

**NUFFIELD
COUNCIL^{ON}
BIOETHICS**

**Donor conception:
ethical aspects of information disclosure**

Call for evidence

March 2012

Call for evidence: key issues

The Nuffield Council on Bioethics is carrying out an inquiry on the ethical issues that arise in connection with the **disclosure of information** about genetic origin in the context of families created through assisted reproduction using donor gametes (eggs or sperm), embryos, or surrogacy. Information about a person's genetic origins should be understood as including: the fact that a person is donor-conceived; non-identifying information about the donor (for example medical or genetic information that may be of future relevance to the health of any offspring conceived as a result of the donation); and identifying information that might enable the person to contact the donor (such as name and last-known contact details).

Donor-conceived offspring may not have genetic links with one or either of their social/legal parents.¹ Their parents may, or may not, choose to tell them that they are donor-conceived; and they are likely to have only limited information about the family and medical history of the donor(s). Donor-conceived children conceived after 1 April 2005 as a result of treatment in a UK-licensed clinic are legally entitled at the age of 18 to find out the identity of their donor and, if they wish, to seek to make contact with the donor and potentially also with any unknown half siblings. Donors are entitled to find out the number, sex and year of birth of any children born as a result of their donation but receive no other information unless that child, on reaching adulthood, makes contact.

Access to information about a donor-conceived person's genetic origins thus raises a number of ethical questions: these include both how the (sometimes conflicting) interests of all the various parties involved in donor conception may properly be balanced; and what role the state, the public sector, or health and social care professionals more generally, should play in what is often seen as the private domain of the family.

The Terms of Reference for this inquiry are as follows:

In the context of families created through assisted reproduction using donor gametes, the Working Party will consider the impact of the disclosure/non-disclosure of information about a child's genetic origins, with particular reference to:

¹ Some children born as a result of surrogacy are conceived with gametes from both 'commissioning' parents and hence do not have a donor in the usual sense. However, under UK law such a pregnancy will still be treated as deriving from donated gametes (donated to the surrogate mother), and disclosure issues with respect to third party involvement in the child's conception will still arise. Such surrogacy arrangements have therefore been included in this inquiry.

1. *the wide range of stakeholders involved, the complexity of the relationships between them, and the ethical values at stake;*
2. *the quality of the evidence currently available as to both the medical and social importance of genetic information in this context;*
3. *the support available to both donors and donor-conceived families, for example in connection with future contact; and*
4. *the role of the law and professional guidelines in determining the provision of both general and specific information about donors to donor-conceived children and their families, and in intervening in families' decisions with respect to disclosure.*

The Council will publish a report on this issue, making policy recommendations where appropriate, in spring 2013.

Consultation questions

In order to inform and support the Working Party's deliberations, the Council would like to invite anyone with an interest (personal, professional or general) in this field to contribute views, examples and evidence within the scope of the terms of reference. The questions on which the Council is particularly interested in hearing your views are set out below. **Please feel free to answer any or all of these questions, or to give your views in any other way on the issues within the scope of the terms of reference.** Where possible, it would help us if you could explain the reasoning behind your answers.

1. What ethical concerns arise in the disclosure, or not, of information in connection with donor conception?
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?
3. What information, if any, do parents need about a donor in order to enable them to carry out their parenting role? Please explain.
4. What information might a donor-conceived person need about the donor, either during childhood or once they become adult? Please explain.
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?
6. Where information about inherited medical risk becomes apparent after donation has taken place, who should be told, and by whom?
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?
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?
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?

10. What responsibilities arise in connection with the disclosure of information?
Where do these responsibilities lie? (for example with government, fertility clinics, professionals or families?)
11. What support is required in connection with these responsibilities?
12. Do you have any other comments? Please highlight any relevant areas you think we have omitted, or any other views you would like to express about information disclosure in the context of donor conception.

How to respond

We would prefer it if you could send your response to us electronically. Responses can be sent via email to Kate Harvey (kharvey@nuffieldbioethics.org), with 'Donor conception' in the subject line. It will greatly assist the Working Party if responses are in the form of a single Word document, with numbered paragraphs throughout.

Please ensure that you also include a completed response form with your submission, which can be found on page 7 of this document or downloaded from www.nuffieldbioethics.org/donor-conception.

If you would prefer to respond by post, please send your submission to:

Kate Harvey
Nuffield Council on Bioethics
28 Bedford Square
London
WC1B 3JS

Telephone: +44 (0)20 7681 9619

Fax: +44 (0)20 7323 6203

Website: www.nuffieldbioethics.org/donor-conception

Closing date for responses: 15 May 2012, 5pm.

For more information about the Working Party, or the Nuffield Council, please follow the links listed below:

[Terms of reference of the Working Party](#)

[List of Working Party members](#)

[Terms of reference of the Council](#)

[List of Council members](#)

Respondent's form

Please complete and return with your response by **15 May 2012**. We will **not** publish your name without your express permission.

Your details:

Name:

Organisation (if applicable):

Address:

Email:

About your response:

Are you responding personally (on your own behalf) or on behalf of your organisation?

- Personal Organisation

May we include your name/your organisation's name in the list of respondents that will be published in the final report?

- Yes No, I/we would prefer to be anonymous

If you have answered 'yes', please give your name or your organisation's name as it should appear in print (this is the name that we will use in the list of respondents in the report):

May we quote your response in the report and make it available on the Council's website when the report is published?

- Yes, attributed to myself or my organisation No
 Yes, anonymously*

*If you select this option, please note that your response will be published in full (but excluding this form), and if you wish to be anonymous you should ensure that your name, and any other identifying information, does not appear in the main text of your response. The Nuffield Council on Bioethics cannot take responsibility for anonymising responses in which the individual or organisation is identifiable from the content of their response.

Obtaining consent to publish a response does not commit the Council to publishing it. We will also not publish any response where it appears to us that to do so might result in detriment to the Council's reputation or render it liable to legal proceedings.

Why are you interested in this consultation? (tick as many as apply)

- Personal interest (donor-conceived person)
 - Personal interest (parent of donor-conceived child)
 - Personal interest (donor)
 - Other personal interest (please state):
 - Working in health or social care (with donors/families at time of donation)
 - Working in health or social care (with families/individuals after birth of child)
 - Work in/represent a charity or support group
 - Work in/represent a professional body or government
 - Academic/research interest
 - Legal/regulatory interest
 - General interest
 - Other (please state):
-

Please let us know where you heard about the consultation:

- Received notification by email
 - Newspaper, radio or television
 - Nuffield Council on Bioethics website
 - Twitter
 - Other website (please state):
-
- Other (please state):
-

Using your information

We ask for your postal and email address so that we can let you know when the report is published and notify you about activities related to this project. (Please note that we do not make your postal or email address available to anyone else, and we do not include it with the list of respondents in the report.)

May we keep your postal and email addresses for these purposes?

- Yes
- No

Would you like to receive our newsletter by e-mail which provides you with information about all of the Council's activities?

- Yes
- No

