

Biosamples as gifts? How participants in biobanking projects talk about donation

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Abstract

Background In the UK, altruism has featured explicitly as an underpinning principle for biobanking. However, conceptualizing donation as altruistic downplays the role of reciprocity and personal or family benefit.

Objective To investigate how biosample donors talk about their donation and whether they regard samples as ‘gifts’.

Methods In this qualitative study, 21 people, both healthy volunteers and people with health conditions, who had been invited to give biosamples took part in semi-structured narrative interviews. The data were transcribed verbatim and thematically analysed.

Results The term ‘gift’ was considered appropriate by some, but it also evoked puzzlement, especially in relation to ‘waste’ material (e.g. urine or tumour samples). Whilst ‘giving’ or ‘donating’ were commonly mentioned, the noun ‘gift’ signified something more special and deliberate. Analysis suggested biosamples could be interpreted as gifts in several different ways, including unreserved gift; reciprocal gift; collective gift; unwanted/low-value gift; and gift as an exaggeration.

Discussion and conclusions Although people describe a network of exchange consistent with anthropological understandings of gift relationships, lay (and biomedical) understandings of the term ‘gift’ may differ from anthropological definitions. For donors (and researchers), value is attached to the information derived from the sample, rather than the sample itself. Consequently, when asking people for biosamples, we should avoid using the term ‘gift’. Acknowledging the value of participation and the information the sample holds may mean more to potential donors.

Introduction

Biobanking, governance and consent

In 1999, a UK public inquiry followed the discovery that a pathologist at Liverpool’s Alder

Hey children’s hospital had retained organs for research without parental consent. This led to the UK Human Tissue Act 2004 and the regulatory Human Tissue Authority from 2006. Media analysis suggests that reporting of such incidents created a climate of public horror,

with images of fragmented bodies and 'stolen hearts'¹ (p 38–39):

The organ retention scandal was exceptionally powerful in its designation of villains, victims, heroes, and its organization of the 'proper' responses to events and actions, in particular by polarizing the interests of the medical/scientific community and the lay community.... Politicians during the scandal aimed to align themselves with the apparent victims, and were notable for their unwillingness to defend the medical agenda and their readiness to take the part of presumed 'public opinion' as it appeared to them to be represented in media reports.

Such reporting presumes that all body parts are special and that suspicion of and resistance to using human tissue in medical research are widespread. In bioethics and social science literatures, a discourse of 'social unease' about biosamples has predominated,² in which bodily integrity, dignity, personhood and autonomy are set against a rising tide of commodification and capitalist exploitation.^{3,4} Waldby and Mitchell⁵ (p 24) argue that Titmuss⁶ view of voluntary blood donation as 'intrinsically ethical...has simply rendered the body an open source of free biological material for commercial use'. Some have therefore argued for retention of individual property rights over biosamples, potentially resulting in paying participants royalties or profit shares.⁷

The issue is further complicated by developments in genetics and increasingly widespread storage of DNA samples, generating public concerns about a surveillance society, and other fears such as genetic manipulation and cloning.^{8–10}

Biobanks are repositories of biosamples, which are used to conduct research into the prevention, diagnosis and treatment of a range of diseases. The question of biobank regulation and the relationship between donors and research has generated much ethical and socio-legal debate.^{11–15} This fits within a wider literature around trust and the feasibility (or not) of fully informed consent.¹⁶ This particularly affects biobanking given the long-term nature of sample storage and the difficulty of antic-

ipating every possible future use, coupled with growing pressure from funders to share research data as a public good.¹⁷

However, much of this is either theoretical debate or single legal case analysis rather than empirical work to gauge how far 'social unease' really represents public views.² Empirical studies of the views and reasoning of people who have contributed samples for research have identified generally supportive and willing attitudes.^{18–20} Donors may have concerns, but there is a mismatch between what matters to them and researchers' 'remarkable fixation on the consent issue'²¹ (p 440), which, to some extent, is dictated by the regulatory system in which they work. In fact, the evidence on what matters to donors is conflicting and hard to interpret. From questionnaire survey research, Hoeyer²¹ suggests we can identify 'few messages other than "people feel differently about these issues"', although he offers 'a few general insights for cautious contemplation'²¹ (p 437), including:

1. Views vary by the type of tissue asked for and the position of the donors (e.g. whether they themselves have an illness which could benefit from the research)
2. Many donors are interested in accessing research results, particularly those relevant to their own health
3. Only a minority would never participate in biobank research
4. Most think the donor should have a say concerning retention of tissue, but it is unclear whether people prefer broad or specific consent
5. A majority accept commercial access to public biobanks if it helps science

Hoeyer's review of qualitative studies²¹ of potential and actual donors suggests these offer more consistent results than surveys, especially that informed consent is a low priority, and donors rarely read, recall or use the information they receive. Consent procedures may even be interpreted as protecting research institu-

tions rather than participants. Motivations for participation often seem to concern mutual benefit and reciprocity more than 'purely' altruistic considerations.

A review of sociological evidence²² supports these findings, suggesting that trust can help explain the apparent paradox that people are aware of risk but remain generally willing to donate: people know they *may* be harmed, but they *do not expect* to be harmed, because they trust science, researchers and institutional governance. Most people do not see tissue as 'sacred' or an intrinsic part of themselves, or something they own. On the contrary, diseased tissue may be seen as a 'foreign and unwelcome invader'²² (p 801), and other samples just as waste. The personal information attached to the sample may have more value than the sample itself.

Altruism, reciprocity and the gift relationship

Altruism has featured explicitly in the UK as an underpinning principle for biobanking, rather than the property rights-based approach.²³ For example, the Nuffield Council on Bioethics²⁴ (p 68) described donating tissue as 'a gift...free of all claims' and 'a voluntary transfer...with no expectation of its return' – which anthropologists might consider a misunderstanding of gifting as an exchange relationship based on mutual obligation.²⁵ Similarly, the UK Medical Research Council²⁶ (p 3) states unequivocally: 'Samples of human biological material obtained for use in research should be treated as gifts' and when it funded the UK Brain Banks Network thanked donors and their families 'for their altruistic donation'.²⁷ When announcing a new brain imaging study in 2014, UK Biobank Director Sir Rory Collins was reported as saying: 'UK Biobank is a remarkable example of altruism. Participants have got involved not for themselves, but to improve the health of future generations'.²⁸

Critiquing what she calls the 'fallacy of altruism', Kanellopoulou²³ (p 42) identifies a shift towards a model of mutual exchange between donors and researchers. She proposes

a distinction between a free (unconditional) one-off gift and a 'conditional gift', which involves the 'exchange of reciprocal returns implied by on-going collaborative interaction and dynamic relations between mutually engaged parties'²³ (p 46). Equally, Haines and Whong-Barr²⁹ note that motivation to donate is not as altruistic as often presumed; there is an assumption amongst donors of reciprocity and benefit sharing. They assert that using the concepts of donation and non-donation is too simplistic to understand participation in biobank research, which they describe as 'a highly varied social process, with multiple meanings'²⁹ (p 152).

Similarly, a European study of public attitudes to biobanks³⁰ (p 9) concludes reciprocity is an essential principle:

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

Tutton's³¹ study of blood sample donation for DNA research in Orkney also found mixed reasons for taking part. Some participants foregrounded helping the genetics researcher and helping the Orkney community to understand its history, with no personal expectation of return. Some anticipated medical research benefits, including genetic insights into Orkney's high multiple sclerosis rates. But participants also valued personal feedback about their genetic ancestry. Tutton³¹ concludes that altruism can only partially explain why people give samples for research. One of the authors of this paper has argued similarly in relation to clinical trial participation.³²

Widdows and Cordell³³ argue that we need to pay attention to wider 'corporate goods' which may accrue from biobank research, which go beyond individual benefits and reciprocity. The wider public good of improved health for future generations (and the social

and economic benefits which may flow from it) does not directly benefit any single biobank participant, but collectively benefits us all as members of society. They suggest we should not think in terms of individual *versus* community, protecting individual rights 'against some faceless mass'³³ (p 23), but rather in terms of respecting whole communities *of which we are all part*.

Many discussions around gifts and reciprocity in biobanking cite Titmuss's study⁶ comparing UK and US systems of blood donation. He concluded that the UK system of unpaid all voluntary donation exemplified a 'gift relationship' characterized by 'creative altruism' in which the recipient is anonymous and the donor expects no immediate or direct personal reward. Although he also invokes a more anthropological view of gift giving as an exchange, and blood donation as an expression of reciprocal social solidarity, he has been criticized for overemphasizing altruism.³²

Whilst many studies allude to Titmuss⁶ to frame analysis of people's accounts of their motivations and attitudes, few have directly asked people what they think of biosamples as gifts. An exception is Dixon-Woods and colleagues' study¹⁹ of the attitudes of parents, whose children have cancer, to tissue samples as 'gifts'. They found that the blood donation 'gift' model did not match families' views, and the samples were not valued by the donors. Parents consented on condition there was no risk, pain, or inconvenience to their child. Using the term 'gift' appeared troubling – rather than persuading family members to consent, it provoked some discomfort, and even offence. Thus, the term 'gift' could undermine rather than secure the co-operation of potential donors.

However, these family accounts did demonstrate *some* key features of Titmuss's⁶ 'gift relationship', particularly tissue banking as a means of affirming social solidarity with a well-defined childhood cancer 'illness community'. Consent was directed towards helping others in the interests of common (rather than individual) good, without expecting reward.

We build on Dixon-Woods and colleagues' study¹⁹ by asking biobanking participants explicitly about their attitudes to biosamples as gifts and add to the evidence in several ways. Firstly, we examine the responses of self-consenting adults, rather than parents consenting for their children. Secondly, we assess the responses of healthy volunteers and people affected by a wider range of conditions. Finally, we explore how people feel about different types of sample (including urine, blood and tumour samples).

Methods

Sample and recruitment

Twenty-one people were recruited who had given biosamples for research or had been invited and declined. Some had given samples more than once or had consented on one occasion but declined on another. One had declined the only time he was asked (for a population biobank). All were white British. Some were recruited for us by researchers at specific biobanks; others came from media advertising, snowballing or word of mouth. The sample included both healthy volunteers and people with a health condition (see Table 1). The research was approved by the Berkshire Research Ethics Committee (ref: 09/H0505/66).

Data collection, coding and analysis

LL interviewed participants in 2010–11 at home or elsewhere if preferred. Participants were initially invited to talk about their biobanking experience in their own words, with little interruption from the interviewer. This opening question indicated that we were interested to know how they got involved and why, what happened when they took part, what information they remember being given and how they felt looking back. This was followed by semi-structured prompting around these and other topics. Prompts relevant to this paper included questions around motivations for taking part, and a specific question about

Table 1 Sample characteristics

Participant	Type of biobanking	Gender and age
01	Cancer and population biobank	F, 55
02	Cancer	M, 58
03	Healthy volunteer, population biobank (declined)	M, 43
04	Healthy volunteer, diabetes biobank (declined population biobank)	F, 49
05	Cancer	F, 52
06	Healthy volunteer, population biobank	F, 49
07	Healthy volunteer, population biobank and diabetes biobank	F, 52
08	Hepatitis C virus	M, 54
09	Motor neurone disease	F, 56
10	Hepatitis C virus	M, 66
11	Healthy volunteer, diabetes biobank (accepted and declined on different occasions)	M, 49
12	Motor neurone disease	M, 63
13	Motor neurone disease	M, 61
14	Healthy volunteer, stroke study as family member control and population biobank	F, 62
15	High-risk pregnancy and healthy volunteer, population biobank	F, 45
16	Motor neurone disease	M, 54
17	High-risk pregnancy	F, 37
18	Hepatitis C virus	M, 49
19	Healthy volunteer, pregnancy biobank	F (age withheld)
20	Healthy volunteer, population biobank	M, 33
21	Healthy volunteer, population biobank	F, 44

biosamples as gifts. The exact wording of this question varied depending on the individual context and what had already been said during the interview, but a typical formulation would be 'Some people describe donating a tissue sample as being like giving a gift. Do you see your donation in that way?' Interviews lasted approximately an hour; they were video or

audio recorded, transcribed verbatim and analysed thematically.

Interview transcripts were first coded (by AMB) using NVIVO software and an initial coding framework developed by both authors in discussion. This included the full range of anticipated and emergent themes (e.g. recruitment and information, deciding whether to donate, experiences of actual donation, feedback and communication) and was refined through constant comparison. We reflected on specific comments about the differential value of samples in response to questions about type of donation (especially tumour, urine and blood). We also reflected on the links between attitudes to samples and whether or not the person was healthy or had an illness. For this paper, we jointly analysed in more detail the range of perspectives expressed within the codes relating to reasons for participating, and attitudes to the term 'gift', paying particular attention to use of language. Wider findings are available on the health information Website healthtalk.org.

Results

General reasons for taking part

Before discussing responses regarding samples as gifts, we summarize people's motives for taking part in biobanking. Consistent with the literature, they gave a range of reasons. Compared to genetics research or clinical trials, biobanking offers fewer obvious familial or personal benefits, especially for healthy volunteers; not surprisingly, therefore, 'altruistic' or social motivations were commonly expressed. However, personal benefits were also noted, most commonly by people with an illness or condition, but also by healthy volunteers.

Reasons for taking part included aiding medical science; improving understanding and treatment of health and illness for future patients; gaining potential personal benefits (e.g. a free health check/information about one's health; obtaining better care; aiding the potential development of a cure for one's con-

dition); intellectual curiosity; and showing gratitude to the NHS and previous research participants for current standards of care and treatment. One person mentioned a sense of karmic value alongside diffuse reciprocity, the notion that good actions may be repaid by different people across time and across generations, as part of a general system of neighbourly behaviour rather than individual reciprocation:

The motive was there: there but for the grace of God go I. And this kind of karma may come back and protect me. I know that's all spooky nonsense [...] At various points in my past I've needed help, and at some point in the future I may need help (Female, healthy volunteer, population biobank)

In addition to benefits reported as initial motivating factors, people later perceived other advantages which they said might encourage them to take part again, including the rapport and sense of partnership they enjoyed with researchers.

Many viewed the decision to take part in biobanking as less of a 'Why?' and more of a 'Why not?' Trust in UK research regulation was high and biosample donation was seen as unproblematic. Whilst some wanted to know how their sample would be protected, several said they had not read the information leaflets they were given because they were confident it would be appropriately handled by the researchers and safeguarded by regulations.

Biosamples as gifts

We now present five original interpretations of biosamples as gifts: unreserved, reciprocal, collective, unwanted/low-value and exaggerated gift.

'Gift' as an appropriate term – the unreserved gift

For most people interviewed, biobanking seemed simple to do; many were surprised or puzzled to think there was even a story to tell, let alone that anyone would be interested to hear it. Many said they had not considered their donation as a gift until explicitly questioned about it, a gift not routinely thought of as such, but for a few this resonated (see Box 1).

This view seemed more common amongst people with a specific health condition, perhaps reflecting the sense of an illness community (a shared sense of identity with others who experience the same illness) with future beneficiaries of the research. It is important also to note the point that a sample may be 'very easy to give', although in the case of the MND biobank taking part included an option to have a lumbar puncture to donate spinal fluid. Two of the four people interviewed with motor neurone disease (MND) had declined this element of the research as too invasive.

The last of the three quotations in Box 1 is interesting in the way the respondent moves from a question about a 'gift' to a more mundane verbal form, 'I've given it'. We return to this point later. Her remark 'It's something I can do' also relates to other points in her interview where she described research participation as a way of regaining control when faced by terminal illness, 'almost to get back at the disease'. As she explained:

The thought of just sitting, waiting for the disease to take over seemed very alien. And so I thought the only proactive thing that I could do about the disease was maybe to take part in any research.

Thus, whilst she perceived no direct health benefit, an alternative form of personal benefit is evident, in helping her make sense of a distressing situation.

A reciprocal gift

For some people, the notion of a direct relationship with past or future beneficiaries of health care and medical research was explicit, not just in terms of an illness community but also sometimes one's own family (see Box 2). One woman, who did not herself find the language of gift appropriate, nonetheless identified reciprocal exchange at the heart of her motivation. Her twin brother received a lot of care including (unsuccessful) experimental surgery. As a healthy donor to a diabetes biobank, she felt she was giving back on his behalf. Another woman recovering from breast cancer felt more at ease with the language of gift, even though it had not occurred to her before.

Box 1 Biosamples as an unreserved gift

I would say unequivocally, yes. It is, for me personally, a gift, and that's where I stand (Man with MND)

Yes, it strikes a chord with me that when I give a sample or a donation it is like giving a gift, though it's one that I'm very happy to give, and in the case of an extra urine sample, for example, it's very, very easy to give (Woman who gave samples both as a healthy volunteer and during high-risk pregnancy)

I suppose it is [a gift] in a sense, really. It's something I can do, and I feel I have no claim whatsoever over it, that I've given it (Woman with MND)

It is significant that breast cancer can have a genetic component; the potential to help others in one's family may therefore temper the sense of altruism. Note, for example, the force of 'but' in the second extract in Box 2 – 'there is no personal benefit to you at this time. But of course we all think about generations to come and our families' – implying that even if there is no personal benefit now there may be later in the form of familial benefit, alongside wider social benefit. Note also how her initial definition of a gift (*because* there is no personal benefit) reflects the interpretation of gift in policy documents cited in the introduction ('a gift free of all claims') rather than an anthropological exchange model.

A man with well-controlled hepatitis C virus who had often given blood and liver samples questioned the direction of the gift and highlighted the reciprocal importance of research which might develop a cure during his lifetime.

That's valuable time that's being spent on something very important. And it's probably as important to me as it is to the people doing the research. So who's getting the gift? Me, or them?

However, although he personally did not find it appropriate for what he described as 'tissue, odd bits, pints of blood' (see 'gift as exaggeration' below), he added, 'I can see "gift" might resonate with some people. I can't offhand think of a better term'.

Collective gift

One woman, musing on the difference between the kind of gift relationship involved in blood donation versus biosamples for research, used a

comparison with the office whip-round. This was an isolated but intriguing conceptualization.

I suppose you could regard that [biobanking] more like a sort of collection for a gift or something, you know - a collection for a leaving gift or something in the office - rather than the personal gift. (Female healthy volunteer, population biobank)

This is an interesting representation of the social distance between donor and recipient, suggesting both how the 'gift' in itself is worthless or of low value unless combined with others' contributions, and how this in turn undermines any sense of personal relationship with eventual beneficiaries, specifically unlike a blood donation which goes from one person straight to another.

Unwanted or low-value gift

As noted earlier, many people had never before considered donated biosamples as gifts. Many struggled to relate this idea to their own experience, often laughing or giving humorous replies. Consistent with the notion of a collective gift, where one's own contribution has little intrinsic value until combined with others, some people considered it at best a low-value or unwanted gift.

I don't regard that I'm giving it as a gift. Maybe a free gift? No, I don't think of it as a gift. (Female healthy volunteer to both a population and a diabetes biobank)

A woman who had contributed to a population biobank but also gave breast cancer tumour samples for research agreed with the

Box 2 Reciprocal gifts

I like to think that maybe I'm helping future generations overcome some of the problems that we all have. One of things that the studies always do tell me is that what they're looking for is not to help me in my lifetime, because studies take 30, 40 years, you know, to come to fruition, but it's for, it will help other people. And I think going back over my life people must have done that for my brother to have those operations. And I suppose I came to think of it in terms of, "I'll do my little bit to help". (Woman, healthy volunteer)

I hadn't thought of it in those terms, but, yes, I think it is [a gift], because they're very keen to stress that there is no personal benefit to you at this time. But of course we all think about generations to come and our families, and I would hope that in some way it can contribute to better health and better diagnosis and treatment for family, you know, generations to come. (Woman who gave samples both as a healthy volunteer and during breast cancer treatment)

idea of participation as a gift, but in relation to her tumour sample commented:

The alternative is it gets thrown away. Well, if somebody else can use it... You get Christmas gifts you don't want, so you recycle them through the charity shop or something. That's the same thing. I know that's perhaps trivializing it. But if somebody can get use out of it, why not?

'Gift' as an exaggeration

Underlying many of these responses was a sense that the use of the word 'gift' was overstating the value of biosamples, an exaggeration some saw as faintly ridiculous. This view was particularly associated with tumour and urine samples, although for some people it applied equally to blood (see Box 3).

Interestingly, the man with hepatitis C virus quoted in Box 3 went on to say of his donations, 'I suppose it's my philanthropic side – and that I've found surprisingly rare in other people, which has surprised me over the years'. Thus, 'philanthropy' resonated with him even if 'gift' did not.

However, others saw blood as something different. This may partly reflect the more invasive nature of donating blood samples, compared to something which is excreted or is being removed anyway. Perhaps more significantly, people often found it difficult to separate blood for research from therapeutic

blood donation in their thinking, which in turn reveals the special significance attached to blood as a valuable and life-giving substance. This contrasts with waste products such as urine or a positively 'unwelcome invader' such as a tumour. An example of this way of thinking is given in Box 4.

The example in Box 4 brings us back to the use of language. Whilst the verbs 'give' and 'donate' were used readily in people's talk about biosamples, the noun 'gift' seems to imply something more special and deliberate, evoking an image of a gift-wrapped present. As one healthy volunteer commented, reminding us of the benefits she derived from participation:

To me giving a gift's sort of a bigger thing...As I've said before, to me there were some benefits [laughs] because, you know, you were relaxing all day...But I mean to me, giving - I mean you go to your GP and he could say, "Well, I need a blood sample." But you wouldn't say you were giving him a gift, would you?

Discussion and conclusions

We have explored people's thoughts about the concept of donating biosamples as 'gifts'. We found that attitudes to donation are ambiguous and this is consistent with previous research.²² Participants cited several reasons for donating, often being motivated by multiple factors. The findings from our qualitative sample also accord with survey findings sug-

Box 3 Gift as exaggeration

I think saying it's a gift is over-egging it, really... If you were to give your little finger it might be a gift (Woman with cancer)

No, I don't feel that I'm giving a gift. I just feel like I'm helping society (Woman, healthy volunteer)

To me if I give a monetary donation to help research, yes, that's a gift, but if I'm giving a body part or something like that, I don't see that as being a gift. I think that's something altogether different (Man with MND)

Bizzarely I think it's a bit of an honour, really. I wouldn't call it a gift. I don't think it is [um] - I mean if that's, if that hits some people's buttons, great. It's just a "why wouldn't you?" It's a more naturally "yes" thing than "no" thing (Woman, healthy volunteer)

If I'm sitting here and someone comes along and says, you know, "Give us a few phials of your blood because we might be able to do something with it", I'm just not going to think twice about it. It's not a gift (Man with MND)

Never thought of it in that concept [gift]. No, it's not really the way I've thought of it. It's a, [um] I am [pause] - I probably view my body quite mechanically in that it's all quite renewable. None of your body is more than, what is it, five years old? And, [um] you know, tissue, odd bits, pint of blood here, whatever, is, [um] somebody's got a very good use for it. Well, I've had a very good use for it over the years (Man with hepatitis C virus)

gesting that people may not find biosample donation as ethically troubling as some ethicists presume; for many the donation of 'waste' products (e.g. tumour or urine) evokes little concern, confirming previous findings that people trust research regulation and perceive few actual risks.²²

Equally, our conceptualization of reciprocal gifts and especially the collective gift adds weight to Widdows and Cordell's³³ notion of corporate goods, which go beyond individual benefits and reciprocity. Our participants acknowledge a value in donating even 'low-value/unwanted gifts' for our collective social good.

For this study, it proved very difficult to recruit people from ethnic minority communities and also those who refused to take part in biobanking. As people who had consented to donate samples felt they had little to tell, those who declined would presumably find it even harder to see what they could contribute in an interview. We interviewed one man who declined primarily because of concerns about data protection. It would be valuable to have more perspectives from people who decline donation.

Our findings reveal a range of previously unexplored perspectives on the notion of biosamples as gifts. Consistent with Dixon-Woods *et al.*,¹⁹ our more diverse sample of self-consenting adults indicates that the word itself resonates with some (especially those living with an illness), but not with others (both healthy volunteers and those living with an illness), and that all samples as gifts are not considered equal. However, this is generally not because they regard the sample as some intrinsically important part of themselves, rather it is seen as something minor and trivial; easy to give; something potentially benefitting themselves and others; and which affirms social solidarity through diffuse or asynchronous reciprocity. Even if they invoke concepts and language which could be seen as consistent with anthropological understandings of an exchange network, people are commonly sceptical of the actual word 'gift', seeing it as an overstatement, and tend to adopt a lay definition (similar to the biomedical discourse) of a 'gift free of all claims' without feeling they are creating obligations in return. Nor do they seem to expect any continuing relationship with the biobank.

Box 4 Urine contrasted with blood

The reflections of this woman who donated blood and urine samples during a high-risk pregnancy indicate the different values people ascribe to waste products (e.g. urine) versus blood:

Interviewer There is some literature around the giving of tissue and blood samples as a kind of gift... Does 'gift' sound the right sort of terminology for giving blood and urine samples to you?

[um] Not urine. [laughs] Because I can't imagine that would be, anyone would want to make any use of that. [um] I don't. Yeah. [laughs] 'Hello, happy birthday'. I do think with blood - I mean I'm, because I've had a platelet transfusion in the past I'm no longer allowed to, I'm no longer qualified to give blood. [um] I do think blood is a gift. I'm not so sure about other bodily fluids being gifts. [laughs] [um] But, yeah, no, definitely, blood is definitely a gift if ...

Interviewer Mm. Even if it's for research purposes?

I - yeah, I don't - yeah, I don't see why not. I think because I'm always amazed at how much information they get out of how little... With my last two pregnancies - I mean, there was blood taken all the time, every time. And they're like, 'Oh, you know, out of this they'll take like a hundred different things'. And I think it is such a, for such a little thing to be able to gain so much information is invaluable.

Although this woman made fun of the notion of urine being handed over as a birthday present, she could still see the importance of urine for research. For her, it was thus consistent to see the research value of a sample at the same time as laughing at the incongruity of an image of a 'gift' of urine. She went on to say:

Saying it's a waste product is quite true. But I mean, in my case, yeah, urine shows up a massive amount of information. [um] Probably not as much as blood but, yeah, I suppose there is just something associated with, "Here, have my urine," [laughs] "and do something with it." But, yes, I suppose as a source of information...

Tutton³¹ (p 537) contrasts blood sample donation for his DNA study in Orkney with blood donation for transfusion and concludes that there is a difference between:

...the 'corporeal' economy of blood transfusion, in which the blood itself is of immense value and is used to assist someone in emergency medical need, with the informational economy of research, in which blood is merely an easy way of getting to the DNA.

This distinction resonates with our findings and helps explain why 'gift' can seem a troubling or inappropriate word for biosamples. The gift – the value – is in the giving, in the collective contribution to research, rather than in the sample itself. Focusing on the value of participation and the information derived rather than the value of the physical sample might have more intuitive appeal to potential participants. Perhaps this is not limited to biobanking, but could also be extended to other types of clinical research, including clinical trials.

Practical implications arising from this study are that we should avoid the term 'gift' in communicating with patients and seeking consent for donation, given that it holds such different meaning for different people and therefore offers little utility in representing participants' views. Governing bodies should exercise caution when setting discourses around donation, whilst recognizing that the public holds positive attitudes towards helping others and donating biosamples.

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Conflict of Interest

The authors declare no conflict of interests.

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