

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.

Donor conception response

1. Ethical concerns which may arise in disclosure, or not, of information in connection with donor conception :
Lack of disclosure:
 - compromises the donor conceived child in relation to loss of human rights/biological heritage
 - risk of unintentional discovery which could be potentially traumatic for the offspring
 - increased risk of having a relationship with a sibling due to lack of knowledge of existence of sibling connection.
 - donor conceived child would not have full access to medical history/any genetic conditions
 - perpetuating secrets and lies within the family and potential to cause conflict**Disclosure**
 - retrospective access to identifying donor information may compromise the donor.
2. A fertility clinic has an expectation that the family have reached agreement about disclosure before embarking on treatment. If there is disagreement within the family, more time should be taken to consider these options. Members of the multidisciplinary team have a role in providing the couple with access to information about the implications of donor conception.
3. If the parents are using a known donor and are planning to tell the child, there should be enough identifying information provided about the donor that can be shared with the child. If an unknown donor is being used, it would be ideal to have non-identifying information about the donor which could also be shared with the child.
4. A donor-conceived person might need information about the donor's reasons for becoming a donor e.g. the goodwill message as on HFEA Form D. Once the donor – conceived person becomes an adult they should have access to the donor's full identity.
5. It is very important that the donor-conceived person should have access to this information in order to make decisions about their own future health and wellbeing. For example, if a donor's family have a history of heart disease, this would be relevant to the child who could take precautionary measures in diet and lifestyle.
6. The parents of the donor conceived child (if under 18) should be told initially and be offered medical information and advice in order to pass this on to their child. If the donor conceived child is over 18 they should be informed directly (this may have complex implications if the donor conceived child has not been informed of their biological origins).

7. Our experience suggests that it is far less traumatic for a child to be told about their donor origins at a young age. Finding out at a later stage has potential to be psychologically and socially damaging. I am aware, through practice of how damaging the effect of late disclosure can be on the individual and the family.
8. n/a
9. From our experience, working mainly with known egg donors, there is usually an existing relationship with the recipient and an anticipated relationship with the child. Our limited experience of sperm donors who are unknown to the recipient suggests that, at the very least, they would want to know if the treatment has been successful.
10. Responsibility that arises in connection with disclosure of information should be shared with all interested parties in recognising that any child conceived has a right to know of their origins, fertility treatment, law and support networks.
11. Both historical and current Information about donor conception and access to counselling support where required.
12. Our responses have mainly been in relation to patients having treatment within the UK but we are aware and have worked with patients who go on to seek overseas fertility treatment which has different laws and regulations, the outcome of which is unknown.