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From Engaging Publics to Engaging Knowledges: Enacting "Appropriateness" in the Austrian Biobank Infrastructure

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Research paper

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Abstract

While there is consensus on the essential importance of public engagement in further developments of biobanking, the related investigation of public views predominantly focused on the concerns expressed by the publics, and the concrete format of public engagement, without delving into the ways these concerns are constituted. In this paper, we synthetize recent research on public engagement in order to describe the constitution of respective concerns as 'engagement of knowledges'. By shifting from 'publics' to 'knowledges', we draw attention to the interaction dynamic through which citizens embed the new knowledge they receive during expert interactions into the stock of knowledge they already possess. Analyzing our recent investigation of public views on biobanking in the form of citizen-expert panels (CEPs) in the Austrian infrastructure of biobanks (BBMRI.at), we trace this dynamic through citizens' recurrent concerns that the research and consent practices related to biobanking should be "appropriate".

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Introduction

Biobanks are infrastructures providing access to collections of biological samples of body substances. For research purposes, these samples are associated with clinical and personal data. The systematic collection, storage, and distribution of biological, medical, and related lifestyle and personal data and information for research purposes have intensified in recent decades (Schneider, 2010; Müller et al., 2017; del Savio, 2017; Larsson, 2017). In light of the increasing importance of biobanks for global health and biomedical innovations, together with the international stakes for harmonizing theses powerful data collections, questions regarding ethical, legal, and societal issues (ELSI) have become an intrinsic part of biobanking (Caulfield et al., 2012; Gottweis et al., 2011; Hoeyer, 2006; Lipworth et al., 2011; Slokenberga et al., 2017). Especially in the context of the new General Data Protection Regulation (GDPR) in the European Union (Regulation (EU) 2016/679), which will enter into force May 2018, these concerns have become even more pressing as rules of storage and processing of personal data become stricter and as data subjects' rights regarding the processing are enhanced.

Current legal frameworks, both national and transnational, are rarely sufficiently clear to define all possible situations of the use of these data, and different types of consent are debated for future research with biospecimens and data (Gottweis and Kaye, 2012;

Budin-Ljøsne et al., 2017). Scholars and practitioners in biobank-related research have repeatedly emphasized that public engagement strategies must be accorded a crucial place in both legal and societal discourses (Svalastog, 2013; Gaskell et al., 2013). At the same time, they have repeatedly pointed out that these public engagement strategies must reach beyond expert circles (Gottweis et al., 2011), not least because biobanks are reliant on public financing and thus on public support.

Exploring public perceptions, attitudes, and support of human biobanks, and developing concrete strategies and formats of public engagement in biobanking, have become important subjects in academic research. These investigations have nevertheless focused mainly on improving the involvement of publics and patients in current health care policy making (Critchley et al., 2016). Previous experiences from controversies about the Icelandic databases (Pálsson, 2008) or about informed consent in the context of UK Biobank (Hoeyer, 2008) have highlighted the importance of investigating and considering public attitudes toward biobanks in the early stages of the establishment process (Gottweis and Kaye, 2012).

While arguing that engagement of publics plays a significant role in accepting biobanks in biomedical research, some works identify and point out crucial upcoming challenges of public engagement, among them the increased importance of individualism in current health policy debates (Tomlinson et al., 2015; Prainsack, 2014; Locock et al., 2016; Machado and Silva, 2015; Nettleton, 1997), through which the individual becomes both a partner of the research practices and a gate-keeper of further developments. Individualism has at the same time reshaped commonly known cultural or social identities of the publics (Howard, 2007; Beck, 2015; Bauman, 2013) because various identifications with values and beliefs do not follow the usual cultural or sociohistorical categories, might overlap each other, and/or receive a novel meaning that cannot be tracked solely through culture, social structure, or the history of the publics. With such differentiated organization of identities, a path to the relational approach to publics should be set, analyzing the specific ways that individuals acquire and embed new knowledges, because such an approach can help us follow the process of production of knowledge and its being sustained in a particular set of attitudes within a collective, as show Veenstra and Brunett (2014) for health practices, or it is conceived on a more general level by inquiries inspired by social epistemology (Fuller, 2012).

Such a relational approach is suggested in the following through both discussion of the recent work on public engagement models and processes in biomedical research developments and the analysis of our three-year investigation of citizen-expert panels (CEPs) conducted between 2014 and 2016 in the context of the Austrian Biobank infrastructure BBMRI.at, which fosters collaboration between biobanks and the use of biological samples and data for research. As part of exploring the capacities and challenges of the infrastructure, an ELSI work package was designed to gain insight into the spectrum of public views on biobanks through CEPs. Going deliberately beyond the evaluation of CEPs' capability to engage publics, this article intents to make sense of the specific ways that citizens discuss and negotiate biobank-related issues during this public engagement format. We therefore reflect on CEPs as a methodological-cum-epistemological tool to suggest that instead of the engagement of publics, we instead speak about the engagement of knowledges that are embedded in wider social relations. We thus propose shifting our attention from citizens' attitudes toward biobanking (see

Gaskell et al., 2012) to the question of how they process and frame (Goffman, 1974; Braun, 2015; Braun and Könninger, 2017) the information they receive during interactive settings, which results in a specific position on that matter. In the case of Austrian CEPs, this process is enacted through the recurrent concern about the “appropriateness” of research practice and development, which we identified in our data.

By paying closer analytical attention to “appropriateness”, we emphasize a main critique in the current discussion on public engagement that dispels the boundary between lay and expert knowledge. Citizens enter the scene as lays, and this aspect is treated as their identity in the particular public engagement setting. But this identity is more dynamic, as citizens themselves become experts over time and as different types of expertise related to different aspects might be needed during the public discussion on health care developments. As we show through our data, one way to incorporate this dynamic is to reframe the concept of public as a person-oriented engagement and instead speak of ‘knowledge’-oriented engagement. The focus on knowledge not only better suits the practice of engaging we observed in CEPs formats but also situates the engaging of knowledges as a constitutive element of citizen awareness about an issue. To frame sharing of knowledges as a crucial constitutive element of an informed civil society has been discussed in analyses of knowledge in other engagement areas going beyond the particular example of health issues (see, e.g. Goodwin and Jasper, 2009; della Porta, 2013). We argue that taking this intertwining of already available and new knowledges into account when observing and analyzing a public engagement format allows us to further our understanding of the way opinions on biobanking is shaped on the individual level, and it can lead to insights on how to set up further analyses of the current development of the public discourse on biobanking in Europe.

In setting the stage with the Austrian discourse on biobanking, we limit the topic to the recurrently addressed dichotomy between lay and expert knowledge, and we report on significant recent research on public engagement dealing with this dichotomy. We then offer CEPs as an empirical case to investigate this dichotomy from the perspective of knowledge gathering and processing that we observed during our investigation. On the basis of the analysis of the concern related to the appropriateness of research with biobanks samples and data, we propose a knowledge-oriented engagement practice by the CEP participants, thereby suggesting some implications for the current biobanking discourse.

Engagement of knowledges in public discourses in Austrian biobanking

The Austrian example we discuss here speaks to the aforementioned critique of public engagement tools as a legitimacy arena for established actors of science and research (Felt et al., 2007; Fischer, 2009; Nowotny, 2015; Wynne, 2007). To begin with, public awareness and knowledge about biobanking is limited: two thirds of Europeans (EU27) haven’t heard of biobanks (Gaskell et al., 2010: 60). Austrian society, more particularly, tends to be skeptical about the impact of science and innovation in general (European Commission, 2014) and retains a conservative attitude toward biomedical innovations in health care (see e.g. Gaskell et al., 2010; Gaskell et al., 2011; Gudowsky et al., 2012).

Loosely inspired by the case of nanotechnology assessments (Felt et al., 2014), the analysis of the engagement process in CEPs was therefore designed to provide insight into knowledge formation activities and into individual and collective imaginations, about what a biobank is and how data and samples are used or could be used for research. As "mini publics" (Dryzek and Niemayer, 2010), CEPs allow conclusions about shared collective processes of organizing knowledge on innovations in research, for which biobanking and ELSI issues are well-suited examples.

In the course of our investigation, we realized, on the one hand, that CEPs reflect the challenges of the usually addressed dichotomy between experts and lays. As analyses in science and technology studies (STS) have shown (Avard et al., 2009; Irwin, 2006), common public engagement models are conceived in a one-way procedure in which experts deliver the knowledge to the citizens, who can interact with them by asking about, arguing, and contesting it. "Upstream engagement" of publics at early stages of technological developments has been addressed in public policy discourses (Burri, 2009: 498) and was realized in consensus conferences and citizens' panels (Rose et al., 2017; Rowe and Frewer, 2005). Even more importantly, studies have shown that only certain types of publics participate in debates on health issues (Bogner, 2012; Collins and Evans, 2008; Felt and Fochler, 2010). Scholarly works in STS have also identified a lack of systematic ways to translate the public engagement research into society impacts (Wynne, 2007; Marres and Lezaun, 2011) or policy impacts (see e.g. Emery et al., 2015). The constructions of "expert" and "lay" types of knowledge inherent in these models have in fact been challenged by studies emphasizing a different understanding and source of expertise that included also citizens, patients, or activists (Epstein, 1996; Wynne, 1996).

All of these challenges uncovered then for us, on the other hand, the dynamic process in which the new knowledge is embedded that allows participants to formulate their concerns and understandings on biobanking. Our present analysis thus focuses on the process through which participants embed new knowledge on biobanking in their socially shared "stock of knowledge" (Schütz, 1953; Locock et al., 2016). CEPs, in that context, become an epistemological tool to reflect on relational notions of engagement (see, e.g., for trust Engdahl and Lidskog, 2014) and are able to reveal the institutional framework and social constructions in which the process of knowledge formation takes place (Irwin, 2006; Irwin and Horst, 2016). It can, at the same time, be linked to other recent examples of the shift toward knowledge processing, among them the card-based discussion technique IMAGINE (Felt et al., 2014) and the reflexive engagement process in ECOUTER (Wilson et al., 2017). In contrast to representative surveys, these instruments aim at understanding how opinions and attitudes are formed within a set of values, cultural or social grids of interpretation.

In that context, the CEP format represents for us what Sheila Jasanoff (2005) describes as "civic epistemology", grasping publics' assessments of scientific claims based on shared understandings. It allows us to further the approach of the aforementioned public engagement instruments through analysis of the way in which citizens get to "know" about biobanks (i.e., how they build their knowledge on biobanking in interactive settings), thereby reframing citizen engagement as an engagement of "knowledges". Following Jasanoff's argument, interactions in CEPs reveal shared understandings that underlie public assessments of scientific claims and, as such, enable conclusions on how collective assessments in knowledge societies are constituted. Taking citizen imaginations expressed during CEPs into account and analyzing the way they are constituted as engaging of already available and new knowledges allows us to trace the public dimensions of entangled technoscientific and social orders (Rommetveit and Wynne, 2017), in which knowledge is informed by shared "background understandings" (Taylor, 1993).

As we show through the participant's recurrent concern about "appropriate" biobanking practice, including "appropriate" consent forms, understanding how knowledge is generated and applied in CEP "mini publics" also helps us to understand the emergence and framing of public debates on that matter as has been also shown in other areas of public engagement (Della Porta and Felicetti, 2017; della Porta, 2016; Borg and Mayo, 2007). In our conclusion, we show that grasping the engagement of knowledges can help to better understand the larger European public discourses on biobanking.

The construction of "appropriateness" symbolizes for us the conceptual shift in understanding a knowledge-oriented way of understanding public engagement. In discursive practice, appropriateness is used as an organizing tool by the participants to structure what has been said and presented as knowledge during the CEP. Being an intersection of already available and new knowledge, appropriateness serves as a way of dealing with risk and uncertainty. As a concept, it manages the process of how individual concerns become embedded in existing shared understandings (Rose, 2016), enabling actors to think differently about controversies related to both biobanks and other future technological developments, as "risk" and "uncertainty" are hereafter situated within the boundary of appropriateness. At the same time, appropriateness allows us to develop a more sophisticated understanding of public discourse on biobanking and the related policy-making steps because it speaks to the context of the demands to reframe institutional assessment of scientific knowledge (Wynne, 2006).

Conducting and challenging Citizen-Expert Panels

Our development of the CEP tool builds on group-based engagement methods developed in the context of newly emerging technologies. Policy-oriented citizen panels, consensus conferences, and group discussions are examples of settings that address opinions and attitudes on topics where informed knowledge among citizens is limited (Felt et al., 2014; Burri, 2009). The interactive designs of these engagement methods allow different views and attitudes to develop, and they enable research on how underlying meaning is produced (Davies, 2011). These engagement methods illustrate that group discussions can enable manifold interactive processes, thereby generating rich data on meanings behind certain assessments (Bloor et al., 2002).

Accordingly, we adapted these approaches of qualitative methodology to reveal and analyze in depth the process by which citizens form their attitudes, opinions, and preferences regarding biobank governance. In doing so, we conceive the interaction in which this takes place as social practice, where the engagement of already acquired and new knowledge is enacted in individual "doings" and "sayings", which are based on collectively shared understandings (Schatzki, 2001). These activities were encouraged by the CEP design through various discussion settings with and without experts and through mapping tools.

More concretely, the basic design of the public engagement method of CEPs was composed as alternating information and discussion phases facilitated by moderators. Inputs were given by expert presentations that provided insights into the practice of biobanking, informed about the current legal situation, and discussed ethical considerations. Following this information phase, citizens had the opportunity to ask questions as well as introduce and discuss their own ideas, opinions, and attitudes with the practitioners in order to motivate active participation and to engage the public (Avard et al., 2009). After a break, small groups of citizens discussed – in the absence of the professional experts – key questions concerning ELSI in biobanking. Group consensus orientation was used as a formation process and analyzed as an interactive setting where controversial positions can arise. Hence, consensus orientation was utilized as a process, not as an outcome (Horst and Irwin, 2010). This allows analyzing the process as an interactive setting, where understandings are made explicit and positions are being negotiated. This process was supported by visualizing individual positions as well as group consensuses on a poster map in order to motivate the interactive process and collective decision making. Modifications of the tool were undertaken in accordance with the qualitative subject-oriented process and particularly due to the opinion building practice, where meaning was constituted by referring to knowledges, which were associated with biobanking. We are aware that methods not only describe but also produce the objects they attempt to understand (Law, 2006). We therefore reflect the methodological implications of the applied CEP structure (regarding expert inputs and consensus) by understanding them as framing effects (Goffman, 1974). For this paper, by embedding the new information in shared understandings and knowledge, we directed the analytical focus on the process in which citizens managed to engage in a discussion on a topic unfamiliar to most of them.

Altogether, a well-balanced sample – taking into account age, gender, educational background, and experience with medical research – of 114 citizens participated in nine CEPs in Vienna, Graz, and Innsbruck between 2014 and 2016. Participants were recruited by advertisements and via snowball sampling, and members of patient organizations were additionally invited to include patients and their experiences.

The plenary discussion between citizens and experts, as well as the discussions within the working groups, were recorded and transcribed, and in-depth analyzed using coding strategies were drawn from grounded theory methodology (Charmaz, 2014) and supported by qualitative data analysis software (atlas.ti). By this means, patterns of the perceptions, meanings, and discursive understandings of citizens on key issues of biobanking were identified and interpreted. Our analytical focus was on how an object is enacted as part of a (discursive) practice (Mol, 2002: 44). By enacting, people bring events and structures into existence by action. Following the interpretative approach of our methodology, interactive enactment is understood as a social (group) process where meaning and positions are built relying on preconceptions and context (following Weick, 1988). In the present analysis, we do not go in detail into considerations about specific aspects of biobanking but instead look at how their use in participants' argumentation is included in a process through which the new knowledge – received through the public engagement model – becomes embedded in a "stock of knowledge" from other contexts that are more available to the participants.

Understanding appropriateness in biobank-based research

Before we trace in detail how knowledge is engaged in CEPs, it is essential to recall the conditions under which the participants entered the setting. As mentioned earlier, the purposes and aims of biobanks lack public awareness. Furthermore, information that could be made available to prospective donors is limited. This refers particularly to providing precise information about research objectives. In contrast to informed consent for a concrete study, the exact research purposes for samples collected prospectively in biobanks are mostly unclear at the time of donation. Also, with the new EU GDPR imminent – enhancing the rights of data subjects, such as the right to information – consenting practices have already become challenging within the field. Against this background, CEPs not only provide insights into the views and expectations of (potential) donors toward biobanking, but they also allow us to trace the process in which knowledge is built under these conditions and allow us to deduce how public health discourses are shaped.

These circumstances intervene in the opinion building and the consent-oriented process of decision making that we followed in the CEPs. Taking into account the general lack of public knowledge and the limited information available about the intended research, we focus on how knowledge is built in practice. In particular, we focus on how new knowledge is framed and embedded in an available stock of knowledge or in shared understandings. Therefore, the CEP data were interpreted with the intention of learning more about how knowledge about biobanking is built and engaged than about citizens' evaluations of actual biobank practice.

In building a connecting point to manage uncertainty about possible future uses of samples and data and the limited knowledge about biobanking in general, participants relied on an imagination of what kinds of research with samples and genomic data they would consider "appropriate". The concept of "appropriateness" was used in the discussions to enable assessments of unknown or only little known areas, for example about possible uses of samples and data and its risks, institutional and legal frameworks, questions about data privacy and benefits for the public, which is primarily seen in medical research – hence, the concept was foremost attached to institutionalized frameworks in which biobanking practices are performed. Thus, through the imagination of "appropriateness", institutionalized knowledge and underlying shared understandings about biomedical research claims and new knowledge about biobanks are assessed, organized, and enacted in discursive practice. This approach constructed a reference point in developing individual opinions and collective decisions about consenting preferences in the CEP setting. Therefore, "appropriateness" – or more precisely – an imagination of "appropriate" research, is enacted as an empowered engaging of already acquired and new knowledges that create their opinion toward the purpose of the research and its institutional context.

To formulate it in more analytical terms, "appropriateness" is used as a central organizing concept for knowledge formation and for the dynamic process of engaging of already required and new knowledges as outlined earlier. Through appropriateness, participants assess institutionalized knowledge and underlying shared understandings about biomedical research claims and new knowledge about biobanks, and with the help of appropriateness they organize and enact the respective discursive practice.

Appropriateness builds a reference point in developing individual opinions and collective decisions about consenting preferences in the CEP settings.

In the following sections we unpack "appropriateness" in its three main constitutive elements: Based on the needs (1) to cope with uncertainty toward samples and data uses, (2) to deal with a lack of knowledge about biobanking practices, its meanings, and risks, and (3) to handle the unclear future connected to yet-unknown purposes of sample and data use, "appropriateness" is introduced and used as a reference in the discussions to build a knowledge base for individual and collective opinion building.

Coping with uncertainty

A way of dealing with the first element – the effort to cope with an inevitable degree of uncertainty – was to evaluate possible consent options by the participants. They were cautious about the concrete context in which consenting is situated and openly expressed the need for at least some degree of certainty when confronted with the conditions of consent. This evaluation was explicitly connected to the question whether this context is or is not an appropriate one. What is striking in the discussions is that certainty and uncertainty are expressed less directly in the discussions; rather, they became apparent in the concrete emotional reasoning for consent preferences. These emotional reasoning with samples and data and their uses allows us to draw conclusions about shared understandings between members of a society, which lays the foundation for opinion building. In our interpretation of the talks, unclear research purposes have been assessed based on these understandings and expressed in feelings toward the scope of various consent forms and trustworthiness of the institutional context of biobanks. The following quotation by a CEP participant illustrates this pattern:

"As a participant, one probably feel safest in the narrowest form [of consent]. […] because I have the feeling that I am more likely to know what purposes it will be used for. General consent could be everything, including something I cannot even imagine."

This narrative about the wish to know more about the concrete research purpose exemplifies how uncertainty is connected to a possible imagination of data and sample uses. Narrowing the scope of consent seems to allow a more concrete and manageable imagination of the envisioned research conduct. As discussed, biobank-related research is indeed embedded in complex ethical, legal, and societal relations, which makes it difficult to evaluate whether or not the context is "appropriate". In discursive practice, participants related their reasoning to their imaginations of trustworthiness of the institutional context of biobanks, as described in this quotation:

"I have a […] gut feeling. What is most important for me is whether the research facility is public or private. I prefer that the monopoly of knowledge belongs to an institution that is democratically legitimized, for example universities. I have something like a basic trust that it does not get out of control in a democratic state. I am more worried about commercial purposes."

Preferring narrow or broad consent over more general or blank forms, as mentioned in the previous quotations, is related to the imagination of medical research as "appropriate". Uncertainty is associated with sample and data uses that might go beyond imagination and, hence are outside the available "stock of knowledge". In this regard, the "gut feelings" quoted above point to shared understandings about scientific claims and attitudes toward institutional and policy contexts in which research takes place. Thus, "appropriateness" is directed toward the framework in which biobanking is performed.

Analyzing these considerations allow us to trace underlying shared public understandings, perceptions, and – consequently – trust toward research institutions. Hence, this discursive practice in dealing with uncertainty yields an approach of how knowledge about biobanking is built and allows us to understand how subjective security perceptions and trust in research are informed.

Dealing with a lack of knowledge

The just-described first element of constructing appropriateness, which was directed toward coping with uncertainty, is also associated with the second dimension we identified in the data, which is connected to the necessity to deal with a lack of knowledge about biobanking practices, its meanings, and risks. In addressing that, citizens often referred to knowledge from other fields of public discourse that they perceived as neighboring or related. In doing so, they linked uncertainty about biobanking to current debates about data privacy, such as data security in the internet and possible use of data by insurance companies or for forensic investigation, as the following quotation exemplifies:

"It has to be guaranteed that my health insurance and my employer do not get to know about it."

Since the opposing position was raised in the discussions – that, for example, this kind of information could also be used to reduce individual health insurance contributions due to a healthy lifestyle, or that DNA could be used to identify violent criminals – these debates and concerns reveal citizens' imaginations about the kind of information that could be obtained from a sample, which in turn inform their understanding of appropriate uses and, consequently, opinion building. In constructing this connection, citizens increasingly shift their focus from samples to data, as expressed in the following quotation:

"Tissue is, in principle, also just information. Unfortunately, I cannot make use of it, but it contains a lot of genetic material, actually data."

This imagination is developed further in a way that data subjects could be held responsible for issues outside "appropriate" medical research. Furthermore, it is anticipated that data could be linked to other data sources or used for purposes in the future quite different from what has been granted consent in the present. Whereas appropriate research with samples and data is foremost ascribed to state-run institutions, the relationship between state and biobanks is challenged when it comes to identifiability, as the following participant noted:

"To what extent could the state request the data? Things like paternity or drug use, for instance. I could obtain that information from a hair sample. If somebody commits a crime, could it be possible that public authorities force [the biobank] to provide access to the data?"

Overall, in the discursive strategies connected to these narratives, the biological material was imagined as a personalized data storage medium, carrying personal information about the donating subject. Whereas participants widely considered extracted, donated tissue to be waste, information that is imagined as stored in the genetic material itself caused uncertainty toward appropriate and future purposes. To illustrate that, a participant compared the identifiability of genetic information to fingerprints:

"Anonymity in that sense doesn't exist. [Genetic information] are actually relatively clear 'fingerprints', and I think they will become even more noticeably clear in the future"

The various ways the samples were imagined during the discussions allowed participants to justify their demands for more information about biobanking practice and to argue for particular institutional frameworks.

As it was already implied in the first two aspects in the concept of “appropriate” research with biological samples, which we described as coping with uncertainty and – linked to that – a lack of knowledge toward biobanking, concerns about the unclear future about yet-unknown purposes of sample and data constitute the third aspect in considering “appropriateness”.

Dealing with an indistinct future

As already mentioned, “appropriate” uses of samples and data are not only questioned in the current research context but are also directed to future developments. Collecting samples and data prospectively is accompanied by uncertainty toward the possibilities of what future research and technology might be able to reveal. That the purposes of collected samples and data uses in current biobanking practices are not precisely predictable turned out to be a decisive factor for individual and collective consent preferences. Here, appropriateness of biobanking is challenged against the background of institutionalized frameworks, not only in direct connection to medical research, but also to equally unpredictable economic and political developments, as the following quotation illustrates:

“But what comes tomorrow cannot be said. It's all going to change. From the technical to the political level, to the economic level, tomorrow is not what tomorrow is [now]. That’s for sure.”

Whereas the above addressed lack of knowledge refers to concrete sample and data uses for research purposes, considerations about unclear futures in biobanking are directed to areas or actors outside the health care and research systems. In the process of knowledge formation, yet unforeseeable political and economic developments are connected to unclear futures and to developments in biobanking in general, as the following quotation illustrates:

“[W]hat is in ten years, what is in 20 years? What is in 30 years? I think this is exactly the problem with the biobank because it is this indefinite. Indefinite and vague, so to speak. The directions are no longer comprehensible.”

This again also reconnects to the first element of “appropriateness” where dealing with uncertainty was a key obstacle in building knowledge about biobanking. Whereas these concerns were mainly directed to institutions within and outside of health research, they were also connected to individual futures, inhering the potential to reveal significant personal information, which are difficult to handle at the present. In this regard, stored samples are again imagined as carriers of these yet not accessible information.

“Maybe a result shows that I’m somehow genetically predisposed to some disease. Something you cannot test at the moment, but in twenty years you can. Who knows what will be technically possible in 50 years? I cannot predict this at all!”

These anticipations about the potential of future research techniques and the way available knowledge about the frameworks in which biobanks-based research is performed are engaged in the process of individual and collective opinion building, providing important insights into how to improve not only modes of consent but biobanking governance more generally. This is particularly the case because these concerns about the future are also directed toward collaborations, mainly in terms of partnerships with the health industry. Although participants are aware of the benefits of cooperation, be it in terms of national and international research or between public and private institutions, uncertainty culminates in the question: Who does what with which kind of information and what does it mean for the individual? The question highlights again the value of bio-information in the form of samples and data. In managing uncertainty toward mainly unknown future purposes, the question of trust in institutional frameworks is coupled with the individual demand for more information about these contexts and hence, the "appropriateness" of medical research for the public good:

"I would definitely consent to medical studies; hence it does not only benefit myself, but society and that is important. For that reason, I would say, it makes a difference, if it is done by a university or a pharmaceutical company, and the broader it will be and the more someone is able to do with my samples, the more I would be concerned, if I could be inspected as a person, and what could be linked up, which databases. I think that, as a single patient, one rather prefers to be informed about possible uses."

In addition to coping with uncertainty and managing knowledge gaps, considerations about the futures of biobanking are constituting the imagination of "appropriate" research. The condition that biobank samples and data do not have precisely predictable uses is responded with a call for democratically regulated and controlled frameworks. Consequently, this emphasizes the demand for information about the "appropriateness" of the frameworks in which biobanks are operating and collaborating, as highlighted here:

"I am not interested in what is done with my sample concretely, but more generally – what could be possible uses."

Hence, building trust on the individual level needs to be met by transparency, control, and governance, all ensuring that research with samples and data is "appropriate".

In dealing with the situation of necessarily unclear futures of biobanking, the concept of "appropriateness" was used to at least evaluate the context in which future biobanking should take place. For the majority of CEP participants, new knowledge about biobanking and its unpredictable purposes in prospective sample and data collections in biobanking was embedded in knowledge about present institutionalized national and international frameworks. In compensating this uncertainty, trust toward biobanking was measured in connection with trustable frameworks.

Conclusion

In our contribution, we reflect on CEP design as a methodological-cum-epistemological tool to follow how public attitudes toward biobanking are formulated through engagement of already available knowledge with the knowledge newly received during the respective CEP. As we show in the concrete examples of these engagements of knowledge, citizens provide important (local) knowledge on societal contexts and embeddedness of biomedical research not only in terms of concrete attitudes but in particular in terms of the knowledge process through which they create these attitudes. The notion of appropriateness helps people to organize this knowledge process and to embed the new knowledge in the stock of knowledge they already possess. At the same time, the three manifestations of appropriateness during CEP – uncertainty, lack of knowledge, and handling the future – make apparent that citizens are aware of their active role in the public debate; they want to formulate their concerns and lay out their options and preferences for eventual consents and future developments.

In moving beyond the individual dimension of engaging knowledges in the particular setting of CEP, our findings hold implications for the way public discourses on biobanking are enrolled. Two predominant focuses of current biobanking debate are the various opinions about appropriate consent forms (e.g. Budin-Ljøsne et al., 2017; Caulfield and Murdoch, 2017) and the issue of data protection (e.g. Morrison et al., 2017). Our analysis of the knowledge interaction helps us better understand the emplacement of these focuses in the biobanking discussion. First, the way participants handle the knowledge during CEPs allows us to mitigate the prominence of data concerns as concerns specific to biobank research. These concerns are not specifically related to biobanks or even necessarily to health care. Rather, they stem from the stock of knowledge that participants bring to the CEP discussion from other contexts, as data concerns have been prominently discussed in the public discourse during the same period, particularly regarding privacy and the right to know in Western societies (see Inglehart, 2008; Inglehart, 2015).

Furthermore, the demand for security necessarily enhances the role of trust in the experts who speak about biobanking or are put in a prominent public position to argue for particular solutions on biobanking. This trust, that is discussed and mentioned on the individual level during CEPs, is connected by the participants to the discussion about the sample as a carrier of genetic information. It then consequently results in an increased demand for transparency and control of these samples by institutions. One such demand is articulated through appeals to new forms of consent. This is based on the CEP discussions in citizens' attitudes toward consent forms and on the assumption that the more general such forms are – or – the more unclear the purpose of the sample and data usage is, the less there is a trust in the "appropriateness" of research. In that context, new consent patterns are discussed in the context of biobanks, such as "dynamic consent" (Budin-Ljøsne et al., 2017). These new modes of consent gained prominence through the advent of the GDPR, which attributes an explicitly active role to citizens and patients.

Given that context, our findings suggest trends that are discussed in the light of the current global challenges of biobanking discourse. Some citizens are ready to embrace the challenge posed by GDPR: they can and want to handle the information they receive about new developments. While seeing the possibility to be empowered as citizens and patients through GDPR, citizens however need to engage with knowledge – and need to have a space for doing this – in order to be able to formulate their attitudes and opinions within a novel framework and therefore to engage in the knowledge process described above. Appropriateness, in such a process, takes the form of yet another stock of knowledge that could be analyzed in future investigations. A relevant start would be to analyze how biobank research is being understood by researchers as the driving force of biomedical research and how that understanding constitutes a particular imaginary of what is biomedical research and what is biomedical data, which might influence knowledge production beyond the biobanking field.

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