

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.

Venessa Smith, Donor Services Coordinator, The London Women's Clinic

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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?

The importance of a child being able to understand more about themselves in the context of their conception, has been highlighted time and time again with the numerous contacts that the clinic has from donor conceived adults and recipients who used donor sperm or eggs in order to complete their family.

The donor conceived and the donor recipients have very different questions when they request information about their donors. For young adults, it is often whether we are still in touch with the donor and whether there were any other children born.

For the recipients it appears, in general, to be a less positive enquiry. These contacts are often following an extended period of soul searching when recipients (particularly those who previous used anonymous donors) harbour intense levels of guilt regarding on the long term implications of their decisions to use donor gametes.

Despite these very different motivations for contact, it clearly shows the long term impact for all involved and hence, the need for information to be made available.

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?

This issue needs to be discussed prior to conception, so that the appropriate resources/ tools are in place for the family to manage when the time is right. The importance of counselling and support during treatment is key to the process of disclosure and this has been recognised, quite rightly, by regulatory bodies and scientific societies alike. 2

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Evidence based research, has clearly indicated the benefits, to the donor conceived person, of transparency within the family regarding donor conception. In the majority it has proved useful to include the nature of the conception as part of a child's life story, so that it is not a 'surprising/shocking' issue to discover later in life.

There is still some reluctance, in certain cultural groups, to disclose not only any difficulties with reproduction but particularly the need for donor gametes. This is despite overall improved acceptance in much of society. This indicates a clear need for encouraging professionals to address this matter long before conception.

Of course, all families are different, with very specific needs and attitudes. However, the rights of young adults regardless of their cultural background remains the same.

However, to give the responsibility of disclosure to a non family member, except in a very controlled setting, would pose its own problems.

The existence of a family centred mediation service, which is directly linked to the HFEA donor register and therefore would have the maximum amount of information available for the donor conceived, is required to improve information disclosure. This would of course, not devalue the very useful organisations that exist to offer support and guidance for patients embarking on, undergoing or following treatment.

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

The majority of parents, initially request information about medical background and characteristics that will ensure that the child blends in well with the family on both a physical and intellectual level. However, when information requests are made by recipients who have been successful and have young children, the most common requests are for subjective information on donor personality or hobbies and interests. This is generally as a result of a child trying to build a more 'real' picture of their donor parent. Efforts are made to provide this information in advance of questions but often it is not immediately clear what information will be useful, for children as they grow up. More important than specific information about a donor, is for parents to be properly prepared for questions that their child may have, which may be very emotive and challenging.

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

Most importantly, a sense of who their donor is, why they decided to donate and reassurance that, should they want to, they will have the opportunity, at some stage, to ask the donor these questions themselves. The majority of donors that I have spoken with feel very conscious about the importance of the information that is lodged on the HFEA register and often decide to change or update it, once they have 3

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become more confident about their part in the donation program. These updates are very important and we do try and encourage the donors to communicate directly with the HFEA once their period of donation at the clinic is complete.

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?

The medical history of the donor is important; however, with the strict screening regime and selection prior to joining the donation program, patients should feel reassured that their medical interests have been taken care of. It is of course impossible to screen for everything, but a good base level of medical information can always be made available to patients if they have any concerns. We also keep a record of any outcomes that have unexpected medical anomalies so that in the event that a trend is noted all other parents who have conceived with the same donor can be contacted if appropriate.

Key questions are asked of the donors at the initial phase of inclusion on the program, these questionnaires are carefully worded to ensure that potential hereditary problems (or dispositions) can be identified and then discussed with the donor at their medical consultation. The medical consultation is another method of identifying and then excluding any unsuitable donors.

A key area of testing is also related to racial groups. The importance of screening particular donors for hereditary conditions with an ethnic bias is also a key part of the run up to donation. We have had patients that have used donated gametes for this reason – in that both parents are carriers and they do not wish to take a risk of having an unwell child.

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

Unfortunately, this situation has occasionally arisen as a result of the LWC being a regular provider of donor gametes. The policy at LWC is to analyse the risk to other offspring before deciding whether it is necessary for the information to be provided to other parents or the donor.

Of course, as soon as a genetic risk has been identified the donor is immediately removed from the program. We also inform the donor to ensure that he is aware of any potential risk if he intends to have his own children.

Often parents with an affected child do want other families to be aware of medical problems. The need to inform other families is carefully assessed but it does need to be remembered that this may be related to their own anxiety rather than any benefit this information will give to other families. 4

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Interestingly, despite informing other patients (using the same donor) of the potentially hereditary nature of a problem in a half sibling, many opt to have further treatment using the same donor despite the risk. They are advised against this by the clinic. However, they often feel that the full sibling relationship within a family is more important. Some patients also decide against their child being tested at all. Feeling satisfied that their child is 'perfect for them'.

At all stages appropriate referrals and counselling are made freely available for donors, parents and offspring.

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

I have luckily had experience at meeting children and young adults who have been donor conceived.

In my experience, there has been a clear difference in response, which appears to be largely dependant on the way in which the off spring found out about their conception. Increasingly, young people (including teenagers) have been fairly relaxed about being donor conceived, particularly if it has always been openly discussed. One child i met had even discussed it in a school project, which then led to lots of open discussion.

In comparison, one young adult had found out about his conception through discovery of some early medical records. This was devastating for him. Not because he was donor conceived but because he felt lied to. Interestingly, he found the fact that his brother was from a different donor a great relief because he felt that this explained the physical and emotional differences between them that they had both always found very confusing.

We also recently recruited a donor who, who himself had been donor conceived. He donated as a way of passing on his good fortune and was very open about how he felt.

We were introduced to his mother and father and discussed at great length how it felt having a donor conceived child in the 70's. He has since found his American donor father. Sadly not through official channels – but he is now building up a relationship with him and his half siblings.

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?

The one young adult that i have met who has got in contact with his half siblings has worked very hard to build a relationship with them. However, it will always be more like a distant cousin than with a true sibling. In his situation, his half siblings lived quite remote from one another so most contact was via email and this is not always 5

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satisfactory. Even so, he does feel these relationships are crucial to him understand who he is.

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?

Some donors have a huge determination for hearing about the positive outcomes and really wish that they were able to contact the offspring themselves. We routinely hear from donors up to 10 years after their donations with questions relating to what happened to their sperm.

The majority of our sperm donors do not inform their families of their donations. Those that have, have regularly mentioned the difficulties that some parents have in knowing about grandchildren that they will never meet and the fact that their son has provided the families genetic material to anonymous benefactors. One particular donor, who is himself childless, has had to deal with this for many years from his mother who likes to keep tabs on the ages of children that he has helped create.

I have also unfortunately witnessed the breakdown of a number of relationships as soon as the donor reveals to his partner that he was part of the donation program which has resulted in live births. We do offer a counselling service for these couples but it is only occasionally accepted.

Ideally we suggest that donors are open with their families/partners prior to their samples being used.

More support and education does definitely need to be directed at donor's families.

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?)

To ensure that all donors, donor conceived and recipients receive the same advice and/or information, it is crucial that a national organisation deals effectively with all involved.

In the past we have given patients and donors basic outcome information, but now we refer all direct to the HFEA.

To ensure that the info the HFEA have is complete, we update them as much as we can regarding changing contact details and also include as much additional information (such as skills, hobbies etc) as we can when submitting a donor for registration. 6

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

Proper training is the key to successful disclosure and potentially the involvement of donors and the donor conceived in these disclosures to ensure an empathetic response.

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.

I would be really keen to meet and discuss this all in person. I have spent the last 10 years of my career with a donor heavy work load and really hope that my experienced could be helpful to this consultation. 7

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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:

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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

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