

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.

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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?
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?

I do not think families-by-donation should be treated differently from any other family. Hence, even though there might be disagreement among family members, it should not be the regulator's task to force families to disclose. However, from all the – fairly scarce – qualitative and quantitative social scientific research I have come across on this issue, and also from my own interviews with 3 adult donor conceived persons, I take that non-disclosure and subsequent accidental discovery can be experienced as extremely disruptive through individuals. Ensuring a regulatory set-up were disclosure and the thereby arising questions and needs of families-by-donation are met and clinicians do not advise against disclosure would therefore fall into the realm of national policy work, I would argue.

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

My answer pertains mostly to potential differences in access-rights of parents and children: In my PHD research with 14 disclosing families-by-donation in Germany and Britain, I have found that parents put great weight on the highly limited information they obtained on the donor. Small pieces of knowledge are used as a "stepping stone" into the imaginary to envision how the donor is like as a person.

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They also use this information in the familial narration of their family story, mostly starting when the children are still in infancy. (To clarify: The developed family story of course does not centre on this limited donor-information, but on their own history as a couple/family) From my small qualitative study I would argue that this joint familial construction of a family story is building strong and positively experienced family ties. I would therefore argue that rather than making further non-identifying information available to children at a later age, only the donor name and address should be kept for only the children to access when coming of age. I am aware that there have been some discussions and uncertainties in the HFEA on parental access to the stored donor pen portrait et. al. and that they currently make this available to parents. I think that this is absolutely crucial for such a joint family story to develop and should remain that way. I do not think that this purpose for joint familial use is currently reflected in what the donors are told on the actual form, so it might make sense to change some of the information given on that template.

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

I would argue that within the now non-anonymous British set-up, the current basic information on the donor is sufficient. There is no need to produce a highly artificial “time-capsule” with information trying to convey his personality, because children interested will eventually be able to contact their donor and find out what he or she is like as a person. Additionally, in my own research at one large British clinic, I learned that hardly any donors actually fill out the optional sections of the donor-registration form. It might be disappointing for parents or children to learn that their donor has left no pen-portrait, calling either the pen-portrait or its optionality into question. Within clinical practice, I saw that these sections are actually hard to handle, because the donors – given the “grandness” of the task – would prefer to fill out the sections at home, and not in the clinic. They would take them home, but mostly not actually hand in subsequently.

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?

One British adult donor-conceived person I interviewed for my own research expressed great concern over her lack of knowledge on potential genetic diseases in the family, while a second person expressed that this was not of concern to her. It is my impression (from my research, but also from that of other anthropologists, such as Janet Carsten) that, generally, what is often involved in

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the criticism of contemporary adult donor conceived persons of not being able to access information on the donor is actually the understandable lack of personal agency thereby experienced, not straightforward medical concerns. I would hypothesise that on a practical level parents and children would feel less that way if they could answer “mundane” medical history questions during physician’s consultations. In the current situation the medical history section on the donor information form is, to my understanding, geared towards severe conditions. Furthermore, it is filled out in the clinics on the basis of their own donor evaluation, so it is unlikely that much is entered, because the clinics would rather exclude the donor or the donor would not give this information to be positively evaluated. However, besides threatening and unusual hereditary conditions, every donor of course has a medical history. If parents and children could access information on mild allergies or whether – in old age – close relatives had rather died of cancer or cardiac problems etc. this might alleviate the experienced lack of agency of never being able to answer medical history questions at the doctor. (I want to make clear here that I am only arguing from the point of view how to potentially improve the situation for the donor-conceived, not because I myself believe that medical history is highly important medical or personal information) Another possibility would be to raise awareness among physicians that asking for medical history can actually be a problematic experience for many groups of people, not only the donor conceived, and that it should only become an issue in the rare cases where this would be of relevance. From my limited medical knowledge on the issue it seems to me that although there is a heightened interest in medical history, in the age of genetic testing on the one hand, and the realisation of the multifactorial nature of most diseases on the other hand, medical history information is for a large majority of people not actually crucial medical information.

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?

The 14 German and British families I have interviewed had all started telling their children early, often times before the children could even speak. Therefore, no situations were “the talk” and “the finding out” took place, they simply learned about their donor conception along with learning about the world in progressive

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steps of intellectual capability. Hence, one could not actually say that disclosure had much of an impact, it was simply part of family life and no negative experiences were reported to me. A few of the parents told me that there had been situations where the children had made reference to bodily substances or donor conception in creative ways diverging from their parents understanding of donor-conception or the parental need for privacy. Parents talked about an uneasiness about such situations and how it made them think about their own stance towards disclosure and privacy again, but it was not framed as a traumatic experience.

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?

I have interviewed one 26 year old woman who had made contact with her previously unknown donor-half-brother. Over a two year period the two had developed a relationship with hardly any face-to-face interaction or interaction in larger groups of friends or family, but were on the phone to each other every week and also e-mailing back and forth. (They were living in separate cities, but could have reached each other via train in a few hours). The woman described this as an extremely positive relationship, were she could share some of her concerns about being donor-conceived. She also underlined how the half-siblings were now trying to locate their donor together. She conceptualised their relationship as being characterised by expectations of durability or stability, as it is classic for Western perceptions on kin-relations in opposition to friendships.

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.

The German regulatory situation is highly unclear in comparison to the British situation. In the absence of a national registry and clear access rights to non-

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identifying or identifying information, German donor-conceived persons have now set up their own unofficial contact-registry through the US-American genetic genealogy service FamilyTreeDNA. I argue in my research, drawing on this and further examples, that we are currently witnessing an increasing “informational uncontainability” of kinship information: Direct-to-consumer genetic testing and the growing power of all sorts of information retrieval endeavours over the internet make it increasingly hard for regulators or companies to “contain” such information. From my point of view as a social scientist, I would therefore hypothesise that the comprehensive anonymity measures and delay in access to identifying information will in the future not necessarily keep, say, donor-conceived Teenagers from looking for half-siblings and networking via commercial DNA testing services. This could also lead to the identification of donors and their family (they could be registered with such services for different reasons). I would not hypothesise that this would be a highly disruptive experience for the individuals involved, it simply shows that contemporary and future socio-material developments are contesting the gate-keeper status of clinics and regulators concerning kinship information.