

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.

Nuffield Council on Bioethics Donor Conception Consultation

The following outlines our replies to the questions posed by the Donor Conception Consultation

We welcome the consultation on Donor Conception inviting relevant health care professionals and the general public to voice their personal views on how much information should be disclosed to donors and donor conceived individuals and their families. It is important that society recognises and meets the needs of these groups equally.

Whilst health care professionals aim to take into account the implications for all parties involved when donated gametes are used in assisted reproduction we must continue to learn about the ramifications through the experience of donors, donor conceived individual and their families. The long term physical, mental and social wellbeing of an individual and their family should be at the heart of treatments and interventions How much information should be disclosed to all parties can only be fully evaluated following research analysis and debate, thus enabling greater understanding about the needs of all those concerned.

With the advances in reproductive technologies it is vital that society participates in these debates for legislation and regulation to remain relevant and appropriate. All centres offering donor conception treatments should actively encourage donors and recipients to contribute to research and debates to promote greater understanding of their experiences and needs.

We look forward to The Council publishing its report and making policy recommendations where appropriate in the spring of 2013.

1. What ethical concerns arise in the disclosure, or not, of information in connection with donor conception?

The health and social welfare of children/ people born as a result of gamete donation should take priority but this has to be balanced with the needs of the people for

whom, this is the only option to have a child and the needs of the gamete donors and their families.

The concerns of all three groups should be considered with overarching policy, law and guidance which is then applied in individual circumstances.

2. Is the disclosure of a child's donor conception essentially a matter for each individual family to decide? What if there is disagreement within the family? Who else should have a role in making this decision?

The disclosure is a matter for the family to decide but it is essential that before embarking on using assisted conception with donor gametes they are provided with specialist counselling and information to think through the implications for all involved. Equally important is the routine availability of ongoing support for the parents after conception such as that offered by DC networks which we considered should be strongly supported and developed.

3. What information, if any, do parents need about a donor in order to enable them to carry out their parenting role? Please explain.

Medical information is very important as this can have implications for the donor conceived child/person and their future offspring. As our knowledge about genetics and inherited conditions and predisposition to conditions which have a genetic component increases, this becomes even more relevant. Much more difficult are the social relationships. Parents need to understand what information they will be given to give to donor conceived children within the law as it stands at the time of the child's conception.

4. What information might a donor-conceived person need about the donor, either during childhood or once they become adult? Please explain.

Medical information –see below

Information about possible live half siblings i.e. children of the donor and other infertile couples who use the same donor

5. How significant is information about the medical history of the donor and the donor's family for the health and wellbeing of donor-conceived offspring? Do you know of any examples or evidence in this area?

Medical information: they need to know if there is any information about the donor's medical history which could have an impact on their health or that of their children which is relevant to their lifestyle choices.

6. Where information about inherited medical risk becomes apparent after donation has taken place, who should be told, and by whom?

The donor conceived children have a right to know of any serious conditions and there should be processes in place to provide this information in a controlled and supportive way.

7. What is the impact on donor-conceived offspring of finding out about their donor conception at different ages: for example medically, psychologically and socially? Do you know of any examples or evidence in this area?

For all ages we believe the greatest potential for difficulty is finding out in unexpectedly and unintentionally which can be a great shock. Supporting parents bring children up with the information given in an appropriate way is the best way to avoid this. The work of DC Network should be supported and extended to achieve this.

8. What is the impact on donor-conceived offspring of making contact with either the donor or any previously unknown half siblings? Do you know of any examples or evidence in this area?

We do not have experience of this situation.

9. What interests do donors and donors' families have in receiving any form of information about a child born as a result of the donation?

The interests of the donor are complex but they should be motivated by concern about the health and welfare of the children conceived through donation. Information and counselling before making the donation are paramount in helping donors to prepare for the long term consequences of a donation. They should be offered long term support and counselling as well.

10. What responsibilities arise in connection with the disclosure of information? Where do these responsibilities lie?

Health care and allied professionals, donors and recipients all have responsibilities. It is crucial that all these groups are aware of and well informed about their responsibilities and supported with how they cope with them. .

11. What support is required in connection with these responsibilities?

Clear information about the current legal and regulatory requirements.

Access to comprehensive information and counselling during treatment and in the longer term.

Current sources of support and other resources

12. Do you have any other comments?

People having treatment abroad and using donated gametes is a great concern for those receiving treatment, those conceived and the donors who may be exploited and not have the level of information and support which is offered in the UK (though this could be much better). Much more attention should be paid to educating people in the UK about the medical and social "risks" and potential consequences as going abroad for treatment cannot be prohibited.