

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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## **Response to Nuffield Council on Bioethics consultation: 'Given and take? Human bodies in medicine and research'**

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Our contribution to this consultation relates to one specific aspect of the issues covered in the consultation document – the scheme launched by the Newcastle Centre for Life in 2006 to facilitate “egg sharing for stem cell research”, offering subsidised IVF treatment in exchange for a proportion of the “fresh eggs” produced in the course of that treatment. Our full argument in relation to this scheme is developed in the following paper (also attached): Roberts, C. and Throsby, K (2008) “Paid to share: IVF patients, eggs and stem cell research”. *Social Science and Medicine* 66 (1): 159-169. However, we have summarised the key points below, to be taken into consideration both in specific relation to the donation of eggs for research, and in terms of the establishing of broader principles for the donation and receiving of body parts.

- There is no evidence of a demand from women to be “allowed” to donate eggs for research. We suggest that this absence of demand has to be taken seriously (there may be very good reasons why women do not wish to donate). Every measure must be taken to avoid figuring women as roadblocks to scientific development: this figuration may produce an intolerable moral pressure (‘without your eggs we cannot develop cures for Parkinson’s disease, diabetes etc’).
- In donating to research, egg donation differs fundamentally from the donation of embryos. Egg donation involves a bodily resource that is potentially of reproductive use to the woman *at the time of donation*, while embryos are donated only once they have been deemed to be of no reproductive use. Egg donation potentially limits the woman’s chances of a successful IVF outcome by limiting the number of eggs available for fertilisation, and the transfer or cryopreservation of subsequent embryos. It is important, then, to avoid the elision of gamete and embryo donation and to account for the specificities of these distinct processes.
- While egg donation is commonly conceptualised as something that “women” do, in reality, egg sharing for stem cell research (and also for fertility treatment) relies upon a very particular cohort of women: those undergoing fertility treatment and who are most likely to respond positively to hormonal ovarian stimulation (i.e. younger women). Furthermore, given the potential negative impact of egg sharing on reproductive outcomes, and the demonstrated reluctance of women undergoing IVF to donate eggs, egg

sharing schemes are likely to be taken up by those who are more disadvantaged financially and who have less favourable access to NHS funded IVF treatment. Consequently, these incentive schemes can be seen to entrench existing inequities in health care provision (e.g. the postcode lottery in treatment provision and ability to pay for additional cycles).

- The process of undergoing IVF is often a period of substantial suffering and uncertainty, and comes after challenging, and sometimes lengthy, experiences of infertility. Starting IVF is often experienced as a relief, and as an experience of hope, but also great anxiety (having to manage complex medical procedures such as preparing and injecting medication, and undergoing multiple uncomfortable procedures, such as vaginal ultrasounds). Introducing a complex consenting process requiring difficult decisions about potential compromises to treatment outcomes during such a stressful time is very difficult. It is essential to take into account the complex power relations constituting the scene of IVF treatment when thinking about who should approach women to inform them of egg sharing schemes and who should take consent. It should be noted that differences between kinds of nurses (research nurses versus treatment nurses) may not be clear to patients in these circumstances. Treating clinicians are often closely involved in research projects and some have notable public profiles: even if the clinicians do not make requests themselves, patients may feel an obligation to support research that is being done by that team or within that institution.
- The move towards egg sharing schemes entrenches the treatment logic of producing as many eggs as possible through hormonal stimulation, and steers treatment away from alternative interventions such as those involving “natural” cycles or the use of alternative drug regimens that produce fewer eggs but minimise the risks of hormonal stimulation and its potential present and future risks.
- Egg sharing for stem cell research is treated (for example in Newcastle University press releases) at some points as the same as other forms of donation (and therefore, business as usual), and at others as reflecting a special case (and therefore, representing a context where the normal rules of non-payment should not apply). There is a risk now, in turn, that schemes such as this will be mobilised as a precedent for other financial incentive schemes for other body parts. **The scheme requires more critical assessment before it is used as a model for other body parts (it is the subject of a current social scientific study).**

In summary, we urge the working group to take into account the specificities of the processes of donation under consideration, in terms of the particular body parts in question, *who* the anticipated donors are, and when, where and how the consent-taking would take place. We would also urge that the working party consider the gendered implications of those processes, especially (but by no means exclusively)

in the context of reproduction, where it is women who bear the brunt of both the physical medical interventions and the moral responsibility to act altruistically towards others.