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

The disclosure of information in connection with donor conception raises a number of issues, namely:

- Concern for a donor conceived person’s individual identity.
- The potential risks to a donor conceived person if they are not told of their donor conceived origins (i.e. the psychological impact).
- A donor conceived person’s right to know their genetic origins (to avoid a sense of ‘biological bewilderment’ or to ascertain a medical history).
- Concern that donor conceived individuals might form consanguineous relationships as adults in the absence of disclosure of information about their donor conception.
- Concerns about falling numbers of donors when anonymity is lifted and shortages in donor gametes as a result.
- Concerns that donor conceived individuals should be able to make contact with other donor conceived genetic half siblings (e.g. to complete their family story).
- Concerns to balance the interests of parents and the extent of their legal parental autonomy.

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?

The disclosure of a child’s donor conception is no longer purely a matter for individual choice in practice.

In the past, donor conception was relatively unusual and shrouded in secrecy for social, religious and political reasons. Donor conceived individuals were often unaware of their donor conceived origins unless this came to light during a family argument or deathbed confession and this engendered feelings of shock, frustration, confusion and loss that could (and did) have a profoundly negative impact upon their life.
There is now an international trend that increasingly tips the balance in favour of identifiable donation, as illustrated by the UK’s decision to lift donor anonymity in 2005 and the Netherlands decision to do so in 2004. Identifiable donation is therefore already a reality in some parts of the world where there is a centralized record keeping function that is regulated by law and policy.

The development of the internet affords far greater opportunities than ever before for individuals to track down information about their donor conception, donor(s) and donor conceived genetic half siblings. It is therefore increasingly possible for a curious and IT literate donor conceived child or adult to access information about their donor conception through websites, forums and online organizations across the world. The internet has therefore brought about an ‘information revolution’, the full impact of which we have yet to see.

The shape and character of families is changing, with increasing numbers of people building families through assisted conception, gamete donation and surrogacy and the creation of growing numbers of alternative family structures (including same-sex families and solo parents). It therefore makes sense to consider new ways to support and share information about donor conception to help donors, parents and children deal with this positively and constructively and help them understand their legal status, identity and role.

This does, however, raise challenging questions about the extent to which the state should become involved in the personal remit of family building and the sort of help and support it should provide (if at all). It raises sensitive questions about individual rights to have a child and family life free from external intervention, whether individuals should be ‘vetted’ (beyond existing checks at fertility clinics) before embarking upon donor conception and surrogacy and the control and regulation of donor conception information. There is therefore likely to be significant differences of opinion and issues depending upon whether any further help and support is introduced on a mandatory or voluntary basis and the shape this takes.

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

It is arguable that parents need very little information about a donor to carry out their parenting (leaving aside issues about access to medical information) and that parenting is far more about nurture than nature.

However, it can be helpful for parents to have some information about their donor (for example ethnic background and physical characteristics) to share with their child on
an age appropriate basis and to shape their family history and story in light of this. This information can also help parents to select a donor that will provide a close-fitting ethnic and physical match and feel to their family. Whilst this is not essential, it can be an important element for some prospective parents that governs their decision to create a family through donor conception and/or surrogacy rather than adoption.

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

A donor conceived individual may benefit from medical information about their donor:
- If they become ill (which could be the difference between life or death)
- For medical screening purposes to assist with their own family building plans (eg to assess the risks or prevent the passing on of a genetic condition)

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?**

Information about the medical history of the donor and the donor's family could be very important if a donor conceived child becomes seriously ill and needs medical treatment. Such information may assist with an effective medical diagnosis and treatment plan and could be the difference between life or death.

However, this inevitably raises questions about the extent to which donors should be required to provide greater in-depth information about their health and family medical history and the extent of any medical tests to which they should submit for this purpose. As medical science and technology develops all the time this creates issues about the extent of medical and genetic testing and coding and the impact of this information in practice (eg if tests predict a life-limiting prognosis or incurable degenerative disease) – see question 6 below for further comment.

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

Information about an inherited medical risk raises sensitive issues that can have a profound impact in life, particularly if it is of a serious or life-limiting nature. This information could on the one hand help to prevent the spread of an unwanted medical condition and protect lives and public health. That said, it could also negatively affect an individual’s financial position and for example limit their ability to secure a mortgage or life insurance and impact upon their relationships and family life.
This inevitably challenges society’s views and attitudes towards the knowledge, handling and use of such important and significant information. There therefore needs to be ongoing debate and consensus about this issue and the extent to which this information should be collected, stored, shared and acted upon.

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 in this area?**

The impact on donor conceived offspring can vary significantly, depending upon their age, medical history and family background. Some donor conceived individuals do not feel the need to trace their donor or donor conceived genetic half siblings, whilst others feel a deep-seated need to make contact with them to complete their family story and make sense of themselves and their place in the world.

Attitudes can also change over time, depending upon an individual’s circumstances and events can trigger a need to contact their donor or donor conceived half-siblings, of for individuals to want to conceive a child through gamete donation, for example following the death of a family member or close friend, a bout of ill-health or the failure of a significant relationship.

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?**

It can lead to the formation of enriching family relationships between genetic half siblings. It can help donor conceived individuals to complete their family history and story and help them make sense of their identity and place in the world. It can ease anxiety and worry about their origins and background and help them improve self-confidence and self-esteem. It can also stop them worrying about the possibility of forming an intimate relationship with someone to whom they are genetically connected.

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?**

It can be helpful to donors to receive information about a child born as a result of their donation. This can help them prepare themselves for the fact that their donor offspring may contact them at some point in the future (given the lifting of donor anonymity in the UK in 2005 and greater accessibility of information on the internet).
It can help donors reconcile their donation (and the birth of any donor offspring) with their own family and children and help them come to terms with this.

It can also give donors an important sense of fulfilment to know that their donation has helped someone else have a much wanted child and this is significant given the altruistic context of donation in the UK.

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?)**

The handling and disclosure of donor information brings with it significant responsibilities for government, fertility clinics, professional and families. It is no longer purely the preserve of personal choice. This information is so important that all of these groups need to work together effectively to provide help and support to donors, donor conceived children and parents. No one group should act in isolation since it is and will continue to be difficult to balance the needs of donors, donor conceived children and parents and adapt to developments in medical science and changing attitudes and structures associated with family life.

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

There needs to be greater understanding and consensus about gamete donation, surrogacy and alternative family structures amongst society as a whole. There is still much work to be done to improve knowledge and understanding about modern forms of family building and the implications of this. Too often, people operate on a need-to-know basis that focuses upon the medical issues and treatment plans required to establish a pregnancy and do not take full account of the wider issues.

It would be helpful to introduce public campaigns designed to raise awareness of infertility and assisted conception in all its forms. This would help people to better understand the issues, support family building and protect family life. Parents and families are increasingly hard pressed sections of society, with approximately half of all current UK families experiencing serious issues of conflict (whether this is financial, emotional, drug or drink related). Creating a family and parenting children is demanding and these challenges become even harder when people also have to factor in the additional challenges associated with donor conception, fertility treatment and surrogacy. The introduction of further family friendly law would also be helpful to support parents and families conceived through donor conception (eg maternity rights for intended mothers in surrogacy cases) and greater employment flexibility for those undergoing fertility and donor conception treatment and surrogacy.
Donor conception and surrogacy can raise complex legal issues and it is not yet an intuitive reaction amongst fertility patients and prospective parents that this should be underpinned by a proper understanding of the relevant law. Expert legal advice and help in the pre-conception stages and ongoing legal support for parents throughout their child's minority is vital. This helps to build strong legal foundations and give parents and other significant adults (including known donors) the legal tools, language and consensus they need to ensure they can effectively parent their donor conceived children with confidence and minimize problems and disputes. It also helps them reach agreement about when and how their child’s donor conceived origins should be shared and discussed with their child.

The legal issues become particularly complex in relation to known donation and co-parenting arrangements (involving perhaps three or four adults), where fertility patients and prospective parents and donors struggle to grapple with their roles and identities in relation to the child and family life, including who will be a legal parent and who will acquire and exercise parental responsibility for the child. This can create a lack of clarity about the legal framework and identity of the family and confused and mis-matched expectations which has lead to a number of difficult and hard fought court cases in recent years where legal status and legal involvement with a child has fallen into dispute between parents and donors. If parents and donors are struggling to come to terms with these issues (as is the English family court) it brings added challenges for them to effectively communicate and deal with these issues with their donor conceived children.

Put simply, the law has not kept pace with modern family building and donor conception, including known donation, co-parenting, surrogacy and the growth of alternative families. The law in England and Wales does not adequately meet the specific needs of those building families through surrogacy, known donation, co-parenting or cross-border fertility treatment and gamete donation (see question 12 below for further comment). The law therefore needs to be revisited and updated to meet these needs.

Infertility affects one in seven couples in the UK (and this is broadly similar in other parts of the world) and it is not broadly encompassed in the same way as other medical conditions (eg cancer). There needs to be better access to funding for fertility treatment on the NHS (including IVF with gamete donation), compliance with NICE guidance across all PCT’s and an end to the IVF postcode lottery, although this does of course raise difficult and challenging funding issues in what remains a difficult economic climate.
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.

There is currently a lack of international regulation, law and policy concerning donor conception, the disclosure of donor information and surrogacy. Each jurisdiction takes its own approach and this creates a patchwork of conflicting law and policy, which can in international surrogacy cases leave surrogate born children stateless and parentless in legal limbo, with no means of tracing their donor or other donor conceived genetic half-siblings later in life.

As the world becomes increasingly globalized and increasing numbers of people cross borders for fertility treatment this creates issues and varying experiences, for example the conception of a child in one jurisdiction using an anonymous donor that is then parented in a jurisdiction where donors are identifiable and the additional challenges this may bring, the full extent of which we have yet to fully see and understand.

There is also growing demand for known donation and private donation on an international scale as people feel this provides a more personal element to their family building plans that for some is preferable to an arms-length arrangement with an egg or sperm bank donor. This brings added challenges for societies, law and policy makers and there needs to be wider debate about these issues and associated issues of donor information and disclosure within this context.

Medical treatment and personal choice play a large part in the overall make-up and experience of donor conception and surrogacy that is fast-moving and continually evolving. There is also a natural element of tension and conflicting interests between donors, donor conceived individuals and parents that make this a particularly difficult area to legislate and regulate.

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