Publics and Biobanks in Europe: Explaining Heterogeneity

George Gaskell, Herbert Gottweis, Johannes Starkbaum, Jacqueline EW Broerse, Monica Gerber, Ursula Gottweis, Abbi Hobbs, Helén Ilpo, Maria Pashou, Karoliina Snell, Alexandra Soulier,
INTRODUCTION

How do Europeans view biobanks? What do they know about them, and how do they want biobanks to operate? Where are the public sensitivities? And what do Europeans think about the fact that more and more biobanks are cooperating to build huge data infrastructures? These topics will be discussed in this working paper.

How publics perceive biobank projects is of great importance for these projects and will considerably influence their development and future success. Biobanks are dependent not only on donors but also on societal and political support.

When people participate in a biobank study, they typically donate blood, tissue, and body fluid, including DNA data. Donating bio-specimens is unlike donating blood for blood transfusions. Once the blood is donated, it disappears into a large system of blood supply (Waldby and Mitchell, 2007). However, in a biobank or cohort study, the samples attain their scientific value by being linked with personal information such as medical records and social and environmental data. Donated tissue or DNA has the potential to become a scientific-technological resource for further research. This raises a range of ethical issues affecting donors and society including forms of consent, privacy and data protection, and benefit sharing.

Our research shows that the public perception of biobanks in Europe is characterized by striking heterogeneity. While there is a cluster of North European countries that are rather enthusiastic about the prospect of biobank research, the publics of many Central and Southern European countries harbour substantial reservations when it comes to participating in biobank research, donating tissue, and giving broad consent for research. In this paper we describe the differing patterns in the public perception of Biobanks in Europe and explore with qualitative
and quantitative data what may underpin these different perceptions. We then discuss the implications of the findings for recruitment, operation, and governance of biobanks and suggest how Europe can move towards responsible innovation (von Schomberg 2011).

Methodology

The overall aim of our investigation was to analyse how people in Europe perceive biobanks and research using biobank data, and to identify the issues they consider to be of central importance and relevance. For this purpose, we created a comprehensive data set of qualitative and quantitative data using focus group and social survey methodologies.

Focus group methodology is a well-established method in the social sciences. It is designed to explore, with groups of six to ten participants, the ‘whats’ and ‘whys’ lying behind people’s views, opinions, and articulations. The typical focus group in our study had a mix of gender, educational backgrounds, and ages corresponding to the average distribution in the European population (Krueger and Casey, 2009; Bloor et al, 2001). For our project this meant that the participants were purposely selected to represent the characteristics of the anticipated population of different European population biobank projects. In total, we conducted 60 focus groups in Austria, Finland, Germany, Greece, the Netherlands, and the United Kingdom. This sample provides a diverse scope of countries, where publics show significantly different attitudes toward biotechnology (Gaskell et al, 2010). Of these 60 groups, 39 were sampled for mirroring broader publics and 21 were sampled for people who have prior experiences with biobanks and cohort studies.
We developed a general focus group design that was used in each of the countries. The focus groups were structured along the following lines. We started with a brief questionnaire to gain insight into participants’ knowledge of biobanks and their activities. After providing a general description of biobanks, we asked participants to name possible advantages and disadvantages of biobanks. Next, we discussed various issues using vignettes: privacy, informed consent, benefit sharing, and internationalisation. We ended the session with a discussion of the governance of biobanks and the willingness of participants to engage in biobank research. All focus group discussions were audiotaped with the informed consent of the participants.

To ensure comparability across research in seven countries, we used a structured content analysis (Mayring, 2008; Krippendorff, 2004) followed by interpretive analyses to reveal meaning structures and dynamics beyond the manifest content (Fischer, 2003). These analyses were supported by computer-assisted, qualitative data analysis software that facilitated data management and international exchange and control (Lewins and Silver, 2008). A common coding structure was created and continuously adapted in regular online conferences.

Based on an initial pilot study with focus groups conducted in the Netherlands and Austria, we developed a set of questions on biobanks for the 2010 Eurobarometer on the Life Sciences and Biotechnology (Gaskell et al, 2010). This Eurobarometer survey, conducted in February 2010 under the auspices of DG Research of the European Commission, uses probability sampling to obtain representative samples of adults (circa 1000 per country) in each of the 27 member states, plus Croatia, Iceland, Norway, Switzerland, and Turkey. The survey questionnaire was devised as part of a European Commission Science in Society project, Sensitive Technologies and European Public Ethics (STEPE). The top-line findings of the survey are reported in Gaskell and Gottweis (2011) and Gottweis et al (2011). Here, based on further univariate and multivariate analyses, we look in greater detail at the data on biobanks to complement the outcomes of the focus group discussions.
Understanding Heterogeneity

In this paper we argue that European public perception of biobanks displays a strongly heterogeneous picture. We now turn to examining what lies behind this heterogeneous European public opinion landscape. We find that the willingness to participate in biobank research, and the readiness to accept broad consent is dependent on a range of interconnected factors: 1) the public’s engagement with biobanks; 2) views about privacy and data security issues; 3) trust in the socio-political system, key actors and institutions involved in biobanks; and 4) the issue of benefit sharing. Together, these interrelated factors play a significant role in public responses to biobanks, and we will describe each of these factors and their interconnectedness in turn.

Awareness and Engagement

One of the most remarkable finding of our research is the limited awareness of Europeans concerning biobanks (Gaskell and Gottweis, 2011). More than two thirds of all Europeans said they have never heard of biobanks, and only 17% answered that they had actively talked or searched for information about biobanks in the past. Those who are better informed are concentrated in Northern Europe – in Sweden, Finland, and Iceland.
Furthermore, there is a strong correlation between people having heard or talked about biobanks, and the intention to participate in biobanks. If people have heard or talked about biobanks, which is more likely in North European countries, but also in Estonia, which has a much-discussed biobank, they are more willing to participate in such studies than if they have never heard or talked about biobanks, as in Austria, Bulgaria, or Turkey. Interestingly, passive awareness creates a substantially bigger increment in intention to participate, an increase of 15%, than active engagement, which adds an additional 7%.

**Privacy and data collection**

The connection of biological and lifestyle data in biobanks raises issues of privacy and data protection. When people have little or no engagement with biobanks, their unwillingness to participate may be not so much a rejection of biobanks per se, but rather a hesitation to divulge personal information to a little-understood endeavour and purpose.

Our focus group data show that people are aware of and concerned about privacy issues. However, this does not necessarily lead to a rejection of biobanks, which was similarly reported in other quantitative studies (Kaufman et al. 2009). However, people entertain serious concerns about data abuse by insurances or employers in all countries, and expect biobanks to offer the best possible protection. Data security is an issue even in countries where people expressed broad support for biobanking. In Finland, for example, providing the social security number was a highly contested issue during the focus group discussions. People talked with concern about media stories about data leaks and data hacking, and about historical experiences such as the political system in the former German Democratic
Republic. Relating these experiences to biobanking, they conclude that data can never be fully protected, now or in the future.

Privacy issues are perceived in a broader setting and as embedded in wider societal developments, rather than as an isolated part of biobank research. Many people are accustomed to providing data in their daily lives and are resigned to privacy violations.

FG4 UK P45: “My information is already out there I’m sure, anyone who wants, finds it if they really look. So, although I would be concerned about it, I don’t think it would be a swaying factor on whether I decided to take part in a biobank – but it’s always a concern I have.”

However, all medical data, be it specimens or health records, is distinctively perceived as sensitive in relation to other personal data. While in the Netherlands, France, the UK, and Finland people seem more concerned about medical records, Germany, Austria, and Greece are in the group of countries with the highest concerns about biological data and genetic profiles (Gaskell et al., 2010: 62). In Austria and Germany, people reflected on the history of eugenics during World War II, but in all countries there are concerns about the future, with possible new forms of discrimination and eugenics based on biological determinism.

The boundary between personal and biological data is often blurred in people’s explanations; they dwell on the long-term nature of biobanks and the inevitable uncertainty of the future. It is often not what biobanks are, but what they might become, that frightens people:

FG3 UK, P24: “I’m just a little bit sceptical about how the data might end up being used in the future, because we don’t know what will happen in the future yet.”

While, as we have shown, the willingness to participate in biobank research is related to engagement, at the same time our focus group research shows that even in countries with high willingness to participate in biobanks, people worry about data security and privacy
protection. However, as we will demonstrate, such concerns may be attenuated by trust and beliefs about benefit sharing.

**Informed consent**

Biobanks and related research need to obtain broad consent from participants in order to operate efficiently and successfully. To seek consent for every separate research project would be costly and time consuming. Yet, as shown in table 5, 67% of Europeans opt for narrow consent and only 24% for broad consent. Of the countries in which we conducted focus groups, the preference for narrow consent is higher in Greece, France, and Germany; Austria and the UK are at the European average; and the Netherlands and Finland are in a group of countries that are most relaxed over the issue of consent (Gaskell *et al*, 2010: 64).

It is notable that, as with participation, the willingness to give broad consent is related to engagement with Biobanks. The more people have heard about biobanks, the more likely they are to agree to broad consent.
Our focus groups show that the views lying behind preferences for broad consent are related to people’s understandings of the longer-term aims of biobanks. When, during the group discussions, people are informed about the aims and rationale of biobanks and the ways in which research will be conducted, they tend to reflect on the practical necessity of broad consent.

FG4_NL_P9: “I think there’s no other way. Of course, things change over a period of 30 years and if you participate, you know this.”

Furthermore, focus group data provides evidence that the preference for narrow consent has much to do with the wish to have some control over the content and direction of research done on collected personal samples. People fear with broad consent that, regardless of the initial motivation for collection and storage, others, with different motives, might gain access. When people worry that research could be done that is contrary to their interest or ethical values, they choose the better-to-be-safe-than-sorry-option: narrow consent. These expectations are often linked to much-debated examples such as human cloning or eugenics. Only if people are confident that biobanks will operate within an ethical framework are they willing to grant broad consent for long-term research. It is often not the data per se, but rather research goals and future application that are at issue.

FG8 GER, P7: “I would only go for narrow consent, because with broad consent, it bothers me that it says: “research on all diseases”. There I have a problem. Who decides what a disease is. Is a blue eye a disease? [...] Or black hair? I don’t want to get involved in that, being part of it, in this kind of research. That is too much for me. I want to know exactly what happens with my things.”
However, across all the countries, people mainly make a clear distinction between broad and blanket consent (Hansson et al., 2006). Even those who were generally willing for their samples to be used for all biomedical research that sought to help people were not willing for such information to be used solely for commercial gain, or for non-medical research without societal benefit.

*Benefit sharing and individual feedback*

When people donate to a biobank, many think that this is not a free gift; they participate with the expectation of getting something in return. Supporting science and medicine is a strong incentive across Europe. At the same time, many people assume that they will receive insights into their health status, and they look forward to the possibility of regular health checks with the opportunity of meetings with medical experts.

Within this broad picture of expectations of personal and societal benefits, there are subtle differences between countries. Where access to the health care system is perceived as difficult or uneven, such as in Greece, Germany, the Netherlands, or the UK, potential participants in biobank research think that they should be offered personal feedback. Perhaps counter-intuitively, in the context of the public national health system of some countries, services are often perceived as difficult to access and private-public insurance systems are perceived as uneven – even if the public system is of high quality by European standards. With participation approximating a health check, people see feedback on their health status as a reasonable return.
FG2 GR, P11: “I am expecting results of the analysis of my check-ups. Since I am giving something, I am expecting something. If there is no return, there is no reason for me to participate.”

FG8 GER, P7: „The uncomplicated contact with specialists. [...]. They might tell me knowledge that my family doctor does not have, because they are actually doing this research, and I think this could be a great incentive, to take part in such study [...] and get the possibility for special audiences or the opportunity to talk with a professor, who usually does not have any private patients.”

By contrast, in those countries where people perceive the health care system to be readily accessible, there are more frequent mentions of generalised, societal, benefits. In Finland, for example, participation is seen as a civic duty, and the perception is that biobanks will be beneficial for society through medical research and progress is prevalent.

Interestingly, finding out about one’s health status can be a double-edged sword, as well, at least in some cases. In particular, respondents in the Netherlands and France expressed fears about knowing too much, especially if the feedback highlighted risks, and learning about the possibility of developing diseases where no options for prevention or treatment are available. However, in general, feedback is perceived as a modest gesture and sometimes even as a condition for participation and for the acceptance of data coupling.
Conclusions: Dealing with European Heterogeneity

Our research on the public perception of biobanks in Europe has yielded a highly heterogeneous public opinion picture. Again, Europe does not seem to be united when it comes to thinking about biobanks. This has a range of implications, such as for possibly one day emerging European regulations for biobank research or the idea of harmonizing the ethics of biobank research. But, above all, our research has demonstrated against the background of empirical heterogeneity the causes behind this heterogeneity which hardly seems to be set in stone.

Above all, there is a serious information deficit when it comes to biobank research in Europe. Whereas some regions seem to have high knowledge levels, the opposite seems to be the case in others. This in itself would probably not be that relevant if it were not for the fact that information level seems to correlate positively with the readiness to participate in biobank research and to give broad consent. This results was not necessarily to be expected, and also could just have yielded the opposite result. In green biotechnology, for example, a more of information about it tends to correlate strongly with its rejection (O’Neill 2002). But this is not the problem of biobanks and, thus communicating and engaging the public are most warranted activities.

Secondly, our data show that people in a number of countries see participation in biobanks as a risk as they are afraid that data collected about them by biobanks could be used against their interests. This issue becomes especially salient if there is a lack of trust in public institutions. The best possible protection of privacy and personal data thus is a key issue in biobank research.
Thirdly, successful biobanking is a matter of creating reciprocity. Reciprocity can take different forms, be it in terms of appreciation, personal or common benefit or trust. People want to feel that they are part of something larger and that biobanks do their best to operate within their value systems and protect their donated data.

In Scandinavian welfare states, such as Finland, participation in biobank studies is often framed as civic duty or as in the public interest and people are comparably well informed about biobanks. Offering health checks in return for participation is not much of an issue. Anyhow, in countries like Germany, with a health care system in which many people feel equal access is a problem, offering extensive health checks creates reciprocity and encourages public participation, as successful projects like KORA (Cooperative Health Research in the Augsburg Region) demonstrate. The situation is similar in other countries where people have equal experiences. Even though UK Biobank managed data collection in time, feedback mechanisms might have improved the response rate and thus people's readiness to participate. Depending on the particular situation of a country and its health care system, biobank operators are well advised to think about how to "reciprocate".

Fourthly, knowledge and trust building are essential for setting up and operating biobanks. Only if people know about and trust biobanks to operate in their personal or societal interest, they will support them. An entrusted reciprocation is most likely the case if people perceive themselves as recognized participant. This also implies that great efforts are put to provide data protection. However, any new data scandal could seriously hurt future recruitment and the image of biobanks.

Lastly, the operation of biobanks must be sensitive to the given national context. Whether there is a culture of trust in key actors, is clearly highly significant. This is, for example in Finland and the Netherlands, associated with a more relaxed attitude to consent and the sensitivity of genetic data. In the other countries where levels of awareness and potential
participation are lower, demands for specific consent and the sensitivity of genetic data are higher. It may well be that confronted by the novelty of biobanks, and in the absence of a culture of trust, people opt for a precautionary approach. In these cases, dissemination efforts and feedback systems will be the key for operating biobanks. Publics in France, the United Kingdom and Germany show moderate levels of trust, and moderate awareness of risks involved. These comparably balanced attitudes are congruent with people’s moderate willingness for participation. However, French and German people show specific sensitivities regarding ethical questions and biological data, whereas publics in the United Kingdom seem particularly critical regarding international cooperation. In countries where people lack social and political trust, people seem not willing to delegate control to biobanks. In Greece, the massive decline of trust in national authorities due to its performance during the financial crisis can be almost seen as textbook example for this scenario. Different than in the UK, international cooperation is perceived as positive control mechanism. In countries such as the Austria, with comparably moderate trust levels, but awareness for ethical issues, and low demands for participation, people show sensitivity for long-term developments and opt for individual control. This case demonstrates the importance of transparent structures and clear research objectives, which is in practice a tricky matter.

We can see that with any matter, be it the protection of privacy, the prediction of long-term aims or feed-backing findings, there are certain difficulties. On that account it is the interconnectedness of all these issues that matters. Connecting biobanks with society remains an extensive challenge that needs to be addressed with local context sensitivity and a good understanding of the empirical dimensions of how people perceive biobanks. Being credible about societal contributions of biobanks and acting respectfully on participants is the key for successfully connecting biobanks with society.
Acknowledgements

G. Gaskell’s contribution to this paper is supported by the research project “Sensitive Technologies and European Public Ethics” (STEPE), funded by the Science in Society Programme of the European Commission’s FP7 (www.stepe.eu). H. Gottweis’ research was supported by grants from the Austrian Genome Project (GEN-AU) for the projects GATiB (Genome Austrian Tissue Bank) and PrivatGen and by the European Union Programme for Research and Development (FP 7) project Biobanking and Biomolecular Research Infrastructure (BBMRI) and by the National Research Foundation of Korea Grant funded by the Korean Government (NRF-2010-330-B00169).

REFERENCES


Hansson et al (2006). Should donors be allowed to give broad consent to future biobank research? Lancer Oncol 7: 266-269


Von Schomberg, R. (2011). The quest for the right impacts of science and technology: an outlook toward a framework for responsible research and innovation. (http://www.responsible-innovation.nl/conference/con11/)
