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# Tissue donation to biobanks: a review of sociological studies

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## Abstract

Collections of human tissue (biobanks) are thought to be an essential resource for biomedical research. Biobanks, have however, been a source of debate in both bioethics and sociology. In recent years this theorizing has been supplemented with empirical research, including a significant body of qualitative research, into donors' experiences and attitudes. To date, this literature has not been synthesised. We report the findings of a review of qualitative literature regarding the ways in which lay people construct and experience the process of donation to biobanks. Our aim was to determine what the qualitative research literature tells us about the process of donating to biobanks, and how this can enrich existing insights from quantitative research and from theoretical sociology and bioethics. Qualitative research shows that donation to biobanks is a complex process shaped by donors' embeddedness in a number of social contexts; by complex relations of trust in biomedicine; and by the ambiguous status of human tissue. While these findings are theoretically and practically useful, current sociological theorizing is very general. A more detailed and nuanced 'sociology of biobanking' is needed, and this might be best achieved by exploring specific theoretical questions in a variety of biobanking settings.

## Background and rationale

### Background

In recent years, the focus of biomedical research has shifted from individual bodies and physical entities to studies based on networks of data and collections of tissue (Sleeboom-Faulkner 2009). Stored collections of normal and diseased human tissue ('biobanks') have therefore become an essential resource for medical research ('biobanking research') (Korn 1996). The blood, tissue (*e.g.* connective tissue), parts of organs or whole organs (referred to broadly as 'tissue') that make up biobanks may be removed from healthy donors, from patients in the

course of medical diagnosis or therapy, or during postmortem examinations. This provides a means by which characteristics of interest, such as anatomico-pathological abnormalities or genetic types (polymorphisms), can be correlated with disease aetiology, prognosis and treatment responsiveness.

### **Theorisations of biobanking**

Over the past decade, a large literature, both theoretical and empirical, has emerged around biobanking. Theoretical discussions of biobanking frequently take the form of ethical debates, many of which focus on the means of obtaining consent for the long-term storage and use of tissues, the management of donor (genetic) privacy, and the commercialisation and ownership of the tissue and the products of tissue-based research (*e.g.* Furness 2004, Savulescu 2002, van Diest and Savulescu 2002). Ethical disagreements frequently centre around the tension between individual autonomy and the ‘common good’—a tension which is seen to have particular salience in the context of biobanking because of the dependence of researchers upon entire communities (including healthy populations), many of whom are unlikely to benefit from the results of the research. Concern for donor autonomy has, however, recently been qualified somewhat by the recognition that autonomy is relational and that trust, solidarity and community should be taken into account when thinking about the ethical problems of biobanking and their possible solutions (*e.g.* Barr 2004, Hansson *et al.* 2006, Hoeyer and Lynöe 2006, Lipworth *et al.* 2006, van Diest and Savulescu 2002).

Sociologists have recognised that biobanks are political entities, created and maintained through numerous acts of policymaking and persuasion (Fletcher 2004). Much of the sociological literature has, therefore, focused on organisational and governmental motivations for establishing biobanks and the complex relationships between government, academic and commercial organizations, while critiques of the social organization of biobanks have tended to focus on the problems associated with the late-capitalist commodification or ‘marketisation’ of the human body and the formation of tissue-based economies, including potential effects on the sanctity of the body, human psychological development, dignity, wellbeing, agency and kinship. Such views of biobanking tend to translate into efforts to regulate science so as to reduce such commercially-driven opportunism and exploitation (Hoeyer 2007, Sharp 2007, Waldby and Mitchell 2006).

Attempts have also been made to theorise the actions and motivations of donors, many by reference to Titmuss’s (1970) account of blood donation in Britain in the 1960s in terms of the ‘gift’ and ‘gift relationship’ (Titmuss 1970). With respect to donors’ motivations, concern has been raised about the ways in which donors’ have learned to objectify and accept the removal of parts of their bodies to serve (more affluent) others (Scheper-Hughes 2001), as well as on the costs for individuals and the community of the public’s often unrealistic expectations of potential benefits (Petersen 2009). The latter are seen to stem, at least in part, from the tendency of government policies to utilise emotive language, such as the language of ‘public participation’, ‘altruism’ and the ‘gift’ in order to promote tissue donation (Tutton 2004). Recognition that donors may not be adequately informed and are potentially subject to manipulation has led some theorists to question traditional individualistic approaches to informed consent, and to emphasise the importance of community consultation and public

control of biobank resources (i.e. 'scientific citizenship') (Kaye 2004, Weldon 2004), thus creating a nexus between bioethical and sociological critiques.

### **Empirical research into biobanking**

While biobanking has been the subject of theoretical examination in both sociology and moral philosophy, over the past five years research into biobanking has taken an empirical turn. The justification for such studies has been that ethical and sociological theorizing is too far removed from social reality and that empirical ethics and sociology are crucial adjuncts to theoretical work (Kon 2009). Many of the empirical studies of biobanking have been quantitative, often in the form of large-scale surveys. Such surveys have been conducted with many 'biobank populations' including; contributors to twin registries (Toccaceli *et al.* 2009), biobanks in general practice (Treweek *et al.* 2009), obstetric and paediatric biobanks (*e.g.* Joseph *et al.* 2008, Neidich *et al.* 2008), and large-scale population gene biobanks (*e.g.* Kettis-Lindblad *et al.* 2006).

To a large extent, these surveys have done what surveys do best; that is, they provide statistical correlations between such things as participation rates and various demographic factors such as education, age, gender, socio-economic status, family history of disease and so forth (*e.g.* Chen *et al.* 2005, Joseph *et al.* 2008, Kettis-Lindblad *et al.* 2006, McQuillan *et al.* 2003). But these surveys have also provided an insight into donor understandings, values and experiences. While no formal meta-analyses of biobanking surveys have been conducted, some patterns have emerged from the published quantitative data on biobanks. First, there is a generally high level of public understanding of, and support for biobanking and a willingness to contribute to biobanks (*e.g.* Kettis-Lindblad *et al.* 2006, Nilstun and Hermerén 2006, Toccaceli *et al.* 2009). This support appears to derive from a number of motivating factors including altruism, 'pragmatism' (i.e. a desire to contribute to research advancements as part of a balanced relationship between participants and researchers) and personal benefit through, for example, access to research data (*e.g.* Joseph *et al.* 2008, Kettis-Lindblad *et al.* 2006, Neidich *et al.* 2008, Toccaceli *et al.* 2009).

While most surveys suggest that people want to be asked for consent to the storage and use of their tissue, there is a general willingness to give open-ended consent (*e.g.* Kaphingst *et al.* 2006). At the same time, however, there are concerns, particularly about confidentiality, genetic discrimination and potential misuses of tissue (*e.g.* for eugenic research) (*e.g.* People Science and Policy Ltd 2002), and there is an expectation that access to, and uses of, tissue is transparent and controlled by institutional ethics committees, which are generally more highly trusted than, for example, political or commercial organizations (*e.g.* Chen *et al.* 2005, Joseph *et al.* 2008, Kettis-Lindblad *et al.* 2006, Treweek *et al.* 2009). In this regard, several surveys have demonstrated that the public is not *a priori* against commercial access to tissue, and that concerns about commercialization, while present, do not generally preclude participation, particularly if benefits will be publicly shared (*e.g.* Jack and Womack 2003, Stegmayr and Asplund 2002, Treweek *et al.* 2009).

While these quantitative studies have generated important data, there is widespread acknowledgment of the limitations of 'closed' response categories for questions surrounding donors' attitudes and experiences (Toccaceli *et al.* 2009) and of the need for a deeper and more

nuanced understanding of donor values which can best be achieved using qualitative methods (e.g. Dixon-Woods *et al.* 2008). This is in keeping with the more general recognition within empirical bioethics and sociology that qualitative research is important because it provides the richness and detail necessary for the development of a nuanced understanding of social phenomena (Mason 2002).

While qualitative research has the potential to challenge theoretical assumptions and assist with policymaking, it can be difficult for theorists and policymakers to access and make use of this information since studies tend to be published in isolation, making reference to only a selected sample of similar studies. Moreover, isolated studies preclude the drawing of higher-level theoretical and practical conclusions from existing studies. We set out, therefore, to systematically review the published qualitative research on lay conceptualisations of biobanking and the donation process with the aims of: 1) determining what the qualitative research literature tells us about how lay people construct and experience donation to biobanks, and what this adds to existing quantitative research, 2) synthesising this information in order to generate higher level theoretical and practical conclusions, 3) making this information accessible and useful to theorists and policymakers and 4) identifying any gaps in existing knowledge where further research is needed.

## **Method**

### **Data collection**

In late 2009 and early 2010 we undertook a search of Medline, PsycINFO, and Sociological Abstracts databases using the search terms 'biobank', 'tissue bank', 'tumo(u)r bank', 'gene bank', 'organ bank', 'DNA bank' (and other synonyms of 'bank' such as 'collection', 'repository', 'database' and 'retention'). These terms were combined with terms relevant to a number of qualitative methodologies (such as 'grounded theory', 'ethnography', 'case study', and 'narrative') and common qualitative data collection techniques (such as 'interview', 'focus group'). The search was undertaken in two stages: 1) initial database search 2) secondary search of the reference lists of papers identified in stage 1. Since biobanking has only recently emerged as a topic of interest, no time limit was placed on the search and we used the origins of the databases as our date limits. As proposed by Sandelowski and Barroso, our aim was to recall as many papers as possible (that is, we sought sensitivity more than specificity), and to this end we employed a dynamic and iterative searching strategy, following leads to maximise the inclusiveness of our search (Sandelowski and Barroso 2007).

A study was included if:

- at least some of the study participants were lay people, with lay people defined as anyone who was not a healthcare professional, researcher or policymaker;
- the aim of the published study was (at least in part) to explore how/what lay people thought about biobanking and the process of donation. We therefore excluded discourse analyses of policy documents and studies of professional perspectives even though they were qualitative.

- the data collection and analysis method were reported as qualitative by the authors.

We excluded studies about biobanks that were established for educational or therapeutic (rather than research) purposes (*e.g.* blood banks, bone marrow banks, bone banks, cornea banks). We also excluded studies of collections of reproductive tissue (gametes, embryos) since the scientific, ethical and legal issues raised by these kinds of biobanks are distinct and we excluded collections of tissue intended only for genealogical research. We also excluded reports of research that had not been published in the academic literature. We identified 36 relevant articles published between 2002 and 2009 (see Table 1-**Refer to pages 25 onwards**).

### **Appraisal**

All papers were independently reviewed and analysed by two authors (WL and RF). Excluding papers on the basis of methodological quality was made difficult by a frequent lack of detail in reporting methods and methodology, and we faced the well-recognised epistemological challenges in attempting to define quality criteria and critically compare different qualitative methodologies (Kuper *et al.* 2008). As our aim was to find maximum variability and make a useful interpretation of the literature, rather than to identify the ‘best’ publications on the topic or carry out a formal meta-synthesis of one particular question, we decided, as Thomas and Harden and others have done (Atkins *et al.* 2008, Thomas and Harden 2008), to include all articles that were deemed worthy of publication in peer-reviewed journals or edited collections of papers.

### **Research questions and data analysis**

Qualitative studies were treated as primary data sources. In reading each study, we asked the following open-ended questions:

- 1) How do the authors justify their methodology?
- 2) What does the study tell us about the ways in which lay people conceptualise and experience biobanking and the process of donation? What does this add to survey research?
- 3) What theoretical (ethical and/or sociological) and practical conclusions do the authors draw from their results?

### **A note on data presentation**

The referencing system used in the results section is different from the introduction and discussion in that article citations are numbered according to their alphabetical order in Supplementary Table 1. A full citation for each may be found in Table 1. This form of referencing is aimed to facilitate rapid reference to the table so as to contextualise the authors’ arguments and findings.

## Results

### Characteristics of studies

A total of 36 qualitative studies were included. In most studies, sampling was purposive and aimed at maximal variation rather than population representativeness. Populations studied included people who had previously donated tissue for research, people who were in the process of considering donation and people who had never before been asked to donate or considered the issues surrounding biobanking. In some cases, donor proxies were studied, such as parents, who were asked to discuss their decision to donate their children's tissue and family members who were asked to discuss their reactions to non-consensual post-mortem organ retention. Qualitative studies examined the full range of biobanking practices. Tissue types included collections of blood from healthy donors, collections of diseased tissue (especially tumours) removed during the course of diagnosis or treatment, and collections of tissue removed during postmortem examination. Some of the biobanks studied were earmarked for research into specific diseases (or groups of diseases), while others had broad and open-ended research briefs (the latter was particularly the case for population biobanks). In keeping with the variety of biobanks studied, donor populations of interest included entire populations of countries or geographical regions (population biobanks), people with a particular disease and/or risk factor, and people with particular demographic characteristics.

Research methods most commonly involved semi-structured interviews and/or focus groups with a few studies performing ethnographic observation of public deliberations or consent procedures. As discussed above, few papers went into detail about their methodological, epistemological or ontological assumptions. Data analysis was most commonly described as inductive and thematic and used one or another variant of constant comparison to develop and analyse themes. Research questions were usually open-ended, with the aim of examining some combination of donors' attitudes, experiences, and justifications for participation or refusal to take part in specific kinds of biobanking.

**Table 1 (pages 25 onwards)** summarises the characteristics of included studies.

### Justifications for the research

Justifications given for studying biobanking as a topic were fairly uniform, irrespective of the authors' discipline (bioethics, sociology, anthropology, public health, pathology, etc). General arguments for exploring the topic included the importance of biobanks as scientific resources, particularly in the context of advances in genomics and 'personalised medicine', as well as the need to pay attention to an area that has been relatively neglected within research and public health ethics, in which obvious historical abuses have occurred and in which social criticism and legal scrutiny seem to be rapidly increasing [1,3,4,7,11].

Justifications given for studying the topic *empirically* were also fairly uniform. The most common justification was the need to take seriously the ethos of ‘public engagement’ ‘community consultation’ and ‘deliberative democracy’ so as to identify and explore any disjunctions between public opinion and current biomedical practices, laws and policies and to include public views in policy debates and legal resolutions [5,8,12,22,25,31,34]. Another common justification was the need to explore differences among subsets of lay populations and to compare the perspectives of the lay public and biomedical or bioscientific professionals [1,8,13,22]. More generally, it was argued that there is a need to modulate the ‘activist’ tendencies of those who have begun ‘speaking for’ those who contribute tissue for research purposes, and that we need to avoid making assumptions about public views on the basis of isolated incidents or regulatory trends [5,33]. More specific justifications for empirical research into biobanking included the need to empirically explore public attitudes towards consent, personal benefits, feedback of results, commercialisation and donor privacy [1,2,3,4,7,9,13,26,27,32].

A number of scholars emphasised the problems associated with discussions of biobanking that are dominated by abstract theories and disconnected from ‘real-world’ insights. Organising concepts, such as ‘gift’ and ‘participation’—concepts that are often taken for granted in theoretical discussions of organ and tissue donation—were seen as worthy of empirical investigation [2,4]. Trust and perceptions of risk were also seen as issues demanding detailed empirical interrogation—including taking a ‘practical view’ of trust with a focus on the sorts of evidence that people require in order to place their trust well [23], and considering the possibility that tissue donors might have complex relationships with risk than are evident in typical arguments about the ‘risk society’ [4]. Along similar lines, it was noted that notions of ‘benefit’ also demand empirical exploration, given that there is likely to be cultural variation around what benefits are (*e.g.* monetary benefits, health benefits) and how they can be delivered—expectations that are, in turn, closely linked to the promises that are made by scientists [12].

A number of researchers also spoke of the need to empirically interrogate bioethical analytical frameworks [4,14,17,18]. More specifically, several authors noted that ‘biobanking ethics’ is a power-laden and socially constituted discourse that needs to be situated and analysed in its socio-historical context and that there was a need to pay attention to ‘ethicality’—the situated, specific and experiential ethics talk of citizens embedded within socially and historically constituted life-worlds [4,9,14,17,18,30]. And even where bioethical frameworks were seen to be appropriate, it was recognised that empirical research is needed for bioethical principles to be put into practice so that the maximum good can be done while minimising infringements of autonomy, integrity and justice [9].

While few authors made a clear distinction between the need for qualitative or quantitative research, there was recognition that qualitative research was needed in order to explore the

context of answers to survey questions [23]; to explain apparent paradoxes (such as surveys showing high levels of concern in the context of almost universal agreement to donate) [13]); to open up the 'black box' of donor decision-making [13,16] and to explore the various 'subject-positions' that people assume in the course of a discussion about biobanking [35]. More generally, it was argued that in-depth qualitative inquiry was needed in order to display ethnographic sensitivity towards the dilemmas and values of social agents—i.e. to explore the 'social life of moral concerns' [18,19].

## **Key findings of qualitative studies**

### **1. Qualitative findings that confirm, refine and qualify the results of surveys**

To some extent, the findings of qualitative studies—particularly those that were not theoretically oriented—simply confirmed, qualified and refined the results of surveys. Given space limitations, these findings are summarised briefly here.

#### ***Knowledge of, and support for biobanking***

In keeping with the findings of surveys, lay people generally appeared to have a good understanding of the basic principles of biobanking research and the capacity to understand information provided to them [3,11,22,28,29]. Qualitative research also showed that the lay public was generally supportive of biobanking, optimistic about its potential, and willing to participate [7, 8,9,31 34]. Qualitative studies also confirmed survey findings by suggesting that people had many reasons for donating to biobanks, including altruism [4,7,8,9,10,19,24,27,28], reciprocity [2,5,10,24,27], and the expectation of personal benefit through new therapies [2,9,11,27,28], direct feedback of study results [4,8,9,21,22], the clinical encounter surrounding donation (*e.g.* a test or physical examination) or monetary compensation [10,22,25,28]. At the same time, others justified their participation on the basis that they simply did not mind donating, particularly when there was so little (perceived) cost or risk involved as compared, for example, to participation in clinical trials [4,13,14].

#### ***Concerns about biobanking***

For the most part qualitative studies corroborated survey findings showing that people recognised at least some potential risks associated with biobanking. The major concern to emerge inductively from qualitative research was the potential for breach of data security and release of personal (genetic) information to third parties including the police, insurance companies and employers, with resulting stigma and discrimination [3,8,9,11,21,22,23,25,27,31,35]. But concerns about confidentiality were qualified: many did not consider information to be sensitive or delicate, and privacy concerns did not always emerge as

a dominant theme in interviews and focus groups [9,28,34]. Indeed, some lay people expressed concern that excessive focus on donor privacy might impede medical research [21,31]. Also, as will be discussed below, few expected to come to harm as a result of their participation.

### ***Specific preferences regarding the governance of biobanks***

As has been reported in many surveys, most qualitative studies have found that, while people had concerns about consent procedures [11,25,28,31]), most people wanted to be asked, at least initially, about use of their tissue in research and wanted to be told whether the tissue would be accessed in future for different research purposes, including commercial research [1,5,8,11,13,22,31,33]. But while people wished to be asked for permission to store their tissue sample, they did not necessarily want large amounts of detailed information about the biobank [2,6,16,18,19,32,35]. Indeed, observations and discussions of consent processes showed that, while people wanted to be asked, they did not seem particularly interested in the information they were offered during the consent process [6,16,18,19]. Furthermore, few people demanded recurrent, project-specific consent and few wished to place limits on the uses to which their tissue could be put [3,19,31]. In contrast, there were mixed views as to whether people should be able to withdraw their tissue [3,21,22,31].

With respect to the feedback of information, there was a widespread expectation that, as a fair exchange for participation, donors should be given general feedback on the progress of the research and provided with aggregated results [1,3,8,9,11,21,27,28]. In contrast, whether donors should be given personal results that may have clinical implications for them or for their families was a source of much greater disagreement among lay donors [2,3,7,9,11,21,22,26,27,28].

When asked to think about access to biobank resources, people generally had little concern about publicly-funded academic researchers accessing their tissue and personal information [3,11,24,28]. Slightly greater concern surrounded access by non-academic, government-funded researchers [3,11] while most concern surrounded access by commercial researchers. Few studies, however, found that donors believed that commercial researchers or entities should be completely prohibited from accessing public biobanks, provided that the benefits of their research would be shared [3,4,8,11,12,15,18,23,24,28,30,34]. And, notwithstanding theoretical sociological concerns about commercial exploitation of tissue donors, very few people expressed an interest in owning their tissue or benefiting financially from the outcomes of the research [1,11,12,18].

Importantly, qualitative studies also made it clear that there is a public expectation that all biobanks—whether public or private—should have in place formal mechanisms (including institutional review committees and public consultation) for controlling biobank resources and for ensuring that research is appropriate and that benefits of research are shared [7,11,12,18,23,24,31,35]. Finally, it was recognised that whatever group was ultimately responsible for the establishment or functioning of a biobank, this group needed to be legally accountable as well as open, empathic and responsive to donors' and the general public's concerns about the ways in which biobanks were being administered or utilised [8,11,33].

## **2. Qualitative findings that contribute new insights to ethical and sociological theory**

While qualitative research provided useful confirmation and refinement of quantitative studies into biobanks, the great strength of these qualitative studies lay in their capacity to enrich sociological theory. Observations of particular theoretical relevance included the findings that:

- 1) Donation always occurs in a social context;
- 2) People are aware of the potential risks of biobanking, but usually do not expect to be harmed;
- 3) People do not always consider tissue to be 'sacred' or a part of their identity.

### ***The social context of donation***

Qualitative research demonstrated that donations are always socially situated and that the decision to donate is a relational activity, whether locally, civically or societally. People could, for example, experience pressure to donate from family members or as a result of their respect or liking for a particular clinician or researcher [2,4,9,10,22,36]. In this regard it is worth noting that people generally appeared to understand the necessity for clinicians to sometimes assume dual roles as both an 'instrument of care' and a recruiter for research [2]. Qualitative studies also found that perceived membership of a disease community or an ethnic community could have a powerful influence on the decision to donate, as people considered themselves to be united by a sense of common purpose, in which values and interests were shared and members of the community were to be trusted [5,27]. Finally, qualitative research demonstrated that people could also be motivated by a broader sense of citizenship to contribute to population level biobanks, although this motivation appeared to be strongly contextual (*e.g.* such expressions were most common in welfare states with public health systems) [16,19,35].

### ***The importance of trust in modulating perceived risk***

In addition to elucidating the specific concerns that people had about biobanks and about biobanking research, qualitative studies provided an explanation for the apparent paradox, evident from quantitative studies, that there is no simple linear association between perception of risk and (un)willingness to donate. First, as described above, qualitative research demonstrated that people were willing to subject themselves to risk because of a commitment to scientific progress, reciprocity or the expectation of personal benefit. Second, qualitative studies repeatedly demonstrated that, while aware of the potential risks of biobanks, people generally had a high level of trust in biomedical researchers and research institutions and did not expect to come to harm. Indeed, in some studies, recognition of potential risks of donating to biobanks emerged only after persistent enquiry [3,11,21,24,27,32].

In some studies, people explicitly described having high levels of trust in biobanking researchers, while, in other studies, expressions of trust were less direct, but suggested by a belief that scientists would stay true to their promises, in the sense of both generating new epidemiological insights into disease and treatment [4,5,11,21,27,32,34] and complying with ethical and legal guidelines and taking steps to avoid causing harm [3,25,27]. Trust was also evident in the finding (discussed above) that people did not demand recurrent, project-specific consent, excessively rigid regulation or complete control over the uses of their tissue.

The trust that donors or potential donors had in biobanking researchers appeared to be based on either an explicit assessment of the risks and benefits of biobanking and the trustworthiness of researchers or a relatively unreflective 'faith' in researchers or the scientific endeavour [4,5,25]. Where people were able to explicitly articulate the basis of their trust, it was clear that their expectation of protection stemmed largely from the reassurance that they felt from biobanks being embedded in public research institutions with oversight processes [5,21,24,31]. (Interestingly, individual scientists were sometimes viewed as less trustworthy than the public organizations in which they carry out their research [1,4,24]). Indeed, it was clear that trust stemmed largely from the expectation of some form of public oversight and control of the biobank, either through institutions or legal and health systems as a whole [18,34].

Finally, the salience of trust was evident in the fact that, in the relatively rare cases in which people did refuse to donate, they did so not so much because of the potential risks of donation, but because protection of donors could not be assumed or assured [2,3,9,11,14,20,25,33]. Not surprisingly, trust was found to be low among indigenous groups [30] and in populations whose trust had previously been breached (*e.g.* parents whose children's organs had been retained without consent) [33]. Instances of overt mistrust of biobanks and biobanking researchers were, however, extremely uncommon, suggesting that, despite the 'scandals' that form such a large part of the ethical and sociological literature on tissue donation, trust in the entities carrying out biobanking research is often high and stable.

### ***The status of tissue and personal information***

The third observation of theoretical relevance was that most lay donors did not seem to be deeply concerned about personal 'defilement' or loss of identity because tissue was 'sacred' or intrinsic to the self. Indeed, diseased tissue (such as tumour samples) was often seen as a completely foreign and unwelcome invader, while other types of tissue, such as placental tissue, were seen as 'waste material' of no particular significance (except perhaps to specific cultural groups) [2,5]. Interestingly, even DNA was not always seen to hold particular value except insofar as it could be misused, leading to discrimination [4,23]. In this regard, it was noteworthy that some people attached more significance to personal information than to tissue samples (although it is not clear to what extent this stemmed from a poor understanding

that tissue can be a source of personal information) [2,9,15,18,19]. Such findings do, however, need to be qualified by the fact that most qualitative studies have been conducted in Western or Westernised populations, and not in indigenous or migrant communities where tissue might hold a greater significance [29]. Moreover, qualitative research has shown that even in Western populations, different kinds of tissue (*e.g.* whole organs) hold more value than other tissues and the value attached to tissue could change over time and differ in different contexts [1,5,33]. Interestingly, the qualitative interview itself sometimes made donors more cognisant of the significance of their tissue, as they learned more about the potential risks and benefits of biobanking research [17].

### **Theoretical and practical conclusions drawn from the studies**

In addition to being interested in the results of qualitative studies of biobanking, we were also interested in the more abstract theoretical and practical conclusions drawn by qualitative researchers, with a view to comparing these with *a priori* theoretical and policy discussions of biobanking. In this regard, a key finding was that the majority of authors of qualitative studies did not reflect theoretically on their findings, and those who did focused on a similar—albeit differently expressed—range of theoretical issues and came to similar practical conclusions.

### ***Authors' reflections on the social context of donation***

A number of authors attempted to make theoretical sense of the social context of donation, Haimes and Whong-Barr [13,14] argued that it is better to use the word 'participation' than 'donation' to reflect what is a highly social process with multiple meanings [13,14]. They argued that it is too simplistic to think of there being just two groups: donors and non-donors. Rather, there are varying levels of donation and non-donation and there are different ways that individuals donate or do not donate. Whether or not people agree to donate, they are constructing themselves as 'ethical beings' and trying to demonstrate that they are 'being ethical', however this might be defined in the specific context in which the act of donation is taking place.

Drawing on Haimes and Whong-Barr's ideas, Hoeyer and colleagues argued that the intersubjective 'transaction' that occurs when blood or tissue is donated in the clinical setting needs to be viewed as a moral negotiation between a donor and a health care practitioner [16,17,19]. This, they argued, might explain why donors lack interest in the consent form, because in the clinic, people adopt practiced roles in which they enjoy the care of health professional and wish to transfer responsibility for decision-making to the medical profession and to the state. And while this may appear passive, it remains an expression of embodied agency and ethical communication (as well as perhaps an act of resistance to an imposed sense

of responsibility for the outcomes of research). The act, therefore, has 'intersubjective texture' in that, the 'personhood' involved in making the decision is a transitory 'we', not an autonomous 'I'. To explain why donors may still wish to be asked for permission to store tissue even if they have little interest in consent forms, Hoeyer and colleagues drew upon the Foucaultian idea of 'practices of the self' (Rabinow 1997), according to which it 'feels right' to be given a choice and to present oneself as a responsible actor, without the implications of the choice and responsibility necessarily being considered in depth. They concluded that, when understood this way, we can recognise that apparently uninterested individuals are also responsible actors, but that their concern is more with public oversight and knowledge than with informed consent.

Haddow [10] focused on the familial context of some donations, concentrating her gaze on the finding that familial recruiting is often carried out by women. She concluded that, despite the rhetoric of fluidity in sociological theorising of the family, in biobanking research there remain traditional expectations of female responsibility for maintaining family relationships. Her work also examined the way in which people participate in biobanking for the good of future generations, arguing that there is a temporality embodied in biobank participation, which acknowledges the impact of the past on the present (though the conduit of presumed biological connectivity) but looks to the future in order to maintain a family lineage that avoids biological harm.

Other research emphasised the importance of the norm of reciprocity in motivating people to donate. Hoeyer, for example, [16] noted that this norm is likely to have particular salience in welfare states (such as Sweden) which emphasise self-discipline, solidarity, trust in science, right and duties, and in which patients combine their personal health projects with a wish to respond to societal efforts undertaken on their behalf. Combining several theoretical concepts, Hoeyer suggested that donation is an act in which the donor not only wishes to reciprocate for what he/she has received in the past, but also attempts to convey the wish that the rest of the world will feel obliged to do the same. According to this view, the donation of blood and the messages conveyed at the interview can be seen as symbolic exchanges emphasising a commitment to honesty and a shared future. Linking this to donation as an act carried out by an individual within an intersubjective context (discussed above), Hoeyer pointed out that the webs of mutual obligation that create a sense of societal duty are part of a personal frame of experience (including previous encounters with the system), personal hopes and objectives (*e.g.* a health examination); and direct intersubjective negotiation. Reflecting once again on donors' lack of interest in consent forms, Hoeyer suggested that this might be a manifestation of a valid desire to trust the logic of mutual obligations embedded in the state-citizen relationship, in which authorities, rather than patients, take responsibility for scientific enterprises [18].

Viewing societal solidarity from another angle, several authors focused on the ways in which ‘public’ and ‘scientific’ worlds overlap in the context of biobanking. Dixon-Woods et al [5] argued against the idea of there being a large gap between the social worlds and discourses of the ‘public’ and ‘bioscience’ and argued that we should think instead about ‘hybrid social worlds’ in which the boundaries of research are porous and in which the agendas of ‘patients’ and ‘scientists’ are mutually influential—in part through the exchange of rhetoric and imagery relating to research and research materials, as well as the material itself [5]. Haddow et al [11], came to a similar conclusion, arguing that similarities in attitudes between public and professionals regarding a population biobank are indicative of ‘non-codified knowledge’ crystallising around a shared area of relevance and that there is a common stock of knowledge to be drawn upon in discussions about ethical, legal and social issues such as biobanking [11]. In this regard it is noteworthy that they and others suggested that the supposed lay-expert knowledge divide exists not so much between the public and scientists, but between the public and ethicists and other ‘advocates’ who attempt to speak on their behalf [5,11,33,34].

Recognition of the importance of social exchange led several authors to suggest that more attention needs to be paid to ways in which this social system (which is based on both trust and solidarity) can be sustained, including providing donors with tangible benefits (*e.g.* health checks, or feedback of results) and focusing on the ways in which society organises and structures its health and welfare systems so as to ensure that everyone benefits equally from biobanking research (particularly in the context of commercialisation) [4,12,24]. Given the emphasis on the commodification of the body in recent decades, it is noteworthy that no authors argued for the establishment of new property rights and it was argued that property-based approaches would obscure the need to focus on the public and communal nature of research and to ensure that benefits are shared equally [12].

Not all authors, however, were equally convinced by findings suggesting a strong intersubjective bond or sense of solidarity among donors, researchers and health professionals. Rather than speaking of communities bound together through biobanking, a number of researchers emphasised the individuality of each donor or donor community and the wide variety of ways in which individuals and communities constructed themselves in discussions of biobanking. This was framed in a number of ways: donors were seen to be constructing themselves as ‘ethical beings’ acting in different, but equally morally acceptable ways [13,14]; as adopting different ‘subject positions’ and as drawing on a variety of ‘discursive repertoires’ within discourses of participation [35] and as having different ways of constructing their social identities [29]. While it was acknowledged that all of these processes take place in the context of groups, it was also emphasised that there was little reference to over-arching principles, norms or rules about ethical conduct [13,14]. This ‘situated ethicality’ was seen to be particularly evident among indigenous communities, the narratives of whom exhibited a critical awareness of their situatedness [30].

A number of authors also displayed overt scepticism about the extent to which social encounters were truly empowering. It was, argued, for example, that in certain intersubjective (*e.g.* clinical) contexts, people may donate (or refuse to donate) fairly unknowingly [4] and that a strong intersubjective bond could create a relationship of dependence, which makes refusal to donate tantamount to refusal to give a gift, which is to reject the bond of alliance and commonality [16]. At the societal level, it was argued that notions such as ‘genetic solidarity’ may be overlaid in discussions of research participation, and that the extent of lay people’s uncertainty about participation might be obscured by the emphasis in the sociological literature on lay knowledge/expertise and by equating motivations to donate tissue for research with motivations to donate blood for transfusion [4]. Similarly, others argued that institutional discourses of active participation, which draw on the language of active citizenship and community involvement, are both ambiguous (in that people remain uncertain and distrustful) and ethically problematic (in that they are exemplary of neoliberal governmentality, governing individuals through their regulated choices) [35]. Finally, it was noted that the degree of solidarity is likely to depend upon the political context (*e.g.* stronger in a welfare state than in an individualist society) [16,34] and on the extent to which traditional notions such as the gift relationship are being eroded by commercialisation and associated donor expectations of benefit [12].

### ***Authors’ reflections on trust as a mediator of risk perception***

While a small number of authors argued that there are low levels of trust in biobanks and that this threatened their viability [8,23], most concluded that there are high levels of trust in biobanks and biobank researchers and that this is an important mediator of the decision to donate. Indeed, for some authors, this challenges the ‘social unease discourse’ in which actual or potential tissue donors are assumed to be either untrusting and suspicious of biomedical research [1,3,4,5,6,24].

Two practical conclusions of this work on trust in biobanking feature in the literature. First, many authors argue that, given these high levels of (warranted) trust, and donors’ lack of interest in formal and recurrent consent processes, consent should not be excessively onerous. Thus, while initial consent should be obtained, highly detailed or recurrent, project-specific consent should not be imposed unless participants specifically request it [1,2,7,24]. Put another way, more consent is not necessarily better consent and it is legitimate for donors to not want to be fully informed about biobanking research, but rather to participate in a moral exchange characterised by high levels of trust [2,16, 24]. A second, related, practical conclusion is that, while trust might be warranted, it cannot be taken for granted since trust is an emergent property of good social relationships that are built up over time [23]. Suggestions offered by researchers for avoiding ‘doing violence to trust’ [5], included; training researchers to be more sensitive to ethical issues; making transparent the identities of researchers and any commercial

spin offs of research; allowing people to communicate with researchers (perhaps via health professionals) so that their values can be heard and respected; providing feedback on the progress and results of the research; and acting with social responsibility in distributing the benefits of research [1,3,5,8,9,19,24,25,26,29]. Institutional arrangements may also build trust by focusing on protecting human subjects through independent institutional committees and limiting the power given to any one group [2,3,11,19,21,23,24,31]. While it was noted that such measures might be enacted spontaneously by biobankers who recognise the preciousness and fragility of their 'warrants of trust', many authors saw the need for at least some external independent oversight of biobanking organisations (including lay representation despite the difficulties inherent in such inclusiveness) and strong legislation that is responsive to the findings of public consultations [2,5,11,13,14]. At the same time, however, a number of authors cautioned against excessive demands for transparency and external regulation of biobanks, on the grounds that this might not necessarily be conducive to trustworthy behaviour, nor a guarantee of high levels of public trust [2,11,19,23,24].

The view that the public trust in biobanks is warranted and that the focus should be on maintaining this trust was not, however, an entirely uniform conclusion. A few authors, for example, questioned the assumption that trust was reasoned and/or justified, arguing that trust may be based on unwarranted faith, deference, manipulation or misunderstanding. In other words, a few authors saw trust, and the associated 'political economy of hope' (Novas 2006) as naive and unwarranted rather than sophisticated and wise. Not surprisingly, these authors came to very different practical conclusions regarding the governance of biobanks, noting that trust has a complex relationship to informed consent and legislation, and that caution is needed when responding to donors' apparent readiness to transfer their trust to scientists and health professionals [4,5,11].

### ***Authors' reflections on the status of tissue***

The third theoretical area that was given attention by authors of qualitative studies was that of the ambiguous status of human tissue. Dixon Woods et al [5] argued that tissue samples donated to biobanks are 'boundary objects' which can be recognised simultaneously as 'waste' and as precious work objects—precious in the sense that they promote in donors a sense of being embedded in a community of 'biological citizens' (Rose and Novas 2005). Hoeyer [17] used the ambiguous status of tissue to explain how people who profess to not be interested in consent forms become somewhat anxious when asked to discuss donation in the context of a qualitative interview. He concluded that, in the context of a clinical encounter, the blood that is donated is 'only blood', but during an interview, in which people are forced to reflect on the ways in the blood may be (mis)used, the blood comes to be seen as 'part of' the person, integral to his or her personhood and agency. In another paper, Hoeyer [15] argued that the ambiguous status of tissue (as well as that of personal information) can be understood with

reference to the idea of 'the cultural biography of things' according to which different meanings are ascribed to objects throughout their lifetime. According to this view, human tissue passes through different spheres of exchange and can thus be viewed as being 'beyond trade' at one point and 'just a commodity' at another. In the case of biobanking, therefore, donated blood is first conceptualised as a substance, as part of the person which is non-tradeable and provided as a gift with the expectation of improved health in return, while in the course of commercialised research, however, blood may be transformed into information which can be patented and sold.

## **Discussion**

### **General observations**

Qualitative enquiry, and theorising from qualitative findings, can provide a rich and nuanced picture of the ways in which people understand, experience and construct the process of donating tissue to biobanks. It is clear from qualitative research that donation to biobanks is simultaneously intersubjective, familial, communal and societal; is a process involving complex relations of trust which powerfully mediate the perception of risk and the desire for personal control; and is shaped by the many ambiguous meanings ascribed to human tissues, organs and the body more generally. Moreover, in each of these general approaches to biobanking lies a great deal of complexity and disagreement among people with slightly different theoretical orientations.

A number of general observations of relevance to sociology can be made. First, in the existing qualitative literature, many social theories have been used to understand and explain the context and process of biobanking research. While not all authors situated their work theoretically, those who did made reference to wide variety of social theories and theorists. To give a few examples: those attempting to explain people's general willingness to donate to biobanks drew upon theories such as Putnam's norm of generalised reciprocity (Putnam 2000), Titmuss' and Mauss' conceptions of gift relationships (Mauss 2000, Titmuss 1970), Rose and Novas' 'biological citizenship' (Rose and Novas 2005) and Novas' 'political economy of hope' (Novas 2006). To explain why donors might wish to be asked for permission to store tissue, yet show little interest in consent forms and resist taking ultimate responsibility for their decisions, a number of theories were referred to including Rose's idea of informed consent as part of a biopolitical development (Rose 1999) and Foucault's 'practices of the self' (Rabinow 1997). Efforts to account for different styles of participation in biobanks, in the absence of any overarching ethical system, were supported by reference once again to Foucault's 'practices of the self' (Rabinow 1997) as well as to Giddens' (Giddens 1991) and Bauman's (Bauman 1993) accounts of the individualistic 'life politics' of late modernity. Authors wishing to criticise what they perceived to be an excessive focus on consent, and a failure to account for high levels of

public trust, drew upon Power's critique of an 'audit society' (Power 1997), Wolpe's critique of a consumer driven culture in which patients are viewed as customers to be wooed (Wolpe 1998), and O'Neill's ideas about the importance of ensuring genuine institutional trustworthiness rather than focusing entirely on autonomy and shallow accountability (O'Neill 2002). Finally, differential and shifting attitudes towards blood, tissue and personal information were explained with reference, for example to Star's idea of 'boundary objects' (Star and Griesemer 1988) and Mauss' idea that, human beings (and their body parts) might be viewed as subjects only, not to be consumed (Mauss 1985 [1938]).

This variety suggests that there is no single sociological theory or concept that can account for the process of donating to biobanks. Rather, any 'sociology of biobanking' would need to be nuanced and to draw upon a variety of social theories in order to account for the donor population (*e.g.* people with a serious illness vs. healthy donors vs. an ethnic group), the type of tissue being donated (*e.g.* tumour vs. blood vs. DNA) and the context of the donation (*e.g.* recruiting patients in a medical clinic in a welfare state vs. a public drive for a commercially-owned biobank).

A second general observation is that there is a disjunction between the concerns of tissue donors and the concerns of many sociologists, with many academic critiques focusing almost exclusively on issues related to tissue ownership, biopower, commodification of the body and the formation of tissue-based economies. While lay people do have some concerns about these issues, for the most part people are not *a priori* against commercially-funded research, particularly if they can be reassured that the relevant scientific questions will be asked and that benefits will be publicly available. Moreover, the results of qualitative studies suggest that few people feel a strong sense of ownership of their tissue. And where an expectation of reciprocity does emerge (*e.g.* in the expectation that results will be made available), this appears to be based on a generalised reciprocity centred on social exchange rather than on any expectation of direct personal (*e.g.* pecuniary or even non-pecuniary) reward. This is not to suggest that such theoretical concerns are unimportant—indeed, qualitative research makes it even clearer that such awareness is crucial for ensuring that donors are not exploited and that their generosity and trust are warranted—rather, it is important to ensure that these concerns do not obscure other issues that are important to tissue donors.

The final general observation is that, despite the apparent theoretical complexity of biobanking, qualitative and quantitative studies of donation to biobanks, be they theoretically-informed/reflective or not, reach remarkably similar conclusions about the governance of biobanks. First, there is broad agreement that consent is not a panacea. While potential donors should always be asked for their permission in a manner that is sensitive to specific vulnerabilities and desires, it is also generally agreed that people should not be forced to absorb large amounts of technical information or to give recurrent, project-specific consent unless they so desire. Second, there is also general agreement that rigorous oversight of

biobanks is crucial and that this oversight should combine public control and oversight by institutional ethical and scientific review committees. Finally, while the practical demands of distributive justice are complex and unclear, it is generally agreed that the benefits of biobanking research should be shared. In other words, there is general agreement that it is important to take seriously the results of research, which consistently reveals high levels of trust; a desire for, or expectation of, reciprocity and an expectation of public involvement and benefit-sharing. While this convergence at the practical level provides reassurance that such practical approaches have a solid empirical basis, it also raises questions about the value of detailed sociological theorising in this context (and in the context of technological innovation more generally), and whether more practical use can be made of the detailed insights derived from sociology.

### **Future directions**

While qualitative research has provided many important insights into biobanking, such research is, however, unavoidably limited by the difficulties in drawing generalizations from studies of small and disparate groups, and it seems likely that existing qualitative research has largely achieved its potential in this regard. We would suggest, therefore, that future qualitative research should focus on groups that are currently under-represented and under-served (particularly indigenous and migrant communities)—especially given that these populations are so often of scientific ‘interest’ and that it is within these groups that issues regarding the commodification and the status of tissue are most likely to emerge. We would also argue that future research needs to move beyond its current preoccupation with the initial decision to donate, and its tendency to focus on people who have not (yet) donated tissue and are thus considering the issues only hypothetically. Although this is understandable, as most biobanks have been established within the last few years, as time passes, it will become possible—and essential—to focus on the ongoing experience of having one’s tissue stored in a biobank, with a view to determining whether the findings summarised here retain their salience and appropriateness. Finally, we would argue that certain kinds of organ/tissue donation might raise unique issues which would warrant further qualitative exploration. The donation of whole brains, for example (‘brain banking’) may be associated with greater repugnance than would donation of other kinds of tissue.

With respect to future empirically-informed theoretical work, we would argue that such research needs from now on to be more focused. Rather than taking an open-ended approach and then trying to apply theory to emergent data, it may be better to focus future empirical research on specific theoretical questions in specific contexts. This is not intended as a criticism of existing empirical research—in a sense what we are seeing in the context of biobanking is an emerging topic, the theorisation of which necessarily needs to go through a general, ‘scoping’ phase. But if empirically-based sociology is to contribute to more general social theory and to the governance of biobanks, it will probably do so best through more focused inquiry. This is

particularly important given that there are many areas of disagreement regarding, for example, the extent and wisdom of donors' sense of trust and social solidarity. It has, for example, been suggested that there is a need for further research to find out what trust means to people in specific contexts and their reasons for trusting one organisation, system or 'expert' over another (Haddow *et al.* 2008), and we would support such an approach. Similar questions might be asked about the meanings and effects on specific donor groups of intersubjectivity, familial bonds, societal solidarity (*e.g.* 'biological citizenship') and the status of tissue. In this way, a more nuanced and contextually-sensitive 'sociology of biobanking' might be developed which might add, rather than simply refer, to existing sociological theories. Moreover, a more nuanced theorisation of donation of biobanks might contribute to our understanding of other related social processes such as blood, organ and tissue donation for transfusion/transplantation (*i.e.* therapeutic donation), and participation in other kinds of biomedical research. The findings relating to the ambiguous status of tissue might, for example, contribute to our understanding of people's willingness or unwillingness to donate organs and tissues for therapeutic purposes, and might point to different ways of motivating donation (*e.g.* by changing the language used, or setting in which people are asked, so as to make people feel most comfortable about parting with organs or tissues). Similarly, the findings relating to trust might contribute to our understanding of people's willingness or unwillingness to participate in more overtly (physically) risky clinical research.

One question of particular interest would be why it is that many tissue donors are not as concerned about biobanking as are many ethicists, lawyers and sociologists. As discussed in the introduction, a series of well publicised 'scandals' in recent years have led sociologists, lawyers and ethicists to examine the relevant social relationships, legal implications and ethical principles that may be problematic in the biobanking contexts. These issues have been discussed at length, and problems of ownership, confidentiality, relations of power, financial returns, perceptions of risk, relevance of information and consent are amongst the many matters that figure in the various literatures. At the same time, qualitative research indicates that tissue donors do not seem to experience most of these issues as 'problems'. On the contrary, they indicate a high level of trust in the scientists who do the research on their tissues; they readily give consent to donate and attach few preconditions; they feel little sense of ownership of their donated tissue; they express satisfaction at the potential good that may come from their act; they acknowledge, but do not fear, the risk of breaches of confidentiality; they generally dismiss fears of commercial exploitation; and they do these things on their own behalves and on behalf of family members, including children. Biobanking, in short, seems to be working reasonably well, and with the approval of tissue donors. It would therefore be worthwhile to try to elucidate systematically what features of the process make it work so well, despite the scandals that have prompted scholars and researchers to problematise it. While existing qualitative research provides some clues by demonstrating biologically-based social solidarity ('biological citizenship'), high levels of public trust and at least some degree of indifference towards tissue itself, we believe that the resilience of tissue banking needs further explanation. This might be provided, for example, by considering the various ways in which people in different contexts valorise the donation process (if not the tissue itself). While notions

of altruism and reciprocity provide a partial explanation, the lack of concern about risk and the low level of intentionality associated with the act of donation suggests that an alternative, or at least supplementary, explanation might be required.

## Conclusion

Qualitative enquiry can provide us with a rich and nuanced picture of the ways in which people understand, experience and construct the process of donating tissue to biobanks, and can assist us in the ethical management of these important research resources. Existing sociological interpretations of qualitative research further enrich this understanding, with reference to a large number of social theories. A more contextually-specific and nuanced 'sociology of biobanking' is, however, needed, and this might be best achieved by exploring specific theoretical questions in a variety of biobanking settings.

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**Table 1.** Tissue donation to biobanks: a review of sociological studies.

Study number and reference		Details of biobank (note that some biobanks are discussed in more than one article)	Details of qualitative study
1	Asai et al. (2002)	Name/organisation: Hypothetical existing tissue archive Location: Japan Tissue types: Not specified Donors: Not specified Research focus: Not specified	Focus groups with representatives of potential donor (general) population
2	Barr (2006)	Name/organisation: The North Cumbria Community Genetics Project (NCCGP). Location: Northwest England Tissue types: Placenta, umbilical cord, blood Donors: Pregnant women Research focus: Genetic epidemiology (e.g. heart disease, cancer and prenatal viability, neurodegenerative disease and gene repair of damaged DNA).	Interviews with pregnant women who had donated or refused to donate
3	Beskow and Dean (2008)	Name/organisation: The Duke Biorepository Location: North Carolina, United States Tissue types: Leftover blood samples Donors: People from the general population who have had blood drawn for other reasons Research focus: Many diseases including cancer, heart disease, diabetes, and other health problems	Interviews with representatives of potential donor (general) population
4	Busby (2004)	Name/organisation: University hospital/ National Health Service Location: United Kingdom Tissue types: Blood Donors: People with psoriatic arthritis Research focus: Genetic epidemiology (including rare diseases such as psoriatic arthritis)	Interviews with biobank participants
5	Dixon-Woods et al. (2008)	Name/organisation: The tumour bank of the UK Childhood Cancer and Leukaemia Group (CLLG) Location: United Kingdom Tissue types: Residual tumour tissue left over after cancer diagnosis or therapy Donors: Children with cancer Research focus: Cancer research	Interviews with children with cancer and their parents
6	Ducournau (2007)	Name/organisation: Biobank associated with the "GENES project" Location: South of France Tissue types: Blood Donors: Men from the general population aged 45-75 who are recruited specifically for this research Research focus: Genetic epidemiology of cardiovascular disease	Interviews with representatives of potential donor (male, age-defined) population and ethnographic observation of the consent process

7	Elliot et al. (2008)	Name/organisation: Tumour bank of "SIDS and Kids" Location: Australia Tissue types: Several tissue types retained at postmortem Donors: Children who had died of Sudden Infant Death Syndrome Research focus: Asthma	Interviews with parents of SIDS infants
8	Godard et al. (2007)	Name/organisation: Quebec CARTaGENE Project Location: Quebec, Canada Tissue types: Blood Donors: Random selection of the general population Research focus: Global health issues/ disease risk	Focus groups with representatives of potential donor (general) population
9	Gustafsson Stolt et al. (2002)	Name/organisation: ABIS (All Babies in Southeast Sweden). Location: Sweden Tissue types: Blood, hair, milk Donors: Neonates and parents from the general population Research focus: Childhood diabetes and related diseases	Interviews with participant and non-participant mothers
10	Haddow (2009)	Name/organisation: Generation Scotland: The Scottish Family Health Study'' Location: Scotland Tissue types: Blood Donors: General population (with a focus on family groups) Research focus: genetic contributions to diseases that affect the Scottish population e.g., cancer, heart disease and mental illness (especially family-based studies)	Interviews with biobank participants
11	Haddow et al. (2008)	Name/organisation: Generation Scotland Location: Scotland Tissue types: Blood Donors: General population (and family groups within this to facilitate genetic analysis) Research focus: Many common diseases	Interviews and focus groups with representatives of potential donor (general) population
12	Haddow et al. (2007)	Name/organisation: Generation Scotland Location: Scotland Tissue types: Blood Donors: General population (and family groups within this to facilitate genetic analysis) Research focus: Many common diseases	Focus groups with representatives of potential donor (general) population
13	Haines & Whong-Barr (2004)	Name/organisation: The North Cumbria Community Genetics Project (NCCGP). Location: Northwest England Tissue types: Placenta, umbilical cord, blood Donors: Pregnant women Research focus: Genetic epidemiology (e.g. heart disease, cancer and prenatal viability, neurodegenerative disease and gene repair of damaged DNA).	Interviews with participants, non-participants and representatives of potential donor population

14	Haimes & Whong-Barr (2003)	Name/organisation: The North Cumbria Community Genetics Project (NCCGP). Location: Northwest England Tissue types: Placenta, umbilical cord, blood Donors: Pregnant women Research focus: Genetic epidemiology (e.g. heart disease, cancer and prenatal viability, neurodegenerative disease and gene repair of damaged DNA).	Interviews with participants, non-participants and representatives of potential donor population
15	Hoeyer (2002)	Name/organisation: UmanGenomics AB Type: Population biobank Location: Northern Sweden Tissue types: Blood Donors: General population Research focus: Common diseases	Observation and interviews with representatives of potential donor (general) population
16	Hoeyer (2003)	Name/organisation: UmanGenomics AB Location: Northern Sweden Tissue types: Blood Donors: General population Research focus: Common diseases	Observation and interviews with representatives of potential donor (general) population
17	Hoeyer (2004)	Name/organisation: UmanGenomics AB Location: Northern Sweden Tissue types: Blood Donors: General population Research focus: Common diseases	Observation and interviews with representatives of potential donor (general) population
18	Hoeyer (2006)	Name/organisation: UmanGenomics AB Location: Northern Sweden Tissue types: Blood Donors: General population Research focus: Common diseases	Observation and interviews with representatives of potential donor (general) population
19	Hoeyer & Lynöe (2006)	Name/organisation: UmanGenomics AB Location: Northern Sweden Tissue types: Blood Donors: General population Research focus: Common diseases	Observation and interviews with representatives of potential donor (general) population
20	Jack & Womack (2003)	Name/organisation: Tissue bank of Peterborough Hospitals NHS Trust Location: United Kingdom Tissue types: Surgical Donors: Patients undergoing surgery Research focus: Commercial/ pharmaceutical research	Interviews with people who had refused to donate
21	Kaphingst et al. (2006)	Name/organisation: Dana-Farber Cancer Institute Location: United States Tissue types: Blood and breast tumour tissue Donors: Female breast cancer patients Research focus: Breast cancer	Focus groups and interviews with breast cancer patients who had consented to donation

22	Kaufman et al. (2008)	Name/organisation: National Institutes of Health and other federal agencies Location: United States Tissue types: Blood, urine, saliva, hair or nail clippings Donors: General population (including children) Research focus: Many diseases	Focus groups with representatives of potential donor (general) population
23	Levitt &Weldon (2005)	Name/organisation: UK biobank Location: United Kingdom Tissue types: Blood Donors: General population Research focus: Not specified (many diseases) Research focus: Multiple	Focus groups with representatives of potential donor (general) population
24	Lipworth et al. (2009)	Name/organisation: Not specified – refers to several tumour banks Location: Australia Tissue types: Residual tumour tissue Donors: People with cancer Research focus: Cancer research	Interviews with biobank participants and other lay groups
25	McCarty et al. (2008)	Name/organisation: The Marshfield Clinic Personalised Medicine Research Project Location: United States Tissue types: Blood Donors: General population Research focus: Genetic epidemiology, pharmacogenetics, and population genetics	Focus groups with representatives of potential donor (general) population
26	Murphy et al. (2008)	Name/organisation: A proposed genomic biobank Location: United States Tissue types: Blood Donors: General population Research focus: (Hypothetically) asthma, alzheimer's disease	Focus groups with representatives of potential donor (general) population
27	Ormond et al. (2009)	Name/organisation: NUGene Project, Northwestern University Location: United States Tissue types: Blood Donors: General population Research focus: Broad range of diseases	Interviews with biobank participants
28	Richards et al. (2003)	Name/organisation: The Anglican Breast Cancer Study Type: Disease-specific blood collection Tissue types: Blood Donors: Women with breast cancer Research focus: Breast cancer genetic epidemiology	Interviews with biobank participants

29	Rotimi et al. (2007)	Name/organisation: The International HapMap Project Type: Population biobank Location: International Tissue types: Blood Donors: General population Research focus: Relating genetic variation to health, disease and drug response	Interviews and focus groups with representatives of each research population (in Nigeria, Japan, China)
30	Scott et al. (2005)	Name/organisation: Not specified (hypothetical discussions about biobanks in general) Location: New Zealand Tissue types: Not specified Donors: General public Research focus: Not specified	Focus groups with representatives of potential donor (general) population – both indigenous and non-indigenous
31	Secko et al. (2009)	Name/organisation: Hypothetical biobank Location: Canada Tissue types: Not specified Donors: General population Research focus: Not specified	Focus groups with representatives of potential donor (general) population
32	Skolbekken et al. (2005)	Name/organisation: the biobank of the Nord-Trøndelag Health Study (HUNT) Location: Norway Tissue types: Blood Donors: General adult population Research focus: epidemiological studies, including functional genomics	Focus groups with biobank participants
33	Sque et al. (2008)	Name/organisation: Various NHS Hospital Trusts Location: United Kingdom Tissue types: Hearts and other organs Donors: Children who had died Research focus: Not specified (many diseases)	Interviews and focus groups with parents whose children's organs had been retained at postmortem examination
34	Traulsen et al. (2008)	Name/organisation: Icelandic Health Sector Database (linked to biobanks) Location: Iceland Tissue types: Blood Donors: General population Research focus: disease modelling, disease management, and genetic linkage of traits and outcomes	Focus groups with representatives of potential donor (general) population
35	Tutton (2007)	Name/organisation: UK biobank Location: United Kingdom Tissue types: Blood Donors: General population Research focus: Not specified (many diseases)	Focus groups with people with experience of human genetic research and with representatives of potential donor (general) populations

36	Williamson et al. (2004)	Name/organisation: the Avon Longitudinal Study of Parents and Children (ALSPAC) Location: United Kingdom (but part of a larger WHO study involving seven European countries) Tissue types: Maternal blood, maternal urine, cord blood, umbilical cord, placenta, hair and nail clippings, teeth, child's blood, DNA and urine. Donors: Mothers and children Research focus: Genetic epidemiology – including psychiatric and behavioural research (with a longitudinal focus)	Focus groups and interviews with parents and children – both participants and representatives of the eligible population
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