

ARTICLE

Publics and biobanks: Pan-European diversity and the challenge of responsible innovation

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This article examines public perceptions of biobanks in Europe using a multi-method approach combining quantitative and qualitative data. It is shown that public support for biobanks in Europe is variable and dependent on a range of interconnected factors: people's engagement with biobanks; concerns about privacy and data security, and trust in the socio-political system, key actors and institutions involved in biobanks. We argue that the biobank community needs to acknowledge the impact of these factors if they are to successfully develop and integrate biobanks at a pan-European level.

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INTRODUCTION

Biobanks have become a central project in biotechnology and genomics. In Europe, the Biobanking and Biomolecular Resources Research Infrastructure (see www.bbmri.eu) aims to facilitate collaboration between biobanks in order to capitalise on increased sample sizes providing greater opportunities for subgroup segmentation in the exploration of the aetiology—genetic, environmental and life style—of diseases.

When people participate in a biobank, they typically donate blood, tissue and body fluid, including DNA data. These samples attain scientific value by virtue of the linkage of personal information including medical records, social and environmental data. However, this raises a range of ethical issues including forms of consent, privacy and data protection.

Biobanks require large numbers of volunteer participants; stakeholders stress the need for broad consent for on-going research rather than narrow or specific consent for every separate study, as only with the former can the samples be used efficiently and economically for the many potential research questions that define the core rationale of a biobank.^{1–3}

The international literature on biobanks and the public covers a spectrum of issues including privacy, research aims and practices and trust.^{4–7} Empirical research in Europe is concentrated in the north-western countries. This shows that although the public has limited knowledge of biobanks there is moderate to high willingness to participate in them.^{8,9} Although people often cite altruistic reasons for participating, personal interests are also mentioned.¹⁰

The tension between personal and societal interests is widely debated in bioethics.^{11–13} Privacy and confidentiality also feature in empirical studies¹⁴ and there are indications that oversight of research agendas is more valued than confidentiality.^{15,16} Informed consent is

also much discussed in the literature.^{17,18} Findings on consent preferences among members of the public are mixed.^{19,20} Some studies find that agreement to broad consent is dependent on the research topics,²¹ whereas others find that consent is little understood by donors and is not a consuming concern, suggesting that the topic's prominence in bioethics may be misplaced.²² Studies also show that the public would like feedback on the results and that trust in those conducting the research is a prerequisite.^{23,24}

On the basis of two separate studies, one quantitative (a social survey) the other qualitative (focus groups), this paper presents unique pan-European findings on people's willingness to participate in biobanks and preferences for narrow or broad consent. We investigate the potential antecedents of these pivotal decisions—people's engagement with biobanks; concerns about privacy and data security and trust in those involved in biobank operation and research. Finally, we discuss the implications of the findings for recruitment, operation and governance of biobanks with a view to achieving responsible research and innovation in Europe.²⁵

MATERIALS AND METHODS

Survey methods

Procedure. Pilot work using focus groups in The Netherlands and Austria identified key issues of concern to the public and informed the development of a set of questions on biobanks for the 2010 Eurobarometer on the Life Sciences and Biotechnology.²⁶ Conducted in February 2010, this survey uses probability multi-stage sampling to obtain representative samples of adults (circa 1000 per country) in each of the 27 European member states, plus Croatia, Iceland, Norway, Switzerland and Turkey. The questions on biobanks were administered to half of the sample in each country through a randomised split ballot giving a total sample of 15 650. The survey questionnaire was devised as part of an EC Science in Society project; Sensitive Technologies and European Public Ethics (see Supplementary Materials for details of the survey).

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Measures. Willingness to participate was measured by asking respondents whether they would provide information about themselves to a biobank (yes, definitely; yes, probably; no, probably not; no, definitely not). For purposes beyond descriptive statistics the question was recoded into 0 = not willing to participate and 1 = willing to participate.

Informed consent was measured by asking respondents about the type of permission researchers should require for conducting research on data in a biobank (no need to ask for permission; ask for permission only once; ask for permission for every new piece of research). These alternatives were recoded into broad consent (no need to ask permission or ask only once) and narrow consent (ask for permission every new piece of research).

Awareness and engagement was measured using three questions: whether respondents had heard of biobanks, and whether they had talked and/or searched for information about them. These questions were then combined to create three categories: not heard, passive engagement (heard but not talked/searched for information) and active engagement (heard and talked or searched for information).

Concern about data privacy was measured by asking respondents whether they would be reluctant about donating five different types of data (blood samples, tissues, genetic profile, medical records and lifestyle information). The number of these that were of concern to each respondent was counted (0 = low concern, 5 = high concern).

Trust was measured by asking respondents whether they thought that different actors were doing a good job for society in relation to biotechnology (industries, universities, government, ethics committees and medical doctors). The number of actors which each respondent considered to be doing a good job for society was counted (0 = low trust, 5 = high trust). ‘Doing a good job’ or not was designed as a composite measure of three expectations contributing to trust—value compatibility, competence and fiduciary responsibility.²⁷

Analyses. The data was analysed using descriptive, inferential and multivariate statistical procedures. For the descriptive statistics a national weighting procedure was carried out.²⁶ Logistic regression was used to determine the role of engagement, privacy concerns and trust in predicting the odds of being willing to participate and to prefer broad consent over narrow consent. The following personal characteristics were also included in the models as control variables: age, years of education, whether the respondent has studied science at the tertiary level and gender. These models were constructed for all 32 countries together, using robust errors, and separately for each of the seven countries in which focus groups were conducted.

Focus groups

Procedure. Focus groups are organised discussions on topics introduced by a moderator.²⁸ In total, 60 focus groups were conducted in Austria, Finland, Germany, Greece, The Netherlands and the United Kingdom. These countries were chosen as previous research showed that they represent the spectrum of attitudes towards biotechnology.²⁶ For the focus groups we aimed to achieve similarity in the mode of recruitment, the topic guide and the analytic approach across different countries. To this end the moderators held periodic meetings throughout the research to agree on common procedures.

Participants were recruited to comprise a broad cross-section of the adult population. A total of 39 groups were made up of the lay publics, the other 21 were composed of people with prior experience in (bio-) medical research or who had been engaged as patient activists (informed publics, recruited via study registers and from patient groups). Each group comprised between 6 and 12 people and the discussions lasted about 2 h.

Developed out of the current literature,²⁹ the same topic guide was used in all the groups (see Supplementary Materials). After a description of biobanks, participants were asked what they thought might be the advantages and disadvantages of biobanks and about their willingness to engage in biobank research. Next, the issues of data privacy, informed consent, benefit sharing and internationalisation were discussed. The session ended with a discussion of the governance of biobanks. All the group discussions were audio-recorded with informed consent and transcribed in the original language.

Analysis. The transcripts of the discussions were analysed using a structured content analysis.³⁰ Initially, based on the topic guide the coding frame evolved

inductively during team meetings until it captured the core themes of the discussions. Regular meetings were held to ensure inter-coder consistency. Each partner coded their material in the original language and subsequently translated selected parts into English. The formal content analysis was complemented by interpretive analyses designed to reveal the key currents of opinion and associations of ideas. Throughout the process, qualitative data analysis software (Atlas.Ti) was used to facilitate data management, international exchange and consistency.

RESULTS

The presentation of the results takes account of the multi-method design. Each section starts with the findings from the survey, followed by key insights from the focus groups illustrated by exemplary quotations.

Participation and informed consent

The two pivotal indicators of public attitudes towards biobanks are people’s willingness to participate and the type of informed consent that people prefer. In terms of participation, we observe wide variation across Europe. There is a concentration of people in North European countries who say that they will ‘definitely’ or ‘probably’ participate in biobank research, whereas the publics in other countries are more reluctant (see Figure 1).

Despite the need for broad consent 67% of Europeans opt for narrow consent and only 24% for broad consent—see Figure 2. Of the countries in which we conducted focus groups, the preference for narrow consent is high 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.

Explaining differences in participation and informed consent

We expect that willingness to participate in biobank research, and the readiness to accept broad consent to be dependent on a range of interconnected factors: (1) the public’s engagement with biobanks; (2) views about privacy and data security, and (3) trust in the socio-political system, key actors and institutions involved in biobanks.

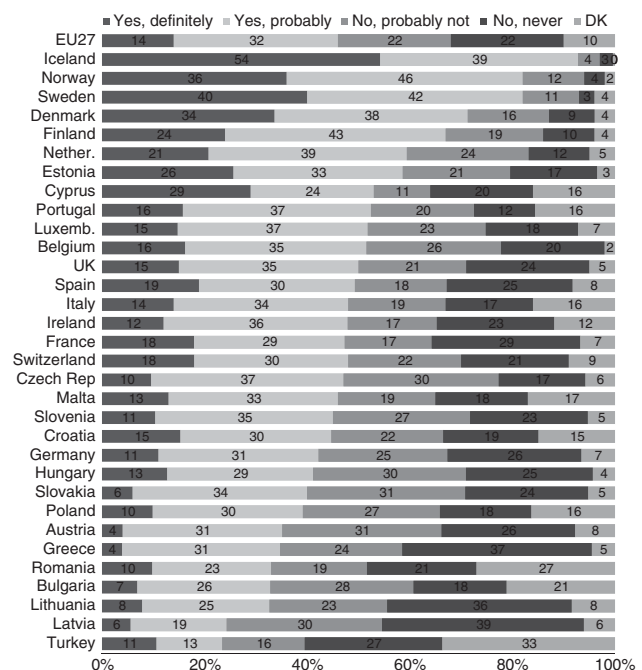


Figure 1 Willingness to provide information about oneself in a biobank.

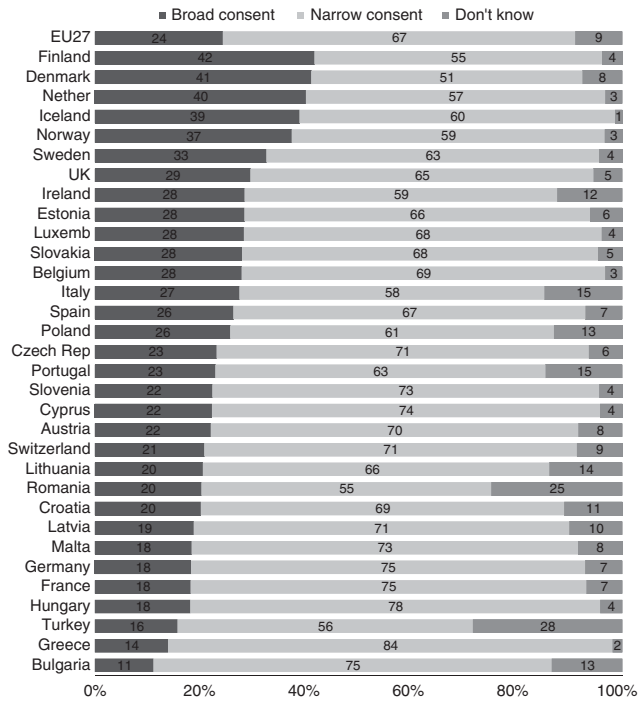


Figure 2 Acceptable forms of consent for research on biobanks.

Awareness and engagement

It is notable that more than two thirds of all Europeans said that they have never heard of biobanks, and only 17% are actively engaged in so far as they say they have 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.

There is a strong association between a country's level of engagement (having heard or talked about biobanks) and the intention to participate in biobanks. Engagement with biobanks is more common in North European countries, and countries with higher levels of engagement also show higher percentages of respondents who are willing to participate in biobanks (see Figure 3). This relationship also holds at an individual level (see Table 1). Those who show active engagement are significantly more willing to participate (74.7%) than those who show passive engagement (60.2%) and those who have not heard of biobanks (42.7%), $\chi^2(2, N = 14\,191) = 1000, P < 0.01$. It might be argued that the measure of engagement merely reflects prior participation in biobanks. This seems implausible, however, as the survey finds that 16% of Britons are actively engaged, but UK Biobank, one of the largest in Europe, amounts to <1% of the population (www.ukbiobank.ac.uk).

As with participation, the willingness to give broad consent is related to engagement with biobanks—as shown in Figure 3. The more people have actively engaged with biobanks, the more likely they are to agree to broad consent. Only 24% of those who have not heard about biobanks favour broad consent. This number increases to 30% and 34% respectively of those who are passively and actively engaged, respectively (see Table 1), $\chi^2(2, N = 14\,312) = 120.97, P < 0.01$.

The focus groups revealed that most of the 'lay public' had never heard of biobanks before and were initially uneasy and suspicious. When people are informed about the aims and rationale of biobanks

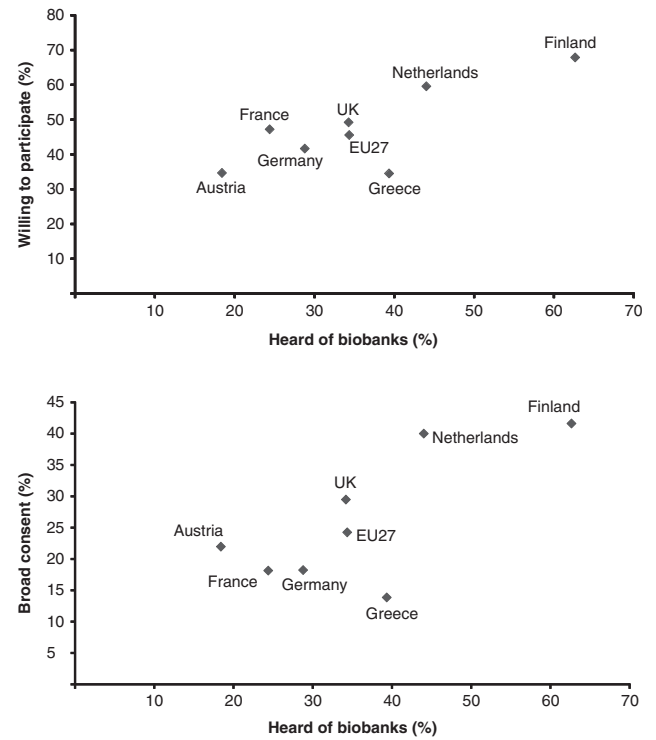


Figure 3 Willingness to participate in biobanks and preference for broad consent by awareness.

and the ways in which research will be conducted, they tend to reflect on the practical necessity of this research and the necessity of broad consent.

FG4_NL_LAY, 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.'

Not surprisingly, existing participants in cohort studies and patient activists were better informed about different aspects of biobanks, and more ready to participate in such research in the future. Overall, however, the concerns expressed by the lay and informed groups were strikingly similar.

The focus groups show that the preference for narrow consent goes hand in hand with wanting to know about and to influence the content and direction of research. When people worry that research might be contrary to their own interests or ethical values, they choose the precautionary option: narrow consent or refusal to participate. People's concerns are often linked to much-debated examples such as human cloning or eugenics. Only if people are confident that biobanks will operate within an acceptable ethical framework are they willing to grant broad consent for research.

FG8_GER_LAY, 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.'

Even those who wanted to support biomedical research were reluctant to support research for commercial gain, or without societal benefit. People associate private interests with inequitable distribution of benefits, biased research aims and potential misuse of personal data.

Table 1 Relationships between willingness to participate, engagement, trust and privacy concerns

	Not heard	Engagement (%)		Total	Trust (means)	Privacy concerns (means)
		Passive engagement	Active engagement			
Not willing to participate	57.3	39.8	25.3	46.8	3.9	1.8
Willing to participate	42.7	60.2	74.7	53.3	4.4	1.2
Narrow consent	75.9	70.3	66.1	72.6	4.2	1.5
Broad consent	24.1	29.7	33.9	27.4	4.2	1.2
Total	100.0	100.0	100.0	100.0	4.2	1.4

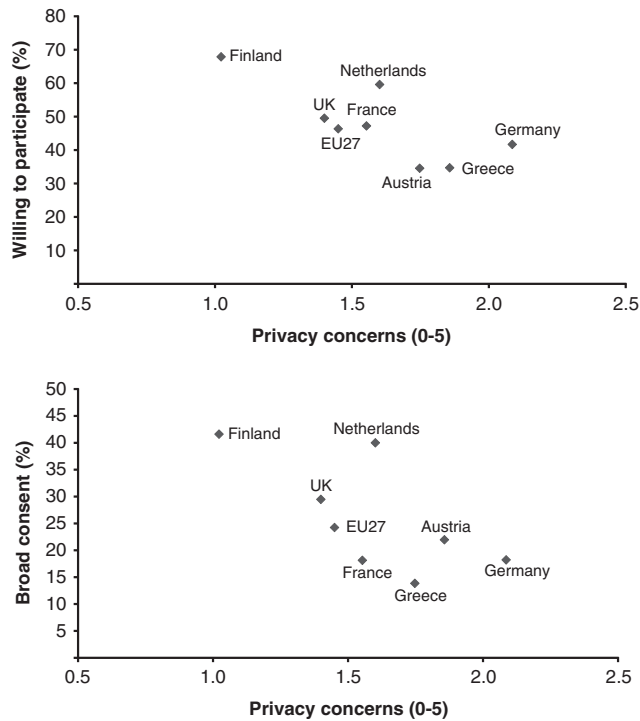


Figure 4 Willingness to participate in biobanks and preference for broad consent by privacy concerns.

Privacy and data collection

Concerns about privacy and data security are associated with lower willingness to participate and a preference for narrow consent: see Figure 4. Table 1 shows that at the individual level those who are willing to participate score lower on the privacy concern scale ($M = 1.2, SD = 0.02$) than those who are not willing to participate ($M = 1.8, SD = 0.02$), $F(1, 14189) = 443.57, P < 0.01$. Similarly, those who favour broad consent are less concerned about privacy ($M = 1.2, SD = 0.02$) than those who favour narrow consent ($M = 1.5, SD = 0.02$), $F(1, 14310) = 138.42, P < 0.01$.

Although concerns about data privacy were frequently discussed in the groups, these do not necessarily lead to a rejection of biobanks. People worry about data abuse by insurance companies and employers and want biobanks to offer the best possible data protection. Data security is an issue even in countries where people expressed broad support for biobanking. People recalled media stories about data leaks and data hacking. In Finland, access to the social security number was a controversial issue, and in Germany people mentioned the political system in the former German Democratic Republic. Relating these experiences to biobanking, led many to conclude that data can never be fully protected, now or in the future.

The problem of privacy is embedded in wider societal developments, rather than a unique feature of biobanks. Many people are accustomed to providing data in their daily lives and are almost resigned to privacy violations.

FG4_UK_LAY, 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.’

Medical data, whether specimens or health records, is perceived as sensitive in comparison with other personal data in The Netherlands, France, the UK and Finland. In Germany and Austria the eugenic experiments of WW11 were cited as reasons to be careful with genetic profiles and biological data. In all countries, people worry about possible new forms of discrimination based on genetic information.

FG3_UK_INFORMED, 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.’

Trust

The survey data shows an association between trust, participation and consent at a country level. In countries where people trust key actors—such as Finland and The Netherlands—respondents reported higher willingness to participate and had a higher preference for broad consent (see Figure 5). At an individual level, higher trust is reported by those who are willing to participate ($M = 4.4, SD = 0.01$) compared with those who are not willing to participate ($M = 3.9, SD = 0.02$) (Table 1), $F(1, 9340) = 375.55, P < 0.01$. However, trust does not have an effect on preferences for consent at this level (Table 1), $F(1, 9432) = 0.56, P > 0.05$.

The data derived from the focus groups highlight the importance of trust. People said that they want to know about research aims, what will be permitted and not permitted and about the actors involved. Feedback on research results is seen as a step towards transparency and trustworthiness. When people expressed doubts about trusting biobanks, it was often because they envisaged a black box—a non-transparent organisation, unknown actors, and blurred and ambiguous research aims.

FG1_AUT_LAY, P1: ‘I want to have access to what is being studied, I want to have a look at what they have from me, what happens with it, and I want the opportunity to conduct an emergency stop.’

In Finland, where people show high levels of social and political trust, the public status of research institutes was set as a condition for participation.

FG3_FIN_LAY, P14: 'Perhaps I have a fundamental trust towards those executing the research and perhaps towards the staff as well. It might depend on the institution, but basically it is so that they use the information for the purpose they were meant for. I have a trusting attitude.'

In Greece, however, a different picture emerges. Many people expressed a lack of trust in their government, politicians and state authorities, and in the ability of these actors to govern biobanks in the public interest—concerns that are likely to be associated with the recent economic crisis.

FG3_GR_LAY, P20: 'We all know that the state authorities here are completely unable to do anything properly.'

Although most countries were positively disposed towards international cooperation on the basis that it would improve research, in Greece this was perceived as a positive control mechanism.

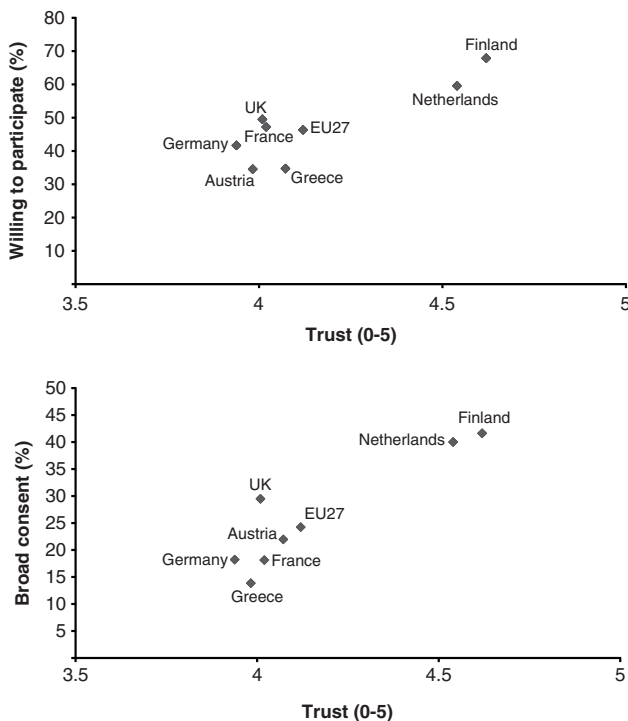


Figure 5 Willingness to participate in biobanks and preference for broad consent by trust.

Trust was not constructed as absolute, but rather as conditional and fluid. Where participants want to maintain some degree of control over the data, they tend to argue for an 'opt-out' model of broad consent. They are willing to give broad consent on enrolment, but they want the opportunity to opt-out or to withdraw if they came to believe that the conditions of participation were not being maintained.

Explaining differences in participation and informed consent: a multivariate approach

Table 2 shows the results of logistic regression models for predicting participation in biobanks (results for consent are similar and any differences are discussed in the text).

Starting with the personal characteristics, we observe that male respondents ($P < 0.01$) and those who have more years of education ($P < 0.01$) are more likely to participate and request broad consent. No significant differences were found for age and whether respondents had studied science.

By contrast, passive ($P < 0.01$) and active ($P < 0.01$) engagement and concerns about data privacy ($P < 0.01$) are consistent and significant predictors of willingness to participate in biobanks and preference for broad consent. Those who are passively engaged with biobanks are 69% more likely than those who have not heard of biobanks to participate and 20% more likely to prefer broad consent. These figures are even higher when considering the difference between those who are actively engaged and those who have not heard of biobanks: the former are 219% more likely to participate and 49% more likely to prefer broad consent. The same effect can be observed when looking at individual countries, with the exception of France and the UK.

Privacy concerns have a negative effect: for every one unit increase in the scale (from 0 to 5), respondents are 21% less likely to participate and 13% less likely to prefer broad consent. The same is true for all countries considered—with the exception of Austria.

Trust has a statistically significant impact in participation when considering all 32 countries ($P < 0.01$) and in all 7 countries taken separately—increasing the likelihood of participation for every one-point increase in trust (in a scale from 0 to 5) by between 35 and 92%. In other words, the more people have trust in industry, doctors, university scientists, government and ethics committees, the greater is the probability that they will sign up to participate in a biobank. However, the latter is not the case for the prediction of broad consent. Controlling for engagement and data privacy concerns, trust does not affect respondents' consent preferences, with the exception of The Netherlands.

Table 2 Relationships between consent preference, engagement, trust and privacy concerns

	All 32 countries	Germany	Greece	Finland	France	The Netherlands	Austria	UK
Age	1.00	0.99	1.01	0.99	1.02*	1.03**	0.99	1.00
Education (years)	1.06**	1.08*	1.01	1.02	1.05	0.95	1.01	1.04
Studied science	0.99	0.82*	1.03	1.25*	1.19	1.21	1.85*	1.14
Male	1.25**	1.44	1.44	0.79	0.58*	1.02	1.15	1.53
Passive engagement	1.69**	2.57**	2.07*	1.76	1.87	1.82	3.22*	1.65
Active engagement	3.19**	1.72	4.34**	2.90**	2.09	4.81**	2.33*	1.54
Trust	1.37**	1.59**	1.54**	1.72**	1.50**	1.92**	1.55**	1.35**
Data privacy concerns	0.79**	0.67**	0.85*	0.73**	0.55**	0.62**	0.94	0.63**

* $P < 0.05$. ** $P < 0.01$.

The lack of effect of trust on broad or narrow consent is surprising but consistent with the focus group findings. People may trust those running a biobank, but still wish to control the use of their data. This can be understood against the background that biobanks are seen as long-term initiatives. People's concerns focus on future developments in which the current bases of trust may be overtaken by events.

Although trust does not predict consent, it may moderate the effect of privacy concerns. We tested this hypothesis by adding an interaction effect between trust and privacy concerns to the previously shown models of participation and consent. We find that the effects of privacy concerns on participation ($P < 0.05$) and preference for consent ($P < 0.05$) are less relevant when respondents trust actors. In the case of participation, when respondents had low trust in actors, every one-point increase in the privacy concern scale decreased the likelihood of participating by 29%. This number decreased to 20% for those who showed high trust in actors. The same was true for predicting preference for broad consent (22% decrease for those who do not trust actors and 11% decrease for those who trust actors). Altogether, these findings suggest that trust is a requirement for participation in biobanks and facilitates acceptance of broad consent.

DISCUSSION

Existing empirical studies, concentrated in northern Europe, point to moderate to high willingness to participate in biobanks and the acceptance of broad consent for research.^{8,9} By contrast, the pan-European findings of the present study show that the publics of Europe are heterogeneous in their response to biobanks. This difference may be attributable to a regional bias in the literature—the majority of studies focus on north-western Europe.

Our findings suggest that obtaining broad consent will be a challenge for European initiatives such as BBMRI that seek coverage from different regions. In southern and eastern Europe we find lower willingness to participate, and a preference for narrow consent. It is notable that these countries are not well represented in European biobanking initiatives.

The diversity of responses across Europe has a number of implications for the prospects of emerging European regulations for biobank research and the plans for harmonising the ethics and policies of biobank research. Lying behind the European diversity is a number of common problems, issues and concerns—many of which are not set in stone and can be addressed by informed and prudent actions on the part of biobank developers and researchers.

The findings suggest that biobanks have not done enough to generate engagement among the public. Some regions—particularly north-western Europe—have achieved relatively high levels of engagement, but Southern and Eastern Europe have not. Given that engagement has been found to relate to readiness to participate in biobank research and to agree to broad consent, public engagement cannot be ignored.

Our findings indicate that people in a number of countries see participation in biobanks as a risk because they worry that samples could be used against their interests. This issue becomes especially salient if there is a lack of trust in public institutions. Assiduous mechanisms for the protection of privacy and personal data should be given careful consideration.

Biobanks will need to consider how to explain to the public the rationale for cooperation with other actors; in particular the private sector, as commercial involvement is perceived with suspicion. The embedding of biobanks in long-trusted organisations committed to advancing scientific knowledge and serving the public interest can help to increase people's trust.

The European Commission's call for responsible innovation with multiple stakeholder involvement throughout the innovation cycle²⁵ receives affirmation from this analysis of the European public and biobanks. Although innovation is a technical process, successful innovation must carry public confidence. Those hesitating to participate in biobanks have lower trust in key actors and have greater concerns about data privacy and security. Such concerns will only be allayed by building trust and transparency and by engaging the public as partners in the biobank project. Connecting biobanks with society remains a considerable challenge that needs to be addressed with sensitivity to the local context and a good understanding of the nature of public concerns. Finally, although this paper concentrates on the antecedents of participation in biobanks, future studies might focus on those already enrolled in biobanks: what do they now think about informed consent, feedback and data privacy, and will they stay enrolled?

CONFLICT OF INTEREST

The authors declare no conflict of interest.

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