

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.

Dr Sonia Allan

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

I believe the primary ethical concern in relation to non-disclosure of information is the impact that this may have on donor conceived people. In particular it is the adults involved in the process (donor(s), recipient parent(s) and the medical professionals involved) that are making decisions concerning disclosure (or rather, non-disclosure) of information, which are primarily focused upon their own concerns/issues. The focus upon the donor conceived individual is lacking, and yet it is the donor conceived person that may be significantly affected by such decisions.

The decision either not to tell the offspring of the method of conception and/or not to give the offspring information about the donor(s) may affect a donor conceived person in numerous ways including:

- the donor conceived person's ability to develop a sense of self;
- placing the donor conceived person at risk, or in fear, of forming a consanguineous relationship (with a half-sibling or even donor);
- denying the donor conceived person access to medical history;
- denying the donor conceived person an opportunity to choose for themselves whether or not they want further information.

Moreover, I question a system that is premised on creating children who will be (and are being) actively deceived. The system is supported by the government (by way of funding) and medical professionals are making significant amounts of money. That there is not only awareness that parents may not tell their children, but at times active encouragement not to tell is very questionable (both ethically, and I would argue legally).

Please refer to the attached documents for further discussion of the legal and ethical issues related to non-disclosure of information to donor conceived people.

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?

No. What this question really asks is whether we should leave it up to the recipient parents to disclose information to the donor conceived person. What we have seen as a result of this being the current situation is resulting secrecy and a lack of openness and honesty with the offspring.

I suggest that parents should be encouraged to tell their children, and that this should be done actively. That is, before engaging in ART parents should be counseled about the importance of disclosure.

I also suggest that a system similar to that in Victoria, Australia be implemented in relation to birth certificates. In Victoria, s153(1) of the *Assisted Reproductive Treatment Act 2008* (Vic) provides for the birth certificate of a donor conceived child to be annotated with the text 'donor conceived' where a 'birth registration statement' specifies that the child was conceived by a donor treatment procedure. This system means that at age 18, when a donor conceived person applies for their birth certificate they will be notified that there is further information held on the birth register about them. They can then choose whether they wish to access this information.

(I note that there are other approaches to ensuring donor conceived people are notified of their conception. These include:

- recording both the individual's genetic and social parentage on the birth certificate of a donor conceived person;
- the issue of a separate certificate to a donor conceived person alerting them to the possibility of information held on the Register of Information; (similar to Victorian model)
- placing a code or symbol on the birth certificate of a donor conceived person;
- the annotation of birth certificates of all individuals to indicate the existence of information held on the register; or
- the issue of two certificates to all people – a 'Certificate of Birth', identifying an individual's legal parentage and a 'Certificate of Genetic Heritage', indicating where an individual's genetic and legal parentage are different.

None of these proposals are without shortcomings¹ and some are more problematic than others. For example, it might be argued that it would be unacceptable (or traumatic) for a person to find out that they were donor conceived by way of application for a birth certificate if their parents have not told them about their conception. On the other hand, that the parents will know that such information will be made available to the donor conceived person might serve as an impetus for them to disclose early. (Noting that early disclosure is supported by research as being the best approach).

¹ For a detailed critique see E. Blyth, L. Frith, C. Jones, J. Speirs, 'The Role of Birth Certificates in Relation to Access to Biographical and Genetic History in Donor Conception' (2009) 172 *International Journal of Children's Rights* 207–33.

I note that I do not personally favour issuing a birth certificate that is marked in some way when compared to those of non donor conceived people. This was the practice in the past for adoptees in some jurisdictions and reportedly resulted in individuals feeling stigmatised or resenting that information about their conception may be known to others when they, for example, use their birth certificate to open a bank account, get a driver's licence or any of the many other things for which birth certificates must be shown. My preference would be for the issuance of a separate document or notification of further information.

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

I believe as much identifying and non-identifying information as possible. To be able to be open and honest with their children they need to be able to respond to questions with as much information as the child needs/demands.

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

As much information as possible including:

- Name
- Date of Birth
- Address
- Occupation
- Medical History (Personal and familial to the extent to which it is known) – this should be updated every five years. The onus to update such information should fall to the clinics or registry rather than the donor (who may not follow up).
- Education (Level and Qualifications)
- Eye colour
- Hair colour
- Height
- Weight
- Marital Status
- Number of children (if any)
- Sex
- Year of Birth
- Place of birth
- Nationality/culture with which the donor identifies
- Religion (if any)
- Reason for becoming a donor
- Number of offspring born through other donations
- Identity of other offspring born through other donations
- Interests/hobbies/sporting activities
- **Anything else the donor considers central to their personality would also be useful for a donor-conceived individual to know.

I refer you to the attached articles for further discussion of why donor conceived people seek information, and why as much information as possible is necessary.

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?

Extremely significant. There is great importance for having access to information concerning a biological parent's medical history (eg whether or not there is a familial history of heart disease, diabetes, cancer, mental health issues, and/or other heritable diseases). Donor-conceived individuals who are denied access to familial medical histories are placed at increased risk as a result of not having access to information about their genetic heritage. This becomes very significant as people age.

A donor who donated in the 1970s or 1980s, when donor-conception was shrouded in secrecy, may not until more recently have become aware that they are a carrier of certain diseases.

Similarly, a donor-conceived individual may become aware of a heritable condition, but has no way presently to notify their donor(s) or half-siblings conceived using the same donor gametes.

On the other hand, the release of medical information raises issues about health privacy and confidentiality which are generally protected. Arguably however providing information to a donor conceived person about medical risks / hereditary diseases should fall under one of the many exceptions to maintaining "health privacy" as they do not otherwise have access to this information.

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

All parties to the donor conception should be told – that is the donor, the recipient parents, and the offspring.

It would be the donor's responsibility to alert the clinic.

Counselors should be engaged in the process of telling the family of the risk – and what this means. (Noting that risk does not mean the child will develop the condition, but that it is important that they know of the risk so that they may take measures to prevent whatever condition may develop—eg. through early screening).

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?

In the upcoming special edition of the Journal of Law and Medicine (for which I am the editor), Blyth et al provide an exposé of the 'relatively recent trend in academic research to understand the perceptions and experiences of donor-conceived people who have

learned of the nature of their conception'.² They also note that the 'American Society for Reproductive Medicine and the Australian National Health and Medical Research Council openly advocate parental disclosure while a 2008 amendment to the *Human Fertilisation and Embryology Act 1990* (UK) provides legislative endorsement for early parental disclosure (s 13(6C))', and further that 'some parents have explicitly taken a lead in advocating both disclosure of donor conception and the use of donors who are willing to disclose their identity to offspring'.³ In their review, Blyth et al conclude:

[E]xisting research findings support the conclusion that the future choices of donor-conceived people are necessarily limited when gametes or embryos from an anonymous donor are used and when parent(s) choose not to tell them about the nature of their conception. If a donor-conceived person *never* learns of the circumstances of her or his conception it has sometimes been presumed that no great harm may be done. The accounts of many donor-conceived people in the reviewed studies regarding their thoughts and feelings about themselves, their family and their place within their family both prior to and following disclosure suggest that this presumption may not be robust. In addition, it is clear from these studies that some (though not all) donor-conceived people experience great and long-lasting distress in discovering the circumstances of their conception later, rather than earlier, in life. Our review shows quite clearly that neither the fact of donation nor the identity of an ostensibly anonymous donor will necessarily remain concealed, even if parents are planning never to tell; nor can the reactions of donor-conceived people to acquiring this information be predicted.

Such conclusions are similarly found in the 2010 Australian Senate Legal and Constitutional Affairs References Committee (the Senate Committee) report on Donor Conception Practices in Australia.⁴ Similarly, in a recent inquiry into donor conception practices, the Victorian Law Reform Committee (VLRC) recommended that the Victorian Government introduce legislation to allow *all* donor-conceived people to obtain identifying information about their donors regardless of when they were born. As the basis to their recommendations, the VLRC found, among other things, that 'some donor-conceived people suffer substantial distress when they are unable to obtain information about their donor, and/or if told of their donor-conceived status later in life'.

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?

² Blyth E, Crawshaw M, Frith L and Jones C, 'Donor-conceived People's Views and Experiences of Their Genetic Origins: A Critical Analysis of the research evidence' (2012) 19 *Journal of Law and Medicine* (Forethcoming) which focuses on empirical studies published in English language peer-reviewed journals.

³ Blyth et al.

⁴ Senate Legal and Constitutional Affairs References Committee, *Donor Conception Practices in Australia* (2011) (Senate Report), p 103, Recommendation 1.

To my knowledge, when properly supported, contact arrangements with donors or any half siblings have been generally positive.

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?

There is increasing recognition that donors (particularly those who donated when they were young) also have an interest in receiving information about the donor conceived offspring.

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?)

I believe strongly that we should not be perpetuating a system that is based upon the deception of donor conceived individuals.

The responsibility for disclosure of information lies with all the parties you have listed.

Governments should enact legislation that provides for the donor conceived person to be alerted to the method of conception, and that further information is available to them. (On that note, further information should be held on a register, and should be made available to all donor conceived individuals).

Clinics and professionals are responsible for good record keeping, supporting and encouraging openness and honesty for recipient parents and donors.

Parents are responsible for telling their children.

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

Counselling in relation to donor conception should be available on an ongoing basis and not only occur prior to conception. It should be readily available for recipient parents, donors and offspring. Given that this submission recommends total disclosure and access to information it should be available to assist parents in telling their children about how they were conceived, helping the family address any issues they face in relation to donor conception, and for the donor conceived. It should also be made available to donors to support them in recognising that their donation has resulted in the life of another person who may wish to access information about their genetic heritage. Of course, should all of the parties involved wish to move to also establishing some kind of relationship, they should be supported in doing so – recognising here the complexities again that arise given the many families (and individuals within them) that may be involved.

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 attach

- 1) The draft editorial for a special edition of the Journal of Law and Medicine (which will be published in June/July 2012), for which I am the author and guest editor.

In the editorial I detail research on the secrecy that has surrounded donor conception and the ethical issues that relate to all parties involved (donor(s), recipient parent(s), doctors, and donor conceived people); consider some arguments for/against release of information; consider the recent Australian parliamentary inquiries that have recommended information release; and introduce the Victorian service model for supporting people involved in donor conception regarding such release.

(I note that for the special edition of the journal I commissioned seven articles on various aspects of information release. I will provide the Council with a copy of the journal when it is published in June).

- 2) A copy of a journal article written by me in response to the question of retrospective release of information posed by the Australian Senate Committee Inquiry into Donor Conception:

Allan S, "Psycho-social, Ethical and Legal Arguments For and Against the Retrospective Release of Information about Donors to Donor-conceived Individuals in Australia" (2011) 19 JLM 354.

- 3) I also refer you to previous submissions I have made to various Australian government inquiries on the issue of disclosure to donor conceived people. These specifically address the Australian situation, but may be useful in that they again discuss ethical, psycho-social and legal considerations pertaining to information release.
 - Sonia Allan, *Submission to the New South Wales Law and Safety Committee Inquiry into the Inclusion of Donor Details on the Register of Births* (2011). (By invitation) <http://www.parliament.nsw.gov.au/Prod/parliament/committee.nsf/V3ListSubmissions?open&ParentUNID=7E4018E851966190CA25792D0017F32F> (No 13).
 - Sonia Allan, *Submission Number 2 to the Victorian Parliament Law Reform Committee Inquiry into Donor Conceived Individuals Access to Information about Donors* (2011) <http://www.parliament.vic.gov.au/images/stories/committees/lawreform/iadcpiad/submissions/DCP37 - Dr Sonia Allan.pdf> (No 37).
 - Sonia Allan, *Submission to the Victorian Parliament Law Reform Committee Inquiry into Donor Conceived Individuals Access to Information about Donors* (2010). http://www.parliament.vic.gov.au/images/stories/committees/lawreform/donor-conceived/DCP05-Sonia_Allan.pdf (No 5).

- Sonia Allan, *Submission to the Senate Committee Inquiry into Donor Conception, Access to Genetic Information and Donor Identification* (2010).
http://www.aph.gov.au/Parliamentary_Business/Committees/Senate_Committees?url=legcon_ctte/donor_conception/submissions.htm (No. 30)
- Sonia Allan and Michael Williams, *Assisted Reproductive Technology: Access to Genetic Information and Donor Identification, Proposal for a Federal Register for Donor Conceived Individuals* (Submission to the Commonwealth Attorney General, 2007).