

This response was submitted to the evidence call held by the Nuffield Council on Bioethics on Donor conception: ethical aspects of information sharing between 21 March 2012 and 15 May 2012. The views expressed are solely those of the respondent(s) and not those of the Council.

British Medical Association

Donor conception: disclosure of information

British Medical Association Response

Thank you for seeking the views of the British Medical Association on your consultation on donor conception.

1. In relation to the information that should be provided to those who are conceived through donor conception, the British Medical Association does not support secrecy but supports anonymity. Although the two concepts are often conflated they are very different. The BMA believes parents should be open with their offspring about donor conception but has concerns about the removal of anonymity from donors and did not support this move.
2. This response focuses primarily on these two key issues. The BMA does not have specific knowledge or expertise in relation to the information and support needs of donor conceived individuals or the impact on them of discovering information about their donor conception. Some of the literature in this area is, however, referred to in chapter 8 of the BMA's handbook of ethics and law, *Medical Ethics Today*, and the relevant section is attached for information.

Secrecy and openness

3. As a general principle the BMA would like to see greater openness between parents and their donor-conceived children but believes this should be encouraged rather than forced. The Association did not, for example, support moves in 2008 for information about donor conception to be included on children's birth certificates but supported the requirement on clinics to discuss with those seeking treatment the importance of openness and to help them to find the right way to explain to their children how they were conceived.
4. The evidence from adoption is that disclosure about a child's genetic origins is best handled by parents at their own speed. Children mature at different rates and can absorb, understand and contextualise complex information at different ages. Parents are best placed to understand their child's level of development and to choose the right time to disclose.
5. Taking this responsibility away from parents, by using a formal mechanism (such as putting information on the birth certificate) means that parents lose control over the timing of disclosure. This could result in more unplanned disclosures which the literature suggests can be very damaging to the donor-conceived child or adult.

6. Adding 'donor conceived' or similar to the birth certificate would also result in the young person having no control over who has access to the information given that birth certificates are used for a range of purposes including often at commencement of work with a new employer and can be accessed by others.
7. The BMA believes the right balance has been achieved with the requirement on clinics to provide information to those seeking treatment with donated gametes or embryos.

Donor anonymity

8. In 2002 the BMA's Representative Body passed a motion opposing the removal of anonymity from sperm donors; this remains BMA policy. This stems from serious concerns about the impact of the removal of donor anonymity, both in terms of the number of donors coming forward and in terms of the willingness of parents to inform children about their donor conception.
9. The BMA recognises that people born following donation have a strong interest in knowing the identity of the donor and that this can be very important for some individuals. The Association has been very concerned that a shortage of donors would deny some people the opportunity to have children or may encourage them to make 'informal' arrangements thus exposing themselves to risk of harm.
10. Although data from the Human Fertilisation and Embryology Authority about new donors appears reassuring, the published data do not distinguish between known or directed donors (who will only donate to one person or couple) and those willing to donate to anyone, where up to 10 families can be helped. This makes a difference in terms of the number of people able to receive treatment.
11. The BMA has also been concerned that anonymity was removed before there were clear research data about how this change was likely to affect the willingness of parents to tell their children. If parents are concerned about their offspring contacting the donor this may deter them from revealing information to their children about their donor conception; it is possible that an attempt to provide more openness may, in fact, result in more secrecy.

Medical history

12. The medical history of the donor is clearly relevant and might impact on the donor-conceived individual's future health risks. Where clinics become aware of a significant medical history after donation has occurred, a procedure should be in place for ensuring that the information is reviewed and that the necessary steps are taken to ensure that information is given to the parents of any children born following the donation (or the offspring themselves if they are sufficiently mature) in a timely and sensitive manner. The details of who should provide the information, and how, will depend on the individual circumstances.

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