

Nuffield Council on Bioethics

Donor Conception

Response from the Christian Medical Fellowship

Summary

The Council needs to address the following issues raised by disclosure of information and donor conception:

- The strength of the bonds between genetic parents and donor conceived people;
- Questions of identity, place and family for donor conceived people;
- The lessons to be learnt from disclosure of information for adopted children;
- Why donor conceived people frequently feel a sense of loss if they don't know about their genetic parent/s, despite having very loving social parents;
- Why social parents often feel disquiet about being open and truthful with children from donation;
- The balancing (and definition) of 'rights' for social parents, donor parents and offspring, including the role of consent for each;
- How government and other bodies can best ensure that donor conceived children are informed of their genetic parentage;
- The need for donor conceived people to know their medical histories;
- The need for mandatory counselling;
- The lack of long-term research on the effects of donor conception on children, donors and social parents, including qualitative research.

The Christian Medical Fellowship

We applaud the Nuffield council for generating much needed public discussion of the impact of donor conception and the important questions around disclosure. We welcome the opportunity to contribute to the debate through this consultation.

The Christian Medical Fellowship (CMF) has over 4,000 doctor members and around 1,000 medical student members and is the UK's largest faith-based group of health professionals. A registered charity, it is linked to about 70 similar national bodies in other countries throughout the world. Our doctrinal beliefs and ethical values are outlined on our website: <http://www.cmf.org.uk/>. One of CMF's aims is 'to promote Christian values, especially in bioethics and healthcare, among doctors and medical students, in the church and in society'.

Just as we all have a duty of care to our environment, so too we have a moral

obligation towards future human generations. Children are gifts to be cherished, not commodities to be chosen. Having children is not a right but a privilege that brings with it serious responsibilities. CMF has concerns about donor-assisted conception because it introduces a third party – whether anonymously or not – into the procreative relationship and it deliberately separates biological from the social parents.¹ We therefore do not support gamete donation in principle.

Nevertheless, we recognise that donor conception is legally permitted and will proceed in some cases, therefore we are primarily concerned to protect the welfare of people born from donated gametes.

In particular, we are aware that donor-conceived people are increasingly speaking up about their concerns with identity, and concerns relating to secrecy over their genetic parentage. The desire to know our genetic roots is very strong, almost instinctive. We all belong to one, huge human family, yet we seem to need a sense of belonging to a certain group or place. We all seek a sense of who we are and where we belong. It is this that is broken and then effectively denied to many of those born of donor conception, often at great cost to them. Hence our interest in contributing to this discussion.

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

Following are some of the ethical concerns and questions that are generated by donor conception and by questions over disclosure of information:

- What is a parent - does biology matter?
- Should parenthood be primarily seen as a social and legal rather than a biological concept?
- What are the key needs of identity, kinship and place for donor conceived people?
- What are the psychological effects of secrecy in donation for those born as a result and for their genetic and social parents?
- What will be the medical impact on the children of donor-conceived people who also do not have basic knowledge about themselves and their biological heritage?
- Should people born by donor-assisted conception have a right to choose knowledge about their own genetic history, identity and genetic family?
- Should parents have the right to withhold information from their donor-conceived child, perhaps forever?
- How can a balance be found between the 'rights' of adults to fertility treatment using donors and the future 'rights' of their offspring?
- What regulation is necessary for prospective parents who go abroad to seek an anonymous donor, deliberately bypassing the legal regulations on anonymity in the UK?
- What are the implications of the child's inability to consent?
- Are people being left vulnerable in what is still an under-researched social experiment?

1. Some of the problems with donor conception that we highlight can also arise with adoption, however adoption makes the best of a bad situation, whereas donor conception deliberately and intentionally creates problems. Most people agree that adoption is a mutually beneficial act that provides a child for a childless couple and a loving home for a child who is in need.

The overarching concern with the use of donated gametes in fertility treatments should be first and foremost the people it directly affects. Although that can seem like it is the patient, in reality it is the offspring, as our list of concerns above shows.

Moreover, gamete donation should be seen as more than a moment of donation because it will also impact several generations hence. It is not just a 'one-off', discrete event. The gametes produced now will produce children, who will have their own children and they their own children, each one potentially denied basic genetic information about themselves that the rest of us take for granted.

*'Children of choice have a right to at least one choice of their own: a right to choose knowledge of their parentage – not, that is, to be deliberately deceived about their origins by a medico-legal conspiracy. Without this, they are born as exiles from the kinship network...they may in fact have unknown half-siblings, cousins, aunts or grandparents, but they will never meet them.'*²

The following stories illustrate the importance of disclosure of information for children born of gamete donation:

*'...I have concluded that my father's genetic influence has always been very much a part of who I am. It has shaped the physical way I look; influenced the way I view the world; affected the way I address problem-solving and coloured the way I assess what is important to me. In short it has defined what is essentially, me. I regard my paternal ancestors to be undoubtedly the biggest part of my character, overriding every influence my mother ever exerted over me through her DNA or nurture. **In consequence, I believe that the importance of genetic parenthood far outweighs even the best intentioned legally appointed parenthood.**'* (Emphases hers). A donor conceived adult who only found out about her genetic father at the age of 50.³

"I absolutely, categorically think I should have been told as a child – as soon as I was old enough to process the information. It is such a fundamental piece of information to have about yourself – to know who your parents are. Sometimes I get angry thinking about it." Rachel Pepa, who only found out as an adult that the man she always thought was her father, was not.⁴

"Just as infertility is grieved, because people grieve the loss of having and raising their own genetic children, so too can that loss be mirrored by not knowing or being raised by one's own genetic parents. Indeed, for many, this loss is exacerbated when it is intentionally and institutionally created, unlike infertility...this loss has been identified by leaders in the field as having a lifelong impact." Joanna Rose, who was conceived by donor insemination over thirty years ago.⁵

² *Fathers Not Included: a response to The Human Fertilisation and Embryology Bill, 2008.* The Centre for Social Justice p119.

³ *Fathers Not Included: a response to The Human Fertilisation and Embryology Bill, 2008.* The Centre for Social Justice p40.

⁴ *So who's the daddy? Ethics dilemma over sperm donor boom.* The Independent. 2 April 2012. <http://www.independent.co.uk/life-style/health-and-families/health-news/so-whos-the-daddy-ethics-dilemma-over-sperm-donor-boom-7606835.html>

⁵ McWhinnie, A. Who Am I? Experiences of Donor Conception. Idreos Trust.

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?

CMF believes that children born of donor conception have the right to know about their genetic heritage and this should be ensured. We suggest ideally through parents but if this cannot be guaranteed, through the use of information on birth certificates. We consider below the different roles that families, clinics, government and amended birth certificates may play in disclosure.

The role of social families in disclosure

When donor insemination began commercially in the 1930s, doctors withheld the identities of natural fathers (and, subsequently, natural mothers). This remained the case until the HFEA (Disclosure of Information) Regulations 2004 removed anonymity for gamete donors from April 2005 onwards. Now donor-conceived people born after this date can obtain some information about the identity of their biological father – or mother – when they reach the age of 18. For those born before 2005, the amount of information they receive will depend on their age, the information provided by the donor and whether their donor has re-registered after 2005.

However, the right to information at the age of eighteen is largely illusory in the case of donor-conceived children, unless they know that they are donor-conceived. Children can only find out about their origins if their social parents tell them that they were donor conceived and, unfortunately, many parents of donor-conceived children choose not to tell them about their genetic origins. Research suggests that only 10-20% of people who have a child by donor conception have either told that child, or stated that they will at some point tell that child, how he or she was conceived.⁶

So while it has been agreed in UK law that donor-conceived offspring are entitled to know the identity of their genetic parent, they are not entitled to be informed that their legal parent is not their genetic parent. The law currently preserves the social parents' 'decisional privacy'.

We are concerned that the desire of parents to withhold information is both contrary to the spirit and intention of the law and damaging to the welfare of children.

The role of clinics and government in disclosure

Guidance set out in the current HFEA Code of Practice is clear that clinics should provide non-identifying donor information to parents both prospectively and once the child is born and they should inform parents of their and their children's rights to access information from the HFEA Register, including about donor-conceived siblings (Sections 11 and 20).

However it appears that some clinics are failing to comply with guidance about provision of non-identifying information to parents before age 18.⁷

We fully supported the legal changes to remove donor anonymity but are now concerned that they are not being adequately supported in practice by both parents and clinics. Encouraging, or simply allowing, secrecy makes a mockery of the

⁶ *Fathers Not Included: a response to The Human Fertilisation and Embryology Bill, 2008*. The Centre for Social Justice p54.

⁷ BioNews 27 February 20012. http://www.bionews.org.uk/page_130217.asp

regulations on anonymity.

Consideration should be given as to how to ensure that clinics comply with guidance before and after a child is age 18.

Honesty by parents should always be encouraged but cannot be enforced. Sometimes the desire for a child is so overwhelming that couples do not take the time to consider the long-term effects of using donated gametes in terms of family relationships, the pressure it can put on the parents' relationship or the long-term needs of children.

Therefore the need for mandatory pre-treatment counselling should be seriously considered as an option by clinics and efforts need to be made to improve this service. The Government should give more thought to how it will encourage clinics in this respect, as clinics have the most obvious opportunity and role to help parents to tell their children about their origins.

We are also concerned that any children born of imported donor gametes, that bypass donor anonymity regulations in the UK, may have no chance to trace their biological roots. Allowing such activities to continue contradicts the regulators' expressed intentions and such loopholes should be closed.

Consideration may also need to be given again to retrospective removal of donor anonymity in law. In the Australian state of Victoria, a parliamentary committee has recommended that donor-conceived persons should be told the identity of their biological parent, even if the sperm donor was originally promised anonymity.⁸

Using Birth Certificates for disclosure

A number of organisations have suggested that birth certificates be used to show both legal and social parenthood.⁹

*'...the best means (should) be found for birth certificates to reflect that there are some differences between those who are social/legal parents and those who are genetic parents of the child being registered. We recognise the controversial nature of this issue, but 'decisional privacy' has to be tempered by donor-conceived individuals' rights to be made aware of their biological origins.'*¹⁰

The genetic identity always goes on the birth certificate of adoptees. Normally this is their legal identity as well. If the legal identity is different, however, it is the legal identity that is moved elsewhere. It is not a 'birth' certificate if it only gives cultural or legal information. It has been proposed that donor-conceived people should have two certificates, one for genetic identity, the other for legal identity, as is the case with adoptees.¹¹

The BAAF has similarly suggested that a national system is introduced where people are issued with a certificate of birth showing legal parenthood and another document/certificate that shows a person's genetic inheritance, for example whether

⁸ <http://www.theaustralian.com.au/news/nation/sperm-donor-identities-should-be-revealed-to-children-says-parliamentary-committee/story-e6frg6nf-1226312769131>

⁹ See for example a suggestion by Blythe at *Fathers Not Included: a response to The Human Fertilisation and Embryology Bill, 2008*. The Centre for Social Justice p58.

¹⁰ *Fathers Not Included: a response to The Human Fertilisation and Embryology Bill, 2008*. The Centre for Social Justice.

¹¹ *Ibid.* p54.

they are adopted or born as a result of donor conception or surrogacy. The document showing the date of birth and parental responsibility would be used for public purposes, and the other would only be available to the individual and custodial parents, so as to retain privacy. The birth and legal parenthood certificate would make it clear that this was not necessarily a statement of the person's biological parentage, and that for this information a person should also have a copy of the certificate of genetic heritage. P55.

UK DonorLink, launched by the Government in 2004 and funded by the Department of Health, has also suggested differing 'long' and 'short' versions of birth certificates.

Although some parents and some donor-conceived people are opposed to making this distinction, without such a standard procedure, the right of donor-conceived people to such information will otherwise remain at the discretion of their parents.

In summary, we believe that there is a need for both Government and regulatory intervention, particularly to consider amending birth certificates, to ensure disclosure of information on genetic parenthood for donor-conceived people. Disclosure at 18 should not be left solely in the hands of families to decide. Mandatory pre-treatment counseling should be provided by clinics to help prospective parents consider the long-term needs and rights of donor-conceived people.

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

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

The desire for humans to know their biological roots is very strong, almost instinctive. Almond says that: '*...genetic origin has a special and determining significance.*'¹² Around the world people seek knowledge of their origins – ancient ancestors, forefathers of recent centuries or immediate family. We all belong to one, huge human family, yet we seem to need a sense of belonging to a certain group or place. We seek a sense of who we are and where we belong.

When a desire for knowledge of ancestry is thwarted by modern clinical interventions and legislation, the resulting emotions can be overwhelming. Concerns and anecdotal stories about genetic bewilderment and feelings of distress and loss, led to the April 2005 change in UK law.

*'This suggests that, at a minimum, a child is owed information about the special circumstances in which it came to be born, and parents and doctors are wrong if they conspire to conceal this.'*¹³

Donor-conceived people must have the choice about whether to find out more about their genetic heritage and to meet their biological parent and sometimes siblings. Not all will wish or choose to, but many will.

It is by no means inconceivable that donor-conceived people could unwittingly start a relationship with a half sibling. There has been at least one case, that we are aware of, of twins who married without realising they were siblings and a case of another

¹² Almond, B. *The Fragmenting Family*, 2006. OUP. P113.

¹³ *Ibid.* p113.

set of twins who nearly got married. In both cases the twins in question had been separated at birth and adopted by separate families without realising that they had a twin.¹⁴

If the number of children that are permitted to be born from one donor is increased, this will be exacerbated and will make the disclosure of information imperative.

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?

As society becomes aware of more disorders that have a genetic basis or influence (eg. Genetic disorders, certain cancers and glaucoma), donor-conceived people will increasingly want, and require, information about their genetic heritage in order to take appropriate precautions for their future health (eg. regular check-ups and/or dietary or lifestyle changes). For example, a history of glaucoma in the family qualifies an individual for free screening for this at age 40. If a donor-conceived person develops a major health problem it will become increasingly untenable to deliberately deny them such crucial information.

Although there has been a proliferation of predictive genetic tests for serious illnesses, medical geneticists still often rely in practice on family history and knowledge rather than DNA analysis.

If family genetic history is not accurately reflected in their legal parenthood then false information could continue down the generations, to the donor offspring's children, grandchildren etc., who will also have misleading information about their genetic ancestry.

In adoption procedures it is recognised that the medical histories of their biological parents (especially with respect to inherited diseases) are crucial to any assessment. Children who are unaware of the medical histories of biological parents are therefore significantly disadvantaged. In some cases, secrecy can also disadvantage the donor.

The national adviser to UK Donor Link has said: "*There are big issues around medical treatment. We have had some very sad cases of people opting not to have children because they believed they had inherited a genetic disease such as Huntington's, only to discover their biological parents were not who they thought they were.*"¹⁵

*"I know of cases where a donor has developed a genetic condition and not passed the details on to the HFEA. And there are cases where a child has developed an inherited condition and the parents have not thought to pass the details back so the donor could be informed."*¹⁶

Moreover, if a donor-conceived person has a medical test, not knowing they are

¹⁴ *Fathers Not Included: a response to The Human Fertilisation and Embryology Bill, 2008.* The Centre for Social Justice p53.

¹⁵ So who's the daddy? Ethics dilemma over sperm donor boom. 22 April 2012. <http://www.independent.co.uk/life-style/health-and-families/health-news/so-whos-the-daddy-ethics-dilemma-over-sperm-donor-boom-7606835.html>

¹⁶ So who's the daddy? Ethics dilemma over sperm donor boom. 22 April 2012. <http://www.independent.co.uk/life-style/health-and-families/health-news/so-whos-the-daddy-ethics-dilemma-over-sperm-donor-boom-7606835.html>

donor conceived, they may discover the truth accidentally, which can be particularly devastating.

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?

It is likely that the least harmful scenario is one where the child is told the truth from an early age, and where identifying information is available about the donor. However there is little research evidence to back this up, as far as we are aware. Professor Susan Golombok, from Cambridge University and fertility lawyer Natalie Gamble both suggest that children who are told earlier tend to adjust better.¹⁷

The Centre for Social Justice says that: *‘Telling the truth’ sooner rather than later was recommended by many consultees, to avoid the problem of the ‘ticking time bomb’ – the potential for a family secret to have a devastating effect if a significant revelation about parental relationships emerges at a time of family conflict or stress. If children are to find out that they are donor-conceived, then it is better for them if parents tell them carefully, yet only 10-20% of people who have a child by donor conception have either told that child, or stated that they will at some point tell that child, how he or she was conceived.*¹⁸

We quoted Pepa earlier, who said that: *“I absolutely, categorically think I should have been told as a child – as soon as I was old enough to process the information. It is such a fundamental piece of information to have about yourself...”*¹⁹

Qualitative evidence in this area is limited, however the testimony of donor-conceived adults is increasingly being heard, and generally confirms the benefits of parents being open from an early age, yet such evidence is often dismissed on the grounds that it is anecdotal. More controlled research therefore needs to be done.

We note that whilst Golombok and MacCallum found in their own research that parents of children conceived by assisted reproduction appear to have good relationships with their children, even in families where one parent lacks a genetic link with the child, they nevertheless conclude that: *‘Few studies have included children at adolescence or beyond, and little is known about the consequences of conception by assisted reproduction from the perspective of the individuals concerned...although existing knowledge about the impact of assisted reproduction for parenting and child development does not give undue cause for concern, there remain a number of unanswered questions in relation to children born in this way.*²⁰

McWhinnie has argued that research across the life course, on the psychodynamics of families with donor-conceived children, is particularly lacking. The behavioural emphasis of other research should, she claims, be supplemented by exploratory

¹⁷ *Fathers Not Included: a response to The Human Fertilisation and Embryology Bill, 2008.* The Centre for Social Justice.

¹⁸ Ibid p78.

¹⁹ *So who's the daddy? Ethics dilemma over sperm donor boom.* The Independent. 2 April 2012. <http://www.independent.co.uk/life-style/health-and-families/health-news/so-whos-the-daddy-ethics-dilemma-over-sperm-donor-boom-7606835.html>

²⁰ Golombok S., MacCallum F., 2003, ‘Practitioner Review: Outcomes for parents and children following non-traditional conception: what do clinicians need to know?’ *Journal of Child Psychology and Psychiatry and Allied Disciplines*, 44:3, pp. 303-315

psychosocial studies of inter-personal family relationships. These would offer insights into the family functioning in assisted reproductive technology families where donated gametes have been used.²¹

Other researchers, such as Professor Olga van den Akker of the British Fertility Society have also called for research which would provide a better understanding of the underlying problems encountered at a psychosocial level, such as continued preference for anonymity in donors and denial in large numbers of users of the involvement of a donor in conception. Without challenging the methodological soundness of Golombok's work Professor van den Akker was not unusual in expressing frustration that this is the only research frequently cited, '*and yet the samples are so small.*'²²

Laing and Oderberg also voice concerns about the limited nature of the research: *To the extent that empirical research has been carried out at all, it is often carried out on children rather than adults. The disadvantages of this are that: the long term effects are not measured; many of the children do not know that they are donor-conceived; where they do, they are not aware of the potential significance of it; often third parties such as teachers are engaged by the researchers to report on the children's behaviour, but the former are kept in as much ignorance as the latter...*²³

Whilst robust, the behavioural psychology studies (of a scholar like Golombok) which have tended to predominate, would not have shown up the emotional and identity issues that many donor-conceived adults experience. Qualitative research is required to reveal the complexity of relational dynamics in families with donor-conceived children (where infertility may be an ongoing issue). This would complement behavioural and development studies which can only reveal some of the picture.

We therefore strongly recommend that more efforts should be made to follow up donor-conceived children and to initiate more reliable, well-conducted longitudinal and qualitative studies by *different* research bodies and researchers, so that we have good information on the effects of donor conception upon the resultant children and the most beneficial age at which children should be told about their birth circumstances.

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?

Donor-conceived people may have many unknown half-siblings, cousins, aunts and grandparents, whose existence will be concealed from them. While they may acquire an alternative family network that will provide love and security, the loss of their genetic relations may become important to them in the future, particularly when they have children of their own and start to look for such things as shared resemblances, attitudes, interests, tendencies, qualities of character and physical features in their own offspring.

It is not necessary that donor-conceived offspring should have direct access to identifiable information regarding other donor offspring, particularly if there is no guarantee that all parties are informed of their origins. However, it is essential that

²¹ *Fathers Not Included: a response to The Human Fertilisation and Embryology Bill, 2008.* The Centre for Social Justice p48.

²² *Ibid.* p48.

²³ Laing J. & Oderberg D., 2005 'Artificial reproduction, the 'welfare principle' and the Common Good', *Medical Law Review*, 13, pp.328–356, p343.

donor-conceived people can ensure they are not planning to marry and/or have children with a half-sibling. They should be able to access non-identifiable data about other offspring without breach of privacy.

Again, there is a distinct lack of hard evidence on this issue. Most is anecdotal evidence. More qualitative research is required to reveal the complexity of relational dynamics in families with non-biological children (where very often, infertility is an ongoing issue). Such research, taking a life-course perspective, is particularly lacking.

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?

Donors should have access, if they so desire, to the number of live births, and possibly what sex they are. If identifiable data is going to the offspring, it is fair that the donor be aware of their existence beforehand.

The various parties involved in donor conception (donor-conceived individuals, their social parents and donors) need easy access to a service experienced in dealing with kinship loss, reunion advice and support, as well as genetic expertise. Such a body would perform a vital social service, and government (and/or assisted reproduction industry) funding and long-term commitment would send an important signal to all those involved in donor conception of the need to assist those concerned to find out about their origins, or about their offspring, in the case of donors.

We therefore recommend that more public funding and long-term commitment be made to UKDonorLink, or a similar organisation.

The need for donors to access specialist counselling is also set to increase as more children reach the age where they may get in contact with their genetic donor.

A society that creates a legal framework for donor conception technology should also ensure that the 'follow up' infrastructure is also in place.

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?)

Please note our comments at Q2 above. We suggest that parents, clinics, medical professionals and government all have a responsibility towards ensuring the disclosure of information to the offspring of donor conception.

Parents

We concur with Almond that unfortunately; '*Equity in the preservation of personal identity [for donor offspring] has not received as much attention as the rights of adults to fertility treatment.*'²⁴

Even now, children can only find out about their origins if the parents who raised them tell them that they were donor conceived. Many parents of donor-conceived people choose not to tell them about their genetic origins. It is often kept a secret and many children still go through life not knowing who their real biological father is (or mother, in cases of egg donation). This is damaging to offspring and a denial of their right to choose knowledge of their genetic history, identity and genetic family.

²⁴ Almond, B. *The Fragmenting Family*, 2006. OUP. P118.

Clinics

Sometimes the desire for a child is so overwhelming that couples do not take the time to consider the long-term effect of using donated gametes in terms of family relationships, the offspring, or the pressure it can put on the parents' relationship. These couples must be encouraged to be open with their offspring about the donation.

There is a need for strong regulations and oversight for the clinics that help infertile couples become parents through donor conception.

The HFE Code of Practice guidance should make it mandatory for all prospective parents using donated eggs and sperm to receive impartial and accredited preparation prior to treatment. This is crucial for helping prospective parents think about: a) all the issues bound up in parenting a child who is not genetically related to either one or both of them, and b) how they will tell their children about their origins.

Donors' need for counselling is also set to increase as more children reach the age where they may get in contact and donor-conceived individuals may have identity issues which they need help to resolve.

More efforts should be made by clinics to follow up on patients (current and previous patients) and to collect data on the various forms of treatments, particularly new methods, so that we have good information on the effects of treatment upon the resultant children, rather than continuing blindly with this major social experiment.

Medical Profession

We suggest consideration be given to marking on the medical notes the fact that a child is derived from donated gametes, along with any relevant issues from the medical histories of biological parents. Their GP would therefore know and be able to counsel, or direct towards counseling, the parents as they bring the child up. Literature encouraging and helping parents to be open with their children would be helpful.

Government

Government should give consideration to how it will encourage parents to be open with their children about their origins. However 'encouragement' is unlikely to be sufficient to ensure that all parents are indeed open with their children. Despite their rights to know their biological origins, many donor-conceived individuals are unaware of their status, as currently birth records do not register it and many social parents do not, and will not, tell them.

As we have noted at Q2, we and a number of organisations have therefore suggested that birth certificates be used to indicate both legal and social parenthood. The Department of Health has acknowledged a need to review the issue of birth certificates for donor-conceived individuals but we suggest that this is now imperative to move forward.

Government should give thought to further restricting the number of donor offspring produced by a single donor so that the diversity of the gene pool is not compromised in any geographical area. In addition the instances of 'usage' of gametes from a single donor could be scattered around the country rather than all being through a single clinic. This would require considerable national co-operation on the part of infertility clinics.

11. 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.

As a general rule we believe that the same principles and priorities applying to the approval of adoption of children should apply to disclosure of information for donor-conceived people. Section 1 of the *Adoption and Children Act 2002* states:

(2) The paramount consideration of the court or adoption agency must be the child's welfare, throughout his life.(4) The court or adoption agency must have regard to the following matters (among others)(c) the likely effect on the child (throughout his life) of having ceased to be a member of the original family and become an adopted person...(e) any harm (within the meaning of the *Children Act 1989* (c.41)) which the child has suffered or is at risk of suffering,(f) the relationship which the child has with relatives, and with any other person in relation to whom the court or agency considers the relationship to be relevant, including(i) the likelihood of any such relationship continuing and the value to the child of its doing so,(ii) the ability and willingness of any of the child's relatives, or of any such person, to provide the child with a secure environment in which the child can develop, and otherwise to meet the child's needs,(iii) the wishes and feeling of any of the child's relatives, or of any such person, regarding the child.(8) For the purposes of this section (a) references to relationships are not confined to legal relationships,(b) references to a relative, in relation to the child, include the child's mother and father.

Joanna Rose, a donor-conceived adult, has specifically called for 'a precautionary principle' to protect donor-conceived offspring in an acknowledgement that there are inherent risks in assisted reproduction using donors, particularly concerning the identity of those yet to be born and the implications of not being raised by biological kin.²⁵

The limited research to date has focused on outcomes for children, but growing up without birth parents may produce sleeper effects, that manifest well beyond childhood, far later than might be expected.

We therefore reiterate a recommendation made above, at Q7, that more effort should be made to follow up donor-conceived children and to initiate more reliable, well-conducted longitudinal and qualitative studies by *different* research bodies and researchers, and on older ages, so that we have reliable information on the effects of donor conception upon offspring and the most beneficial age at which they should be told about their birth circumstances.

We finally warn that it is quite likely that not registering and disclosing information on donor conception will ultimately leave the Government open to legal challenges in the future for denying children the right to have access to essential information, including medical, about themselves at adulthood.

**Christian Medical Fellowship
Public Policy Department
May 2012**

²⁵ *Fathers Not Included: a response to The Human Fertilisation and Embryology Bill, 2008*. The Centre for Social Justice p62.