

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.

Church of England: Mission and Public Affairs Council

Response of the Mission and Public Affairs Council of the Church of England to the Nuffield Council on Bioethics Consultation on Donor Conception

The Mission & Public Affairs Council of the Church of England is the body responsible for overseeing research and comment on social and political issues on behalf of the Church. The Council comprises a representative group of bishops, clergy and lay people with interest and expertise in the relevant areas, and reports to the General Synod through the Archbishops' Council.

The Mission and public Affairs Council presents a Christian ethos, drawing on the witness of the Christian Scriptures and reflecting on Christian tradition and contemporary thought. Belief in God as Creator and Redeemer, in human beings' intrinsic value as creatures made in the Image of God and in the imperatives of love and justice, underpins the Council's approach. The Council believes that the ethical and social principles that are developed from this foundation may be embraced by people of other faiths or of none.

1. Should children always be told that they are donor-conceived? If so, why?

In principle, individuals ought to have full access to their own personal information; this includes information with regard to their genetic origins. Children have the same rights as adults and care ought to be taken not to withhold information from them, unless this is necessary for their protection or well-being. The UN Convention on the Rights of the Child (article 8) specifically declares that children have a right to the preservation of their identity; some knowledge of their biological parents may be seen as an important way of helping to achieve this. Knowing that they are donor-conceived is not likely to have any greater detrimental effect on children than if they are made aware of this only once they become adults. Donor-conception carries with it responsibilities and potential difficulties, but these ought to be acknowledged and accepted before donor conception is undertaken.

2. Who should decide whether, and if so when, to tell a child that they are donor-conceived? Is this a decision only the parents can take – or should anyone else be involved?

While legislation would remove uncertainty and inconsistent practice with regard to children having knowledge of their genetic origins, this may be too blunt an instrument to utilise in such a sensitive area. Prior to donor conception, parents ought to receive counselling during which the desirability of disclosure ought to be emphasised. It is likely to be in children's best interests that they are made aware of their genetic origins, in an age-appropriate manner, as early in their lives as is practicable. Problems are likely to increase the longer disclosure is withheld.

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3. What information do the parents of donor-conceived children need about the donor to help them look after their child? Why?

Information with regard to the onset of any significant physical or mental illness ought to be made available to the parents of donor-conceived children as this information may assist them in reducing the risk of such illness occurring in their children.

The implications of donor-conception are not restricted to matters of genetics. Inevitably, there are psychological and social implications for children, parents and donors, particularly if a child expresses a wish to make contact with his or her genetic parent(s) once he or she reaches eighteen years of age. In this context, certain 'non-genetic' information is relevant to the well-being of donor children. For example, information with regard to any donor convictions for serious crime (murder, rape, violent crime) ought to be made available to parents as this will assist them in providing early support to their children.

Other personal and social information might also be of use to parents as they help to prepare them for any potential meeting with their genetic parent(s). Such information might include details of education, employment, financial status, family circumstances or sexual orientation. It would, however, represent an invasion of donor privacy to insist that such information *ought* to be made available. It might also have the effect of limiting the number of donors prepared to volunteer for donor-conception programmes. At the same time, should donors choose to make such information available (as is often the case in programmes in the USA) they ought not to be prohibited from doing so, or parents prohibited from giving this information to their children.

4. What information about the donor do donor-conceived children need? Why?

Please see the answer given to question 3. The type of information that younger children will receive will depend on what their parents consider to be in their best interests. Adolescents, incrementally, ought to have the same access to information as their parents, but this will vary according to individual circumstances.

5. What information (if any) might an egg, sperm or embryo donor want about a child born as a result of their donation? Why?

It is natural that donors may wish to know the sex of any children born as a result of their donation as well as information with regard to their physical and mental wellbeing. Some donors may also wish to have access to information about children's academic, sporting, artistic or other achievements. Information that donors *may wish* to have is not the same, however, as information that they *ought* to have. Donation ought to be viewed as an altruistic act and not as a means of 'remote-parenting'. Adolescents (or parents in the case of younger children) would have to give their consent before *any* information could be made available and this ought to be restricted to matters that might have an impact on donor-children

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relationships should children decide to make contact with their genetic parent(s). Such information might include sex, physical/mental health or disability where *children* are concerned that this might have an adverse effect on a genetic parent's response to them.

6. If a donor finds out later that they have a genetic condition, should they try to pass on this information to the child conceived with their egg/sperm?

Any relevant information ought to be given to health professionals, in the first instance. Properly trained health professionals ought then to give adolescents (or parents of younger children) an opportunity to be made aware of this information, should they so wish.

7. What support might donors, donor-conceived children and parents of donor-conceived children need? Who do you think ought to provide it?

Many donors, children and parents will require minimal support, but support ought to be available in the form of counsellors, social workers and health professionals for those children, parents or donors who may suffer psychologically because of their circumstances. The interests of children born from donor conception are paramount and these interests include securing their mental well-being. The criteria for receiving NHS treatment must be clinically based, but it is important to recognise that circumstances arising from donor-conception might have a detrimental effect on an individual's health.

8. Do you have any other comments?

It is *essential* that the counselling that prospective donors and parents are given, *prior* to them deciding to participate in donor-conception programmes, adequately covers the full implications of this practice. If participants are enabled to recognise and consider all that donor-conception may entail, they will be better equipped to deal with difficult issues, should they arise at a later date.