Comment

Gamete Donation Review - not the HFEA's finest hour

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During its 20-year history, the UK's Human Fertilisation and Embryology Authority (HFEA) has notched up significant achievements in the regulation of assisted human reproduction that have rightly drawn respect worldwide. An important characteristic of the HFEA's approach to regulation has been its use of public consultations to inform policy development.

Unfortunately, the recently-concluded Gamete Donor Review (1) is unlikely to be regarded as among the jewels in the HFEA's crown. If the quality of this review is anything to go by, we should not set our expectations too high about the findings, the analysis, or the recommendations for policy change it may prompt.

Of course, criticism of the Review cannot be made in isolation from the terminal outlook and austere financial situation that faces the HFEA. This arose after the installation of the
Conservative-Liberal Democrat Coalition government in May 2011 when the HFEA had already decided to initiate the Review.

Things could and should have been much better. For example, the HFEA was forced to axe a proposed innovative research fellowship partnership with the UK's principal social science research funding body, the Economic and Social Research Council (ESRC). This research would have helped provide robust evidence about contemporary UK gamete donation. By identifying issues that needed addressing, it would have facilitated properly-informed responses to the Review.

Questions should have been asked at the HFEA's highest levels about whether, in the light of its reduced resources, it could conduct a worthwhile Review. It is questionable whether the Review was needed now given the HFEA's other priorities. In any event, the HFEA proceeded with a Review that – in my view – signally failed to live up to the high standards set by predecessor consultations. It certainly lacked the necessary robust underpinning to its evidence base.

The Review was biased from the outset by pre-empting any reasoned consideration of the current 'landscape' of UK donor conception. It did this by setting the scene under the guise of 'The changing landscape of donor conception' and ensuring that (literally) the first question was about improving the supply of donated gametes.

This situation was compounded with a further question asking whether gamete supply could be improved by legislative change or withdrawal from commitments under the EU Tissue Directive. Both are the UK Parliament's prerogative, not the HFEA's. By contrast, concerns about the well-being of those directly involved were given short shrift. These include patients seeking treatment, donors – except how they might profit from 'donating', and donor-conceived individuals.

The failings of this Review stand in stark contrast to the recently-concluded investigation into donor conception undertaken by the Australian Senate (2), in which welfare issues were given their rightful, prioritised place. It is more than a little ironic that 'amateur' politicians undertook a more comprehensive and sophisticated review of donor conception than a body dedicated to these matters – especially given the HFEA's previous track record.

Perhaps the most grievous omission is the HFEA's failure to draw on the information already in its possession. Having been in operation for almost two decades, the HFEA ought to hold an unrivalled store of data that could have usefully informed the Review; for example, information about the reasons for the under-usage of existing donor supplies, the physical and psychological risks to which egg donors may be exposed, and how many donors are required to meet current demand.

More mundanely, the Review referred to problems about current arrangements for reimbursing donors' expenses and sought views on whether more complex systems for paying donors for loss of time and inconvenience should be introduced. Yet the HFEA provided no analysis of clinics' complaints to ascertain the nature of these problems and how they might be resolved.

What is more, the problems with reimbursement appeared - from the information provided - to be caused by the HFEA being excessively bureaucratic. If the HFEA cannot
manage the simple matter of reimbursing donors' expenses, questioning whether it can
set up an adequate system for paying donors for loss of time and inconvenience seems
entirely legitimate. This, of course, is separate from the question of whether it is ethical
to pay donors.

Where 'evidence' is used in the Review, this is highly selective and findings appear to
have been 'cherry picked' to support a particular position. The Review did not, for
example, contain any evidence about whether additional inducements would likely
increase donor recruitment.

It has also emerged that the HFEA may not have best used members of the advisory
group set up to help prepare the Review. Some members of this group feel their views
were ignored and decisions made without appropriate consultation. This begs the
question of whether the group was established so the HFEA could claim it had 'consulted'
with stakeholders who endorsed the Review before it was launched.

I do not know how much time and money the HFEA has invested in this Review. Arguably,
those resources would have been better invested in analysing data already in the HFEA's
possession. It would be honourable and extremely courageous for the members of this
moribund and cash-strapped organisation to accept that the Review's shortcomings mean
it should not prompt policy changes. Instead, issues the Review raises should be properly
reconsidered by the HFEA's successor institution.

SOURCES & REFERENCES

1) Donating sperm and eggs: have your say
Human Fertilisation and Embryology Authority (HFEA) | 2011

2) Inquiry into donor conception in Australia
Australian Senate Committee | 2011

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