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Donors Perceptions of Consent to and Feedback from Biobank Research: Time to Acknowledge Diversity?

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Key Words
Biobanks · Biobank ethics · Feedback · Informed consent · Public attitudes · Public perceptions · Respect for persons

Abstract
Background: Many studies have explored public perspectives on when and how to provide informed consent to biobank research and when to get feedback on research results. Little has been done to explore overarching trends in these studies. ***Methods:*** The article is based on a critical reading of the literature found through Medline searches and the PRIVILEGED project compilation of empirical studies. ***Results:*** I suggest that tissue type, procurement situation including who is asked to provide consent, and the biobank's geographical, social and historical context influence how various potential donors view the issues of consent, re-consent, and feedback of research results. In light of this, universal ethical standards for informed consent to and feedback of research results from biobank research seem to run contrary to the diversity of perceptions and expectations among different donors. ***Conclusion:*** To respect donor interests, it is necessary to pay more attention to diversity with regard to biobank types and different contexts for donation. We should avoid assuming that words like 'biobank' and 'donor' can be used in a generic sense – always referring to the same – if we wish to respect and care for the diverse group of individuals who comprise the donating public.

As biobanks have become increasingly important resources for genetic research, the ethical and regulatory issues surrounding the rights and entitlements of biobank donors have attracted a great amount of scholarly interest. The debate has focused on informed consent and more recently on when or whether to ask for re-consent and on when or whether to provide feedback of research results. These issues all pertain to the relationship between donors and researchers. The existing guidelines and legal frameworks are marked by significant variations in the rules researches are supposed to follow [1–5], and the resulting difficulties for researchers engaged in international collaboration have prompted several attempts of harmonization [6–9]. From the perspective of the legislator, the easy way to go forward seems to be to establish international standards with common criteria for informed consent, re-contact and feedback of research results. The question is, what do the people for whose sake these rules are ostensibly established want?

In this article I lay out trends in studies of public perceptions of consent and feedback of research results [10–12]. Two reviews published 2006 attempted to summarize existing studies but came to opposite conclusions: one suggested that the available studies indicated a preference among donors for one-time general (open) consent [13], while another suggested that donors clearly opted for specific consent [14]. Both articles subscribed to the idea that some sort of underlying consensus among all the donor populations contributing to multiple forms of biobank-

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based research was to be found – though clearly interpreting the data with great liberty to reach their (opposite) conclusions. I suggest that even though the easy way out of the current predicament seems to be global standards – a shared consent and feedback practice – there is no reason to presume universal agreement among donors as a homogenous group, or to think that universal standards will serve local interests and concerns. It would be more productive to pay attention to potential differences among donors and how such differences relate to variance in biobank setups. I am not suggesting that particular organizational biobank factors determine donor attitudes, but I do suggest that contextual circumstances influence the way different donors perceive and position themselves towards biobank research and thereby also how we should interpret their expectations. People engage in biobank research through local practices and gifting relationships. Here they are enabled to – as a diverse group – acquire and manifest socially, culturally and historically mediated hopes, expectations and concerns. I believe that a central task for biobank researchers and legislators is to engage in these relationships with care and respect.

Tissue can be acquired for research in many different manners. These emerge to be so diverse that it seems almost too casual to use a single word – as biobank – to describe all types of tissue repositories. Some biobanks are constructed with the specific intention of facilitating research, while others are established as part of diagnostic routines, screening programmes or therapeutic purposes, and they only later come to be viewed relevant for research. The purpose-built biobanks can be constructed by clinicians knowing a particular group of patients (e.g. Dr. Catalona's famous prostate cancer biobank), by patient groups themselves (e.g. PXE International, where a patient organization established a biobank to facilitate research into their disease) or they can be population-based cohort studies (e.g. UK Biobank). Cohort and cross-sectional studies can be constructed as part of universal healthcare routine practices (e.g. Medical Biobank in Sweden) or independently of healthcare activities (e.g. Human Genome Diversity Project). They can be run by industry, by non-profit private organizations or by public authorities; and each one of these forms can provide access to both public and private research parties on various terms and conditions and with different specification of research purposes. It seems reasonable to assume that donors will acquire different expectations dependent on the type of biobank they contribute to and the recruitment process they engage in. The available survey material does not allow investigation of all these differences, but I nevertheless suggest that it is time to begin exploring potential differences in donor expectations and attitudes towards biobank research and thereby avoid presuming some sort of underlying consensus.

I begin with a short review of trends in studies of public perceptions of consent to biobank research and then move on to feedback of research results. To make sense of what is to some extent contradictory quantitative data, I draw on qualitative studies exploring the type of relationship various donors see themselves as engaged in when contributing to biobank research. The studies have been found using the Medline search engine, by following citations of earlier studies, as well as by drawing on the collection of empirical studies gathered and made available through the PRIVILEGED project (www.privileged.group.shef.ac.uk). In the PRIVILEGED project, scholars from 29 mainly European countries were invited to report on the main findings from national empirical studies that could indicate something about public attitudes to biobanks. They filled in a questionnaire and with this information a homepage was designed with a list of available studies of the participating countries. Certainly, many more studies have been published than I am able to cite in this article, but my aim is not to provide an exhaustive compilation of the literature. I rather wish to begin deciphering trends and pointing out differences in the literature.

Consent and Re-Consent: One Size Fits All?

The position taken on specific or broad consent at the point of procurement will influence the view of re-consent because with one-time general (open) consent, reconsent will rarely be necessary and vice versa. So many studies have explored donor attitudes towards the specificity of informed consent that it is now feasible to begin identifying differences in available studies.

The most obvious difference relates to the questions asked in these surveys and can be considered as either methodological flaws or perhaps just methodological implications. Inquiring whether or not people think they should be asked for consent before their tissue is used for research would indicate that a particular framing of their interests has already taken place and that their potential concerns about and their interest in biobank research has been limited to personal information levels. Mostly surveys seem to find that a majority of potential donors expect to have a say about usage of tissue and medical rec-

ords (e.g. [15–19], though exceptions exist [20]). Re-consent is reported to be a clear expectation in some studies [21], and re-consent procedures have been found feasible with relatively low dropout rates in at least one case [22]. However, as one study took a deliberative approach whereby informants were invited to negotiate their views, it found that informants' interest in re-consent declined significantly following the group debate [23]. The differences in methodological approach seem to have an impact on the result, and it can be difficult to assess what provides the most valid and relevant input to the debate. In two studies conducted in Sweden, people were asked to rank what was most important to them in relation to biobank research participation rather than simply to express their interest in different consent options. Being personally informed about research was mentioned among other concerns that had appeared in preceding qualitative interviews such as the influence of commercial interests on the research agenda. Being personally informed turned out to be the item rated lowest of all concerns (seen as most important by 3.4–4.0%) by members of the general population [24] and by a group of donors [25]. Nevertheless, approximately a fifth of the responding donors would not be willing to accept surrogate decision-making by research ethics committees (RECs). Hence, some donors regard being personally informed as a basic entitlement whereas, at the same time, consider other issues as more important. The framing of questions on the specificity of consent might therefore cover up for more complex interrelated concerns, expectations, and interests among donors, and therefore all such studies should be read with great caution.

Studies also find that diverse groups of donors share a tendency in as far as they pay little attention to information sheets; often forget the information provided; and rarely use the offered information to make up their mind about participation [19, 26–30]. Furthermore, these donors do not necessarily trust informed consent practices to effectually ensure their interests, and in some instances the consent form is viewed as protecting the researcher rather than the donor [28, 31, 32].

However, it is unreasonable to assume that differences in research findings are due to methodological contingencies only. In fact, available studies make it possible to begin discerning circumstances influencing donor attitudes in different ways – in particular in relation to interrelated factors such as tissue type; procurement situation; whose tissue is at stake (own or others); and the geographical social and cultural context.

Concerning *tissue type* it seems relevant that different types of tissue are portrayed differently in the media which might influence some donors. In the UK, for example, the media reports about retention of children's organs at Alder Hey Hospital emphasised brains and hearts much more than other tissue types [33]. Blood tests are generally seen as routine measures of limited significance [34], and blood is accordingly seen as easier to donate than the DNA it contains [35]. Donation rates and donor support for tumour banks are generally very high compared to other types of tissue banks [36–40]. Cancer patients also seem most willing to donate for unspecified purposes with one study for example showing 89.4% in favour of open consent [41]. Such findings point to differences in attitudes depending on the type of tissue collected in a given biobank.

High assent rates for tumour tissue donation might also reflect circumstances related to the *procurement situation*. When people feel threatened by cancer, research can be construed as part of a fight against the disease, whereas participation in cohort studies with healthy participants *introduces* potential risks (in terms of privacy intrusion, etc.) where there might have been none. Studies show that tissue excised during operations conducted on clinical indication (e.g. tumours, arthritic bone or breast tissue) is described as 'alien' and 'not-me' by patients and readily donated [29, 42]. The procurement situation can be seen as part of construing the tissue in ways that facilitate donation. When tissue is collected as part of clinical care or national screening programmes, assent rates are generally high [43]. In Sweden, for example, only one out of 1,600 patients refuse storage of tissue procured during clinical care [44]. Donation rates for a pregnancy cohort in the USA were 68%, which is higher than recruitment in the general population, but lower than among cancer patients [45]. The lowest donation rates seem to be in conjunction with procuring tissue from recently deceased [46], especially when commercial partners are given access to the tissue [47]. Little is known about consent rates to research biobanks in the commercial sector [48].

Low rates of consent to cadaveric donations might also be related to reluctant attitudes toward donating the tissue of others. It can be important *whose tissue* that is procured because it relates to whether the person asked to consent will view consent as compatible with care. One study indicates that people are much more willing to donate their own tissue than that of their children [49]. For similar reasons protection of body integrity of a recently deceased person might appear more appealing than ac-

ceptance of tissue requests for research: in a caring relationship, it could seem preferable to protect the defenseless cadaver against outsiders – including researchers [50]. In childhood cancer research, however, parents are generally willing to consent on behalf of their children [51], and again it might reflect what could be termed an assessment of relative danger and whether researchers are construed as outsiders or helpers in the specific situation. In one study, for example, couples in fertility treatment were inclined to donate so-called spare embryos because they judged fertility doctors as health professionals who had been helping them [52]: donation was viewed as compatible – rather than in potential conflict – with caring for a future child.

Finally, and in continuation of this last point, we should pay attention to the *geographical, social and historical context* of specific biobanks and remember that survey results reflect different place-specific factors and not only the items ideally measured. This should also be read as a caveat to the way in which I have drawn upon and compared studies irrespective of the regions from which they originate. It is naïve to assume that results should not differ in some measure across vastly different contexts. For example, U.S. citizens seem to have less trust in government oversight of biobanks than Scandinavians [19, 53] – even though reports about levels of trust differ significantly even within the same regions [54–58]. Several studies highlight national and organizational context as important features of biobank support [19, 30, 59]. Cultural differences are bound to increase when we consider new biobanks in, for example, China [60], The Gambia [61], Japan [62], India [63], Mexico [64], and Taiwan [65]. Familial obligations, gender issues, economic circumstances, and expectations of healthcare delivery through research participation are all issues which can be expected to be viewed differently, but factors we know very little about.

Taking the point further, I suggest that even within the same country you will find different groups having social and historical reasons to position themselves in special ways towards researchers inviting them to contribute to medical biobanks. In one American study, Afro-Americans cited the Tuskegee scandal as a reason for taking a cautious attitude towards medical researchers inviting them to take part in a medical biobank [53], see also [40, 66]. Similar variations between ethnic groups have been found in the UK [18]. In Sweden, however, it seems to be younger men with higher education – rather than socially vulnerable and marginalized groups – who take the most hesitant attitude toward participation in biobank research [24, 67]. Variance in cultural and socioeconomic history seems to interact with socioeconomic groups in multiple ways making people in quite different types of situation adopt a sceptical attitude to biobank research. If legislators and biobank researchers want to meet biobank donors with respect, a universal consent form will not necessarily do the trick. Rather enrolment practices should reflect local expectations and the sort of obligations imagined by potential participants as being at stake in the local context of recruitment.

Understanding the Interest in Feedback of Research Results

If enrolment and consent practices are embedded in local contexts where the tissue type, mode of procurement, and social, cultural and historical factors influence the perception of biobank research and thereby donor interests in consent differently, context is even more significant in relation to expectations of feedback of research results during the course of a biobank project. The ethical obligation to provide feedback has been discussed in great detail [68–72], and even if the numerous international guidelines suggest a duty to provide relevant feedback, they give quite contradictory advice on when and how feedback should be given to whom [9]. In surveys exploring the views of donors or potential donors, there tends to be overwhelming interest in feedback of research results [16, 17, 36, 62, 66, 73]. There appear to be some regional differences, however, where for example American [66] and Irish [74] respondents seem to want research results irrespective of the availability of treatment options in contrast to Swedes and in particular rural Swedes, who prefer getting individual results only when they are of validated clinical use [24, 75]. Cancer patients and their relatives seem most eager to receive results [36]. Reactions from research participants being sent a risk notification after participation in a large-scale epidemiological research project were mostly positive [76], but reports about negative reactions from women being tested for what turned out to be false-positive research results in a cancer study has also led to recommendation of great care before participants are contacted [37]. Nevertheless, other studies suggest that feedback is seen as a basic right, an indisputable entitlement even, by some research participants [77]. Complicating the issue even more, most of these studies feature a minority insisting on a right not to know about research results. It implies that either way, with or without feedback mechanisms, somebody is likely to find their wishes neglected.

Again we might do a better job of meeting donor expectations if we do not opt for universal solutions, but consider local circumstances and the type of relationships through which tissue samples and phenotypic information have been procured. A number of qualitative studies conducted in the U.S. [53], Canada [16], the UK [26, 27, 35, 42, 54, 55, 78–80], Norway [19], Sweden [30, 81], Austria [29, 31], and France [28] might help us understand better what this means. These studies indicate that people tend to expect an element of *reciprocity* when contributing to biobank research. They rarely want money in return; they expect *care*. Many, but not all, view participation as a duty, as a chance to help, and relate participation to questions of identity: donations can be related to being a proper patient, relative or citizen. In some contexts and by some donors all commercial relations are frowned upon, in others they are tolerated, but it seems essential that collective efforts should lead to collective gains rather than being co-opted by private interests [cf., 82]. Reciprocity can be handled in multiple ways; each relationship enacting its own set of expectations – but all of these studies indicate that people care about the research they contribute to in ways which incur enduring obligations on biobank researchers.

Expectations are indicative of a basic social mechanism related to gifting. When people offer a gift, they do not simply transfer something; they engage in a relationship [83]. The social mechanisms of gifting were originally adapted to analysis of blood donation by Richard Titmuss [84], and his work has later been widely debated and criticised in relation to biobanks too [85]. The point which still stands is that an emphasis on 'altruism' – if understood as a transfer with no strings attached – as a motivation for tissue donations sidesteps this basic insight into the nature of gifting. It construes diverse donor expectations misleadingly. Requests for gifts interact with people's perceptions of obligations in any given relationship. This also pertains to invitations to biobank participation. The preceding forms of relations will influence how the invitation is understood. Accordingly, the type of relationship that is confirmed and transfigured through gifting will differ depending on context and different biobank projects. It will also enact different perceptions of obligations and heterogeneous expectations of these projects. To appreciate the ethical importance of this, it is necessary to abandon the idea of 'free gifts' [86] and instead consider *the type of relationship* people in concrete situations opt for when agreeing to contribute to research efforts. As goes for most relationships, both sides of the relation must express some sort of care; some sort of interest in the other. And there are clear limits as to how much you can expect of donors if very little is offered in return. Hence, to strike a balance, local context must be adequately assessed. People typically express care for research progress, public health issues, and the health of other patients when they donate, but they expect some element of care and obligation in return.

When surveys convey expectations of feedback of research results, such findings can be seen as paradigmatic for expectations of reciprocity. However, when considered in more depth, these expectations might be symbolic rather than concrete. By this I mean that people might simply take it for granted that researchers exhibit care and interest in the donor when research results are produced and that researchers should consider what makes information *relevant* for donors. Researchers first and foremost should bear in mind whether feedback in fact represents *care*. In some instances, it is certainly not very caring to send a notification that people should check-up on what might turn out to be false-positive results for a risk that cannot be alleviated anyway. In relation to some population-based biobanks, the majority of donors probably expect researchers primarily to express care through proper selection of collaborators and research topics rather than through providing feedback [87]. In other disease-specific biobank settings personal results might be seen as the most pertinent expressions of care towards the individual donor [73]. The basic point is that how donors are recruited will influence such expectations, and therefore it will not be advisable to opt for universal standards irrespective of biobank setting, tissue type, cultural context and preceding relationships between researchers and donors.

Conclusion: Making Sense of Contradictory Data

Whereas previous reviews of the literature have tried to make sense of contradictory data by way of searching for an underlying consensus, I have suggested that different results reflect fundamental differences in the type of relationships between donors and researchers that emerge through donations. Such differences are dependent on, for example, the type of tissue donated; the procurement situation; whose tissue is donated; as well as social, cultural and historical circumstances. Because of this diversity we should try to move beyond generic notions of 'biobanks' and 'donors' and unpack the diversity of phenomena they are used to describe. Engagement with local context is essential to meet local expectations. If, indeed,

people generally see their donations as incurring a sort of obligation on researchers to respect their wishes; then how this obligation should be handled will depend on the type of relationship established. A variety of expectations cannot be addressed with harmonized consent sheets, universal information practices or one universal feedback policy. This does not mean that there is no potential room for making universal normative claims on other grounds; only that they should not be based on empirical claims about what 'all donors want'.

Commentators have suggested to adopt the term 'participant' rather than 'donor' to acknowledge the ongoing mutual nature of the relationship here described as established through biobanking and to avoid connotations to an over-and-done-with 'gift' [88]. We might, however, thereby overemphasise the element of participation. It is not an equal relationship and some donors will wish to limit their workload and obligations rather than enhance their influence on decision-making. Rather than emphasising *participation* I believe researchers should ask themselves what type of relationship specific donors have opted for when agreeing to participate. This essentially translates into a basic question: how might the biobank project express care towards donors and donor interests and reciprocate the intentions expressed through donations? As donor tissue increasingly feeds into global research projects with complex scientific and commercial interests at play, this question will prove more and more important. Universal informed consent standards or ethics policies will not address local expectations adequately, and therefore it is time to pay more attention to diversity, locality and context when deliberating biobank ethics.

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