

Can Broad Consent be Informed Consent?

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In biobanks, a broader model of consent is often used and justified by a range of different strategies that make reference to the potential benefits brought by the research it will facilitate combined with the low level of risk involved (provided adequate measures are in place to protect privacy and confidentiality) or a questioning of the centrality of the notion of informed consent. Against this, it has been suggested that the lack of specific information about particular uses of the samples means that such consent cannot be fully autonomous and so is unethical. My answer to the title question is a definite ‘yes’. Broad consent can be informed consent and is justified by appeal to the principle of respect for autonomy. Indeed, I will suggest that the distinction between the various kinds of consent is not a distinction between kinds of consent but between the kinds of choice a person makes. When an individual makes a choice (of any kind) it is important that they do so according to the standards of informed consent and consistent with the choice that they are making.

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On the face of it biobanks offer a great deal of hope for the future progress of medical science (Oosterhuis *et al.*, 2003; Hansson *et al.*, 2006; Helgesson *et al.* 2007; Christensen, 2009). As repositories for various kinds of human biological collections, they can contain a broad range of material including DNA, tissue, tumour samples or blood. They are also likely to include linked clinical and/or phenotypic data on the donors of the samples so that the potential for useful, patient-related research is maximized. Though their specific purposes can vary widely the broad point of biobanks is to house and facilitate on-going research on samples that have already been collected. If the potential that is claimed for them is to be realised, biobanks need to be organized in such a way that their promise has the best chance of being fulfilled and that the individual rights and choices of the research participants are respected as much as is possible. A good deal of this respect is shaped at the point of entry to the biobank in the form of the consent process.

Most easily, when we think of informed consent to participate in research we imagine being very specific about the nature of the research and of the participant’s involvement in it.¹ This involves providing specific information about the nature of the research, who will

be conducting it and what the specific anticipated outputs are. Quite clearly, however, this model of specific consent runs counter to the aims of broad, future-oriented collaborative research that might form part of the purpose of a biobank. In biobanks, a broader model of consent is often used and/or justified by a range of different strategies which make reference to the potential benefits brought by the research it will facilitate combined with the low level of risk involved (provided adequate measures are in place to protect privacy and confidentiality) or a questioning of the centrality of the notion of informed consent (Eriksson and Helgesson, 2005; Barr, 2006; Brekke and Sirnes, 2006; Hansson *et al.*, 2006; Helgesson *et al.*, 2007; Helgesson, 2008; Caulfield and Weijer, 2009; Otlowski, 2009; Hoppe, 2011). Against this, it has been suggested that the lack of specific information about particular uses of the samples means that such consent cannot be fully autonomous and so is unethical (Caulfield *et al.*, 2003; Arnason, 2004; Hofmann, 2008, 2009; Hofmann *et al.*, 2009).

My answer to the title question is a definite ‘yes’. Broad consent can be informed consent and is justified by appeal to the principle of respect for autonomy. Indeed, I will suggest that the distinction between the various kinds of consent (broad, narrow/specific and open/blanket) is not a distinction between kinds of consent but between the kinds of choice a person

makes. When an individual makes a choice (of any kind) it is important that they do so according to the standards of informed consent and consistent with the choice that they are making.

The plan in what follows is to first get clear about the concepts at issue. In this respect, I give an account of what I mean by broad consent as it applies in the context of biobanks. I will also give a brief account of the nature of informed consent and its ethical justification. This part of the article will cover familiar terrain but will highlight those aspects of these concepts that are relevant to the question at hand. The second part of the article considers the scope of decisions that we might legitimately—that is, autonomously—make with specific reference to an example that is analogous to broad consent in the biobank context. The third part of the article considers arguments about the right to genetic ignorance. If, as some have argued, there is no right to genetic ignorance—there is no right not to know—this might be used to undermine the ethical legitimacy of broad consent. In the final part of the article, I will consider two objections to my position.

The Nature of Broad Consent

Here, I will understand broad consent to encapsulate consent to a range of different kind of conditions. Perhaps the clearest and most distinct of these is consent to a particular kind of governance arrangement (Arnason, 2004; Kaye, 2004; Knoppers, 2005; Rothstein, 2005; Hansson, 2006; Wendler, 2006; Laurie, 2009; Hunter and Laurie, 2009). That is, when an individual gives ‘broad consent’ to the use of their sample or data in future research they are giving permission for someone else, usually in the form of the governing body of the biobank, to decide how to use that sample or data. Broad consent though can cover and include other elements besides consent to governance. Consent to governance is an important element to include in an account of broad consent because it helps us to isolate the kind of decisions involved. Other features that we might include here are an account of a general program of research, an account of the general goals of research or an account of the institutional values and aspirations of the biobank.

When we include reference to the governance arrangements in broad consent we acknowledge the importance of how future decisions will be made. When we include an account of the general program of research we acknowledge that in some contexts and for some biobanks the type of research conducted will be

more focussed. For the broadest biobanks, like UK Biobank and other population biobanks the program of research may only be specifiable very generally if at all. In such cases, the broad consent may include reference to the goals of the research that will be conducted using the resources of the biobank or an account of the institutional values and aspirations. Overall, I will understand these four general kinds of consent contents as being elements of broad consent.

I will take it here that the inclusion of an element of consent to a process of governance is an important feature of broad consent though not, given the range of definitions of governance, a necessary one. Crucially, this element does not clearly separate broad consent from open consent—we can easily imagine cases in which there was a process of governance but that it was so minimal as to permit almost any kind of research: ‘You give me your sample and I decide what research it would best serve’. The underlying point here is that the distinction between broad and open consent is probably impossible to draw. My main concern in what follows is to distinguish between narrow consent and the range of consents between broad and open. I will have something to say at the end of the last section about how we might settle the kind of information that it might appropriate to provide in the range of cases between broad and open consent.

Unsurprisingly, broad consent is not an ideal term for this process but it does make some sense. Arguably, the sense the term makes is connected to the breadth of research projects that are and will be included under the auspices of the biobank. It is unclear however that it does justice to the full and complex range of elements mentioned above. In any case, I am more concerned with the content of the kind of consent than with the terminology. I am particularly concerned to distinguish the category of broad consent, understood as described above, from specific or narrow consent.

Informed Consent

Countless pages have been written about the nature and justification of informed consent, the specifics of which are not relevant here. On the standard understanding, the important elements of informed consent are the provision of information, the voluntariness of the choice and the competence of the chooser to make the choice—so the potential research participant should be provided with information relevant to the decision to participate, they should be able to choose freely about their participation and they should be competent to decide

(Allen and McNamara, 2011). There are two key elements of the standard account that are worth emphasizing here. First, when we speak of obtaining informed consent we are invoking a process in which the potential research subject is, among other things provided with information of various sorts about the research and asked to make a decision about entering the trial (Cambon-Thomsen, 2004). The emphasis here is rightly on the decision, one way or the other, to be a part of the research. Second, when considering the proper provision of information it is not enough that the prospective research subject is given the information. There should be some allowance or provision for understanding (Allen and McNamara, 2011). What matters is that the decision is informed by the relevant details of the research and that the individual chooser comprehends and assimilates them into their own set of values, desires and preferences. Again, a good deal has been written about the amount and specificity of the information that is required—the material relevance requirement is here intended to be a version of the subjective standard of information provision (Hoeyer, 2008). In sum, it is important to bear in mind that ‘giving informed consent to X’ is in certain respects shorthand for ‘making a decision, with appropriate understanding, to X’.

In the context of consent to participate in a biobank much of the discussion revolves around the amount of information that is given (and indeed can be given) to prospective participants. The general worry is that the details of the research are unknown at the time of donation so the donor cannot be informed about the precise nature of the research in which they (and their samples) are involved. Importantly, at the time of donation the information about future research is not available and so cannot be disclosed (Allen and McNamara, 2011). The research participant then, does not know the relevant facts of the specific research and so does not know to what they consent. This is the fundamental objection to broad consent to participate in a biobank (and one which the argument of this article directly addresses).

The primary justification of the requirement to obtain informed consent is respect for autonomy (O'Neill, 2002; Beauchamp and Childress, 2008; Kihlbom 2008). On the standard understanding of autonomy as the capacity for self-governance, the general idea is that an individual's capacity to govern their own life is of significant value and worthy of respect. That is, we attribute moral worth to the individual's ability to determine the shape and course of their lives—from the very general, ‘policy’ decisions to very particular preferences and whims (Manson and O'Neill, 2007).

Since we attribute value to the capacity to make these decisions, asking the individual to choose whether or not to participate in research amounts to the proper respect of this capacity. It is crucial that the capacity that is being respected, the capacity for autonomy, is a general decision-making one that applies just as much to the very important ‘life’ decisions that a person makes as it does to particular, local decisions about daily life choices.

The moral obligation to obtain informed consent can also be justified by appeal to a concern for the welfare of the research participant. That is, by asking the individual to decide whether to participate we allow them assess and value the various risks and benefits by their own lights, thus generally achieving a better, more personalised assessment of the risk of harm balanced against the potential benefits. However, if we were primarily concerned with protecting people from harm then sometimes, perhaps often, we would ignore what they actually want precisely because it is harmful (e.g. smoking, drinking, etc.). In the research context, informed consent most clearly functions precisely to enable individual participants to choose to take on certain risks for the sake of the possible benefits and according to their own plan of the course of their lives (Edwards *et al.*, 2004). Thus in research, the requirement to obtain informed consent is not primarily justified by the need for protection from harm or risk of harm, but by the requirement that we respect autonomy.

The Scope of the Choice

What is important about the respect for autonomy justification and the corresponding idea of self-governance is that it does not specify anything about the scope of the choices and decisions that an individual is entitled to make about the way in which they govern their life. Indeed ‘governing’ here involves ‘laying down laws’ to oneself at all levels not just making first order decisions. Indeed the various levels of choices that individuals might legitimately and actually make can be seen in discussions of weakness of will and addiction. In particular, the idea of second order desires to desire discussed by Frankfurt and others provides us with clear examples of precisely the kind of orders of decisions at issues here (Frankfurt, 1971). A person may decide that they do not want to eat cake and adopt a strategy which takes away the possibility of choice or, more simply, they may decide to decide not to eat cake any more. Two other more complex examples of choices of this kind are

career decisions and long-term relationship commitments like marriage. One might argue that the kind of choice that one makes in relationships like marriage is a choice to commit—a choice to continue to choose in particular ways. But even if this is not the case, the commitment to a marriage looks like a decision about, among other things, future choices. Moreover, these decisions look to be perfectly normal and reasonable decisions made by autonomous agents with full information relative to the kind of decision being made. Autonomy, here understood as self-governance, and its moral significance entitles an individual to make decisions, to make decisions about the kind of decisions they make, to decide about the way in which they make decisions and to decide not to make some decisions.

It is important to notice that these future-choice limiting or determining choices are not necessarily liberty restricting (Hofmann, 2008). In many cases, they simply change the range and nature of the choices that the individual will make. There are clearly cases where autonomous decisions that individuals make *do* restrict their future liberty. The case of Ulysses and the Sirens is a pertinent one: Ulysses' choice to be bound to the mast restricted his liberty to act when he heard the Sirens (Elster, 2000). Buying a house is an interesting example here. In some cases buying a house can be liberty restricting (no longer having the money or the same degree of freedom to move) but it need not. I may buy a house just because I wish to make a commitment to living in a particular area and no longer wish to have to make decisions about housing. These latter decisions do not undermine my actual capacity for autonomous decision making in the future irrespective of whether they restrict my liberty. Instead the decision to commit to living in area is an autonomous decision about the kinds of decisions that I am prepared to make in the future.

A useful way to see how the distinction between levels of decision works in the case of biobank consent is to consider an analogous case of broad consent. Fred is at a restaurant with a number of colleagues. Without having seen the menu, he gets called away to the telephone. He asks one of his dinner companions to choose from the menu for him. A brief discussion ensues about the general kind of food that he would like and any immediately obvious dietary or taste restrictions. Fred's companion orders his meal. Of course the idea is that Fred's decision is a perfectly ordinary one which plainly illustrates the exercise of autonomy and is analogous to broad consent to participate in a biobank.

There are various ways in which we can adjust this example to make it more specifically like broad consent

in the biobanks case: for example, the designated companion might agree with Fred that he will consult with the other companions in the process of deciding (we could even suggest that in cases of dispute that all companions will vote)—this parallels the idea of consent to governance (Kaye 2004; Laurie 2009; Hunter and Laurie 2009). Fred's companion might also suggest some mechanism for handling the case where he orders someone that Fred doesn't want: it might be agreed that Fred can withdraw from the arrangement and that the companion will eat the food or it will be sent back—this parallels considerations about withdrawal from a biobank and the mechanisms for doing so (Eriksson and Helgesson, 2005). Finally, it might also be in the (collective) interest of the whole party that this person (or indeed any person) decides for Fred, in this way the whole party can expect to eat sooner (Hansson *et al.*, 2006; Christensen 2009).

On the face of it then, there is nothing in the justification of the requirement to obtain informed consent that implies that the nature of the choice must be limited or restricted. There is certainly nothing that requires only specific consent—indeed, the idea that it could require such a thing looks unintelligible. Further, there are plenty of straightforward decisions that autonomous people make regularly that are decisions about future decisions that are analogous to the broad consent decision to participate in a biobank.

The Right Not to Know

Having made this very general claim, we can quickly see that there might be some important exceptions. There do look to be some kinds of choices that we generally think individuals are unable to make autonomously or at least, that give us pause for thought. The decision to give up all future choices or to sell oneself into slavery, look to be decisions that are in some way inconsistent with the nature of autonomy, properly understood.² We might also suspect that the concept of autonomy is more closely connected to an idea of rational valuing, so that there are some things that that one cannot autonomously value (Rhodes, 1998; O'Neill, 2002; Manson and O'Neil, 2007). On this view, decisions that aim at the fulfilment of these goals cannot be autonomous. One example that has received some discussion in the literature is the decision to remain ignorant about important genetic information about oneself—say, whether or not I carry a specific gene for a devastating disease, in the light of evidence that it is in my family.

Connecting this set of exceptions to the biobank context is, I take it, the best hope for a defence of the claim that broad consent is not informed consent. Such a connection proceeds by claiming that the decision involved in broad consent is just like the decision to give up all future choices or the decision not to know that I will develop a devastating genetic condition. Understanding these exceptions and possibility of a connection to the biobank context, involves reflecting on the arguments about the existence of a right not to know.

Much of the discussion about the existence of a right not to know occurs in the context of personal genetic information—hence, the right to genetic ignorance (Wilson, 1998). The question in this literature is whether it is justified to remain ignorant about certain (presumably important) genetic information about oneself. One immediate and perhaps relevant difference here is that the genetic information and the ability to retrieve it, already exists at the time of the choice. This is very often not the case in biobanks (Allen and McNamara, 2011). At the time of consent (just as at the time of delegation in the restaurant case), the actual research uses of the donated material are not determined.

An initial form of the argument here is that autonomy requires information, so decisions made without information are not autonomous and are not worthy of respect.³ Someone who does not have the relevant genetic knowledge cannot make autonomous decisions. Of course, put in this way, the argument has the absurd consequence that the restaurant case provides us with an example of a non-autonomous decision.⁴ The arguments here are more subtle than this suggests but there does remain a puzzle about ordinary cases like the restaurant case. Harris and Keywood point out that ‘patients should be provided with an appropriate level of information to enable them to operate as rational “choosers”’ (Harris and Keywood 2001: 422) where, clearly, knowing important genetic facts about oneself is taken to be an important part of being a rational chooser.

There are two key arguments that are presented by opponents of the right to genetic ignorance: (i) that ignorance (and specifically this kind of ignorance) is contradictory to autonomy and (ii) that autonomously deciding to take certain risks is irresponsible (i.e. deciding not to know certain things is irresponsible).⁵ Harm to others is sometimes taken to a factor here, but we must be careful about how it features in relation to the arguments at issue here. Although it may be an important ethical issue in general, it is not relevant here because

such harms would be candidates to overrule autonomous decisions not to show that they were not autonomous.

In terms of the irresponsibility of decisions to take on certain risks, even if it can be shown that some decisions fail to be autonomous on the grounds that they are irresponsible, it is hard to see how these risks are involved in the decision to participate in a biobank. We should of course be careful here about the judgement of responsibility. There might be certain situations in which deciding not to decide is irresponsible but where the decision is an autonomous one: autonomous individuals can make irresponsible and yet autonomous decisions.

So how might the contradiction argument play out? There are interesting difficulties that arise from cases like the deciding never to decide kind of case. The particular account of autonomy will in large part determine what counts as contradictory. It is also a distinct possibility that a contradiction is practically impossible. It is hard to imagine how the decision never to decide could be actualized without some liberty-limiting enforcement mechanism. But then the problem looks to rest with the mechanism rather than the decision—we ought not to limit our own decisions in this way (cf. Suicide or slavery). But a problem with the mechanism is not a problem with the exercise of autonomy. Instead, the contradiction argument reduces to the irresponsibility claim—it is not that the decisions in question fail to be autonomous, they fail to be worthy of respect.

Any account should do justice to common intuitions about or instances of what might count as rational choosing. I take it that the restaurant case is one such case. I also take it that this case points to a class of cases where we legitimately and autonomously decide not to decide or to defer decision. There are many other examples where we adopt a policy that means that others decide on our behalf (that is, without us having full information about all decisions). Of course, this does not rule out the idea that some decisions not to decide do undermine our ability to be rational choosers (selling oneself into slavery being one). I suspect that there are various relevant criteria that might be helpful here which guard against certain levels of harm and against basic incoherencies and that these criteria that are at issue in the debate about genetic ignorance. Broad consent to participate in a biobank reaches neither of these levels: it does not involve the levels of expected harms or failures of obligation to others of the significance of those being discussed in the genetic knowledge

case and nor does it involve a basic inconsistency of the kind involved in deciding never to decide.

Overall, the important distinction that I have suggested here is that between kinds of decisions (or the scope of the choice). This matters because if the decisions are of a different kind then the knowledge that is appropriately possessed by the decider in order to make such decisions autonomously is also different. So it is true that Fred cannot autonomously decide what to order for dinner because he does not have the appropriate information about the options. However the decision that matters here is of a different order—it is the decision to delegate decision making (about what to order). The information that is appropriately required to make this decision an informed one is not the same as the first order decision (deciding what to order). Here the relevant information is about the designated companion and the decision making process that will be used.

The force of this distinction is that it avoids the debate about the right not to know. The broad consent case is not one where a right not to know is being asserted, instead a different kind of decision is being made with entirely the appropriate level of information to make it an informed and so autonomous decision.

Objections

In this final section, I will consider two objections to the account and justification of broad consent as informed consent that I have outlined above. The first targets the analogy between the restaurant case and broad consent to participate in a biobank. The second suggests that my arguments are too strong and equally justify open or blanket consent.

The first objection targets the analogy between the restaurant case and broad consent to participate in a biobank. It might be objected that the restaurant example is importantly different from the biobank case and so cannot play the analogical role that I have given it.⁶ The particular feature that is important here and which undermines the analogy is the role of the interests of the individual in each case. In the restaurant example we presume that the designated companion will choose an option that is, in his opinion, something that Fred will like and perhaps would choose himself—i.e. the designated chooser's goal is centrally taken to revolve around Fred's interests. In the biobank context this is not the case. Very clearly the biobank primarily serves the public interest and if any other interests are involved these are likely to include those of the

individual researcher accessing the biobank and, depending on the governance arrangements, commercial interests. The individual donor's interests will be served primarily insofar as they are included in the public interest. Notice that in the restaurant case, Fred's interests may not always trump other considerations. The designated chooser might decide against ordering one of Fred's favourite dishes, the soufflé, on the grounds that it would delay everyone else's meal. Overall though, the point stands: the restaurant case is to be distinguished from the biobank case because the designated chooser is charged primarily with making a decision that is in the interests of the absent individual.

There are two points to make in response to this concern. First, this objection slightly misses the point of the analogy. The main thrust of the example is to demonstrate an overall kind of autonomous decision, namely, decisions to allow others decide. So although the nature of the decision to be made by the delegated chooser is different, the decision to delegate is of the same form. Moreover, the extensions to the restaurant case (which make it closer to the biobank situation) illustrate the kinds of information that might be important for the agent's decision to delegate. Second and perhaps most importantly, it is unclear what follows about my argument from this observation. Even if we think that the fact that the biobank-related decisions are ruled out as unethical because they are not in the donor's best interests, this is distinct from claims about whether the donor's decision to participate was autonomous. There are a whole range of motivations that an agent may autonomously have only one of which is their own best interests. I may for instance autonomously choose to behave in a way that will benefit others or I may do something because I think it is worthwhile or of value independently of the consequences. In each of these cases, my choice remains autonomous and, on the face of it, worthy of respect. It may be, of course, that the decision that I make is not in my best interests and may be overruled on paternalistic grounds. What matters here is that the decision made by the person delegating their future decisions is motivated by something that they value. Over and above this feature of autonomous decision making, the role played by best interests is separate from questions about the agent's consent.

A second way in which the restaurant decision differs from the biobank one is that the decision in the restaurant case is a one-off decision but the biobank decision is not. So when an individual agrees to participate in a biobank there samples are used multiple times for different research projects. Thus the biobank case is more akin to a case in which Fred agrees, for a certain

membership fee, to be a part of a diners club in which he will have no say in what food is served to him but where he is given information about the committee making the decisions and the kind of principles that govern their decisions.⁷ Again this poses no problem for the analogy properly understood. The restaurant case provides an illustration of a kind of decision—the decision to allow others to decide (or the decision not to decide)—that can be autonomous and is dependent on the provision of a different sort of information. This dining club case alternative is another illustration of the kind of decision with the details adjusted to fit a different aspect of the biobank case.

A second objection claims that my defence of broad consent is too strong—it justifies open or blanket consent as well as broad consent. Indeed, it looks as though any kind of consent follows from this argument. So whereas I set out to show that broad consent is informed consent, I have produced an argument that shows that open or blanket consent can count as informed consent also.

In responding to this objection, we first need to be clear about the way in which the justifications function. There is always the possibility that the individual can opt out of taking in the information—by not reading it, by not paying attention, or by bluffing in some way about their knowledge. There is, to this extent, a certain amount of liberty that is maintained in the consent process irrespective of the kind of consent. Questions about when we might be entitled to restrict an individual's liberty in these cases will take us back to the issues about the relationship between the obligation to respect autonomy and the obligation to promote or to ensure maximal autonomy—specifically, under what circumstances we are justified in preventing an individual from exercising their liberty in this respect.

With this in mind, it is indeed true that the general form of my argument applies equally to open or blanket consent cases. That is, there do look to be cases where an individual can autonomously decide to allow anything at all to be done with their tissue. These will be cases where for example the relevant details are of no significance—say for a general type of research that the individual wholeheartedly supports and where there is complete anonymisation. Overall this is not surprising. My argument is primarily one that shows that specific consent is not the only morally legitimate form of informed consent and as such it argues that broad consent can be informed consent. I have not here been concerned to separate morally broad consent from open consent.

The argument that is required to show that broad consent is preferable to or more justified than open consent has a very different form and is outside the scope of this article. However, the main issue is about how biobank institutions ought to structure the consent process rather than what forms of consent are legitimate. The focus, then, is on what is a fair and legitimate process would be all things considered. Part of this argument will mimic the arguments given in the case of specific consent for the level of information that is required. So the information provided should include all relevant information that is material to the decision in questions—that is, the decision to allow someone else to decide. The other part of the argument will involve claims about how research should be conducted and, specifically, governed, in our society. I take it that there are substantial benefits to be accrued through the conduct of research and that biobanking may well assist in delivering these benefits. I also take it both that individuals are largely capable of and entitled to make their own decisions about participating in research but that society has a responsibility to ensure that the institutions supporting research are constructed to provide an appropriate degree of protection. These arguments require special attention but together, in my view, they form the outline of an argument which shows that broad consent is preferable to open consent to participate in a biobank.

Conclusion

In this article, I have argued for a view of the kind of decision involved in consenting to participate in a biobank that differs from a very significant proportion of the literature on the ethics of broad consent. Typically, the debate takes broad consent to be a lesser form of consent largely because it is undertaken without information about the specific research that will be conducted using the biobank's samples. This understanding has led to a marked split in the literature. In generalized terms, one side of this split maintains the over-riding ethical importance of the principle of respect for autonomy and its requirement of fully informed consent. Consequently, because broad consent is not fully informed, it is ethically problematic. The other side of this split broadly suggests that the principle of respect for autonomy and its requirement of fully informed consent can sometimes be justifiably weakened (or sacrificed altogether) in cases of minimal risk and/or significant public benefit. There is clearly scope for disagreement here about the level of risk and the

significance of the benefits associated with biobanks and so whether the deficiencies of broad consent are justified, but in principle such trade-offs can be ethically legitimate. In short, both sides take broad consent to be deficient.

The position articulated here suggests that broad consent involves a different kind of decision, a decision to allow others to decide, and correspondingly involves a different sort of information from that required for other kinds of decision. Broad consent, as described here, provides the appropriate information for the kind of decision involved and so counts as informed consent for those decisions. Just as I am justified in deciding to allow my dinner colleague to order my meal for me, so, broad consent is an acceptable form of consent to participate in a biobank. Even if we do think that the nature of autonomy is such as to make certain kinds of choices unintelligible or autonomy-defeating, these will not extend to the decision involved in broad consent to participate in a biobank.

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Notes

1. In what follows I refer to informed consent rather than to valid consent. I take it that information provision (and hence informed consent) is one component of valid consent and that valid consent is the more accurate, morally significant term. However, the literature on the topic of broad consent in couched in terms of informed consent and, here, the focus is primarily on the informational element of the consent process.
2. I realize that that the more standard legal interpretation of this is that the reason we cannot sell ourselves into slavery is that we do not own our

bodies. This has always seemed an odd construction when extended to ethics. Understanding this to be a case where one cannot autonomously choose seems more satisfactory and makes it more like the decision to give up future choices combined with the liberty-restricting enforcement of that decision. Indeed one might think, contra Harris and Keywood (2001), that what makes the decision to enslave one-self problematic is not that contradicts autonomy in some way but that involves the imposition of a certain kind of liberty-denying enforcement. The newly enslaved individual remains perfectly capable of autonomous choice but is now denied the freedom to exercise that ability. In this respect, choosing slavery is distinct from choosing suicide since in the latter the person ceases both to be autonomous and to have the exercise of that ability denied (because they are dead). The immediate consequence of this is that one can on the face of it consent to being enslaved. Such slavery would then be wrong only when it ceased being voluntary—that is, when the enslaved individual autonomously chose not to accept the liberty restricting sanctions and those sanctions continued to be applied.

3. The principle of respect for autonomy implies an obligation to respect autonomous decisions of agents which in turn implies a right that one's autonomous decisions are respected. If a decision is not autonomous then correspondingly there is no right for that decision to be respected. If the decision is to remain in ignorant of certain facts and this is not autonomous, then, on this argument there is no right for this decision to be respected (Kihlbom 2008; Foster and Herring, forthcoming).
4. The absurdity is generated by my original supposition that the Fred's choice is both rational and autonomous. I have indicated why this is a plausible assumption to make, but it is of course possible to bite the bullet and insist that Fred has not made an autonomous decision.
5. Harris and Keywood (2001) insist that such decisions are 'inimical' to autonomy but fail to elaborate on the ways in which this is case. It seems to me that they may mean a combination of the two mentioned.
6. Thanks to Christian Lenk for pointing out this objection.
7. Thanks to an anonymous referee for this helpful example.

References

- Allen, J. and McNamara, B. (2011). Reconsidering the Value of Consent in Biobank Research'. *Bioethics*, **25**, 155–166.
- Arnason, V. (2004). Coding and Consent: Moral Challenges of the Database Project in Iceland. *Bioethics*, **18**, 2–49.
- Barr, M. (2006). I'm not Really Read up on Genetics: Biobanks and the Social Context of Informed Consent. *Biosocieties*, **1**, 251–262.
- Beauchamp, T. and Childress, J. (2008). *The Principles of Biomedical Ethics*. 6th edn. Oxford: Oxford University Press.
- Brekke, O. and Sirnes, T. (2006). Population Biobanks: the Ethical Gravity of Informed Consent. *Biosocieties*, **1**, 385–398.
- Cambon-Thomsen, A. (2004). The Social and Ethical Issues of Post-Genomic Human Biobanks. *Nature Review Genetics*, **5**, 6–13.
- Caulfield, T. and Weijer, C. (2009). Minimal Risk and Large-scale Biobank and Cohort Research. *Health Law Review*, **17**, 2–3.
- Caulfield, T., Upshur, R. E. and Daar, A. (2003). DNA Databanks and Consent: a Suggested Policy Option Involving an Authorization Model. *BMC Medical Ethics*, **4**, E1.
- Christensen, E. (2009). Biobanks and our Common Good. In Solbakk, J. H., Holm, S. and Hofmann, B. (eds), *The Ethics of Research Biobanking*. Dordrecht: Springer, pp. 101–114.
- Edwards, S. J. L., Kirchin, S. and Huxtable, R. (2004). Research Ethics Committees and Paternalism. *Journal of Medical Ethics*, **30**, 88–91.
- Elster, J. (2000). *Ulysses Unbound: Studies in Rationality, Precommitment, and Constraints*. Cambridge: Cambridge University Press.
- Eriksson, S. and Helgesson, G. (2005). Potential Harms, Anonymization, and the Right to Withdraw Consent to Biobank Research. *European Journal of Human Genetics*, **13**, 1071–1076.
- Frankfurt, H. G. (1971). Freedom of the Will and the Concept of a Person. *Journal of Philosophy*, **68**, 5–20.
- Foster, C. and Herring, J. (forthcoming). "Please don't Tell me": The Right not to Know. *Cambridge Quarterly of Healthcare Ethics*.
- Hansson, M., Dillner, J., Bartram, C., Carlson, J. and Helgesson, G. (2006). Should Donors be Allowed to give Broad Consent to Future Biobank Research? *Lancet Oncology*, **7**, 266–269.
- Harris, J. and Keywood, K. (2001). Ignorance, Information and Autonomy. *Theoretical Medicine and Ethics*, **22**, 415–436.
- Helgesson, G. (2008). Reply to: Bypassing Consent for Research on Biological Material. *Nature Biotechnology*, **26**, 980–981.
- Helgesson, G., Dillner, J., Carlson, J., Bartram, C. R. and Hansson, M. G. (2007). Ethical Framework for Previously Collected Biobank Samples. *Nature Biotechnology*, **25**, 973–976.
- Hoeyer, K. (2008). The Ethics of Research Biobanking: A Critical Review of the Literature. *Biotechnology and Genetic Engineering Reviews*, **25**, 429–452.
- Hofmann, B. (2008). Bypassing Consent for Research on Biological Material. *Nature Biotechnology*, **26**, 979–980.
- Hofmann, B. (2009). Broadening Consent – and Diluting Ethics? *Journal of Medical Ethics*, **35**, 125–129.
- Hofmann, B., Solbakk, J. H. and Holm, S. (2009). Consent to Biobank Research: One Size Fits All? In Solbakk, J. H., Holm, S. and Hofmann, B. (eds), *The Ethics of Research Biobanking*. Dordrecht: Springer, pp. 3–24.
- Hoppe, N. (2011). Risky Business: Re-Evaluating Participant Risk in Biobanking. In Lenk, C., Hoppe, N., Beier, K. and Wiesemann, C. (eds), *Human Tissue Research: A European Perspective on the Ethical and Legal Challenges*. Oxford: Oxford University Press, pp. 35–45.
- Hunter, K. and Laurie, G. (2009). Involving Publics in Biobank Governance: Moving Beyond Existing Approaches. In Widdows, H. and Mullen, C. (eds), *The Governance of Genetic Information: Who Decides?* Cambridge: Cambridge University Press, pp. 151–177.
- Kaye, J. (2004). Broad Consent – the Only Option for Population Genetic Databases? In Arnason, G., Nordal, S. and Arnason, V. (eds), *Blood and Data: Ethical, Legal and Social Aspects of Human Genetic Databases*. Reykjavik: University of Iceland Press, pp. 103–109.
- Kihlbom, U. (2008). Autonomy and Negatively Informed Consent. *Journal of Medical Ethics*, **34**, 146–149.
- Knoppers, B. M. (2005). Consent Revisited: Points to Consider. *Health Law Review*, **13**, 33–38.
- Laurie, G. (2009). Role of the UK Biobank Ethics and Governance Council. *The Lancet*, **374**, 1676.
- Manson, N. and O'Neill, O. (2007). *Rethinking Informed Consent in Bioethics*. Cambridge: Cambridge University Press.

- O'Neill, O. (2002). *Autonomy and Trust in Bioethics*. Cambridge: Cambridge University Press.
- Oosterhuis, J. W., Coebergh, J. W. and van Veen, E. B. (2003). Tumour Banks: Well-Guarded Treasures in the Interest of Patients. *Nature Reviews Cancer*, **3**, 73–77.
- Otlowski, M. (2009). Developing an Appropriate Consent Model for Biobanks: in Defence of 'Broad' Consent. In Kaye, J. and Stranger, M. (eds), *Principles and Practice in Biobank Governance*. Farnham: Ashgate, pp. 79–92.
- Rhodes, R. (1998). Genetic Links, Family Ties and Social Bonds: Rights and Responsibilities in the Face of Genetic Knowledge. *Journal of Medicine and Philosophy*, **23**, 10–30.
- Rothstein, M. A. (2005). Expanding the Ethical Analysis of Biobanks. *Journal of Law, Medicine and Ethics*, **33**, 89–101.
- Wendler, D. (2006). One-time General Consent for Research on Biological Samples. *British Medical Journal*, **332**, 544–547.
- Wilson, J. (1998). To Know or not to Know? Genetic Ignorance, Autonomy and Paternalism. *Bioethics*, **19**, 492–504.