



**From waste product to blood, brains and narratives:
developing a pluralist sociology of contributions to health
research**

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Abstract:	<p>The aim of this paper is to examine the meaning of the concept of donation in health research. Drawing on a set of narrative interviews with people invited to donate biosamples for research and a range of other studies, we identify several conceptual themes that speak to the complexity of the current landscape of critical thinking about donation.</p> <p>These conceptual themes are: the language of 'donation'; a hierarchy of biosamples; alternative informational value; narratives as donation; coincidental donation, convenience and degree of invasiveness; and rights, consent and benefits of research participation.</p> <p>We call for a reconceptualization of research donation to encompass not only the numerous types of sample readily classed as donations, but also other types of data and contributions, including narrative interviews, psychometric data, patient-reported outcome measures, record-linkage, and time and effort. We argue for the development of a pluralist sociology of research donations, and suggest that a 'sociology of research contributions' might better capture this complexity.</p>

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Abstract

The aim of this paper is to examine the meaning of the concept of donation in health research. Drawing on a set of narrative interviews with people invited to donate biosamples for research and a range of other studies, we identify several conceptual themes that speak to the complexity of the current landscape of critical thinking about donation.

These conceptual themes are:

the language of 'donation';

a hierarchy of ~~donations biosamples: from tumour to blood, from waste to value;~~

alternative informational value;

narratives as donation; coincidental donation, convenience and degree of invasiveness;

~~donation after death: brains, eyes, and bodies;~~ and rights, consent and benefits of research participation.

We call for a reconceptualization of research donation to encompass not only the numerous types of sample readily classed as donations, but also other types of data and contributions, including narrative interviews, psychometric data, patient-reported outcome measures, record-linkage, and time and effort. We argue for the development of a pluralist sociology of research donations, and suggest that a 'sociology of research contributions' might better capture this complexity.

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For Peer Review

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Health research 'donations'

In this paper we examine the meaning of 'donation' in the health research context, looking not just at biosamples but other forms of personal donation to research.

In biomedicine research donation is primarily understood as biosamples, bodily fluids and tissue such as urine, blood, brain, tumour, and embryos. Regulatory frameworks and academic literature have tended to treat all types of sample as equally significant, even though this may not adequately reflect the real-life views and motivations of research donors.

Alongside biosamples, people often give consent for personal biometric and lifestyle information to be collected and used, and for medical record linkage. However, such information is rarely considered through a 'donation' lens; rather the debate is framed in terms of data protection and anonymity.

People contribute to interdisciplinary health research in a range of other ways, including, for example, committing time and effort, agreeing to experimental treatments (such as in clinical trials), taking part in surveys, completing patient-reported outcome measures and giving interviews.

We suggest that a sociology of 'donation' as a single entity is problematic. We seek to reconceptualise research donation, extending the current 'hierarchy of donation' identified by Machin and Cherkassky (2015) to encompass these various forms of contribution.

Biosamples and donation

Theorising donation for research takes place against a backdrop of two major competing influences. On the one hand, Titmuss' (1970) analysis of blood donation as a 'gift relationship' looms large. There is long-standing debate as to how far Titmuss departed from or acknowledges the relevance of traditional anthropological understandings of the gift relationship as a network of reciprocal obligations (Tutton 2002; Rapport & Maggs 2002). Whatever Titmuss intended, his emphasis on the 'free human gift' with no immediate expectation of return has been co-opted beyond therapeutic donation (i.e. donation of blood and organs for treatment purposes) into medical research policy, our focus in this paper.

Altruism has been promoted by medical research agencies as the underpinning principle for biosample donation (Kanellopoulou, 2009; Machin & Cherkassky, 2015). People are urged to donate partly to fulfil their desire to help others, but also because this will promote the kind of community where their donation would be reciprocated (Moorlock et al., 2014).

Donation is less about individual gratification and instead about a community duty (Whitfield, 2014) that donors can relate to, generating a sense of solidarity within unknown others in a 'community'. For example embryo donors believe they are supporting infertility research, and by default, the benefactors of their donated embryos are not completely anonymous due to the imaginatively shared experience of infertility (Scully et al., 2012).

The very word 'donation' exemplifies this emphasis on altruism – implying a one-way philanthropic act (see 'the language of donation' below). The language of gift has been

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2
3 actively promoted by government and health agencies to secure human tissue for various
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5 uses (Tutton 2004; Shaw 2008). On the other hand, concerns about exploitation of donated
6
7 material have led to a body of socio-ethical literature promoting personal property rights
8
9 over biosamples, exemplified by the polemical titles of Andrews and Nelkin's (2001) 'Body
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11 Bazaar: the market for human tissues in the biotechnology age' and Scheper-Hughes' (2001)
12
13 'Bodies for sale – whole or in parts'. More recently, Swiss participants expressed anger that
14
15 they would not be compensated for giving up their embryos and that through donation
16
17 researchers were getting something for nothing (Scully et al., 2012).
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22 Following the Alder Hey scandal in the UK during the 1980s-1990s and the disputed research
23
24 use of cancer cells derived without consent from the late Henrietta Lacks in the US (Hudson
25
26 & Collins, 2013), reasonable concerns about consent and future use of samples have
27
28 evolved into a socio-ethical presumption that all body parts deserve special respect and
29
30 protection. However, empirical literature suggests the public may not see things through
31
32 the same lens as theorists. In previous work ([anon for peer review](#)), authors one and two
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34 ([Locock & Boylan, 2016](#)) explored whether patients and healthy members of the public
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36 contributing to biobanks saw donation as a gift; while the term resonated for a few people,
37
38 for others it seemed exaggerated and even slightly ridiculous. Whilst people were
39
40 concerned to some degree about the governance of research and future use of samples,
41
42 there was little evidence of wanting to retain property rights or seeing samples as a special
43
44 part of oneself. This is consistent with reviews of attitudes to donation (see [Hoeyer, 2008](#));
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46 Lipworth et al., 2011), suggesting neither a gift nor a property rights model is a good 'fit' with
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48 public views.
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3 Importantly, however, Hoeyer (2008) argues that people's views vary depending on the type
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5 of tissue being donated and the position of the donors in relation to the research project
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7 (for example whether they are ill or healthy). He also suggests that donors can
8
9 simultaneously hold apparently conflicting views that a blood sample is '*both* a few drops of
10
11 blood of no consequence *and* important as "part of" the donors.' (Hoeyer 2004:98, original
12
13 italics). Bahadur et al. (2010) confirm that context and purpose of donation, the extent to
14
15 which tissue is seen as valuable or waste product, and the identity of the potential recipient
16
17 all play an influential role in donor attitudes towards both therapeutic and research
18
19 donation, specifically donors' decisions to donate or not.
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25 Machin and Cherkassky (2015:145) claim that the context and purpose of donation results in
26
27 a hierarchy forming based on the value of a body part or outcome acquired through, and
28
29 attached to, the process of donation. As a result, 'all donors and their donations are
30
31 therefore not equal.' (p.146) Here, we aim to explore and broaden this hierarchy. By
32
33 stabilizing the hierarchy so that one purpose of donation is the focus, i.e. research, we are
34
35 able to draw attention to the significance of time and effort within donation. Ontologically,
36
37 time and effort have rarely been acknowledged as 'donated', perhaps as a product of what
38
39 has previously mattered in health research i.e. the physical body (discussed further below).
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44 The creation of a donation can require varying investment from a donor according to what is
45
46 being donated, e.g. compare the physical and emotional labour for embryo donors to the
47
48 convenience of donating a urine sample. This element of generating a donation
49
50 demonstrates the range of emotional attachment donors can have towards their donations,
51
52 raising the question if donating a brain tumour is somehow lower in the hierarchy than
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54 donating aborted fetal tissue, based upon the initial (moral) origins of the donation. In
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3 essence, the epistemological status of the donation can vary according to the ease with
4
5 which the donation is collected and acquired, e.g. surgery, blood test, -and the health status
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7 of the donor, e.g. collected as part of 'care' received or -optional and chosen by a healthy
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9 donor. By focusing on the time and effort considerations to facilitate research donation, we
10
11 argue that a broader view is required for 'what' can be 'donated', with implications for how
12
13 we understand and make sense of 'donation' today.
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21 *Beyond biosamples - other forms of personal research donation?*
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24 We seek to widen the debate on research 'donation' away from its traditional dominant
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26 focus on body parts and fluids, to consider other ways that people may make deeply
27
28 personal contributions to health research, including narratives, personal data, and time and
29
30 effort. These differing forms of donation are rarely considered together in clinical research
31
32 discourse, reflecting a biomedically driven conception of what matters in health research –
33
34 namely the purely physical body – rather than a socially driven, experiential understanding
35
36 of the self. Drawing on the work of Merleau-Ponty, who argued the inextricable link
37
38 between mind and body, we contest this current conception, propose that it is lacking and
39
40 argue for a broader definition.
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46 Since the seventeenth century, the body has come to be viewed through the scientific lens,
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48 'a material object whose anatomical and functional properties can be characterised
49
50 according to general scientific law' (Leder, 1990: 5). The contents and processes of the mind,
51
52 and experiential information collected by the body over time have often been relegated in
53
54 much medical research to a second class of subjectively-informed knowledge, compared
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3 with objective, scientifically-generated knowledge. ~~It is~~ therefore, it is unsurprising that
4
5 clinical research has primarily focused on the body as a resource for measurable, observable
6
7 biosample donations.
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10
11 Merleau-Ponty rejected Cartesian dualism, the notion that the body is an object like any
12
13 other, and argued that human bodies are distinct from other objects and provide a means
14
15 for communication with the world (1962). Thus, the human body is not only a set of
16
17 donatable parts, masses, fluids and samples, but a complex organism interacting with its
18
19 environment to produce an ongoing store of experiences. These experiences are gathered
20
21 through physical communication with the world – seeing, hearing, sensing, tasting, touching
22
23 and, through a series of neural processes, are given emotional colour, interpreted,
24
25 converted to memories and stored for future recall. The body is the meeting point between
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29
30 the person and the world, and is our means for having a world -(1962); as such, all
31
32 experience is embodied. So the body as ‘something one “has”.... has to be augmented with
33
34 an understanding of the body as something that one “is”...the medium by which we are able
35
36 to live our lives, and establish and sustain an individual, reflexive (capable of self-reflection)
37
38 identity’ (Fox, 2012:49)
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43 We therefore suggest that ‘donations’ of experiential information or personal data are in
44
45 fact embodied as they require a state of embodiment to exist. When making physical
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47 donations to research, people also donate time and effort – that which is directly involved in
48
49 the donation process and that involved in getting there (e.g. travel, preparation, fasting,
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51 childcare arrangements, annual leave). Personal information (e.g. cognitive function, lung
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53 capacity, height and weight) and access to medical records also pertain to the body – e.g.
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55 when the body was born; its age; its previous history of interactions with medical
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3 interventions, procedures, drug and vaccines. Future personal information, in the form of
4
5 medical record linkage, may link bodily disease to biosamples many years down the track.
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7 Tutton (2002) contrasts what he calls the 'corporeal' economy of blood transfusion, in which
8
9 blood itself is the valuable life-saving thing, with 'the informational economy of research'
10
11 (p.537), in which blood is only valuable as a route to getting information about DNA. [p.537]
12
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14 Therefore, more attention on informational 'donation' is warranted.
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18 But not only is our body the storage facility containing our repertoire of experiences, it is the
19
20 means through which we verbalise our experiences. As Merleau-Ponty asserts, '...The body
21
22 is much more than an instrument or a means; it is our expression in the world, the visible
23
24 form of our intentions' (1964:5). When people take part in narrative research, they are
25
26 contributing opinions, values, thoughts, reflections and emotions derived from their
27
28 physical and mental experiences. We suggest that the hierarchy of research donations [could](#)
29
30 [should](#) be expanded to include donations of the mind as well as of the body.
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35 Methods

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38 Our purpose in this paper is to stimulate further conceptual discussion of future directions
39
40 for research within the sociology of donations field. Whilst this article is intended to be
41
42 primarily reflective, we feel it is important to ground any such reflection in the views of real
43
44 people, rather than hypothetical ethical or theoretical considerations which may hold little
45
46 meaning or relevance for research participants. In this we follow Shaw's (2015)
47
48 methodological approach, aiming to 'expand the conceptual toolkit' in a way that is 'both
49
50 analytical and empirically oriented, drawing on research that links a series of qualitative
51
52 sociological studies' (pp 952-3). Our analysis is primarily what Heaton (2004) defines as
53
54 'supra-analysis', secondary analysis which 'transcends the focus of the primary study...,'
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3 examining new empirical, theoretical or methodological questions'. We draw in particular
4
5 on a narrative interview study conducted jointly by authors one and two in 2010-11 with 21
6
7 people (table 1) who had been invited to give biosamples for research (approved by
8
9 Berkshire Research Ethics Committee Ref 09/H0505/66). The aim of this study was to
10
11 explore people's experiences of and attitudes towards biobanking and biosample donation,
12
13 both for specific local research studies and for national repositories such as the UK Biobank.
14
15

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17
18 Table 1 about here
19

20
21 However, we also draw more broadly on a linked series of previous studies of medical
22
23 research participation and involvement, examining people's experiences of and motivations
24
25 for such activity ([Locock & Smith 2011a; 2011b; Crocker, Boylan, Bostock Locock, 2016;](#)
26
27 [Locock, Boylan, Snow & Stanisewska, 2017](#)~~anonymised~~). As we extend our discussion to
28
29 non-bodily forms of research donation we draw also on our wider experience of and
30
31 reflections on conducting narrative health research in the UK, including primary and
32
33 secondary analysis. Ethical approval for all these studies included consent for secondary
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35 analysis.
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41 All three authors met for two days of discussion to workshop the data, reflect on the
42
43 literature and develop the conceptual themes.
44

45 46 Conceptual themes 47

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49 From our reflections on the literature and the empirical data, we identify several conceptual
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51 themes which explore the various dimensions of research donation and extend our thinking
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53 beyond traditional models: the language of 'donation'; a hierarchy of biosamples: from
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55 tumour to blood, brains and bodies, from waste to value; alternative informational value;
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3 narratives as donation; coincidental donation, convenience and degree of invasiveness; and
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5 rights, consent and benefits of research participation.
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10 11 The language of 'donation' 12

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14 Language both reflects and shapes how researchers and participants understand the
15 purpose and act of donation, and the nature of what is donated. Examining the language
16 used can thus shed light on underlying assumptions. The very word 'donation' is
17 problematic, conjuring up an image of charity, voluntarism and selfless giving to an
18 imagined or 'fictive' other (Whitfield 2013). 'Donor' similarly calls to mind both philanthropy
19 and – in the medical context – the therapeutic act of the blood donor and organ donor.
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21 Whitfield identifies the use of 'donor' as a wartime propaganda device in response to the
22 marketing challenge of attracting people to give blood to newly collectivised, mechanised
23 and impersonal blood banks.
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29 Drawing on the analogy of donating unwanted items to a charity shop, O'Neill (2009)
30 suggests that three criteria must be met for the word 'donation' to apply:
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- 37 - the item is surplus to our needs
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- 39 - we can easily replace it if needed, if the surplus does not last
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- 41 - the recipient is an anonymous needy individual.
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50 She argues that although therapeutic blood donation does seem to meet these criteria,
51 generally 'bodily donations are obviously different from giving to Oxfam' (p.154). In fact in
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3 our studies, Jane¹ explicitly compared giving tumour samples for research to recycling
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5 unwanted Christmas gifts 'through the charity shop'. O'Neill focuses primarily on
6
7 therapeutic rather than research donation but does consider dead body donation for
8
9 anatomical research. This she concludes does not meet the criteria, because although the
10
11 body may be surplus to the individual's needs, families may still feel a 'need' for an intact
12
13 body and the idea of it being easily replaceable makes no sense. Furthermore (echoing
14
15 Whitfield) she suggests the donation to an intermediate organisation, such as a university,
16
17 removes even the 'fictive' needy individual from the equation.
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22
23 In a previous paper ([anon for peer review Locock & Boylan, 2016](#)), we noted that while the
24
25 verbs 'give' and 'donate' were used readily in people's talk about biosamples, the noun 'gift'
26
27 seemed to hold more substantial meaning as something deliberate and almost ceremonial,
28
29 distinct from the everyday word 'giving'. In our studies Debbie laughed at the idea that
30
31 giving a urine sample for research might be a gift. She mimed the act of handing over a
32
33 present, saying sarcastically, 'Hello, happy birthday'. Whilst this might not be true of all
34
35 types of sample, and people frequently distinguished blood from other types of sample (see
36
37 'a hierarchy of donations' below), it underlines the complexity of seeing 'donation' as a
38
39 single process with a common meaning for all parties. Mahon-Daly (2012) in her study of
40
41 blood donation notes different attitudes in people using 'donate' or 'give', arguing that
42
43 language of 'donating their blood was linked to more expression of altruism.... Donating
44
45 infers a bestowing action, with the freedom for the recipient to do what they want with the
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47 gift. Giving may be more like "letting someone have".' (p.234-5) However, her suggestion
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57 ¹ Where primary data is used for illustration, we have changed participants' names.
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3 that the latter 'implies that the giver wants to have a say in the gift after it has been given'
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5 does not resonate with our findings, which suggest 'giving' was a much more casual act.
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9 In the research donation context, we reflect that nouns such as 'sample', 'biosample',
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11 'material' and 'tissue' may also generate particular meanings, redolent of objectifying
12
13 scientific practice. They may exercise a depersonalising effect, distancing the item to be
14
15 scrutinised from the person. We are unable to think of any parallel collective word in
16
17 therapeutic donation, where the discourse is more likely to be around what specifically is
18
19 given (blood donation, organ donation, bone marrow donation). The verb 'harvest' occurs
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21 both in official information and in the talk of donors. While the implication of fruitful
22
23 productivity has a certain positive note, 'harvest' also conveys an impersonal and almost
24
25 industrial process.
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29
30 Narratives and personal medical data are rarely conceptualised using the same language as
31
32 that used to describe biosamples, which may minimise their potential for being considered
33
34 as donations. But people routinely talk about 'giving' an interview, and interviews, personal
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36 information and information contained in medical records, conceivably meet O'Neill's
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38 (2009) criteria for donations. We explore this further in 'alternative information value'.
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46 A hierarchy of biosamples: from tumour to blood, brains and bodies, from waste to value

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48
49 In line with Hoeyer's (2004) and Bahadur et al's (2010) conclusions that the type of sample
50
51 affects the attitude of the donor, we have also found a spectrum of concern, from
52
53 distasteful waste product at one end to valued, life-giving material at the other. Perhaps the
54
55 most extreme form of waste product is tumour, which is not just passively unwanted in the
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3 sense of being of no value, but actively unwanted in the sense of being a harmful 'thing',
4
5 invading the body.
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9 In cancer and other serious diseases, donation to research may be experienced as the taking
10
11 back of control over one's body and illness. The excised tumour – which would otherwise
12
13 simply be thrown away with the rubbish – is harnessed for good, perhaps diminishing its
14
15 threatening and repellent nature. ~~It is~~ Tumour tissue certainly 'surplus to requirements', as
16
17 O'Neill (2009) suggests, though the idea that anyone would want to replace it or that an
18
19 'anonymous needy individual', in this case a scientific researcher, is waiting for it are less
20
21 relevant. Nonetheless, particularly in the context of possibly hereditary cancers, participants
22
23 could anticipate a direct familial benefit for their own descendants, as well as a more diffuse
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25 benefit to 'other people like me in future'.
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31 Urine and saliva may fall further along the continuum, unvalued and faintly distasteful, but
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33 not as toxic as tumour samples. Urine, in particular, is difficult for people to conceptualise as
34
35 valuable to anyone other than a researcher. People may struggle to see why donating
36
37 something that would otherwise be flushed down the toilet could ever be considered
38
39 controversial, risky or indeed special. Saliva can be understood as a source of valuable DNA
40
41 information (for example in forensic dramas or paternity cases); even so in our -participants
42
43 it evoked remarkably little concern.
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48 At the opposite end of the spectrum of live biosample donations lies blood, with all its
49
50 physical and symbolic significance. Blood keeps us alive; it represents familial bonds ('blood
51
52 relatives'); and in the Judaeo-Christian tradition it holds sacramental and sacrificial meaning.
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54 Blood-related metaphors permeate the language: we talk of something 'coursing through
55
56 our veins' or being 'in our blood', conveying something essential to our identity. Yet even in
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3 the case of blood, people may take a very pragmatic and unconcerned attitude to its use for
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5 research. Gerry, a participant who had Motor Neurone Disease (MND), said he wouldn't
6
7 think twice about 'a few phials of blood'. Jim, who had hepatitis C, said he saw blood in a
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9 similar way to other tissue samples he had given over the years, drawing on an objectifying
10
11 metaphor of the body as something he viewed 'quite mechanically' and highlighting the
12
13 ability of blood and cells to replace themselves.
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18 However, ~~it is noticeable in~~ ~~according to~~ our participants' accounts suggest that keeping a
19
20 clear separation between research and therapeutic donation of blood can be hard. Blood
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22 donation – perhaps because of Titmuss or many media campaigns – seems strongly
23
24 associated in the public imagination with therapeutic donation and saving lives, and
25
26 narratives often slipped into this territory. Debbie, for example, having laughed at the idea
27
28 of urine as a gift, drew a specific contrast between blood and other bodily fluids, drawing on
29
30 her own past history of both giving and receiving blood for therapeutic purposes.
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35 Asked specifically whether this applied to research blood donation, she confirmed that she
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37 still saw it in these terms 'because I'm always amazed at how much information they get out
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39 of how little.' We return to this in 'Alternative informational value'.
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43 Research biodonations after death – either specific body parts which can only be donated
44
45 after death, such as brains and corneas, or whole bodies for scientific research – represent a
46
47 very different form of donation to 'live' biosample donation. Organs such as hearts, eyes
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49 and brains carry an emotional investment which may make them "troubling to donate
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51 compared with 'lesser' body parts or materials even when the donation takes place post-
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53 mortem." (Bahadur et al., 2010, p.871).
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3 Duncan had already signed up to give his brain to an MND research 'brain bank'. He said it
4
5 was an obvious decision – 'a bit of a no-brainer'. Steve, a cancer patient, could not
6
7 understand why 'people get all precious about it'. Like Duncan, he took a pragmatic view of
8
9 death and waste, commenting that the body is 'either burnt or it rots, one of the two', so it
10
11 might as well be 'put to good use'.
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15 Others expressed uncertainty and in some cases a degree of squeamishness. Bruce found
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17 brain donation and his own death 'an odd thing to think about'. Here and in other cases the
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19 squeamishness seemed less about the specific body part and more the sheer fact of
20
21 mortality and the dead body. Aileen held a similar view that 'when you're dead, you're
22
23 dead', but identified a certain 'horror factor', perhaps akin to Midgely's (2000) 'yuk factor' in
24
25 relation to biotechnology. Debbie, although willing in principle to donate her brain, found
26
27 the idea of a 'brain bank' 'really horrendous', and joked 'I would like to withdraw a brain,
28
29 please.'
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35 Alongside the brain, donations involving the eyes and corneas evoke similarly mixed
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37 emotions.
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41 Anne, a healthy volunteer, contrasted her own pragmatic view about using body parts after
42
43 her death with that of family members, who were 'very happy to donate some things but
44
45 not other things', explaining 'lots of people can't bear the idea of donating their eyes.'
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49 Whole-body donation after death is also a source of conflicting and ambivalent views. Jane,
50
51 who had not thought about it before, felt brain donation for research would be acceptable,
52
53 but felt less sure about whole-body donation, especially use of her body by medical
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55 students and the 'feeling of being scrutinised'.
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3 Ellen, by contrast, was actively considering donating her whole body to medical science. She
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5 cried as she recalled a TV programme about how one medical school holds a 'service of
6
7 thanks every year for the families of those who have donated their bodies.... it makes me
8
9 even more inclined to do it.'

10
11
12
13 In the few years before the fieldwork was conducted, Gunther von Hagens' 'Bodyworlds'
14
15 exhibition of plastinated bodies had visited the UK and a human dissection was shown on
16
17 TV. This seemed a step too far for some people. In Steve's words:

20
21 I wouldn't like the indignity of being dissected in public like that German guy did
22
23 recently...An organ, specific organs I wouldn't have a problem with.
24

25
26 A common thread in these views is the importance of bodily dignity and a sense that the
27
28 body is the self, requiring respect and shielding from inappropriate scrutiny. As Steve
29
30 implies, this is in contrast to 'specific organs' – as in living donation, people express nuances
31
32 and gradations within donation after death, which are rarely reflected in the media or the
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34 academic literature.
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36

37 38 39 Alternative informational value

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42 Earlier we noted how Debbie articulated that the value of blood samples for research lay
43
44 not so much in its life-giving properties but in the information derived from it. This
45
46 prompted her to somewhat re-evaluate her views about the informational value of urine.
47
48 This resonates with Machin and Cherkassky's (2015) emphasis on how the *purpose* of
49
50 donation may generate different meanings. Yet intuitively Debbie could not believe urine
51
52 was likely to yield as much valuable information as blood. Informational value is not
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54 necessarily immediately obvious.
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3 Whilst biosamples are traditionally seen as 'donations', other forms of information are
4
5 differently conceptualised and differently valued, not even featuring in the assumed
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7 hierarchy of donations. When donating to the biobank, people are usually asked to consent
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9 to linking their data to their medical records and to provide accompanying personal
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11 information. Linking to medical records results in a holistic picture of current health to be
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13 established, allows for information to be tracked over the life course and for the
14
15 development of future information through research, e.g. genetic marker studies. Other
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17 information might include questionnaires about lifestyle, psychometric measures of
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19 cognitive functioning, and other biometrics, such as measurements of weight, height, BMI,
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21 blood pressure, etc. The participants recognised the value in this information: Janet
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23 explained that although it is not hard and fast like that gleaned from a blood test, it is
24
25 important to give honest answers.
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32 It's very tempting to exaggerate where you know it's good to do it and underplay it
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34 when it's good not to, like the alcohol. But...unless we give honest answers here it's
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36 not going to help the research. And when it comes to things like your blood test,
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38 then you can't fake that, so why fake the other parts of it...?
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42 Biosamples, seen as objective, scientific samples containing encoded information that
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44 requires careful work to extract, are judged inherently more valuable than self-reported
45
46 information, which is considered likely to be inaccurate. However, the linkage and
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48 triangulation of a range of data is more valuable than any single sample alone, consistent
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50 with Hoeyer's assertion that ~~there is~~ more value lies in the information derived from the
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52 sample than in the sample itself. This reinforces the case for widening the definition of
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54 donation beyond biosamples alone.
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Narratives as donation

Also neglected from the traditional hierarchy of donation, the value held by narrative interviews donated to qualitative health research studies is distinct. Biosamples and supplementary information require each other to extract maximum value, whereas the value of a narrative is more self-contained and intrinsic, and both need interpretation and analysis to achieve their full value. Mazanderani et al. (2013) extend Mitchell and Waldby's (2010) notion of biovalue in relation to tissue samples to the value which may be derived from narrative interviews. This 'biographical value' may include value to social scientists, clinical researchers and doctors, in understanding better the embodied experience of illness, but also value to the self and to other patients. Narratives (particularly celebrities') could also raise the profile of a disease and generate pressure for research funding and better treatment.

In donating an interview to health research, people may consent to the archiving of their interview for use in secondary analysis, meaning that after their participation has ceased, potentially after their death, their narrative still exists, and still has a purpose for social science. Just as donated bodies can be used in a variety of settings (education and training, research, organ harvesting, etc.), interviews can be repurposed to answer different research questions. Equally, ~~it is important to treat~~ donated interviews should be treated with the same dignity with which people expect their bodies to be treated after death, starting with informed consent and ensuring they are fully informed about the potential future uses of their donated experiences.

Stories of personal experience may contribute to research in ways which go beyond data collection and research participation. In the UK, the involvement of patients and members

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2
3 of the public ('PPI') in research has become an accepted part of research process. This may
4
5 include reviewing information sheets to setting research priorities and designing research
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7 studies. Patients bring their physical and emotional experience of illness and treatment to
8
9 bear on research to improve its relevance and acceptability for other people. Although there
10
11 is a substantial literature on motivations for PPI, which includes discussion of altruism,
12
13 voluntarism and the potential to help others, this has not to our knowledge previously been
14
15 couched in terms of 'research donation'.
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20 Returning to O'Neill's criteria for how we understand donation, firstly, interviews and other
21
22 additional information are surplus to our needs. Secondly, such donations do not need to be
23
24 replenished – stories of personal experience can be retold or reinterpreted and giving
25
26 personal information does not create a deficit. Finally, many people who give their stories
27
28 say they were motivated by altruism or to ensure others have improved experiences
29
30 (Lucius-Hoene et al., 2013; Peel et al., 2006). Michael, a biobanking participant with
31
32 Hepatitis C, was happy when the consultant asked him to tell his story to a group of medical
33
34 students:
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40 'I poured my heart out to them. One in twelve people have this horrible, evil little
41
42 virus, and I want to do as much as I can to help others and to help this study'
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45 Coincidental donation, convenience and degree of invasiveness

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47
48 As the above suggests, another factor affecting people's attitudes to donating biosamples is
49
50 not just the nature of the sample being taken but also the level of burden, discomfort, time
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52 and effort involved, and indeed perceived personal benefit, factors which inevitably affect
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3 contributions to other types of research, such as narrative interviews or indeed clinical trial
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5 participation.
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8 People in our studies providing research biosamples during the course of their treatment
9
10 commonly regarded this as uncontroversial and were unconcerned about future uses. One
11
12 said, 'it's not as if you've got to go into hospital for special surgery or to have extra blood
13
14 taken'. Even if extra visits are required, this may not be seen as particularly inconvenient.
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17
18 Ellen, who gave additional blood and urine samples during her IVF pregnancy, - recalled the
19
20 research midwives being 'terribly apologetic' that this would involve an extra blood and
21
22 urine test every month but she was 'very, very happy to do all of this'.
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24

25
26 We also spoke to several people who had been invited to take part in the UK Biobank,
27
28 involving a two-hour visit to a special UK Biobank centre. This degree of inconvenience was
29
30 certainly off-putting for some. Aileen (a frequent participant in diabetes research) explained
31
32 that a letter came with a fixed appointment time and it 'just didn't fit in with what was
33
34 going on at that time' so she opted out.
35
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37
38 Yet her commitment to the diabetes research centre was extensive and often involved
39
40 lengthy visits which she said she enjoyed. Others took part willingly in the UK Biobank,
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42 although – as is often the case with research participation – not necessarily having read the
43
44 leaflet fully.
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46

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48 At the more invasive end of the spectrum, four -of our participants who had MND had
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50 contributed to an MND biobank which included giving spinal fluid samples via lumbar
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52 puncture. Such an invasive procedure creates a wholly different experience of donation. In
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54 this case participants were offered the option to take part in other aspects of the study, but
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3 omit the lumbar puncture, which Duncan and Gerry did; Duncan previously had a bad
4
5 experience of it, and Gerry explained that although he did not normally mind needles and
6
7 blood samples, 'It was just that one area of the body I just didn't want them to touch.'

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9
10 By contrast Sam agreed to have a lumbar puncture, saying 'I have a good pain threshold and
11
12 my one thought always is, "I'm going to help, no matter how uncomfortable, how long it
13
14 takes".'

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16
17 We also spoke to several healthy participants in diabetes research, some of whom
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19 consented to invasive procedures (being injected with adrenaline and then having fat
20
21 biopsies taken from the abdomen and thigh). Aileen had withdrawn from one study which
22
23 required a blood sample from an artery in her leg because it was too painful:
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29 It did put me off slightly at the time...Because they've got more invasive as they've
30
31 gone on you do start to think, "...Do I really want to go through this?" But having
32
33 said that, if the letter came through next week or in a month's time, I'd probably do
34
35 it again.
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38
39 Motivation to donate biosamples in our studies was often tied to people's jobs (e.g. Aileen
40
41 was -a healthcare assistant) or family history. Another regular participant at the diabetes
42
43 research centre had a family history of heart disease and high cholesterol, and found the
44
45 regular blood tests reassuring. As -the son of a pathologist, he was familiar with biosample
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47 research. Commonly people used terms like 'giving back' to the NHS for care received, by
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49 themselves or family.
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54 Willingness to get involved in such invasive testing may thus depend on a range of factors,
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56 including perceived personal health and other benefits; familiarity with healthcare and
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3 health research; a sense of moral commitment and diffuse reciprocity; perceived degree of
4
5 risk or discomfort; and severity of illness. Arguably any research donation requires a certain
6
7 amount of time and inconvenience, and the impact of this should not be minimised. Time
8
9 getting to the appointment may be invisible to researchers. One UK Biobank participant said
10
11 she put a fruitcake in the oven before heading to the appointment, in the belief (having not
12
13 read the leaflet) that 'I was going to pop along, give a blood test, answer a few questions
14
15 and whip away. And if it said two hours would I still have done it?'

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20 ~~It is important to bring t~~Time and effort must be brought into the discussion about
21
22 donation, and not solely when thinking about barriers and facilitators. Widening the
23
24 definition to include these factors encourages researchers to be mindful of what donation
25
26 entails and ensures that the donor is respected and credited for every aspect of their
27
28 participation.
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33 In comparison with lumbar punctures and other physical donations, narrative donations
34
35 may perhaps seem minimally invasive on the surface. However, participating in an interview
36
37 requires time, the amount of which is often indeterminable at the outset, and mental effort
38
39 – recalling and describing past experiences, worries, thoughts, and managing the emotional
40
41 labour involved in the process. Despite being seen as 'inherently innocuous' (Peel et al.,
42
43 2006), narrative interviews can focus on sensitive topics that invoke a range of emotions;
44
45 they can be enjoyable, but can also arouse feelings of anger and distress (Peel et al., 2006;
46
47 Lucius-Hoene et al., 2013). The specifics of the time and effort involved in narrative
48
49 donation, requires us to think differently about according them a position in the hierarchy of
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51 donations.
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57 Rights, consent and benefits of research participation
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3 A consistent theme across our studies (including participation in clinical trials and cohort
4 studies as well as biobanking) has been not just willingness to participate in research, but
5 active enthusiasm for doing so and a strong sense of personal gain. This is not simply a
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9
10 'therapeutic misconception', as it is often described, but rather a rational assessment of a
11
12 wide range of personal benefits, including enjoyment and satisfaction, learning about
13
14 science, enhanced relationships with a clinical team providing your care, and increased
15
16 monitoring or feedback about one's health. ([Locock & Smith 2011b; Locock & Boylan,](#)
17
18 [2016anon for peer review](#)). Over several studies, a theme of disappointment has emerged
19
20 that the right to be told about research opportunities in the NHS Constitution is not always
21
22 enacted.
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27 This assessment is underpinned by trust in regulation and in the source of the invitation to
28
29 take part. This is not to say that people feel information and consent are unimportant;
30
31 rather many feel they should have a choice about how much depth they want to go into,
32
33 and that if they wish to make their decision based on cursory reading of the information
34
35 that is their adult right. In saying this, they mirror the behaviour of most of us when faced
36
37 with lengthy terms and conditions – they tick the box and move on (Bakos et al. 2014). Of
38
39 course some people want to read every detail, and some people are inherently cautious
40
41 about sharing their data. The phrase 'Big Brother' was used more than once in connection
42
43 with the UK Biobank and suspicion about the use to which samples might be put in future.
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45 But many people seem relaxed about this, particularly in the case of 'waste' material such as
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tumour or urine. We have found little evident sense of property rights, and considerable
concern about burdensome over-reactions to situations such as Alder Hey, as Bruce argued:

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3 I never understood all this fuss that came out - I know what they did at Alder Hey
4
5 wasn't transparent, but I don't think it was wrong. ...This incredible bureaucracy that
6
7 was loaded on the NHS to track down body parts....You get the impression that any
8
9 bit of your body they take, you have to sign a consent form or you can expect to ask
10
11 for it back next year. ...I'm not hugely attached to my body and I hope nobody else
12
13 will be after I'm dead, and certainly to the extent of lumbering a stretched NHS with
14
15 extra costs just for a bit of . . . I mean, I trim my toenails and they go in the bin.
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19 [laughs]
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21

22
23 There is certainly potential for personal benefit in Taking part in narrative interview studies
24
25 in health research certainly offers potential for personal benefit. In their study about
26
27 participation in qualitative interviews, Lucius-Hoene et al. (2013) reported that participants
28
29 found the experience exceptional as they had an opportunity to talk uninterrupted about
30
31 their condition and to be taken seriously by the interviewer. The interview presented an
32
33 opportunity to reflect on their feeling about their illness and learn about themselves. Many
34
35 of their participants found it an important and deeply moving experience, describing it as a
36
37 liberating and pleasurable event that made them feel valued and renewed their sense of
38
39 engagement with their lives. But for others it was a more negative experience, causing them
40
41 to feel anger and distress. For a third group it did not seem to hold any positive or negative
42
43 significance. This lack of significance chimes with the notion of interview participation as
44
45 'inherently innocuous' (Peel et al., 2006).
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51 These experiences of interview studies resonate with how people talk about their
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53 experiences of donating biosamples: donation can be meaningful and beneficial; or
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3 donation may not be particularly significant and may be easy and uncontroversial to do; and
4
5 it can occasionally be negative, perhaps experienced as burdensome, invasive or painful.
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10 11 Concluding remarks

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14 As Bahadur et al. (2010) argue, 'one of the significant limitations of principlist, bioethics-
15 based regulatory governance is that.... it necessarily presupposes that all donors have a
16 standard set of concerns and moral values' (p.872).
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21 In this paper we have added to the evidence that such a 'one-size-fits-all' understanding of
22 research donation is not helpful. [We argue for a more nuanced understanding of](#)
23 [biosamples, but also crucially that other forms of research contribution, including](#)
24 [narratives, lifestyle and biometric data, agreement to take part in a study and involvement](#)
25 [in research design, can all be conceived of as forms of embodied donation.](#)
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35 Biosample donation takes widely differing forms with very different consequences for
36 individual donors; yet much of the ethical literature and research ethics processes treat all
37 bodily samples as equivalent – equally risky, equally concerning, and equally in need of
38 stringent conditions. Equally, relatively low-risk research studies using qualitative methods
39 or gathering self-report information are treated to similar levels of ethical scrutiny. This
40 discourse takes little account of the real-life responses of actual participants. Hoeyer (2010)
41 has challenged attempts by scholars, faced with contradictory data about people's attitudes,
42 to find an underlying consensus, and establish a single universal principle for
43 conceptualising the relationship with donors. He queries whether generic terms such as
44 'biobank' and 'donor' are fit for purpose in capturing this variety of motivations and wishes.
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3 It is easy to argue that casual attitudes to donation amongst patients result from simple lack
4
5 of awareness; certainly in interviewing or gathering self-report information it is possible to
6
7 create more anxiety by asking questions, and presenting scenarios where the potential for
8
9 harm is foregrounded. The very act of questioning people or involving them in a
10
11 hypothetical deliberative process may plant a seed of doubt that their judgements have
12
13 been under-informed and they 'ought' to think differently as responsible citizens (Hoeyer
14
15 2003). But a counter-argument – that people are mature decision-makers who have a right
16
17 to take a casual attitude if they wish – is rarely made. The right to donate, the right to trust
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19 in researchers and research regulation, and the right not to have to read lengthy,
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21 impenetrable and risk-averse participant information get little attention compared to the
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23 right to anonymity, and concerns about data protection, bodily integrity and autonomy.

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30 Hoeyer (2010) notes a move to adopt the term 'participant' rather than 'donor'

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33 '...to acknowledge the ongoing mutual nature of the relationship....and to avoid
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35 connotations to an over-and-done-with 'gift'. We might, however, thereby
36
37 overemphasise the element of participation. It is not an equal relationship and some
38
39 donors will wish to limit their workload and obligations rather than enhance their
40
41 influence on decision-making. Rather than emphasising *participation* I believe
42
43 researchers should ask themselves what type of relationship specific donors have
44
45 opted for when agreeing to participate.' (p.350)

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51 Thus even within the biobanking world, a pluralist sociology of donations is needed.

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53
54 | More importantly, moving beyond biosamples, other types of contribution, including
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56 supplementary information (medical records, cognitive tests, lifestyle questionnaires, etc.),
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3 qualitative interviews, clinical trial participation, general time and effort in taking part in
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5 research, and even patient involvement in research design, have traditionally [and](#)
6
7 [regrettably](#) been omitted from the donation literature. We argue that not only ~~can~~ [should](#)
8
9 they be regarded as donations in their own right, but [their](#) contribution to more valuable
10
11 triangulated information that allows for increased scientific endeavour, sometimes over
12
13 many years, [must be acknowledged and further explored](#). There is an important place for
14
15 this type of donation, which further demonstrates the need to pluralise current definitions
16
17 of 'donation'. The donation is not just the sample, but is so much more – and so much else.
18
19 The ongoing nature of many research contributions fits with the concept of 'dynamic
20
21 consent' in biobanking (Kaye et al. 2015), which provides continuing digital contact with
22
23 participants and enables them to see and agree to how both samples and data may be re-
24
25 used beyond the original purpose if they wish. Kaye et al. suggest dynamic consent could
26
27 extend to other forms of clinical research beyond biobanking; we believe the idea could
28
29 usefully be applied to narrative social science research too.
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37 In past work author two -has focused on motivations for taking part in clinical trials, and
38
39 particularly the degree of perceived personal benefit involved, challenging the discourse of
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41 altruism, which is so routinely invoked ([Locock & Smith 2011a; 2011b](#)). Neat dichotomies
42
43 between personal benefit and benefitting others – between 'altruistic' donation and self-
44
45 interest – fail to capture the messiness of real people's motivations. Lucius-Hoene et al.
46
47 (2013) have shown how the same complexity exists in reasons for narrative research
48
49 participation. A pluralist sociology of research donations needs to embrace not just
50
51 hierarchies of different types of donation and varying levels of value attached to them, but
52
53 also the range of motivations and the shifting boundary between donation and exchange.
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We suggest that a 'sociology of research contributions' might be a more nuanced way to express the mutual and sometimes ongoing relationship between researchers and participants across a range of study types.

For Peer Review

Table 1 Sample characteristics, biobanking study

Participant	Type of biobanking/sample	Gender and age
01	Blood and tumour samples, cancer; blood, saliva and urine, population biobank	F, 55
02	Blood and tumour samples, cancer	M, 58
03	Healthy volunteer, population biobank (declined)	M, 43
04	Healthy volunteer, blood samples and fat biopsies, diabetes research (declined population biobank)	F, 49
05	Blood samples, cancer	F, 52
06	Healthy volunteer, blood, saliva and urine, population biobank	F, 49
07	Healthy volunteer, blood, saliva and urine, population biobank; blood samples and fat biopsies, diabetes research	F, 52
08	Blood and liver tissue samples, Hepatitis C Virus	M, 54
09	Blood and spinal fluid samples, Motor Neurone Disease; blood samples, MND DNA bank	F, 56
10	Blood samples, Hepatitis C Virus	M, 66
11	Healthy volunteer, blood samples and fat biopsies, diabetes research (accepted and declined on different occasions)	M, 49
12	Blood and spinal fluid samples, Motor Neurone Disease	M, 63
13	Blood samples and post-mortem brain bank, Motor Neurone Disease (spinal fluid samples declined)	M, 61
14	Healthy volunteer, blood samples, stroke study as family member control; blood, saliva and urine, population biobank	F, 62

15	Blood and urine samples, high risk pregnancy; healthy volunteer, blood, saliva and urine, population biobank	F, 45
16	Blood samples, Motor Neurone Disease (spinal fluid samples declined)	M, 54
17	Blood and urine samples, high risk pregnancy	F, 37
18	Blood samples, Hepatitis C Virus	M, 49
19	Healthy volunteer, blood and umbilical cord blood samples, pregnancy biobank	F (age withheld)
20	Healthy volunteer, blood and urine, population biobank	M, 33
21	Healthy volunteer, blood and urine, population biobank	F, 44

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