

This response was submitted to the consultation held by the Nuffield Council on Bioethics on Give and take? Human bodies in medicine and research between April 2010 and July 2010. The views expressed are solely those of the respondent(s) and not those of the Council.

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Consultation Paper: Give and take? Human bodies in medicine and research

This is a personal response. I have a long working interest in the questions of this consultation, particularly those raised by assisted conception technologies, and more recently by the storage and collection of human tissues, although I no longer work in public institutional life.

I give my points in the context of social research studies, which come from local and particular examples. This is about the life of persons, not necessarily the same as 'the public' or civil society responses. I see them as starting points or ways into thinking, and I hope that they will be helpful.

Maximising health and welfare (p. 16); Q. 2 The specialness of reproductive material (p. 13)

There are several different ways that reproductive material might be considered special, but the point I'd like to focus on and to make in this consultation is: the removal and use of female reproductive material is a women's health issue. Entwined with this is the value identified in this consultation, maximising health and welfare. Other values are relevant but this seems fundamental. [Point 1]

To explain: technologies of procreation which emerged in the 1980s - IVF and surrogacy with human egg, sperm, and embryo donation - were clearly matters of women's health and reproduction, certainly for women's health activists and for women such as myself who were finding sympathetic spaces to do research from feminist viewpoints. Yet, arguments being made in the top medical and science journals were not so sensitive in the very early stages. The fact that women are in the forefront, that women's bodies are where human ova and embryos come from, was hardly noticed. There was an argument that ova donation is no different than sperm donation, as in an editorial in the journal *Nature*, which thought it 'illogical' to see a difference between the two, forgetting that removing women's eggs is a medical procedure and often involves fertility drugs, and that it may change the terms of biological motherhood as happens with egg donation.¹ Women defined their motherhood for themselves, depending on the circumstances of the egg donation. One woman might know herself to be the biological mother because the child came from her egg although another woman carried the pregnancy. Another woman, genetically unrelated to the child - she has received an egg donation - feels that she is the true biological mother because she has borne the pregnancy for 9 months. There are no easy endpoints to identity and relatedness. Some

¹ I discussed these things in Patricia Spallone, 1989, *Beyond Conception: the New Politics of Reproduction*, Macmillan, London; Bergin & Garvey, Massachusetts.

frozen embryos have names on them and yet will be discarded or not allowed to be used. Some will be donated to research.

My view is that it is still important to see through the lens of gender in these contexts, although women's and men's lives, and different forms of family life, are recognised now in many real ways; and that this is not only about concern for women, but an opening to illuminate broader questions of this consultation.

Let me give a current example.

Decision-making: autonomy, solidarity, reciprocity (p. 16); Q. 10 how should these be prioritised or balanced? (p. 17)

Karen Throsby's study² considered women's experiences, in Britain, of making decisions to end IVF treatment. Although most participants did not dispute the principle of these decisions ultimately residing with the woman, those decisions were always made in the broader context of social relations, either in direct consultation with others, or based on assumptions about the views and preferences of involved others. The women would turn to friends or family for help in talking through these decisions, or they would account for known or assumed preferences of their partners in their decisions, and so on. An example of this is the long discussions that many of the couples in the study engaged in prior to making difficult decisions, both between the couple, and with friends and family. There were a number of cases of situations where male partners were unwilling to engage in these discussions. However, even in these cases, the subsequent decision cannot be described as strictly autonomous, since the women would turn to friends or family for help in talking through those decisions, or they would account for known or assumed preferences of their partners in their decisions, even in the absence of their direct input. The accounting of the views of key others was important in the decision making process because many of the women worried that their partners might resent the decision to stop treatment later in life, without having a biological child, and therefore they needed to be sure that the decision was a mutual one. Several also felt it was necessary to consider the feelings of their own parents in making the decision to stop, since this might deprive them of the opportunity to be grandparents.

Conversely, several of the women in this study wanted to continue treatment (or try a new form of treatment), but worried that their male partners would veto it by refusing to participate. Consequently, they made decisions that minimised the grounds for objection – for example, in one case, the woman chose to pursue the procedure ICSI (in spite of its

² First discussed in Karen Throsby, 2002, *"Calling it a day": the decision to end IVF treatment*, PhD thesis, London School of Economics, University of London. Published in K Throsby, 2004, *When IVF Fails: Feminism, Infertility and the Negotiation of Normality*, Houndmills, Palgrave. I have paraphrased our conversation and her text, from when we discussed her work as colleagues at LSE some years ago. Permission from Karen Throsby to use for this response, 1 July 2010.

lower chances of success in their case) rather than using donor sperm in order to secure his continued co-operation even though she preferred the donor sperm option.

There are several points I'd like to draw:

- These are the social relations of decision making: particularly, many women did not want to be left alone with a decision to proceed or not with a medical procedure which has reverberations for family life, and not just nuclear family life. This is about relationships and making children and grandchildren, making relations. [Point 2]
- How much on balance is about the 'specialness' of procreation and how much about being a human social being is hard to know, but there is a sense from Throsby's study and others that the work of making future generations creates a specialness, and I want to suggest that this might be relevant to other such decision making, such as about donating reproductive material. [Point 3]
- Be that as it may, these women didn't act like lone individuals. The decision making process for those women was not strictly autonomous. To use the vocabulary of the consultation, the value they brought to bear might be called solidarity, 'we're all in this together'. [Point 4]

Another insight about the strangeness of strict autonomy in European medical settings comes through in a study of blood donations to Swedish Biobank by Klaus Hoeyer³. Informed consent by potential blood donors became the main focus of the ethics policy of the new Biobank. Alongside was the re-invention of an autonomous individual of medical ethics for the purpose: an individual with a newfound responsibility to become informed and make a personal choice to participate in biobank. This did not fit the self-perception of the blood donors, who recognised the biobank within the national health care system, and identified with its ethos of solidarity. Hoeyer argued that rather than being part of this social milieu, they were pitted against it, positioned to join or not to join up. Their concerns around public interest and the public value of biobank, exemplified in a debate over public ownership in negotiations, eventually fell by the wayside.

People's resistance to identifying themselves as lone individuals in Hoeyer's study chimes with Throsby's study, and others, at a time when the autonomous individual of medical ethics has been considered fragile. So, are we moving away from the notion of strict autonomous individuality, and towards a sense of persons in relationships, with commitment to building new models of consent? Is it time to? What will this look like? At the same time, I and no one I know would want to lose protection against abuse that the consent process offers, nor to give over responsibility for consent to another person or authority.

My personal view, to address Q. 10 in the context of decision making and consent to donate, is that I would wish to retain my right to consent, of course, and be supported in that decision making process, and be respected. But inter-levered with this activity are public- and private-sphere values of solidarity and reciprocity and justice. The activity might

³ Klaus Hoeyer, 'Studying ethics as policy: the naming and framing of moral problems in genetic research', *Current Anthropology*, Vol. 46, Supplement, December 2005, S71-81; and Pat Spallone, Comment, pp. S85-6.

be going on in different locations (health care and biomedicine as well as personally and domestically). Here is where I am finding a renewed interest in rights, which are rooted in local and particular realities but also can find larger human dimensions that are shared.⁴ Is it necessary to say that while I have a strong sense of solidarity in the health service, I wouldn't want anyone or the state obliging me and others to donate our bodily material? I would wish to consider that sort of decision for myself.

Ownership and the value human body parts

In Klaus Hoeyer's study of Swedish Biobank, the blood samples were not objectified or depersonalised but instead they became highly personalised, not by the donors themselves, but by the authorities defining their status. Hoeyer explains that before the 1990s, the authorities thought of blood as a thing that could be marketed, but this was re-interpreted by the time of biobanks because of a sense that DNA in the blood carried the 'essence' of a person⁵.

'Subjectifying' bodily material is not new, but rather a theme that seems to be found in other ethnographic studies. Organs are alive even if disembodied (Margaret Lock); gametes need names (Jeanette Edwards); and research embryos are special (Sarah Franklin).⁶

In these ways, persons may still feel a personal relationship to blood, cells, tissues and organs donated for medical research or clinical use. My point is that a disembodied body part may have both private and public value at once. This is a helpful starting point, I think, to address questions about ownership and property in the body. [Point 5]

My personal view, at an early stage of thinking on ownership of bodily material, divides into two. Reproductive bodily material should probably always be outside the property paradigm. I do not base this on some special status of the embryo (as in an anti-abortion stance, which I do not subscribe to), but for other reasons. In part, some gametes and embryos will be destined for assisted reproduction, for making babies, and the difficulty of making a division between donations for research and those for reproduction in a timely way, and what these processes mean for women (and men) involved, seems impossible to delineate well⁷. I also

⁴ The best analogy I have for the work of re-thinking the individual with a view to protecting persons here is Conor Gearty's work on human rights. He grounds these in the local and particular while not shy of identifying universal values and principles. Gearty's first 2005 Hamlyn Lecture is helpful, where he talks about individually based human rights and recognises plurality, and where and how individuals live, in groups, communities, relationships. Published in Conor Gearty, 2006, *Can Human Rights Survive?*, Cambridge University Press, Cambridge.

⁵ Klaus Hoeyer, personal message, 2 July 2010.

⁶ Margaret Lock, 2001, 'The Alienation of Body Tissue and the Biopolitics of Immortalised Cell Lines', *Body and Society*, vol. 7(203): 63-91; Jeanette Edwards, 2000, *Born and Bred: Idioms of Kinship and New Reproductive Technologies in England*, Oxford University Press; Celia Roberts and Sarah Franklin, 2004, 'Experiencing new forms of genetic choice: Findings from an ethnographic study of preimplantation genetic diagnosis', *Human Fertility*, December, vol. 7(4): 285-293(9) The latter two studies are Britain based.

⁷ This argument is based on Elizabeth Sourbut's work as a recent PhD student at University of York, with thanks.

wonder if other human bodily material should remain outside a property paradigm as well, not because DNA carries some 'essence' of the person, but at least to keep benefit in the public domain, just as the NHS is in the public domain.

However, these things aren't written in stone. Klaus Hoeyer adds recently, 'The [bodily] material can create many different types of partial connections...In some situations and for some people, they will appear as objects, mere things, and in others as part of subjects.' Which is to say, they can be objects or not clearly objects too. Body parts can be both: mine and theirs, subject and objects, public and private at the same time. Body parts can be as ambiguous as human embryos, it seems. Blood can be special (or not).

Q. 5 First-in-human clinical trials: what do you consider the costs, risks, or benefits? (p. 13); benefit sharing.

I am a potential subject of such a clinical trial for new medicines, in particular either for epilepsy or for benign venous brain lesions. I would expect no personal benefit from volunteering the loan of my body for such drugs trials, and fair risks and costs to body and mind, and maybe 'soul' too. It is difficult to make a parallel to providing bodily material, in terms of risks and benefits of that sort. I cannot imagine what it must be like to donate a kidney.

The point I would like to make here concerns distribution of benefits of clinical research trials for new drugs. I would not wish to be paid to participate in such a trial or to share in the monetary benefits, but I would wish to see some of those benefits shared with the public sector, at least with the NHS that provides health services, although I haven't thought this out completely. Another sector on my mind is that of medical charities, which fall under the civil society banner, although I'm not sure about this or how such benefit sharing might happen, perhaps through the public health sector. The bottom line is to promote benefit sharing of this kind, and I would extend this to medical biobanking and similar kinds of sample donations, a view I came to when working on these themes in public life. [Point 6]

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