which specific consent and presumed consent fail to achieve on either end. Where people draw the line on what forms of consent they accept is affected by whether they value freedom of choice or effortlessness more.

Participants regarded informed consent as a source of information and as the manifestation of regulations around the use of data and samples though with different practical relevance, e.g., from a mere formality to a written and necessary proof that one has said yes (2022_7). The informed consent procedure increases trust because of the provision of information and offering a legal framework. Whether (and how) this information is incorporated is a different matter, but it is good to make the information available in the first place. The effect that informed consent can have on the relation to one's contribution and samples will surface again in the next subchapter.

6.3. Making Sense of Samples and Data

In this subchapter, I will look at how people relate to the data and samples they contributed, in the sense of how they value and distinguish between them, feel connected to them, and what impact these samples and data could have. With this, I will further approximate my main research question of how people relate to their contribution of biodata in the context of biobank informed consent processes.

6.3.1. Distinguishing & Valuing Samples and Data

Let us begin by looking at how data and samples are recognised in the first place, where people draw the line between them, and how this differentiation is connected to valuation. I have already outlined that participants have an imagined value hierarchy of biomaterial, which influences their willingness to contribute something, e.g., not even batting an eye about giving blood (2022_5), now I will also include data in this discussion. It cannot be generalised how people relate to their data in comparison to their sample, but I want to present two attitudes that I constructed from the data. First, most interviewees did

not perceive a difference between samples and data and stated that there should be no difference in how they are handled, e.g., concerning use and access. This is interesting because legally samples and data differ. How data can be used is determined in the GDPR and the FOG, while the use of human biomaterial is a grey area. But due to being a grey area, the handling of biomaterial is more restricted and usually requires informed consent whereas data can be used for research without informed consent, an issue the participants were not aware of. So, while those participants did not distinguish between them, the law does.

The second observation was that another, smaller group of the participants regarded the data as more expressive and more closely linked to them than the samples:

> *So what I see more as a part of me is that they have linked my data to it, that they somehow have it somewhere, when I was born and what sex I am and what do I know. (...) I see myself more involved in that than in the fact that there are now somehow a few millilitres of blood of mine that were once in my body or something. (2022_1)*

> *The samples, in health status theoretically could have changed so much in a year that that might not be meaningful and relevant anymore, but the data definitely. (2022_6)*

The data is considered a more permanent and representative part of themselves and more sensitive, whereas the samples are only a snapshot in time. The data were also considered more vulnerable since it was doubted or considered less likely and less of interest that someone would break into a biobank and steal something from a freezer (2022_1). This relates to a different point, namely the value created through the combination of samples and data: samples only become valuable through the data, so data is regarded as more attractive and interesting on its own.

> *But it's often very useful to have all this data, otherwise you might not be able to do anything with the samples. (2022_4)*

> *So, I don't think that you can ever get a sample with zero information. It's kind of useless. (2022_5)*

The samples are seen as rather worthless without accompanying data giving the samples contextualisation and enabling the comparison to other samples (and their data). Fittingly then, some participants used the word "biodatabank" when referring to biobanks. The term includes the role of data and the inseparability from the sample and data, while 'biobank' suggests a focus on the biomaterial. Yet, despite the data being important and necessary for the analysis of the samples, the samples were usually more present in the accounts during the interview as they are more tangible and as people also did not know what data the biobank had collected from them.

6.3.2. Owning, Lending, or Handing Over? – Ownership Relations

Having already established that samples and dates can have different meanings for participants, I will now concentrate more on the sense of ownership that people have towards them and the role of informed consent therein. In particular, the option for withdrawal shaped how people perceived the relation to the samples and who is owning them. For some of those who still regarded it as theirs the contribution of biomaterial was, or rather is, a loan: the biobank can only use the sample as long as it is granted by the 'lender'. They stated that if they ever found out about any misconducts, they would make use of the withdrawal option. Though they do not get it back in the literal sense, they have control over it and deprive the biobank of this sample and the data, meaning that they still have some remaining control over the samples (2022_7). At this point it is interesting to look back at the actual informed consent. It states that by signing the informed consent, people transfer the ownership to the biobank (*Einverständniserklärung*, n.d.), therefore the sense of ownership is based on a different understanding of the informed consent and the meaning of the option for withdrawal.

While it then might not be surprising that people who still consider it theirs are interested in knowing what would happen with the samples and what they are used for, also people who stated that it is not their sample anymore, expressed interest in it. This interest could simply be attributed to their general interest in science and research; however, their participation seems to play a role as that is the distinctive difference between a study where their sample would be used and any other study. At the same time, while expressing interest in knowing how their samples and data are used, the entitlements to information and control people felt differed, as it was connected to their perceived sense of ownership. When talking about whether she is no longer the owner of the data or the samples, a participant said:

> *I think that's why I said I don't have this feeling like I need to know where it's used. It would be cool and more for interest, but I feel like I gave up my rights to that sample. I didn't even know I could retract it, but if I couldn't retract it, it wouldn't have stopped me because at that time I was in the mindset of I'm giving this up. It's out of my control now. (2022_5)*

So in this case, handing the sample over to the biobank marks a turning point for how she relates to it; by consenting she gives up her right to decide what happens with the sample and does not need to have control over it since she gave it away and it is no longer hers. Her consent legitimises that the biobank is the owner. In a similar vein, in the context of knowing what the samples are used for, another person said:

> *I would find it exciting; I don't know if I find it necessary or if I find I have the right to do it because it's my body part or something. I don't find that either somehow, because I mean, all people have blood, everybody has, so that's like, I don't have, that's not, so no loss and*

no benefit from me. So it's just, it's not a swap deal for me, I don't have that, so it's not like I'm saying I'm entitled to it for life or something. (2022_1)

Here it becomes clear that how people relate to the material is influenced by how they value what they give away: blood is nothing special or specific to her, everyone has it, and it is replenishable so that it does not mean a loss to her, even if it is her 'body part'. They do not feel that for giving this material to the biobank, the biobank owes them any feedback on the use of the samples. So, basically, by agreeing to participate, people accept to give up on control over the material. It is not necessarily that they do not care anymore or are not interested but rather that they lost their entitlement to it and that it is out of their control. Consequently, they also do not think about it anymore:

I don't think it matters [who uses the sample]. It's a donation, once it's out of my control, it's done with. (2022_5)

I do not think about that study or my sample at all now. I just turned it in and thought to myself, yeah, it's done. (2022_4)

The moment of giving it away is a critical point for how they think about it; what's gone is gone. So, there is a kind of closure, at least in the sense that they are not concerned with it anymore because it is gone and it is no longer in their control what happens to it. Though it can be argued that it remains temporary because of the option for withdrawal, in practice this option is rarely used, and the participants could also not come up with situations where they would make use of it. This renders the contribution to a biobank an isolated event for most participants. That they no longer thought about their participation was only interrupted by our request for an interview, through which they willingly reengaged with the topic.

This 'over and done with' attitude is not surprising given that it is a small and effortless procedure, which fitted conveniently into their daily lives, and thus probably did not take up a lot of mental capacity, reinforced by being part of the study and in most cases connected to a vaccination, which often had a more immediate impact on them. Beyond the contribution, solely the study was sometimes a topic of conversation due to the antibody level they received, which was discussed with family and friends. (2022_4, 2022_5). Concerning biobanking, participants have difficulties imagining what samples and data could be used for, so it remains abstract to them, and they can't build up a mental imagery of their contribution. Therefore, they no longer engage with it; it is not on their mind anymore, so to say, out of body, out of mind. Though they are not (strongly) affected by their contribution, they are nevertheless interested in it.

6.3.3. Receiving Information

The fact that they no longer think about it, independent of whether they see themselves as the owner or not, seems to be due to the non-existent practices of providing any feedback or information to participants in biobanking. After all, when asked about it most respondents expressed interest in receiving information about their samples, such as how and when they are used and the results of research. Therefore, I will first look into what forms this desire for information can take and what rationales are behind it, whereas in the second part, I discuss what impact information *could* have.

Wanting Information – "Knowing what is used for"

The desire for information was quite heterogeneous, yet a majority of the people showed interest in receiving information back. Even so, I will begin with those that showed little interest: two participants did not care what their samples are used for and did not want to be informed about it, however, their condition was that it should serve a good cause (2022_2), with one of them elaborating that she "wouldn't actually care what they're used for. I would just be happy that they are used, so that this is not just storage and a lot of money is spent on it and then nobody can access it, but that this is really used sensibly" (2022_4). So, the contribution should not have been in vain; it should have been worth the costs and efforts that were taken up (by the biobank) to collect and store the sample. But as they do not desire to have information about it, they assume that their expectations are fulfilled. The only situation where this would be different is in the case of incidental findings. One of the participants from above would "of course" be interested in receiving information if something is found out about his personal health condition (2022_2), as it could also be of interest to his family. For others, this was not as obvious since it is a difficult matter to decide beforehand whether one wants to know that information. People were aware that the effect such a piece of information could have could be enormous, and it would make a difference whether e.g., their condition or even just predisposition is treatable or not, so it is a "double-edged sword" (Hoeyer, 2009, p. 251). Due to the potential power it can have, if this information were ever available for sharing, it should be determined in advance by the participants if they want to know, in order to maintain their right to not know and balance it against the right to be

While some participants were only interested in results that concerned themselves personally, others would be interested in the study results more generally and they attributed that to their general interest in research, often connected to their profession or being personally affected by a disease (2022_1, 2022_5, 2022_7).[17]

[17] It is important to keep in mind that there might be an inherent bias and higher interest in results than in the general population as these people also volunteered to participate in studies and in our interview.

For the first group, it is more about learning about themselves and gaining potential benefits from the feedback, while for the other group, it is rather about meaningfulness; that they see to which research they have contributed and that their participation had an impact, which is positive feedback to them already. So, their interest is shaped by their personal background and what they can derive value from.

Getting information was also considered a kind of incentive or compensation for the participation, as these two quotes show:

> *If you already make that available, especially if then you also have not received any expense allowance or whatever for it, that you just know what it was used for. (2022_3)*

> *So if I know exactly what it is used for, I don't need an incentive and otherwise the incentive. (2022_6)*

As such, the information becomes a kind of currency and the information offsets their participation and the absent compensation. Connected to this, it was argued that offering information could have positive side effects, like increased engagement and support due to being able to see the impact of it, making the value of biobanking visible:

> *(...) if you get general information and positive, maybe, hopefully, that you have gained knowledge, then that would be good for general awareness. Maybe you can also spread the word and more people would be willing to do it. Part of the publicity campaign. It's good feedback, after all. (2023_8)*

He was not the only one to consider feedback as rewarding and encouraging to people; knowing that it has been used (effectively) makes it more attractive, also because then there is more the participants can potentially talk about to others. Besides, it conveys the bigger picture of which biobanking is part **(**2022_5). Currently, biobanks have nothing to offer to their participants, that's why it is a pragmatic solution to have the collection of biobank samples attached to either clinical care or studies. But this is fine: participants do not expect more information, it is not necessary for their participation, though they would not disdain it. It was also understood that it is not possible to receive more information concerning the use of the samples due to the nature of biobanking with its collection of samples for uncertain future use.

Nevertheless, I want to take a glimpse at how people would like to receive the information if it were an option. There is limited interest in more active participation and people do not want to become more involved (e.g., by being asked for consent over and over again) and do not wish to actively look for information but prefer being a passive receiver of information. This is imagined in the form of emails or newsletters, which would cause costs and effort for the biobank. However, the bureaucratic effort behind it was rarely acknowledged or not considered their problem and they imagined it to be rather

easy as they assumed there would be mailing lists at hand in the biobanks, neglecting the privacy of their data. An alternative that would require more active participation is an online portal, where they would have to log in to receive information. The idea was generally taken up positively since it increases transparency and trust. But it does not entail that people will actually use it (or only seldomly), especially not if it requires effort from their side. Yet, in principle having the option for information is valued for the transparency and agency that it offers. So, although people show interest, they also claim that they are potentially not interested enough and/or do not have time to actively engage in it.

Impact of Information & Knowledge – "One may not know everything about oneself."

Having discussed the existing interest in information, I want to move on to which impact this could have on the participants. Though I could rarely observe accounts about how the contribution directly affected the participants, it was possible to make out that biobanks could have the potential to be formative for a sense of self. This became particularly obvious in accounts of their participation in the COVID-19 booster vaccine study, which was the 'precursor' for their biobank participation. As part of the study, people received their antibody levels which were on the one hand seen as an incentive to take part in the study as they were interested in it, and secondly, it had the capacity to lead to certain feelings regarding their immunity status which can impact their behaviour. Back then, at the end of 2021, when the study took place, learning about one's antibody levels had practical implications for their life, e.g., concerning travelling. It affected their sense of protection, as the results could indicate a certainty that the vaccination was effective, or alternatively that they should get another vaccination, as this person recalls: "No, only that I have these antibodies, this antibody titer determined, because that was such a, yes, such a topic at that time, how high are the antibodies and how are you then rather protected or not" (2022_4). The antibody level was an indicator that they otherwise would have had to pay for themselves if they wanted to obtain it and it is not just of value for research, but the results can be integrated into the understanding of one's body.

Generally, knowledge can change the relation to and understandings of one's body, not only with the results of research. How biomaterial is understood in the first place and what can be deducted from it also plays a role. As presented earlier, one person did not hesitate to donate blood because she believes that not a lot can be done with it (2022_04), forgetting or not knowing that blood also contains DNA, therefore with the blood sample, her genetic information is available to research. The potential implications of a contribution are not known to her as she underestimates the characteristics of blood and the abilities of biomedical research. This affected her willingness to contribute. The other way around it is also imaginable that people who are aware of these aspects could be more hesitant to contribute something if they are uncomfortable handing out their DNA. One's knowledge and understanding of the body hence have practical consequences.

Naturally, the impact of the antibody titer results tells us more about the study than about the biobank, but it gives us clues about how biobanks could lead to similar impacts (leaving aside the question of whether this is desirable in the first place). By providing feedback, in particular individual results, people receive knowledge about themselves which they incorporate into their daily lives and affects how they think about their health, body, etc., since as one person states "One may not know everything about oneself" (2022_4). However, this is not envisaged for biobanks, for some good reasons, including too much effort and costs for the biobanks or insecurities that could come up when participants receive results out of context. Receiving knowledge about oneself strongly affects self-understanding, but it is likely to remain in the sphere of personal health services (e.g., medical appointments) as well as commercial providers like 23andme or self-tracking (e.g., Lupton, 2020; Tutton & Prainsack, 2011).

To sum up, people no longer think about their participation and have no strong feeling of connection to the sample, independent of whether they see themselves as the owner or not. However, information about the use of samples and data is appreciated; when asked about it there is an interest in receiving information. Yet, it is not a necessity for deciding to participate, at least not for these interviewees. The information they would receive could have the power to impact them and affect their self-understanding, thus strengthening their physical involvement in biobanking and potentially leading to an ongoing engagement with it. As this is not foreseen in the near future of biobanking the role of the passive participant is likely to continue, and biobanks will remain in the background. The topic of providing feedback is taken up again in the discussion.

6.4. Relating to Others

After looking at how people relate to informed consent, samples and data, non-human actors in the bigger context of biobanking, I am lastly going to delve into how participants relate to other humans in the network. In order to put the views of my participants into a broader frame and situate their contribution in relation to others and within society, I will discuss what significance they attributed to their contribution and the ways in which they included and excluded other people in their accounts.

6.4.1. Including Others

Directly following from the motivations for the participation, we can adopt public good as a primary example of how the participants included others in their thinking. Though the 'others' remain rather abstract in these cases, they show that other people are involved in one's consideration when contributing. It was also emphasised that no one is excluded from the general public (2023_8). However, when there is only a single actor that is mainly profiting from it, it no longer falls into the narrative of the common good, and therefore the rationales behind their participation would shift in such

a case, e.g., as discussed, receiving a compensation. Other people also play a role in the case of reciprocity (2022_6, 2022_4, 2022_2), as without doing it yourself, you can't expect others to do it, and one day you might be in need of *something* yourself. As one participant talked about the opt-out system for organ donation in Austria, where you have to sign off, "I have also dealt with that before because I thought to myself, but if I sign that, then somehow I also don't have the possibility that I can then, so to speak, expect that from someone else" (2022_4). Though she discusses reciprocity in the case of organ donation, it is in a broader sense indicating that medical issues are a give and take. To take, you need to give, so people are assigned a role if they want to be part of it; it somewhat becomes their obligation to participate if they also want to benefit from it. Albeit this does not hold legally, as one does not need to be an organ donor themselves in order to receive organs, the participants so to say cannot expect it from others if they don't do it themselves. The issue is thus rather approached in a socioethical manner than a legal one.

In a more specific way than common good and reciprocity, people took into account how others might feel about certain practices, so they differentiated between their personal opinion and what they deemed alright and what other people might (dis)like:

> *I always start from the general public like that, and I know there are so many critical people in this world. (2022_3)*
>
> *So basically I don't have a problem with that [opt-out system] now, but I would imagine that might bother some people. (2022_6)*

While they might be open to an opt-out solution or are not bothered by the use of samples for research without consent, they understand that other people might not want it which then relativises their support for these options. They simultaneously draw a distinction between themself and those who think differently and show consideration for them. The participants act (or at least think) with circumspection, they reflect that it is not concerning them alone. It was acknowledged that people have different levels of knowledge and can have certain fears even if the participants personally do not have them. If these are overlooked tensions can arise, e.g., when people are not aware of a contribution and find out afterwards. This could lead to feeling deceived and being upset as in the case of the mother of a participant's friend in the context of being a possible organ donor without knowledge (2022_5). So, while the lack of knowledge of others can be seen as an obstacle to medical research, these people should not be passed by but receive better information. This points out the value of informed consent as the main place where the provision of information takes place. It was also mentioned that population biobanks could help to increase the support and awareness among the general public: "I think it's a great idea because I think it is, again, people feel better when everybody else is doing it. So, if it just becomes a normalised thing, then it might become, people accept this is normal" (2022_5). Through a

population biobank, a community context is created, and the participation of some people helps to convince others to contribute as well, and it becomes a common endeavour to advance research. This already indicates that beliefs are influenced by other people and decision-making does not take place in a vacuum, as we also already could see when discussing the reasons for participation. These insights could be used in the future to increase support and awareness of biobanks.

The entanglements with others lead us to a relational understanding of personhood: every participant is embedded in society in a variety of different ways and their relationships affect their interests and who they are, entailing that "almost everything we do is self- *and* other-regarding at the same time" (Prainsack & Buyx, 2017, p. 52, emphasis in original). The relationality was reflected in several accounts, beginning with having the opportunity to contribute in the first place (e.g., fulfilling the criteria, working at a hospital, connected to booster study), which is dependent on personal circumstances that are grounded in the past. This networked character to others became particularly visible regarding the compatibility of the contribution with obligations like their jobs, as participants would not be willing to take a day off solely to contribute to a biobank, so they needed to have allowance to do it within their work time (2022_7):

> *Since I was allowed to do it during working hours anyway, I thought well, then I'll just register there. (2022_6)*
>
> *Just that I was absent from work once for half an hour or an hour. But that was agreed with my supervisor that that was okay, yes. (2022_3)*

Compatibility with their daily lives is crucial; it is a presupposition for a convenient experience, otherwise, they would not have been in a position to do it in the first place. Again, others are involved, here as an enabler (or alternatively as a restrictor) whose endorsement is required for the participation, emphasising the relational nature of personhood. Not only had the job to be compatible but also was often factored in otherwise: "I hear it from colleagues how difficult it is to recruit and to get participants and then I guess I was always heightened and looking for advertisements that I would fit the criteria" (2022_5). Because of her work, she has a personal connection to the field and insights, which made her want to give something back. Through the connection to the colleagues, people had a stronger sense of responsibility to contribute something and help them: "Because if it's from MedUni anyway, and I work at MedUni, they'll probably be happy to have more subjects there anyway, so to speak" (2022_6).

What did not matter so much in their participation was the contact with clinical staff and physicians. As it often was a variety of different people that they had contact with for different parts of their contribution, no strong allegiance developed. In the case of the booster study, receiving a vaccine is a preventive measure, therefore not as embedded in a care relation in comparison to already being sick, and it does not take a long time, therefore just requiring a short encounter with the clinical staff. Only

in two cases this looked slightly different because of their context: one participant has a chronic disease and received an earlier appointment with a specialist due to the participation in the study (so an extra incentive to take part in the study), while another one has been taking part in a longitudinal study for over 10 years and is familiar with the people who work there. For them, the personal interaction played a bigger role as they emphasised the value of non-anonymous encounters in these contexts. It is already an indication that a contribution in a hospital context, where people are part of a closer care relationship, may take different forms than in the context of a study participation, since in both situations partly different factors come into play. Generally, it is important, also for the study participants, to have a safe and friendly environment and to not feel pressured.

6.4.2. Excluding Others

After looking at how participants included others in their contemplations on contributing to a biobank, I will shift to rather excluding narratives that came up, where participants demarcate themselves from others. In a way this also an inclusion of others in their considerations, but in a rather negative way, as it is to set a boundary to those who have not contributed or who have deviating opinions.

These were instances where the national context came to matter, though only a few times the situation in Austria was explicitly discussed. One participant had the belief that: “You have to think about it yourself, if you need blood, a kidney, whatever, then you are happy if you get one. Nobody wants to give something away, so in a sense, that's an Austrian affliction” (2022_2). Here we also see the approach of reciprocity that the participant took; giving something helps yourself in a roundabout way if you ever need something. He sees it as a national problem that people generally do not want to give anything, so relating the willingness to participate (which is in practice not really an issue) to the national level. With his participation, he can counteract the problem. The participation then advances to a (political) statement, as it helps to fight this “Austrian affliction” and helps to keep the society together, which becomes more evident in the next statement: “As I said, it [serves] the general public, because there is a certain division in society, quite simply in order to perhaps reduce it a bit” (2_2022). The participant refers to the divide that occurred at that time due to strongly different persuasions regarding COVID-19 vaccinations and other response measures. With participation in the study(!), one takes a clear position and tries to reduce this division by contributing to a study about vaccinations, which might help to showcase their effectiveness, while also getting a vaccination themselves, so they can act upon the vaccination discussion and contribute to resolve the situation through their participation, at least from their point of view. With their contribution, they position themselves responsibly (see Bister, 2010) and express a pro-science stance, and the further contribution to the biobank conforms to the stance already taken at that time.

The "Austrian affliction" described above, so the lack of people who are willing to give something away, was also mentioned by others, though without making it a national characteristic. When being asked how many people they believe agree to contribute, most participants assumed that the number of participants was rather low:

> *Probably very low. I think people are just very mindful of their time. They're like, I don't want to waste my time doing something basically voluntary, right? So, probably, I don't know, maybe less than 10% of people, I'm sure. (2022_5)*

> *Probably not that many, unfortunately, although it wouldn't be a big effort now. Especially with the, that was now only a blood sample and saliva. (2022_3)*[18]

Despite it not being a big effort, which was a major reason for them, people do not think that many others would contribute. Being mindful of their time, being too critical or being uninformed were stated as reasons why others would not want to participate. The perception that most people say 'no' made their own participation more needed and made it feel like they could contribute something of value, which became clear when asking them if they think their contribution makes a difference:

> *As an individual, I think, it doesn't make that much difference, but if everybody would think like that, then we would just have a problem again, just like on many other topics, that you just then don't find people, don't have data together then and so on, that's why yes. (2022_3)*

> *I feel everyone counts because when you need a specific amount of information and just like anything, if everybody says, "Oh, I'm just one person", it's like voting. If everybody has this mentality, then no one's going to go. (2022_5)*

Those who thought that not many others donate also attributed more value to their own contribution and thought that it eventually makes a difference. If you think along these lines the motivation to give something away can be heightened, as one's contribution gains significance. Yet, one is not alone in this, because only with others participating, research can produce meaningful results. To feel like making a difference one has to see past the fact that an individual's impact is limited and focus on the sum of all the individuals that is important, similar to the democratic act of voting.

Connected to this is also the belief that participants are needed and that not having enough samples for research is an issue (2022_3). Another one articulated that she was looking for ways to give something back to research, being a researcher herself and knowing how difficult it can be to obtain the necessary

[18] Though I asked them about the biobank participation, I cannot exclude that the interviewees might have referred to the participation rate in the study instead.

samples for one's work (2022_5). So, part of their motivation is to do it because others won't and therefore help those that are needing samples.

Only two participants had more realistic imaginations concerning how many people consent, though their estimates were still lower than the actual numbers: "I think that certainly around 70, 80% say yes" (2022_4) and "if it is explained to them within the framework of a study, then I actually believe that most of them say yes. So 80%" (2022_7). For them, because of and not despite the little effort people say yes, and they believe that the biobank contribution makes sense to most people in a given context. Nevertheless, they still think that about one in five people say no. These were also people who put less significance on their own contribution.

6.4.3. Include, Exclude, Conclude

How others were included and excluded in the participants' accounts depended on the context and how they wanted to position themselves, e.g., seeing it as a national problem or being a researcher. At the same time, including and excluding others can't be seen as separate from each other: when people demarcate between themselves and others, the others are still included in their reasoning, so both inclusive and exclusive narratives of others are two sides of the same coin. One's own position is defined over the positions of others and what they do or do not do. It once again emphasises the relationality, and surrounding their contribution we can see a big network where many actors are connected in a variety of ways. When it comes to a contribution, the participant has already been impacted by other (f)actors in the network, generally any kind of circumstances, non-human and human, such as time and place that enable convenience, and their jobs and other responsibilities or needs that need to be compatible with it. So, the bigger embeddedness in society plays a role. Taking these things into consideration can be regarded as a way of expressing their sense of citizenship. Here, in the case of the studies, most people participated in a COVID-19 booster study, which also entailed getting the booster vaccination. In Austria, the corona vaccination was, like other measures against the pandemic, a highly controversial issue that was met with protest. Nevertheless, the Austrian government implemented a general vaccine mandate for a short while at the beginning of 2022 (Kurakin, 2022). Though the study took place prior to the mandate, it is likely that most of the participants were required to be vaccinated in order to perform their job, since they worked in the hospital context. By being vaccinated, they fulfil an obligation and also take some responsibility, protecting themselves and others. As this is only a particular case that precedes the biobank participation it is difficult to draw any conclusions from it for general biobanking, but in other situations, e.g., being in the hospital for a treatment, certain roles are also imposed on and expected from the participants. Therefore, it again emphasises that the biobank contribution cannot be seen as separate from the context in which it takes place.

Furthermore, the participants see themselves in relation to other contributors (or non-contributors), which has an impact on how they value their own contribution. For some, it means that their participation is influenced by others not doing it, so they see a stronger urgency to participate themselves, but also it is a way to help others and to contribute to the bigger structure of medicine and research from which they also benefit (2022_1). All these rationales can be consolidated under the idea of being a better citizen through one's contribution (which is enabled by the convenience of the contribution). Yet, while we can take some glimpses at where biobanks relate to other parts of their lives, for many the participation was no longer a topic that they discussed with others; only the antibody level was sometimes brought up in conversation, some people recalled (2022_4, 2022_6). The biobank participation is not a big deal to them: "I don't think I'm going to run around the world and advertise and promote this, but in principle, if someone were to ask me about concerns and so on, I think I would encourage them" (2022_1, see also 2022_6), which shows a certain level of low effort and passiveness towards biobanking again.

Effortlessness and passiveness were some of the recurring themes in the last 35 pages, and this going back and forth shows the connection of many points in one way or another and that they cannot be separated from each other. I presented a variety of aspects involved in the understanding of one's contribution to the biobank, trying to capture the different ways in which people relate to the sample and data, the informed consent, and other people, revealing an assemblage with many contingencies. How people act and feel about things depends on other considerations and valuations, shaped by other non-human and human actors, and as it is not fixed, changes in attitudes and public perception can always appear. Biobanking and one's contribution to it need to be seen in a bigger context, recognising the actors that impact each other, but differing in how much each actor matters individually. While the contribution to a biobank is complex, contingent, and not reducible to one aspect, there are still some facets that I consider more prevalent than others, originating from the interplay of the various aspects and the particular cases explored in the interviews. In relation to wider debates and existing literature, I will present and discuss my three main findings in the following chapter.

7. Discussion

Following from the analysis, I will draw out three specific insights and examine them in relation to the existing literature and my chosen concepts, allowing me to address the overarching research question of how people understand their contribution of samples and data in the context of biobank consent processes.

Firstly, I will discuss the nature of the contribution as a *collateral good* and connect it to the literature on citizenship, particularly focusing on the notion of solidarity. Secondly, I present informed consent, or rather the idea of it, as a mediator for how people understand their contribution. In this context, I will examine the concept of boundary objects and OPPs to provide insights into the different ways in which informed consent mediates individuals' understandings. The third and last point I want to make is the observation that people tend to no longer actively think about their contribution. Once the material has left their bodies, it is no longer on their minds. Yet, it is important to acknowledge that this aspect, like many others in biobanking, is contingent and could be otherwise. The implications of my findings for the future relationship between biobanks and participants are discussed below, including the return of results, the role of language, and citizenship.

7.1. Collateral Good

While biobanks are something that the participants support and consider as good, an overarching theme that dominated accounts of their participation was the low effort that was required from their side. Due to the context of their contribution and more generally due to the context in which one is asked, the biobank contribution remains in the background of another situation, e.g., a study or clinical care. They participated precisely because it takes no extra effort due to being connected to another situation, and because it does not interrupt their daily lives. This turns their contribution to research and the common good into something that is a positive side effect of another act; it is a *collateral good.*

My interview partners all had already decided to participate in a study (which was also part of something else in most cases) when asked to contribute something to a biobank, and if it had required more effort or if they had been asked to give away something additional to what is taken from them anyway, they would have had to reconsider whether they want to participate or would need more reasons to do so. Instances like bone marrow donation or kidney donation, which are not happening in the context of biobanking, are more demanding and more impactful because they come with stronger motivations, are often more personal and affect the contributor in several ways (physically, emotionally, time-wise...). In contrast, a biobank contribution is rather incidental; people are already at the place of the contribution, and that's also one of the main differences e.g., to a blood donation, where the decision to

donate precedes the place where it is taken, while it is the other way round in this case: the place leads to a donation, not the donation to a place, so the context is crucial.

The absences of effort and risks characterise the contribution, else if there were disadvantages, they would not participate, also because biobanks offer no incentives that could offset them. Participants do not feel a strong involvement, because they do not actually lose or risk anything; the material is taken anyway (for the study or clinical care), particularly, it was mainly *just* blood and saliva that was taken and there is no harm. As such, there is nothing at stake for them, which is also shown that when their samples are not used, it does not bother them. Instead, participation is a mixture of pragmatism and effortlessness, through which one can easily do something good.

This insight has (some theoretical) consequences. For example, while biobank participation has often been connected to solidarity (e.g., Bühler et al., 2019; Locock & Boylan, 2016), I would argue, taking Barbara Prainsack and Alena Buyx's (2017) definition of solidarity as the starting point, with which they are especially addressing biomedical contexts, that a contribution to a biobank does not qualify as an act of solidarity. According to them, "solidarity is an enacted commitment to carry 'costs' (financial, social, emotional or otherwise) to assist others with whom a person or persons recognize similarity in a relevant aspect" (Prainsack & Buyx, 2017, p. 52). Comparing this with my findings, where one of the most prominent reasons for participation was the minimal effort required from them and the general lack of costs, it is questionable if the contributions of my interviewees to a biobank were practices of solidarity. For Buyx and Prainsack risks and potential future harm like re-identification are also costs, but these were either not perceived or considered inherent by the participants. If they are not perceived as actual costs, it takes away the first pillar of solidarity: a solidaristic act requires consciously taking costs on oneself to help others, which does not seem to be the case here. The second characteristic of solidarity according to their definition is recognising similarity to others, which is not (always) fulfilled either. Biobanking remains quite abstract to most people, which is why similarity to others was not an apparent strong motivation for participation and remained superficial, e.g., being in a position where one might also be in need of something, just like others might be helped through their contribution. The similarity to others played a bigger role in a few specific cases, e.g., a participant suffering from a certain disease, whose contribution could help other affected people without necessarily helping herself, or the researcher who knew that her colleagues have difficulties getting samples. This shows that solidarity is context-dependent, affecting if and to whom one shows solidarity. Rather than similarities, people often acknowledged the differences between them and others, e.g., how they prefer a certain kind of consent while others would disapprove of it, and they believe they belong to the minority of people who give their consent, therefore with their own contribution, they can stand out from others and be a better citizen.

A biobank contribution might bear characteristics of a solidaristic act, e.g., the contribution to the common good and helping others, whether it be other patients or researchers, but the context "shapes and determines whether an action can be regarded as solidaristic" (Prainsack & Buyx, 2017, p. 47). Solidarity needs to be enacted, meaning that one needs to have the intention to act in solidarity, the outcome alone is not enough. This is how biobank participation might differ from study participation, e.g., if we think about the person who took a stand in the COVID-19 controversies by partaking in the study to show his support. The study participation was a conscious choice (but also affected by the situation of receiving the vaccination) while the biobank contribution was a concomitant of the study and hence an act of effortlessness and convenience, not fulfilling the standards of a solidaristic act.

As such it is also a demarcation to blood donation, which is usually an act of solidarity, where people take considerable costs (such as time and the impact of blood loss) and make a conscious choice to help others who are in concrete situations where they need a blood transfusion immediately. Also, participation in a study offers more room for acting in solidarity. A community feeling can come up and it can be more formative for one's identity. Often, these aspects are less applicable to biobanking compared to blood donation or study participation. Still, there are also circumstances where "biobanks play a key role in delineating collective identities" (Gottweis, 2008, p. 33), for example in cases of more distinct groups like specific population banks or patient organisations that create biobanks for research on a certain disease. Such activism and a sense of community, which are prominent in these cases, may not be found in the biobanking cases I have encountered, as the focus is broader and goes beyond a particular disease or condition. We cannot find a solidaristic community, as there is no contact among the participants and no sense of community created aside from participating in a study and receiving a vaccine. Whether those are acts of solidarity is another discussion.

7.2. Informed Consent as a Mediator

After delineating the position that the contribution takes for the participants, I will look at what role informed consent plays in how the participants understood their contribution. While it is somewhat difficult to say what difference the informed consent made for their contribution(s), since I do not know how they thought about it prior to the process, we saw in 6.2.2. that informed consent can influence how they relate to their contribution. Informed consent is the place where information is materialised and comes to matter: it is a regulatory measure and is also understood as such, to basically all participants it is an obligatory formality that one needs to pass through. However, this does not mean that informed consent always fulfils its function of informing and assigning the correct roles. This is partly due to only being present in the moment of signing it and also only playing a limited role there, because of the contextual embeddedness described above and because, though the information might be acknowledged, it is filtered in a confirming way. The information is let through on the nod, and this

negligent behaviour towards informed consent, as with other data practices, is considered normal. Yet, the information taken up is formative for how people relate to their contribution, regardless of whether the information is correctly remembered. If this information is ignored or forgotten, the impact is naturally diminished but is nevertheless still shaping the relation. For some, the option for withdrawal leads them to still consider the samples their own and gives them a certain sense of control over it, while for others the informed consent is a turning point at which they give up any entitlements to the samples. What a person takes away from the informed consent depends on their circumstances and beliefs, so the entire process defines if and how the information is properly understood, meaning it cannot be predicted, how and if it will be understood. As Bruno Latour said, "specificity has to be taken into account every time" (Latour, 2005, p. 39), for example, the reasons for which one is there, the value they attribute to the sample and if they have been in the hospital before because then they are likely not asked for their consent again. Therefore, we have to consider the wider assemblage.

This brings our attention back to the concepts of obligatory passage points and boundary objects, which offer perspectives for situations where different actors interact. Informed consent can have varying effects on individuals, displaying its multiplicity and serving as both an obligatory passage point and a boundary object, depending on how people perceive it. This observation follows from the accounts provided by the interviewees, particularly regarding their understanding of their relation to the contributed data and samples. In cases where people's interpretations deviated from the conveyed information, such to whom the samples belong, the informed consent process takes the role of a boundary object, bridging the gap between different understandings, allowing for compatibility and providing a common ground. The informed consent enables communication and coordination between these two groups; the information is vague enough to allow the identification of the participants with it, particularly if not properly read or remembered correctly, as it then fits better to their beliefs. Importantly, informed consent is only collected once and on further stays at the hospital, consent is not collected again, so this point of information is not always passed. As a result, people might be unaware of the continued gathering of their biomaterial. So, the informed consent is not fixed but context-dependent, and because of the option for withdrawal, the participation in the network is contingent.

Alternatively, when people regarded the consent process as a turning point, signifying the transfer of ownership, meaning that they are no longer the owners of their samples and data, the process resembles an obligatory passage point: interests are aligned and roles are successfully assigned as the participant is enrolled in the network and the material is transferred. As a result, "these entities are dissociated from previous relations and placed into new desired associations so that they can perform appropriately within a network" (Michael, 2017, p. 157). The consent, obtained for allowing the use of the samples for research, negotiates between researchers and participants and sustains the network. As people are only asked once for their consent, thereby also consenting to future collections, informed consent is a

singular instance, which renders the contribution ongoing in the sense that it is open, when and for how long samples are potentially collected, provided that the participants are in the hospital again. Without much further effort from all actors involved, the collection is maintained and thus stabilises the network, potentially at the expense of insufficient awareness on the side of the participant. At the same time, the contribution at that point in time is finalised in the contributor's eyes since it is transferred to the biobank. Here a stronger unidirectional dynamic can be observed compared to the participants who still considered themselves to be the owner of their samples. Nevertheless, it is not fixed as the option for withdrawal exists for all participants.

Regardless of the perspective that is taken to address informed consent, both the obligatory passage point and the boundary object can be described as mediators. In both cases, the informed consent process translates and transforms the aspects that it is supposed to communicate, thus acting as a mediator that shapes the relations and behaviours in the network, and consequently the structure and outcome of it (Latour, 2005; Michael, 2017). Despite the potential for misunderstandings, the informed consent process still facilitates communication and serves as an overall facilitator by collecting written agreement. In this way, the informed consent process establishes and maintains relationships that are ongoing because of the option for withdrawal, and in both cases consent is contingent. This is why it is important for biobanks to secure the participants' participation in order to ensure the network's stability, e.g., by keeping the interest aligned and maintaining trust. One way to improve this could be for informed consent to become a "faithful intermediary" (Latour, 2005) that simply transports information and achieves its desired outcome. However, the question arises as to whether this is ever possible. Communication is a complex process that often involves differing interpretations between sender and receiver, and merely providing more information does not necessarily resolve this issue. Besides, what effect does it have? Does it have 'real' consequences?[19] Looking at the interviews, it seems that there is no practical impact of understanding their contribution differently. Though their sense of entitlements may vary, the action for withdrawal is the same in both cases and is hardly relevant in practice since it is rarely utilised. Besides, participants no longer engage with their contribution and feel no strong attachment to it afterwards, independent from whether they see themselves as owners or not. Nevertheless, I cannot rule out that people with a sense of ownership might be more prone to withdraw their consent than those who feel no entitlement over the material if the hypothetical scenario arises where they would make use of it.

[19] In accordance with the Thomas theorem, "if men [sic] define situations as real, they are real in their consequences" (Thomas & Thomas, 1928, p. 572), which reminds of the first premise of symbolic interactionism: "human beings act toward things on the basis of the meanings that the things have for them" (Blumer, 1986, p. 2).

More problematic than the differing takeaways from the informed consent process is arguably the discrepancy between the ideal of informed consent and its practical implementation (that is partly following from it). It is imagined that individuals make informed and free decisions on their own and are responsible for them. This constructs a certain idea of a citizen, however, if people cannot remember a lot or base their understandings on misconceptions and consequently, their decision to participate is not determined by the information they received, this idea(l) can hardly be fulfilled. Participants are not the responsible individuals they are imagined to be (e.g., Bister, 2010), "who, given sufficient information, are able to make free, informed, rational and thus moral choices with respect to their participation" (Corrigan, 2004, p. 86). As such, individual voluntary consent can be seen as part of "governmental programs and regulatory technologies (…) to construct autonomous subject whose choices and desires are aligned with the objectives of the state and other social authorities and institutions" (Petersen & Lupton, 2000, pp. 63-64). The informed consent process therefore "reflects dominant neoliberal modes of subjectification" (Tutton & Prainsack, 2011, p. 1084). However, as I tried to illustrate in my analysis, the contribution to a biobank is not an isolated decision of an individual based on the information provided, but the results of its context. This shows us how participants construct themselves in contrast to the top-down construction: acting on trust (and hence sometimes deliberately not reading the informed consent), not taking up the responsibility while simultaneously wanting to keep some control over their samples, being pragmatic, so contributing to the common good when it is convenient. In my interviews, participants take a rather passive role because of the one-way dynamic and effortlessness, but the enactment of citizenship can easily look different in cases with more involvement and interaction.

Furthermore, the effect informed consent could have could be bigger in practice, as the informed consent process is the moment, if people read and engage with it, where they are being halted to think about what a donation entails and how they think about their body. The informed consent process has the potential to establish a connection between the sample and the participant (Hoeyer, 2004a), which might usually not be contemplated, but with the informed consent procedure attention is drawn to it. It is then becoming a space where one's relation to the body and the boundaries of it are re-imagined (Bister, 2010). With new perceptions of the body that arise through the informed consent, new possibilities open up that allow one to use the body to act in a social and responsible manner. While informed consent can have such an effect, for example in cases of patients whose tissue from the breast or abdomen was collected for a specific study following plastic surgery and who were given quite extensive face-to-face information about the study's informed consent (Bister, 2010), for my interview partners this was not the case. My interviewees, mostly healthy study participants in the context of a COVID-19 vaccination, were less affected physically and in terms of time spent at the hospital. The biobank contribution was embedded in the study, so the focus was on the study, and they potentially

received less information about the biobank contribution and had less time and opportunity to think about their participation and the use of their sample.

Yet, despite the shortcomings of the informed consent process, the participants were generally satisfied with it and deemed broad consent as widely appropriate, while other options were discarded, as they are either too effortful and bureaucratic or limiting free choices. As effortlessness and agency are both highly valued, broad consent is a sound compromise, considering the accounts of my interviewees.

7.3. Out of Body, out of Mind

While the informed consent might act as a mediator on how people relate to and understand their contribution to biobanking, it does not create a strong feeling of connection to the sample. Regardless of whether they see themselves as the owner or not, people no longer think about their participation or discuss it with others after the contribution has happened. Participants stated that they do not care or, though they are interested, they do not feel entitled to know what happens with their samples and data once they have given it away. One reason for the indifference towards one's contribution - and this indifference is not meant in a negative way - is the unspecificity of biobanking: when the data and samples are collected it is not known what they will be used for, neither to contributors nor biobank. As a consequence, the contribution remains quite abstract and fades from their memory if not sustained. For this reason, I chose the title 'out of body, out of mind', reminiscent of the German proverbs 'Was weg ist, ist weg' (engl. 'When gone then gone') and 'Aus den Augen, aus den Sinn' (engl.: 'Out of sight, out of mind'), to which I added a more literal meaning: when biomaterial is taken from their body, it seems to no longer take up space in their mind.

Additionally, beyond the informed consent process, there is no information on their contribution that the participants can integrate and be impacted by. Feedback (concerning use or results) is probably the thing that affects someone's self-understanding the most, e.g., in the form of their antibody status, which can give them a sense of (in)security. However, in biobanking, feedback is not foreseen, but in the case of the studies, in which the biobank contributions were situated, we could see that it can have an effect and is an incentive to participate. It is not surprising then that their contributions to a biobank have limited influence and consequences for the participants, especially if it happens simultaneously to a situation that is specific, has more relevance to them and where they receive information, e.g., in study or medical examination. The biobank contribution, with its absence of effort and effect, leaves no lasting impact.

For people to think about it again, it requires particular occasions, here an interview and being explicitly interrogated about it, or receiving feedback. So to say, interest has to be created by providing the option for it. Thinking about the participation is elicited through a context in which one is confronted with the

topic, like the interview, but it rarely happens that people still think about their biobank contribution on their own. It, therefore, mirrors the biobank contribution, which is always embedded in another context that allows for it. As receiving feedback is not possible in the case of biobanks, the participants do not give much further attention to it. This does not mean that they generally are not interested or that they do not care at all but as there is no information offered, they do not have the chance to engage with it and trust that their samples are used for a good purpose and handled according to their expectations. Therefore, it is no longer on their minds unless elicited by external impulses. To the participants, the contribution is a rather singular instance, despite remaining open through the, for them, crucial option for withdrawal which affects their feelings of ownership and being in control. But as they can not imagine that they will ever make use of it, it does not play a role in practice. The contribution is passively ongoing in addition to already passively happening due to *only* being a side product of something else. Overall, their biobank contribution does not matter a lot to the participants, they are not personally affected by it, but they also do not mind this situation. Even more, this might actually be an advantage of biobanking: since people are not personally affected by it, it does not take up a lot of space in their lives and thus a biobank contribution is easily compatible and does not need to compete for attention. People have other things on their minds and as we live in a complex world, it is impossible to think of all the invisible infrastructures we are in contact with. Even if they matter to us and affect our daily lives, there is not enough capacity to think about all of them, like waste disposal infrastructures,[20] satellite communication, or food supply chains, to name a few examples. These are all highly interesting and relevant for a functioning society, but there is no time to engage with all of them. This does not mean to be completely ignorant of them, one should at least be aware of them and acknowledge their existence, but a more active engagement is not necessary for their functioning.

Though, when asked about it, people showed interest in receiving information about the use of the samples and feedback on results. Receiving information increases transparency and could have the power to impact their self-understanding, as the antibody level did, thus strengthening their personal connection to biobanking and potentially leading to stronger visibility of biobanks and a longer lasting engagement with it. However, even if there is interest in feedback, people prefer a passive role reflecting the effortlessness that brought them to the biobank contribution in the first place.

Besides, whether or not results should be returned is contested. Some voices argue that there is an obligation to share results, as people have a right to information and it could be an additional motivation (Kettis-Lindblad et al., 2007). On the other hand, it is argued that giving feedback does not align with the purpose of research, as research is not about the individual and feedback takes away the altruistic

[20] They furthermore have in common that they both handle material that is no longer needed.

and solidary facette of biobanking (Stjernschantz Forsberg et al., 2009) (though as pointed out it is not mainly an act of altruism nor of solidarity). Furthermore, it could violate the non-malevolence principle, as giving feedback could lead to harm and distress, e.g., when a certain disease or a predisposition for it is revealed, so it is important to also respect the right not to know and people should be able to choose if they want to receive incidental findings. Thus, information is a "double-edged sword" (Hoeyer, 2009, p. 251), and it needs to be made sure that the results are understandable and people receive support to make sense of the information (Kettis-Lindblad et al., 2007). Currently, the lack of resources and corresponding infrastructures are practical obstacles to the return of results, so the no-return policy is not in actual peril.

However, there could be at least a possible option for knowing how one's sample and data are used: the right of access by the subject, as is the case in the GDPR, meaning that people would receive information about what is collected and what it is used for if they request it (Hartlev, 2021).[21] While this requires more effort from the participants, it would probably be possible to keep the cost low on the side of the biobank, as most of my interviewees would not want to go to the trouble of finding out information if the initiative were on them. As one participant pointed out while discussing the possibility of a donor portal: by actively seeking information, "the onus would be on you" (2022_5) and the biobank would not have to contact thousands of people by default, thus the right of access is a middle way between participants' interests and rights and the cost for the biobank. The donor portal could be a way where people could make use of the right, but it could also be achieved via mail and other forms of communication. If a biobank has the necessary resources for implementing such a feedback loop they should consider it, and it is claimed that "raw data access - and other measures to increase transparency - require only moderate effort and marginal resources from a biobank" (Prainsack & Buyx, 2017, p. 113). It could also be thought of to adapt the legal framework and create a biobank law, as is already the case in other countries (e.g., Tzortzatou & Siapka, 2021), in which, among other things, a right of access could be included. On purely hypothetical grounds, this could also be a solution to how personal feedback could be given while both complying with the right to know and the right not to know if people only receive personal feedback if they happen to ask for it.

This is one way patients can become involved, which is of interest, as it is often argued that for lasting success, "an alternative approach, in which donors are made partners by staying connected to research" (Saha & Hurlbut, 2011, p. 312) is needed. A stronger involvement would especially benefit the researchers as they can collect more samples and data from the same person. But what is there to gain for the participants if not feedback and more information? Such an active partnership would require

[21] As biobanks use the data for research purposes, they are exempted from the GDPR's right of access (Tzortzatou & Siapka, 2021).

more resources on both sides but could increase the awareness of knowledge about and engagement with biobanks. At the same time, the question is whether the efforts are worth it since trust and participation are already high with a minimum of resources and commitment. There is talk of seeking a partnership, but the insights from the interviews show that people participate precisely because of the low effortfulness and convenience, therefore the idea of being partners might not resonate much with them. Even more, proposing a closer relationship that comes with certain expectations and requires more effort and therefore might deter them, hence it is not desirable neither for participants nor the biobank. But it could be an option for those who are interested in a more active concurrence.

If a partnership wants to be achieved - and the term alone already implies a (stronger) form of equality - a lot would have to change, it could no longer be a one-directional relation. The biobank also needs to reach out to the public and not just ask them to give more. This could be done by providing feedback or by giving more control to the participants, e.g., via a donor portal. In a closer relation more responsibilities, requirements and costs are demanded from both sides, meaning that there is also more to lose if the network breaks down. The fleeting encounter between biobanks and participants as it is now having the advantage of not asking for much.

Cases where a closer engagement with participants can be observed are services such as 23andme (Tutton & Prainsack, 2011), which have more power to change an individual's sense of self through their commercial offering of genetic testing and feedback. 23andme is about personal gain through insights into health and ancestry, thus contributing to identity construction. In addition, 23andme has an active online community. Here, participants or rather consumers gain more knowledge in return because they “have chosen to give more than the minimum” (Saha & Hurlbut, 2011, p. 313). Biobanks do not have the resources of a commercial actor, but in contrast, as a rather invisible infrastructure that is embedded in the hospital context, they have the ability to seamlessly collect samples without charging fees, but also without being able to give anything back.

7.4. What now? Further Implications

Having presented and already engaged in some discussion regarding my three main findings, I would like to further explore what implications this has for biobanking practices and the participants. In doing so, I will focus primarily on the further engagement of participants in biobanks and link it to the discussion on returning results, informed consent processes and other ways of communication. This section will be complemented by reflections on the language and framing of biobank participation, as well as citizenship.

7.4.1. Engagement

The discussion about engagement does not start with the return of results, but already with the information about and understanding of biobanks. My interviewees, who were generally highly educated and often familiar with the healthcare field due to their work at a hospital, had little knowledge about biobanks.[22] The interviews revealed that there were several blind spots and misconceptions about biobanks and their practices. These included the meaning of anonymity and pseudonymity; the implications of broad consent, e.g., not being asked for consent again in future studies or hospital visits; the transfer of ownership, as often it was thought to just be a loan; possible users of samples, e.g., non-academic and academic institutions; withdrawal does not mean deletion of samples and data. This is just an exemplary list of aspects that should be communicated more clearly as they are often involved in creating a false sense of security. Some of these are even mentioned in the informed consent but should be made more explicit, for example, industry collaborations, or how one can prompt the complete erasure of one's samples and data at withdrawal.[23] Disclosing these aspects upfront can increase trust and transparency, whereas if it comes out in hindsight, it could cast a bad light on biobanks. Though this could make people more aware of risks, it provides a good basis for making an actually informed decision, of course, only if the participants read it, which remains the participant's individual responsibility. Whether (and how) this information is received and whether more information makes a difference in practice is therefore another question, but it is good to make the information available in the first place.

Moreover, there are not only misunderstandings in relation to biobanks, but also to research and medicine in general. People underestimate what can be possibly done with their samples and what they are used for. Some participants' willingness was affected by their reasoning that not a lot can be done with their blood, however, it contains their DNA and thus their genetic information. In theory, it is conceivable that, as with HeLa cells, cells from their samples could be multiplied indefinitely, and they would not know about it. As I did not discuss this example with my interviewees, this would be an interesting topic for future research; what people think is possible to do with their sample, and how they would feel if their samples were used in such a way.

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[22] A personal anecdote reflects this: whenever I was asked what my master's thesis was, very few actually knew what a biobank was. What my friends and family had on their minds were commercial semen banks, blood banks, or a plant seed bank, they thought of sustainable finance banks, or something with corpses.

[23] Even though biobanks mention some of these aspects in the informed consent, they are often vague, and can easily go unnoticed. This became even more apparent in interviews with non-donors with whom we discussed excerpts from an exemplary informed consent and asked how they would understand things like non-academic institutions or the option for withdrawal.

Not only do more information and a better understanding but also having more options to choose from lead to a more considered and autonomous decision-making. Currently, there is no real choice other than yes or no (Hoeyer & Lynöe 2006) and refusing the consent altogether might seem quite drastic to many, even if they have doubts. Informed consent does not reflect the nuances of people's attitudes. This could be changed through the donor portal, where people can make decisions according to their desired level of engagement, for example, by having additional options in the initial consent that allow you to exclude commercial use or specific research they do not agree with. However, it is difficult to include all possible options in a consent, e.g., such as the exclusion of creating a cell line as with HeLa cells (Saha & Hurlbut, 2011) (which would presuppose that the participants know what a cell line is). While having options to choose from gives participants control and empowers them, it can also burden and overwhelm them to make these decisions. Therefore, it should always be a choice of not having to decide and being able to still give broad consent. The feeling of control would still be preserved if they make this decision for themselves.

In addition, the decision to participate should not be taken as irrevocable. Currently, after the one-time collection of the broad consent, people are not asked anymore and are not informed about any future collections of samples from them. Although the interviewees discarded being asked for their consent on each occasion, an option could be to remind them verbally of their consent to the biobank when they are in the hospital again. This would give them the chance to re-evaluate their decisions and could create more awareness for the biobank at the same time. It increases autonomy as just because they said yes once doesn't mean they would say yes in another situation, e.g., involving a different tissue which to them has more value. Of course, there is a risk that people will say no, but in return, they are better-informed participants. Practically, however, in the hectic and demanding everyday life of a hospital, there may not be any time left for providing this information, and clinical staff may also not feel responsible for biobank matters.

Paying attention to context is a good cue: another way to get closer to the ideal of informed consent would be to take it out of the, for most people, rather unusual situation of hospitalisation. Often times patients are under stress and have other issues, and there are other informed consent processes in place too, e.g., for operations (Dixon-Woods et al., 2006). The biobank contribution collected in the clinical context is part of a care relationship with a certain dynamic, as the patients are in a “position of weakness and dependence” (Bochud et al., 2017, p. 6). A way to slightly circumvent this power imbalance could be to give the informed consent prior to their hospital stay if it is already known that they will come to the hospital by mail etc. A study from Switzerland where people received information before their scheduled hospitalisation found that the participation rate was similar to the usual one and the patients were “better informed and ready for a deeper discussion on research” (Bochud et al., 2017, p. 6). That would allow them to engage with it more thoroughly and not just skim it. Either way, people who do

not want to receive the information, cannot be forced to take the information up. It will be interesting to see if implementing different measures has an impact on how people make decisions and how they understand their contribution. The above applies more to people embedded in clinical care, and not study participants like my interviewees, of whom some spontaneously decided to partake in a study when they were queueing for the vaccination.

7.4.2. Language

When talking about engagement, one aspect should not be forgotten: language. It frames how we talk about and understand biobanks and one's engagement with them. Language is a tool that shapes how we look at the world, and we can make use of this. As has been shown, people often have no concrete imaginations about biobanks and no examples they can refer to. By providing specific narratives about how samples can be used to the participants, their participation can become less abstract. Also, a narrative where they are part of something, to which they and others are more strongly connected, such as population biobanks, could increase engagement as it creates a specific context and possibly a sense of community. Besides, if people know that others are donating, they might be more willing to do the same, my interviewees thought, so potentially increasing people's participation. This also reflects the relational character of participation. Also putting more emphasis on biobanks' embeddedness in the healthcare system could already point this out.

Another approach to finding a suitable narrative might be to incorporate the aspect of data more prominently when talking about the biobank. A neologism that was repeatedly used by my interviewees was "biodatabank". Such wording puts more focus on the data. This is a more realistic representation given the importance of data in research and the inseparability of samples and data, and also given how some people value data as opposed to their samples. It might even be less ambiguous and vague compared to biobanks. Framing it more strongly in regard to data could make the prominence and importance of data in research clearer, which in contrast to the specimen collection, is less tangible. Also, according to the GDPR, data can be used for research without informed consent, so e.g., in consent processes the sample is more relevant. I'm not as delusional as to believe that the well-established term biobank will be changed, but perhaps the use of "biodatabank" by the interviewees is an indication that data should be included more in the framing of biobanks.

The narratives currently in place often talk about altruism (e.g., Locock & Boylan, 2016; Tutton, 2007), and heavily make use of the term 'donation'. However, donation as we encounter it in blood donation or organ donation comes with connotations that do not apply to a contribution to a biobank. It was clear from the interviews that a donation to a biobank is perceived differently than a blood donation (or organ donation), as it is seen as more altruistic, social, and costly; it is more of a *donation*, whereas a biobank contribution remains quite abstract, is effortless and is regarded a rather scientific act. Moreover, it was

at times perceived as a loan and less ultimate compared to a blood donation due to the option for withdrawal, leading to a different relationship with the material. Thus, although the same term is used to describe these instances, there is a difference in the nature of these contributions. Yet, there is a lack of alternative terms to describe it, aside from the very general terms participation and contribution. Thought should be given to how contributions to biobanks could be phrased and conceptualised differently, reflecting the participants' perceptions and doing justice to what a biobank contribution is and what it is not.

7.4.3. Citizenship

In the existing literature on participation in biobanking, frequently framings of the contribution as an act of citizenship can be encountered (e.g., Árnason, 2009; Tutton, 2007), as by contributing to biobanks, the participants potentially enact certain values and an idea of what it means to be a citizen, while at the same time the informed consent carries a certain idea of citizenship, so both sides are involved in the co-construction of citizenship.

In the interviews I conducted, due to the described nature of the contribution as an effortless side effect, the role of citizenship was not as active as often imagined. Yet. there certainly were traces of it even if these took a rather passive form. For example, according to Rose and Novas (2005) the biological dimension of citizenship is individualising as well as collectivising, e.g., collective movements are crucial in knowledge production and the individual is affected through available information and together they are involved in the "political economy of hope" of finding treatments. While in biobanking this collective character is less distinct, as the participants are not organised among themselves and do not have a singular disease that connects them, a collective imagination is still present: the more people participate, the more samples and data are available for research, therefore further facilitating and advancing biomedicine, producing meaningful results and contributing to the common good. So, the reliance on individuals to participate in order to have masses of samples and data for research emphasises that the self can never be separated from the collective (Faulks, 2003). Besides, the research and its results potentially also relate back to the individual in the form of improved personalised medicine, but on the other hand, in the case of biobanking, information is not directly returned to them. Therefore, both the individual and collective nature of biological citizenship are not as pronounced in biobanking as in the case of activist groups or personal genetic testing.

While active citizenship is regarded as important for public health (Lupton and Peterson.), as common goals are easier achieved if all actively contribute, in the concrete case of biobanking, the lack of active engagement may not be a significant problem: due to the circumstances, it is an effortless byproduct and does not provide any personal benefit to the participant, thereby contrasting e.g., solidary health system and certain public health measures, e.g., wearing a mask and vaccinations. As a consequence,

the proposed notion of bio(data)-citizenship by Felt et al. (2020) is not as pronounced in the case of biobanking, e.g., no strong impact on identity formation, but nevertheless captures characteristics of the situation of contribution, where samples, data and the situatedness of the individual interact. Furthermore, passive citizenship is nonetheless citizenship, participating passively is better than not participating at all, and there is currently no way to participate more actively in biobanking. If there is a desire for more active engagement, it is necessary to provide participants with something in return, which would then accentuate the bio(data)-citizenship.

Furthermore, participation offers the opportunity for individuals to position themselves and express certain opinions and values. Regarding it this way, a biobank contribution is the instrumentalisation of the body. By differentiating themselves from others with whom they disagree, participants can support their beliefs about society and perceive themselves as more responsible citizens compared to those who choose not to participate. In some cases, interview accounts contained hints of a sense of obligation or responsibility to donate, as some participants believed that if they themselves didn't contribute, they couldn't expect others to do so either, and then maybe no one would do it; in this context it was also compared to voting. These insights highlight the inherent relationality and entanglement involved in biobank participation, as it emphasises that individuals do not exist in isolation. It is therefore more than appropriate to speak of citizenship in these instances.

8. Concluding Remarks

In this concluding chapter, I will present a synthesis of my main findings and the implications following from it, while also contemplating the limitations of this work and proposing further research efforts. In the course of this master's thesis, I have attempted to point out the contingent and complex yet convenient nature of a contribution to a biobank. Following from presented findings, the answer to my main research question: "How do people understand their contribution of samples and data in the context of biobank consent processes?" is threefold.

First, based on the statements of my interviewees, it became apparent that a contribution to a biobank is first and foremost an effortless byproduct. Due to the context and the embedding in a study, there are no additional requirements demanded from the participant. Moreover, there is often an absence of disadvantages, thus there are no reasons that contradict contributing. As a consequence, participants can conveniently support a cause they consider good in addition to what they are already doing; their contribution is, therefore, a *collateral good*. However, because of the low effort and interaction with other factors, like the attributed value to the material, there is also no special meaning attached to their contribution; it is not an act of solidarity or the like, but an act of convenience. As biobanks are also just an enabler and mediator in the larger context of research, they are not in focus.

This finding of a *collateral good* follows from the embeddedness of the participation in another context, highlighting the interconnected nature of participation. The contribution to a biobank cannot be considered separately from its surrounding context. This context not only includes the immediate setting of the contribution, such as a study or clinical care, and the human and non-human actors involved in that specific situation, but also the wider environment and circumstances of people's daily lives, such as compatibility with their jobs, their values regarding biomaterial, and opinion on discourses like the normalisation of data collection, all play a role in enabling or hindering participation. The participants are always intricately entangled with other actors, also on rather abstract levels, for example with the healthcare system.

Additionally, participants' considerations and decisions are shaped by others, by demarcating themselves from others through their participation, or by including them in their considerations and justificatory practices of sensible procedures in the context of biobanking. How people act and feel about things is contingent upon various considerations and valuations, which in turn are also shaped by a wide array of human and non-human actors. Consequently, the assemblage surrounding participation is not fixed but dynamic, which is why it is important to continuously reflect on its practices and composition.

Secondly, how the contribution is understood is impacted by the informed consent. But it is not informed consent itself that acts as a mediator but participants' perceptions of it and what they think is part of it. Often their understanding and relation to their contribution are based on misconceptions or partial knowledge at best. As a result of the different understandings of informed consent, a division stood out: people who see the sample as still theirs and as just a loan to the biobank, and others who give it away to the biobank and thus think they lose their entitlements to it. Following from this observation, I argued that the informed consent for the first group is a boundary object, while for the latter it shares more characteristics with an obligatory passage point. Either way, the engagement with the informed consent was not as strong and sometimes not remembered at all, in this way the impact of it was also diminished. But we see that it plays a role in how the contribution is understood and it is the formalisation of their contribution and basically the only moment in which they engage with it. Therefore, the information should be as clear as possible. The misunderstandings I outlined should be attempted to be avoided as much as possible, e.g., by making implicit assumptions explicit and not relying on vague wordings. Of course, if people do not remember it or do not read it all, it is doubtful that the changes will have an effect, and even with more information it might still be understood differently than intended. Yet, if there are opportunities to improve the declaration of consent, these should be implemented, since already providing information increases transparency, which could be strengthened further by providing options one can choose from. While there is room for improvement,

broad consent is nevertheless widely accepted and even preferred, as it offers a compromise that to a large extent does allow for freedom of choice and effortlessness.

Lastly, my eponymous observation was that people do not (actively) think about their participation afterwards, it basically has no lasting effect on them; hence 'out of body, out of mind'. People participate because it requires so little effort and is a side effect of another situation, so they are not engaging intensely with it and there is no strong connection, therefore the contribution also has little or no impact on their self-perception. Being a mere side effect is a strength and weakness of biobanking at the same time: while there is an advantage for biobanks to be in the background of a more tangible situation, as it allows for high numbers of enrolments and makes it easy to obtain samples, it has the disadvantage that people don't care as much about it and therefore does not receive a lot of attention. After having contributed, people no longer think about it, because there are no impulses, but the interviews - the accounts in them and the interviews themselves - show that when there are impulses, people start thinking about it. This opens up possibilities to make the engagement more permanent. While receiving feedback is unlikely to be actionable, participants could at least have the option to find out what their samples are used for by actively requesting it from the biobank, if they are interested.

With these findings, I position myself slightly in contrast to the literature and empirical work that argued for more active partnerships (Saha & Hurlbut, 2011; Tutton, 2007) and claimed that there is willingness on the side of the participants to engage more (Bochud et al., 2017). However, this needs to be looked at in a more nuanced way as between passive participation and partnerships there are a lot of other possible relations. I oppose the term partnership due to its implications of equality, which currently is not fulfilled and is also not desirable in the future. Neither for many participants, who would prefer being passive receivers and for the interaction to be effortless, nor for a biobank, as for achieving a partnership, they would have to give things back to the participants which would be resource intensive. A more active role would likely come with more effort, and could potentially endanger their participation, hence it is not desirable neither for participants nor the biobank. This would be an advantage of the right of access, since many participants are not willing to put effort into acquiring information, it is expectable that the costs caused by such a measure would remain manageable for a biobank.

However, strengthening the relation between biobank and participant can be worthwhile if both sides profit from it. It would certainly be an improvement to offer more control and choices to the participants, as in this way transparency and engagement can be increased and ongoing support can be secured. Yet, this role should not be imposed on the participants. I would therefore suggest refraining from framing calls for more engagement between biobank and participants as 'partnerships' since it raises expectations that might not be met and require considerable efforts from all sides. But those participants who desire a stronger involvement should have the option to choose it.

As it is now, biobanks are successful in terms of a high willingness to participate, but they fall short of ensuring that their participants are as autonomous and informed as intended by the practice of informed consent. Yet, my findings also indicate directions on how this can be changed in order to address these shortcomings. I have outlined several strategies to enhance engagement and understanding, such as using engaging language, implementing a donor portal or a right of access, promoting population biobanks, and improving the informed consent process. However, it is important to acknowledge that there are potential risks associated with these efforts, such as overburdening and thereby deterring participants, which could potentially lead to a lower participation rate. Nonetheless, in the long run, in this way, trust can be established and sustained, and participants who are better informed can make more autonomous decisions. For this, it would also be beneficial to have more options than just yes and no, as it would better reflect the contingency, fluidity and variety of participants' understandings, beliefs and preferences. Thereby, it is initially irrelevant whether these options will be used by the participants, just their mere existence creates transparency and the feeling of control, as the perception and importance of the option for withdrawal impressively showed.

Although this study is based on a specific group of interviewees who contributed to an Austrian hospital-based biobank within the context of a study participation, it is of relevance to biobanking endeavours more generally. Through the interviews, I gained a deeper understanding of the factors that shape participation, like convenience and contextualisation, and based on this, I hope to have pointed out biobanking practices that are compatible with participants' attitudes and align with ethical and social responsibilities. Even though I laid out that their contribution has little lasting impact on them and is a side effect, their contribution should not be belittled, and they should not be put by others in a passive position of being a source for samples. Participants should be provided with the possibility of agency, e.g., in the form of the right of access, as control over their contribution is valued by them and these options further mitigate risks. It is a way to appropriately appreciate those who enable biobanking in the first place by providing samples. Although the contribution may seem insignificant or without any direct impact on the participants, it does not mean that they do not care about it. They have expectations and conditions regarding how their samples are handled and trust in the biobank that these expectations are met. But trust is not unconditional and needs to be maintained. At the same time, participants should acknowledge biobanks for what they do. As of now, their participation is strongly characterised by absences of risk and effort, while there are not so many narratives that positively justify the existence of biobanks, aside from the vague and abstract narratives of contributing to the common good and to research. Emphasising the possible uses and the participant's involvement in the production of knowledge could affect the perception of biobanks.

The biomedical field has come a long way and made significant ethical progress over time, moving away from past regular practices like taking samples for research without people's knowledge as in the

case of Henrietta Lacks. While the practices have luckily evolved to a higher moral standard, there is still room for improvement, especially given the affordances of new technologies and the possibilities for engagement. It is important to not rest on the achievements from the past but to continuously explore and adapt to changes in the field and in the environment, like the increasing importance of big data as well as regulatory responses to it like the GDPR, or disruptions like pandemics or political shifts. They affect people's understandings and attitudes, so how they think about biobanks and their contribution today can be different tomorrow. Therefore, biobanks should re-evaluate their practices continuously and pay attention to the understandings and preferences of the participants. Not primarily for the sake of collecting samples, but to ensure the establishment and maintenance of long-term trust. Therefore, by understanding what participants value and how various factors affect them, biobanks can develop and offer meaningful choices to participants which helps to construct informed and more autonomous participants.

8.1. Limitations & Future Research

As with any work, if one chooses certain concepts and methods and focuses on certain issues, one neglects others, so there are several limitations to this work, some of which have already been mentioned throughout the work.

To begin with, due to the difficulty in acquiring people who had previously contributed material to a biobank and the sampling strategy we chose, a very specific sample emerged. All persons took part in a study, 7 out of the 8 were part of a study where they also received a booster vaccination. Therefore, the data and my findings may tell us mainly about a contribution to a biobank as part of a study and not so much about people who are asked to do so during their hospital stay. The context is a different one, as with the study, they have already agreed to contribute to research. Thus, there is also a bias in the sample of people saying 'yes'; 'yes' to the study, 'yes' to the biobank, 'yes' to the interview.

Another aspect, that slightly confined my work, is that I also had to cover other aspects of the project in the interviews and was therefore not always able to go into as much depth as would have been beneficial to my thesis. Often, participants' accounts of their contribution and impacts of it remained superficial, which made me wonder if I was not asking well enough, or whether it was simply not a comprehensive topic (as I've now worked out in the analyses, for the reasons presented). At the same time, I did not want to be too bold in my questioning and thereby generate certain answers merely because I asked for them.

In the analysis, too, some points may have been neglected. If you decide on a focus, you naturally leave out many other aspects. Therefore, many essential topics concerning biobanking, like biovalue, biopolitics and the commercialisation of samples and bodies, are not given enough attention.

Some recommendations for future research projects result directly from these limitations, like conducting interviews with people who have contributed something to a biobank in the context of clinical care. In this way the possible differences to study participants could be studied, revealing how much the context in which one is asked matters and if there are other motivations at play, e.g., a stronger impact of the care relationship and a different kind of affectedness.

Furthermore, it would be relevant to engage with people who said ‘no’, even if that is a very small number. Their reason for saying ‘no’ might be more insightful for understanding how biobanks can be improved than the insights from people who are already willing to contribute to them. By doing so, a symmetrical picture of engagements with biobanks can be drawn. However, given how difficult it is already to recruit donors, finding explicit non-donors might be almost impossible, as there are several methodological challenges: it would be difficult to get access to any contact details, the pool of possible participants is quite small and people who are not willing to contribute to a biobank, might not agree to give an interview. It should be noted that people who say ‘no’ are also registered with the information that they denied their consent, so that they will not be asked again in the future (personal communication, 28/29.11.2022). Therefore, biobanks still have some data about them.

In regard to the future, the donor portal which was mentioned several times as a way to increase transparency, control and engagement is a promiseful research subject. It would be interesting to see how it is received by the participants and how much impact it has in practice. Such an evaluation from a socioethical perspective of course also applies to the other measures I mentioned, should they be implemented. Just as practices in biobanking will change and give new insights in the future, so will social science research on it. With this work, I hope to have contributed a fair share to it, in particular to how biobank contributions are currently understood, the role of informed consent therein, and the implications of this, including ways how it could be otherwise.

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10. Appendix

10.1. English Abstract

Biobanks are repositories that enable the collection, storage, and access of large amounts of biomaterials such as blood, urine, and tissue. Those are needed in large quantities for biomedical research in order to improve diagnostic procedures and treatments. As non-commercial biobanks are dependent on the voluntary participation of citizens, it is important to understand how people think about biobanking. With changes in biomedicine and the datafication of our lives, converging aspects in the case of biobanking, different ways of living and thinking are continuously evolving. These affect how people relate to their own bodies and others. Therefore, this study aims at investigating how people understand their contribution to a biobank. The access point for the investigation is the practice of informed consent which is obligatory prior to the contribution and where, for example, responsibility and ownership are delegated. Hence, a certain idea of a participant and their relation to the biomaterial is inscribed. By conducting semi-structured interviews with people who have contributed to one of the biobanks belonging to the Austrian BBRMI-ERIC node, empirical data is gathered and analysed following a constructivist Grounded Theory approach. Drawing on Actor-Network-Theory (ANT) in combination with the notion of citizenship, the entanglements of the participants with other actors, human and non-human, are put in focus. The analysis of the collected data shows that participation is perceived as an effortless side product; informed consent and how it is understood mediates how people think about their contribution, and their contribution has no lasting impact on them. Knowing more about participants' understandings of their contributions to a biobank, the findings of this study can help to create sustainable biobanking practices, as they might point to ways in which public support and interest can be secured if more is.

10.2. German Abstract

Biobanken sind Einrichtungen, die die Sammlung, Lagerung und den Zugang zu großen Beständen von Biomaterialien wie Blut, Urin und Gewebe ermöglichen, die in großen Mengen für die biomedizinische Forschung benötigt werden, um Diagnoseverfahren und Behandlungen zu verbessern. Da nichtkommerzielle Biobanken auf die freiwillige Beteiligung von Bürger*innen angewiesen sind, ist es wichtig zu verstehen, wie Menschen über Biobanken denken und welche Beziehung sie zu ihnen haben. Durch Entwicklungen in der biomedizinischen Forschung und der zunehmenden Datafizierung des Lebens, die im Fall des Biobankings zusammenkommen, entwickeln sich ständig neue Lebens- und Denkweisen, die das Verhältnis der Menschen zu ihrem Körper und zu anderen beeinflussen. In dieser Studie soll daher untersucht werden, wie Personen ihren Beitrag zu einer Biobank verstehen.

Ausgangspunkt der Arbeit ist der Moment der Einverständniserklärung, die in der Regel obligatorisch ist und bei der zum Beispiel Verantwortung und Eigentumsrecht zugeteilt werden und somit eine bestimmte Vorstellung entsteht, wie die Teilnehmenden und ihr Verhältnis zum Biomaterial und zur Biobank zu sein haben. Durch semi-strukturierte Interviews mit Personen, die bereits etwas zu einer Biobank des österreichischen BBRMI-ERIC-Knotens beigetragen haben, werden empirische Daten nach einem konstruktivistischen Grounded Theory-Ansatz erhoben und ausgewertet. Ausgehend von der Actor-Network-Theory (ANT) in Kombination mit dem Begriff „Citizenship“ werden die Verflechtungen der Teilnehmenden mit anderen menschlichen und nicht-menschlichen Akteur*innen in den Mittelpunkt gestellt. Die Analyse der erhobenen Daten lässt erkennen, dass die Teilnahme als ein müheloses Nebenprodukt verstanden wird; die Einverständniserklärung, beziehungsweise die Art und Weise, wie sie aufgenommen wird, hat Einfluss darauf, wie die Menschen über ihren Beitrag denken; jedoch wird nach der Teilnahme kaum noch daran gedacht. Die Ergebnisse dieser Studie können dazu beitragen, nachhaltige Biobank-Praktiken aufrechtzuerhalten und zu erschaffen, da sie Wege aufzeigen, um die öffentliche Unterstützung und das Interesse zu sichern.