

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.

Trustees and Steering Group of the Donor Conception Network

Response from the Trustees and Steering Group of the Donor Conception Network

Preamble

The Donor Conception Network has been in existence for 19 years. Over that time there has been a continuous involvement with thousands of donor conception families of all ages, conception procedure types, and gender composition.

Most of our responses below apply to the situation regarding the majority of donor conception procedures practised in licensed clinics in the UK: egg, sperm or embryo donation using gamete or embryos where the identity of the donors are unknown to the recipients, but will be available to the offspring when adult. It should be recognised however that a significant minority of procedures resulting in the birth of donor conceived children in the UK fall outside this pattern.

There are an increasing number of “known donors”: that is women or couples who find a person willing to become a donor to help them. They do so often because they want to be able to identify the donor and are uncomfortable with the lack of access to identifiable information (until the child reaches 18), or because of the waiting times experienced in UK clinics – or the costs of treatment seem prohibitive.

There are also family members who become donors. Brother, sisters or other family members volunteer to become donors to help their relations.

It should also be borne in mind that a significant but unknown number of donor children born in the UK were conceived as a result of procedures performed outside the UK. Details of the treatments used, information about donors and about children conceived and born do not appear on the register held by the HFEA.

Finally there are children born as a result of surrogacy procedures; these can involve the surrogate mother as the genetic mother, or in gestational surrogacy, procedures in which donated gametes or embryos are used.

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

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1a. Re information that a child is donor conceived: The primary concern is the welfare of the person conceived. Honesty and openness put integrity at the heart of family life, lessening the risk that a child will feel betrayed in the future because they were not told the truth. Being open, however, does not mean that a child/adult may not be curious about their donor or go through a period of sadness or anger at some point in their life.

1b. Non-disclosure means that there is a deception at the heart of a family; children are misled about a genetic connection they would grow up to assume was present; parents will almost certainly be led into telling direct lies about family likenesses or avoiding doing so in an awkward way that is likely to arouse suspicion that something is amiss.

1c. Disclosure may need careful consideration where a child is being raised in a community, faith or culture where donor conception is disapproved of. Under these conditions it may be hard for a child to be proud of who they are and the way they came into the world. In these circumstances parents should be alerted to and supported to consider these issues before and during treatment.

1d. Disclosure may also need careful consideration in the case of a child with profound learning difficulties or developmental delay, where donor conception may not be understood/have much meaning or could cause confusion. However, the key principles of rights and inclusion from the DoH white paper 'Valuing People' would suggest that an individualised assessment be considered in addition with ways to communicate this information in a sensitive and supportive manner in line with the level of comprehension of the child/person concerned.

1e. Re information about the identity of the donor: Access by DC people to identifying information about donors will only be possible en masse from 2023 for those children conceived in the UK since April 2005. Those conceived between August 1991 and April 2005 may be able to have this information if their donors have re-registered as identifiable (very few have). Those conceived prior to August 1991 have to give DNA samples to the bank held by UK Donor Link in order to have a chance of information about or contact with their donor or half-siblings. It is ethically debatable as to whether promises of anonymity made to former donors should be maintained for ever. The Law Reform Committee of the State of Victoria in Australia have recently decided that offspring rights should trump those of donors and recommended that identifying information about donors be available to offspring from all eras, with both donors and offspring able to express a veto on actual contact.

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1f. A secondary, but important, ethical concern is that of support for people as they seek information about their donor or half-siblings. This could be in the form of counselling and/or intermediary services. The Australian law reform report mentioned above makes clear the emotional vulnerability of people as they take part in the journey to finding out more about their donor. The recommendation they make is for a professional service very similar to that being offered by UK DonorLink but which is currently under severe threat of losing funding. The HFEA have never seemed to understand or value the need for such a service for their register enquirers. This needs to change.

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 the decision.

2a. It is in the interest of society in general to have healthy, well balanced people as members. Evidence suggests that early telling may be a protective factor as individuals who are told later in life report more emotional distress. In the interests of promoting positive mental health children should learn about their conception from their parents at an early age. Parents are the right people to share this information and the decision to be open should be made and agreed upon before a couple have donor conception treatment. Sometimes it will take one partner a long time to come to this decision. DC Network runs workshops for potential parents to consider all the issues around donor conception and has been very successful in gently helping bring round reluctant partners to the idea of telling being better for all family members. Where it is clear that potential parents have no intention of telling their future child about his or her conception, clinics ought to recognise that the welfare of the child is at stake and should consider declining to treat.

2b. DC Network's experience is that comfort and confidence with decisions made by potential and actual parents around donor conception is the most important predictor of openness in the family.

2c. The HFEA in the 8th Code of Practice puts an onus on clinics to let would-be parents know that being open with a child is recognised as being better for that child and the whole family than keeping a secret. They also have to let people know where they might find information about how to share this information with their child. Openness is recognised by all mental health and family welfare professionals as the preferred position. Counsellors in clinics have a difficult job because they usually want to encourage openness but often have only one 'implications counselling' session in which to do it. Whilst mandatory further

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counselling sessions might be seen as inconsistent with an understanding of counselling as an activity that must be undertaken voluntarily, preparation for DC parenthood sessions could be made a requirement for all couples and individuals using donor gametes for family formation.

2d. DC Network supports the right of children to know that they are donor conceived. In 2007 we conducted a survey in which an overwhelming majority of the large number of members who responded believed that parents rather than the state are the right people to share this information. We would prefer that all parents come to this position through a combination of education, awareness raising and preparation for being a donor conception family. It may be, however, that the time has now come to re-open the debate that has been simmering for some time about this information being available to donor conceived people via official records of some sort. We do not believe the information should be directly evident on birth certificates but if it were possible to devise a system within or outside the birth registration system that ensures that donor conceived adults are alerted to their status and informed how to retrieve 'their' information, while retaining their right to privacy, we would support this.

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

3a. First of all parents need to feel comfortable about their donor. Sometimes this will mean having all the information that is available whilst others prefer not to have too much, leaving it to the child to find out more for themselves when they are older. Just knowing the information is available should a child want it is often enough. Clinics should not give would-be parents donor information before asking if they want to see it. Being comfortable with the donor implies that they also feel comfortable about the decision they are taking to go ahead with creating or adding to a family by donor conception. These are the most important building blocks for early telling. One of the great anxieties about people going abroad for donation procedures is that European clinics give very little information about donors, leaving parents on shaky ground with regard to confidence about sharing information with their children in the future. It is also important for parents to have accurate information about the likely number of half-siblings. This is available in the UK but cannot be guaranteed with gametes imported from abroad (including the US) and is certainly not available to those who have travelled overseas.

3b. The information that should be available to recipient parents, if they wish to have it, for purposes of feeling comfortable themselves and sharing with their children at appropriate moments as they grow up, is as follows –

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Full description of height, weight and build, eye, hair and skin colour. Any outstanding physical features such as very prominent ears, large nose or more than average number of moles.

Full medical and social history

Education level and current employment

Reason for donating

Pen portrait: written by donor as a description of him/herself, focusing on values in life (is this a good person) and including interests, talents and hobbies.

Later life information: letter to the child: wishing them well in their life, stating how they see their role in relation to the child for the future. This can be helpful in allowing the child to have realistic expectations of the future.

3c. Some parents seek out donors from the USA where considerably more information about donors is available, often including photographs (baby and adult), voice recordings etc.

3d. The donor needs guidance from someone who understands the meaning and uses of the pen portrait and letter to the child before they become available to the potential parents or child. They should not contain information that may be identifying or could be inappropriate. Close scrutiny of these documents by a designated team member, preferably a counsellor, should occur in all cases. Whilst these letters should be truthful, not glossing over revealing mixed motivations for donating or exaggerating attributes, occasionally it may be necessary not to allow a donor to continue with donating because of their attitude or motivation.

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

4a. All of the information given above, although donor conceived people should have a choice about whether they receive information about their donor or not. Like recipient parents, they should not have the information forced on them.

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

5a. There are mixed views in our group about the weight that should be given to medical history, both for recipients as they choose their donor (if they have a choice) and for donor conceived people.

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5b. On the one hand a full medical history is considered to be of vital importance, the absence of which may cause anxiety and possible medical complexities. On the other hand modern genetics seems to be showing that as environment and parenting have such an impact on gene expression and function, other than Mendelian single gene disorders, family medical history is far less important than was previously thought.

5c. What does seem important is making it easy for donors to report disease that may have an hereditary component as it becomes known to him or her, either in their family history (say BCa1 and BCa2 breast cancer genes) or as a personal occurrence. There has been a reported incidence in the US, via the Donor Sibling Registry (DSR), of aortic aneurism in a donor that also affected a proportion of offspring; some having life-saving surgery as a result of knowing what had happened to their donor. Within the DSR there are other clusters of donor conceived children across a number of families who seem to suffer from other disorders that impact on both mental and physical health.

5d. In our culture there is a general societal emphasis on genetic inheritance, encouraged by programmes such as Who Do You Think You Are and the entering into the modern lexicon of phrases such as 'it's in the genes'. It is possible that some donor conceived people may over-value the genetic influence in their development, but it remains true that medical history remains an important factor for many DC offspring.

5e. Medical background is also valued by potential parents as they choose their donor, with a family history free of major disease being another reason for parents to be confident and comfortable about their donor.

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

6a. See above. It needs to be stressed to donors that they must report any information regarding the development of serious inheritable disorders in either themselves or their genetically related family to the HFEA as soon as possible. The HFEA must then take responsibility, with advice from appropriate experts, about whether or not parents and/or offspring should be informed.

6b. It is also possible that donor conceived children/people may develop disorders that could be attributable to the donor but of which the donor is unaware (possibly because he or she is a carrier and has not manifested the condition themselves) or is withholding information about. Parents and offspring have a similar responsibility to donors in reporting such conditions to the HFEA.

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6c. Children conceived outside UK jurisdiction (other than the USA) are unlikely to be able to have access to information about conditions that come to light after they have been conceived because of the lack of central record keeping.

6d. New information about a health risk that is reported to the HFEA should be conveyed to parents, offspring or donors in a sensitive manner, ideally by a member of an intermediary services team. If the HFEA is informed that a former donor has died, donor conceived adults and parents of under 18s should be informed, whether the death was medically relevant or the result of an accident, as it may change expectations for 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.

7a. See Telling and Talking booklets, all publications by Ken Daniels and many other authors. Also, anything written by donor conceived adults. There is a complete consensus that early telling by parents who are comfortable with their decision about using donor conception to create or add to their family, is best for the children and whole family unit.

7b. Starting to 'tell' later than age eight or so carries a risk of a child being shocked by the information and this sense of shock always being associated with information about donor conception. The risk of this happening increases as a child gets older. Developmentally, probably the worst time to tell a child is during early teenage years as they are beginning to separate and differentiate themselves from parents, but do not yet have a secure sense of new individual identity or ipseity.

7c. There are many accounts by adults that speak of being knocked sideways by information about being donor conceived being given to them in teenage years and beyond. The responses from then on vary considerably. Some people adapt quite easily. Others seem to feel undermined in their sense of identity by the discovery. Some may lose trust in their parents and a very few reject their parents altogether – both non-genetic parent and the one they are related to.

7d. Fundamentally, it is simply not worth the risk of delaying beginning the information sharing process beyond the age of five.

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7e. Supporting research undertaken by Vasanti Jadva and colleagues for the Cambridge Centre for Family Research.

Age of disclosure and donor offspring's feelings about finding out they were donor conceived

<http://www.donor-conception-network.org/report%20for%20DSR.pdf>

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?

8a. UK Donor Link have much more experience of this with donor conceived adults than DC Network. Through association with this organisation we have learned that because of the history of secrecy that affects most donor conceived people over about 25, links between DC adults, donors and half siblings sometimes bring joy but are also often complex, difficult connections that do not necessarily bring about the results desired by registrants.

8b. It is likely that as the children in a new generation of families where parents have been open from the start grow up, then connections between half-siblings and donors will become more commonplace and less fraught, with parents helping children manage expectations as they grow up. In DCN we have had some half-sib links made between children under twelve or so. These have mostly been only children in single mother or lesbian families and, as far as it is possible to judge, have been happy and successful connections. Parents have been very supportive of these links.

8c. At one of our national meetings about two years ago a panel of donor conceived young people confirmed the impression we have gained generally that there tends to be more interest in half-siblings than in donors. It is possible that this view has been shaped in some cases (not just those on the panel) by what children/young people feel is a view their parents would be happy for them to express, but it does seem to be widely voiced nevertheless.

8d. The Donor Sibling Registry in the US has made thousands of half-sib links, mostly of young children via their parents, many of whom are single mothers or lesbian families. Research conducted on DSR registrants by the Cambridge Centre for Family Research is listed below –

Offsprings' experiences of searching for and contacting their donor siblings and donor. Vasanti Jadva, Tabitha Freeman, Wendy Kramer, and Susan Golombok* RBM (Reproductive Bio Medicine) online, (2010) March 2010*

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8e. Two large groups of adult siblings, who know who their donors were (now dead), have recently been researched by Professor Eric Blyth and hopefully he will make these – accepted but as yet unpublished – papers available to the Committee.

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?

9a. DC Network has no direct information on this subject. We understand from UK DonorLink and the National Gamete Donation Trust that some former and current donors do have varying levels of interest in the children created with their donated gametes. Many former donors have registered on the Donor Sibling Registry as being willing to have contact with children they have contributed to creating.

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)

10a. The responsibility for changing the culture around donor conception to one where openness is the default mode, belongs to all those named in the question. There has been a sea-change in attitudes to 'telling' in the UK over the past five or six years. During this time people posting on leading web-based fertility forums such as Fertility Friends have moved from strongly advocating secrecy to openness being the norm. Parents still struggle with 'how to tell' but most accept that they should be doing it. Those who have decided not to tell are often very defensive about their position. This is a complete reversal of previous times. It should remain the responsibility of parents to share the information with their children. However, a birth registration system should be considered in due course.

10b. Fertility clinics need to come more strongly on board with the 'telling' message. Counsellors need no convincing of the rightness of this, but many nurses and clinicians remain neutral or ambivalent, preferring to say that it is the parents right to choose whether or not they tell. A clear and consistent message from all staff, from consultants to receptionists is needed.

10c. Responsibility for informing the HFEA when their or their family's medical status changes belongs to donors, BUT clinics and the HFEA should emphasise the need to update medical information and make it easy for donors to do this.

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It is the regulator's responsibility to inform parents/offspring about relevant changes in the donor's medical status.

10d. Donors also have a responsibility to update their contact details with their clinic/HFEA but again, these bodies need to emphasise the need to do this and make the process straightforward.

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

11a. Support for parents

Even parents who are unquestioning in their conviction that openness is the right path, often find actually starting to tell very difficult. The story books for young children produced by DC Network and some others are hugely valued by parents as a way of normalising the DC story – both in content and in form. The Telling and Talking booklets have sold around 2000 copies since they were first produced in 2006. Parents find them valuable in deciding when and how to start and continue telling over the years. Our Telling and Talking workshops where parents can practise language and share experiences with others are always full and the Telling Young Children small groups at our national meetings are over-subscribed.

Simply being able to be in touch with others in a similar situation brings enormous relief.

11b. Whilst most donor conception families do very well, unfortunately a small number each year find themselves in serious trouble or in need of professional guidance and advice to get them through a rough patch. DC Network staff are very good at listening to and supporting parents, but they also know when they need to refer a family to professional and on-going help. There are very few sources of help where there is understanding about donor conception families, and none within the National Health Service. DC Network has links with a few counsellors and psychologists and two agencies with the necessary knowledge, but the vast majority are in London and all require fees to be paid. This is a very unsatisfactory state of affairs.

11c. Support for donors

As an increasing number of donors share with their families the fact of their donation, the more guidance and support they are likely to need. Not just for donors themselves, but their partners and children as well. Identifiable donors have responsibilities to offspring that are far into the future at present (2023 and beyond) and support in managing expectations would be valuable. NGDT offer some support for donors in sharing information about their donation with their own children, but we believe it could and should be expanded.

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Clinics and HFEA should be supporting donors in reporting changes in contact information and updating medical details.

11d. Support for donor conceived people and their families

A national post-donation support and intermediary service of the kind provided in the post-adoption sector should be made available. Intermediary services provide a neutral interface for parties to explore whether they want contact of any sort, to manage different levels of expectation, to think through the implications of any proposed course of action and provide support where the outcome is disappointing for any party. This means professional staffing, largely by people with counselling or equivalent qualifications and skills, but it is often a different role from counselling which also needs to be available for some individuals.

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.

12a. If donor conception treatment services are to be run responsibly then they should not cut corners and must take account of life-time issues. Although adoption has significant differences to donor conception, it does have the benefit that practitioners have the right understanding of the long-term needs of families. The donor conception world is dominated by doctors whose expertise is in the science and clinical practice of helping a woman conceive NOT with the long-term interest of families. Whilst those people conceiving with IVF with their own gametes can happily carry on with their lives following the birth of their baby, those using donor conception have additional issues and responsibilities that are life-long.

12b. Donors and potential parents both need and deserve preparation for their role in bringing about life by donor conception. Funded on-going intermediary and support services should be available for all parties in the donation triangle (and their respective families) throughout their lifetime. This is not cheap but it is the only ethical way to provide services and avoid exploiting people at their most vulnerable times.

12c. Another concern is that of people going abroad for donor conception. Children conceived outside the UK, most often with anonymous donors about whom little is known (an exception being the US), will be in a significantly different position to those children conceived in the UK at the same time with identifiable donors. How children conceived abroad will feel in the future is unknown but some guesses could be made from the experiences of donor conceived adults who are currently speaking out. Hopefully larger numbers of

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these children will be told in supportive ways about their conception outside the UK, but it may be that some of those people seeking treatment abroad are doing so because they wish to avoid the onus to tell. It is in the interests of the children that ethically preferable services in the UK are available, accessible and affordable.