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No 'brownie points' for ill-conceived Donation Review

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One of the principal functions of the Human Fertilisation and Embryology Authority (HFEA) is to regulate all fertility treatment procedures undertaken in the UK using donated [sperm](#), [egg](#) or [embryos](#). To this end, the HFEA may specify arrangements for donor remuneration; limit the number of families with children born using the [gametes](#)/embryos provided by the same donor; and provide guidance on donation within families (although currently there is no formal guidance on the latter).

The HFEA does not have responsibility for donor recruitment. Nevertheless, prompted in large part by concerns over shortages of supplies of donated gametes and embryos, in 2004 it undertook a review of sperm, egg and embryo donation, the SEED Review (1). This resulted in the HFEA's current policies regarding donor compensation and limits on the number of families with children born using the gametes/embryos provided by the same donor. Several years later, similar concerns regarding donor shortages have prompted the HFEA's current Donation Review (2).

While the HFEA's motivation in undertaking the review is understandable, we consider that there are significant problems with the public consultation. First, there are a number of technical problems with the presentation: the consultation appears to be unavailable to anyone without access to the internet; and the background information provided by the HFEA, ostensibly to enlighten respondents, is presented over a number of web pages rather than in one coherent document and web page.

What's more, it is only possible to preview all questions - say for collaborative debate and responses - by downloading the 'factsheets' provided at the end of each 'section'. We think these could deter respondents from attempting to read the background information before completing the questionnaire, or to abandon participation altogether.

Second, the consultation is too heavily weighted towards supply shortages and donor recruitment compared to the interests of donor-conceived individuals and the families in which they are raised, and donors and their families. For example, the section headed 'the wider donation context'

contains two subsections dedicated to supply shortages and none at all to 'welfare' issues per se (instead 'welfare' is subsumed under the list of principles relevant to donation). Recognition of the importance of 'an understanding of the personal and social experience of donor conception' would have made the balance of this section look rather different.

In the subsection headed 'shortages of egg and sperm donors', the consultation claims it is 'often argued that the shortage was exacerbated by the removal of anonymity', but fails to acknowledge the contested nature of such statements. Indeed, in the past the HFEA itself has disputed this claim and the consultation refers to an increase in both sperm and egg donors since 2005, suggesting the picture is complex.

One problematic aspect of the consultation is the use of 'respect for family life' as one of the principles meant to guide ethical decision-making identified in the 'changing landscape of donation' section. This definition appears to combine aspects of Articles Eight and 12 of the European Convention on Human Rights/Human Rights Act, and - in doing so - does not make clear there is no positive right to procreate. Further, this definition does not consider the Article Eight rights regarding identity for donor-conceived offspring.

Third, the consultation's use of 'evidence' appears suspect, since it affords equal weight to good quality research-based evidence and what can be at best described as anecdote. The HFEA refers to its own survey carried out among UK fertility clinics and interviews with some sperm and egg donors, but fails to provide any evidence about the robustness of the study and, therefore, its real value to the consultation process.

If anything, reliance on the survey is merely used to enforce bias in the consultation. The only (anecdotal) 'evidence' supports increased compensation/payment (for example, referring to comments by two clinicians) or raising family limits. It fails to refer to the not inconsiderable 'evidence' from, for example, donor-conceived adults who oppose such increases. If the HFEA had placed greater emphasis on the long term well-being of donor-conceived children, adults and their families and donors and their families, rather than on increasing the supply of donated gametes, this would have been a very different document. One has to wonder whose needs are being served.

Fourth, where the consultation explicitly draws on research, its limitations are not made clear. For example, all published research on egg sharing involves small numbers - especially of 'unsuccessful' donors - and none provides long-term evidence. Therefore, it is simply misleading to say '...These concerns [about egg sharing] have not been born [sic] out...'. The casual approach employed by the HFEA is epitomised by the consultation's references to 'happy' donors (as in 'happy' for their donations to create a specific number of children), without any cited source justifying such a claim of assumed donor 'happiness'.

Fifth, the consultation should be framed within the current regulatory framework of non-anonymity and non-commercialisation of gamete provision, as decreed by parliament. However, even though legislative change is not within the remit of the consultation, the very first question invites participants to indicate whether legislation regarding donor payment and donor anonymity should be changed.

Finally, it is unfortunate that the timing of the consultation appears to preclude consideration of the Nuffield Council on Bioethics' review of the ethical issues raised by the provision of human bodily material in medicine and research (3). The Nuffield Council's Report is due to be published in the autumn (2011), and is likely to have important implications for policy-making about donation of

human reproductive materials. Yet the HFEA clearly states that, following its consultation, 'decisions will be made at the Authority meeting in July' (4).

Since the HFEA's days appears to be numbered [against which we have argued in a previous Commentary (5)], the Donation Review may be one its final consultations. It will not be remembered as one of the HFEA's most polished performances.

SOURCES & REFERENCES

1) [SEED Report: Human Fertilisation & Embryology Authority's review of sperm, egg and embryo donation in the United Kingdom. Retrieved 20 January 2011](#)

Human Fertilisation and Embryology Authority | 2005

2) [Donating sperm and eggs: have your say](#)

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3) [Human Bodies in medicine and research](#)

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4) [Press release: HFEA launches public consultation on sperm and egg donation, 17 January](#)

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5) [Blyth, E., Crawshaw, M., Frith, L., Jones, C., and Speirs, J. Wither the HFEA and the fate of donor registers?](#)

BioNews 572 | 23 August 2010

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