

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.

British Fertility Society



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**NUFFIELD
COUNCIL^{ON}
BIOETHICS**

**Donor conception:
ethical aspects of information disclosure**

Call for evidence

March 2012

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This document represents the British Fertility Society (BFS) response to the Nuffield Council on Bioethics, Donor conception:ethical aspects of information disclosure, Call for Evidence paper.

The British Fertility Society is a multi-disciplinary organization representing professionals with an interest in reproductive medicine. The objectives of the society are:

- To promote high quality practice in the provision of fertility treatment.
- To provide a common forum for members of various disciplines having an interest in the science and treatment of infertility.
- To promote high quality scientific and clinical research in the causes and treatment of infertility.
- To provide professional leadership in the provision and regulation of infertility services.
- To promote the increase of NHS funding for and equity of access to fertility treatments.

The disclosure of information in the context of families created through assisted reproduction using donated gametes and embryos or surrogacy is an important part of the workload of BFS members and as such the society has an interest in this consultation paper.

This document is submitted by the Honorary Secretary whose contact details are:

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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.

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

1a Establishing children's rights as paramount

The primary ethical concern is the welfare of any children born as a result of donor conception. Currently there are regulatory standards regarding the care of, and information provided by, donors and recipients. However there is not the same level of regulation in place regarding the availability of information for donor-conceived children about their genetic background. The BFS would support a review of the current situation in order to bring this area of family building in line with the rest of UK legislation concerning children.

1b Support Services for those affected

The second ethical issue regarding disclosure is the lack of support services for all parties in donor conception – donors, parents and offspring. Not all people seeking information from the Register will require counselling or support, but evidence from the UK Donor Link service (which attempts to facilitate links between offspring, conceived before the HFEA Register was established, and their donors) shows that many people need support and some need counselling. There is evidence of the support needs of all parties affected by donation.^{1, 2,3,4,5} Although the charity Donor Conception Network provides some support (e.g. 'Telling and Talking workshops' for parents), they are unable to offer consistent support, and cannot offer counselling, due to the lack of funding for the work they do. It is already established in law that those seeking information from the Register should be offered a suitable opportunity to receive proper counselling before any information is disclosed, but at present no such support services exist. Recommendations on how to provide such a service, and what the needs of people applying for information from the Register are, has already been documented

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British Fertility Society

and widely accepted by the sector following the publication of the British Infertility Counselling Services Report 'Opening the Record'⁶ The BFS would support a review of how this service could be provided by the most appropriately trained staff.

1c Secrecy

Licensed Treatment Centres are required to inform recipients of the importance of telling their child(ren) about their genetic origins at an early age (HFEA Act as amended 2008). However parents make their own decisions on this. Some will choose to keep this a secret and there is a risk that offspring will find out later in life – with associated emotional harm to the child, the parent/child relationship or of relationship difficulties between the parents when one parent wants to tell and the other doesn't. There is evidence that secrets can be damaging to relationships.^{7, 8}

1d Retrospective Disclosure

If there are changes in legislation, regulation or guidance, this needs to take account of the needs of all donor-conceived offspring and of donors and their families. The current situation of the year in which you were conceived determining whether or not you have a right to identifying information about your donor, or any information, highlights a discrepancy in rights. There is evidence now of others e.g. the Australian Victoria Law Reform Committee⁹ recommending retrospective disclosure of donor's identity with appropriate safeguards in place.

The ethical and legal issue that arises from consideration of granting access rights to origin information to all donor-conceived offspring concerns the consent that donors gave at the time they donated. Prior to April 2005, donors consented to donate eggs and sperm anonymously. Retrospectively granting donor offspring the right to identifying information about their donor without the donor's consent would not be ethical in our view.

Although there is precedent to this in adoption (where birth parents prior to the Adoption Act 1976 relinquished their children for adoption on the understanding at that time that the adopted children would not be able to obtain identifiable information about them), The Adoption Act 1976 gave adoptees in England and Wales the right to see their original birth certificate and obtain other information related to their biological parents. The BFS's view is that it remains the right of individual donors' to decide whether to vary their consent. However, the BFS would welcome and contribute to further debate on the issue of retrospective disclosure.

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The changes in legislation regarding the removal of donor anonymity were communicated through various media strategies and donors who donated (anonymously) between 1991 and 2005 can choose to vary their consent in order to re-register as identifiable. The BFS supports this change in legislation and would favour an approach where as part of a centrally funded and administered awareness campaign, individual donors are contacted to ask if they are willing to re-register as identifiable. The BFS strongly feels that the responsibility for undertaking this task should not fall to Licensed Treatment Centres.

1e Support for Parents

In some Licensed Treatment Centres, people undergoing treatment with donor gametes, and donors, can either opt in or opt out of counselling on the implications of this treatment or donation. Mandatory counselling on the social, ethical, medical, legal etc. implications of this treatment and/or donation for donors and recipients would enable them to work through and prepare for the life-long implications of donating or receiving donated gametes or embryos. The BFS supports the role of counselling within assisted conception services and would endorse the need for mandatory counselling for gamete donors and recipients.

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?

2a. The importance of early disclosure is established in law (Human Fertilisation and Embryology (HFE) Act 1990 (as amended)) and it is a licence condition that clinics inform people having treatment with donor gametes of the importance of this before treatment services are provided and also provide information about how best this can be done. It is usually the counsellors who undertake this task in clinics, and many centres require their patients to take up the offer of counselling so that they are properly prepared and informed. However, as previously noted, this is not the case for all clinics and some recipients and donors will proceed with treatment/donation without a full exploration of these issues. Counsellor's recent practice experience – used to inform the third edition of the British Infertility Counselling Association's Guidelines for Good Practice in Infertility Counselling (2012), suggests:

- Where there is no fertility issue, e.g. with lesbian parents, there is desire and intention to be open;

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- Single women who use donor sperm similarly intend to be open with family, friends and resulting children;
- Most heterosexual couples, since identifying information about donors has been available, recognise the need to be open in terms of a person's right to have information about their genetic origin and also to avoid secrecy. However, they often need guidance and support in how to do this. The most difficult issue is breaking the news to family and friends, followed by the realisation that if they are open with their child, they then cannot control the information flow about their child's method of conception.

However, there appear to be gender issues that affect the degree of comfort a person feels about disclosure:

- Women recipients of donor eggs are sometimes unsure and want to explore the issues including how and when to disclose. They often feel comforted by the fact that they will carry the child and give birth to it. They will also often have discussed their fertility issue with family and friends and feel supported in their decision-making.
- Men however, in heterosexual relationships where donor sperm is needed seem to find the thought of disclosure particularly difficult as they are often quite traumatised from the discovery that they don't have any sperm. In many cases this leads to men having a sense of shame and embarrassment, low self esteem and a perception that they are less masculine than men who are able to have their own genetic children. Their female partners who have witnessed this decline in their male partner's emotional health often want to shield him from further hurt and distress and thus collude with the view of not disclosing donor conception to resulting children. Men are particularly reluctant to discuss their infertility with anyone and often their partner agrees not to talk to others about it, or they will agree on a 'story' to tell others in order to protect the male partner from anticipated negative reactions from others. Men often feel very isolated and their session with the infertility counsellor is sometimes the first time they are able to be open about their feelings and start to come to terms with their infertility.
- Most couples with support, good information and guidance conclude after counselling that they will be open.

2b The purpose of presenting this infertility counselling practice evidence is to suggest that:

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- i. Disclosure is almost guaranteed when the use of donor sperm is for 'lack of male partner' reasons rather than infertility;
- ii. The reasons for intentional non-disclosure are very rarely to do with the welfare of any resulting children. The primary concern is to protect one or more parent from further distress;
- iii. Occasionally there are good 'child centred' reasons for non disclosure where it is perceived that significant harm could be caused by for example the child not being accepted into the extended family. These cases are rare;
- iv. Following good information giving, support, opportunity to explore all the issues and practical guidance on how to disclose, most couples that engage in this process *intend* to be open;

It seems reasonable to conclude that if appropriate support, information and guidance is given to people when they embark on treatment, they are much more likely to disclose and so any further regulation or legal requirement to disclose would not be necessary. It is often the lack of opportunity for this support at the time of diagnosis, pre-treatment and after successful treatment that leads to parental decisions not to disclose. There is evidence in the literature that supports these findings from infertility counselling practice experience.^{10,11,12,13,14,15,16,17}

2c Many potential parents make the decision about whether or not to be open even before the treatment outcome is known so that they are prepared to announce pregnancies with or without the information that donor gametes were used. With decisions made and agreed upon at such an early stage, it is then very difficult for the parent whose feelings have changed to undo what has already been done/said to others. This can lead to conflict within relationships that can be life-long.

If people started donor gamete treatment with the information that early disclosure is in the best interests of any resulting child (in most cases), and the appropriate support to enable them to do this well, disagreements and conflict within families about disclosure would be minimized. One of the roles of infertility counselling is to help couples, where they are being treated together, to come to a position where they are agreed on if, when and how to disclose.

2d It is important to include 'known sperm donors' in this discussion. The issues are often far more complex especially when donation of sperm has taken place outside a

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clinic setting where under current legislation, in some circumstances, the donor would be the legal father.

It is difficult to envisage how disclosure could be encouraged in these cases, as this would stray into other areas of family life where a child (and sometimes the social father) is led to believe that their social father is their genetic father. Where known donation occurs in a clinic setting, the same policy of mandatory counselling on the implications of this should apply.

2e In conclusion, the view of the BFS is that disclosure should be strongly encouraged and that all people undergoing treatment with donor gametes should have counselling on the implications of this treatment that includes the importance of early disclosure and an opportunity to explore how this could be done. The BFS believes that how and when disclosure occurs should be a matter for individual families, providing they have been given the appropriate support and information to enable them to do this in a way that is beneficial for the whole family. The BFS does not consider that it is necessary or desirable to legislate for mandatory disclosure, but is open to further debate on this issue.

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

3a Most prospective parents want as much biographical information about their donor as possible at the point of choosing their donor. Feedback from counsellors exploring the implications of donor conception treatment with patients suggests that parents want some or all of the following information:

- i. Why the donor chose to donate
- ii. How does s/he feel about future contact?
- iii. What s/he looks like
- iv. His/her first name
- v. Is there any family history of inheritable diseases?
- vi. How old is s/he?
- vii. Does s/he have any children?

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- viii. How big is his/her family?
- ix. What does s/he do for a living?
- x. What sort of traits has s/he inherited from his/her family?
- xi. What level of education has s/he attained?
- xii. Does s/he live locally? I.e. are our paths likely to cross and what are the chances of our donor-conceived children meeting other children from the same donor?
- xiii. How many other people has s/he donated to?

Some or all of the above information helps parents at this stage to be confident about their choice of donor and enables them to have confidence in being able to defend their choice of donor should their offspring ask them why they chose that particular person.

Patients report to counsellors that lack of information causes them great anxiety both in relation to the characteristics their child may have and what their child may feel if information is lacking. The former is true even when they are undecided about telling the child or believe they will not do so.

There is a lack of studies focusing on the information needs of parents. However, some studies^{5,18,19} have investigated what information donor-conceived offspring need/want and it is reasonable to conclude that parents would want to be in a position to supply as much of this information as possible to their child/ren.

3c Consanguinity between donor offspring is a concern for parents particularly when they intend to continue to live in the area near the clinic where they are being treated. This concern has been expressed on many occasions during implications counselling sessions with patients. There is some evidence that donor offspring share this concern and that this is one of the reasons cited for donor offspring seeking the identity of and/or contact with their donor and/or donor siblings.^{5, 20,21,22}

3d Single heterosexual women have reported that it is important to them that the sperm donor is someone that they could imagine choosing as a partner. One study demonstrates that there is a correlation between a woman's choice of donor and their choice of long-term partner.²³

Most single heterosexual women are not choosing donor sperm in preference to a partner, but because they do not have a partner at the time when their fertility is likely to

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British Fertility Society

be deteriorating. Good biographical information is very important to these women in choosing a sperm donor.

3e Parents also report that they want easy access to information so that they can have it all to hand to answer their child's questions in the future. Many cannot contemplate a future where they are unable to answer their child's questions. Again, knowledge that disclosure early in a child's life is recommended has led to prospective parents wanting biographical information about the donor from the outset so that they can become familiar with it and be prepared to share details about the donor in layers as the child grows up.

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

4a It is important to recognise that donor offspring's' need for information changes over time. For example, biographical information about the donor is likely to be much less important in early childhood than medical information. Distinction needs to be made between information that is essential to donor offspring – this would include the medical history of the donor and their family, and information that is considered important.¹⁹ In one study, donor- conceived offspring ranked name (61%), health (48%) and information about the donor's family (39%) as the three most important pieces of biographical information that should be available to them.⁵

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?*

5a The BFS's view is that this can be very significant – over and above all other information that donor's provide. UK Donor link reports from its practical experience of supporting Registrants who discovered the fact of their donor conception late in life, that the historical prevalence of non-disclosure has had detrimental affects on the health and decision-making of donor-conceived offspring. For example where their father is known to have had cancer, or other diseases that can be linked to genetics, sperm donor-conceived offspring have incorrectly believed that they are at a greater risk of cancer etc. Access to medical history is becoming increasingly important, as more developments in genetic causes or propensity of particular genes to increase the

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British Fertility Society

likelihood of disease, become known. There are already cases, reported by UK Donor Link, where donor-conceived offspring have undergone invasive tests based on their social father's medical history, which were unnecessary.

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

6a Firstly, it is important to establish the principle that donor-conceived people or their parents if they are minors, have a right to this information whether or not the parents have disclosed, or intend to disclose, their origins. A list of notifiable conditions could be drawn up and all donors be given this list at the time they donate. There may also be a need to link the medical records of donors with the records of donor-conceived offspring so that medical professionals can notify the authorities – currently the HFEA, who would then be responsible for passing this information on. Medical information that comes to light over time is as important as the medical history of donors that is disclosed at the time of donation. It is already established that donor-offspring need/want/have a right to this initial medical information and systems need to be in place to ensure that updated information can be passed on. Again, the systems in place for donor-conceived people relating to donor's medical history are based on prevailing attitudes and knowledge from many years ago. Medical advances and the continual discoveries of measures to prevent or delay the onset of certain diseases, mean that to deny donor offspring access to on-going medical information about their donors is unethical.

6b The welfare of donors needs to be taken into consideration and account must be taken of their needs especially if they, or a member of their family, have been diagnosed with life limiting conditions. It would not be a priority for them to consider the needs of donor-conceived offspring at this time and therefore it makes sense for the system of notification to bypass donors entirely and be the role of medical professions and ultimately the HFEA or whichever organisation holds the Donor Register in the future.

6c If a medical condition becomes apparent in donor offspring, then in exactly the same way, donors should be informed of this. Where donor-conceived children are born with inherited conditions, it would be unethical not to inform donors, whether or not they had disclosed the fact that they had donated to their family, as this knowledge would prompt donors and their own children to have tests. If the donor does not have children at the time this information comes to light, it is essential that s/he be informed to enable investigations and decisions to be made about the possibility of preventing transmission of the condition to any children s/he may have in the future.

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6d The availability of recognised donor conception support services, including access to counselling, is important to help all people affected by any information that comes to light at a later date.

The BFS would welcome a review on how updated medical information about donors could be communicated to their donor-conceived offspring and vice versa.

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?

7a If, as in all other UK children's legislation, the welfare of donor-conceived children is deemed to be paramount, then children need to be told about their donor conception at an early age.

7b It is now established in law and incorporated into the HFEA Code of Practice (8th edition) that:

***20.7** The centre should tell people who seek treatment with donated gametes or embryos that it is best for any resulting child to be told about their origin early in childhood. There is evidence that finding out suddenly, later in life, about donor origins can be emotionally damaging to children and to family relations.*

***20.8** The centre should encourage and prepare patients to be open with their children from an early age about how they were conceived. The centre should give patients information about how counselling may allow them to explore the implications of treatment, in particular how information may be shared with any resultant children*

7c There is evidence of psychological distress and damage to family relationships, where donor-conceived people were either told later in life or discovered that they were donor-conceived by accident.^{10,12,24,25} Parents rarely regret telling their children in infancy. For example, Scheib, Riordan and Rubin¹⁸ reported that early disclosure was generally associated with 'neutral' to 'positive' impact on parent-child relationships, but others often regret not telling and live with considerable distress about the secrecy for the rest of their life. Similarly donor-conceived people rarely report harm when they have been told in infancy, but others often report significant psychological distress when they have found out later in life.

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7d From the studies available – see 7c, there is no evidence that early disclosure is problematic, but it seems that because young children cannot fully grasp what donor conception is, there is a need for disclosure to be an evolving process rather than a one off event.²⁶

7e From a medical point of view, as discussed above, the consequences of late disclosure or discovery are profound including undergoing un-necessary tests, not undergoing necessary tests and making decisions not to have children because of possible inheritance of social mother or father's medical condition/disability.

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?

8a UK Donor link, the Donor Sibling Registry and the Donor Conception Network all have examples and evidence of the impact of making contact with donors or half siblings. There are several studies available at www.donorsiblingregistry.com that recount the experiences of donor-conceived people making connections with previously unknown half siblings and donors. However, no 'case' is identical and the reasons that donor-conceived people search for donors and siblings has to be taken into account when considering the impact. These case examples and studies show that donor-conceived people have very different expectations of contact, which are not necessarily the same as their donors' or half siblings'. For example, some simply want to see what the donors/half siblings look like whereas others hope for an on-going relationship. These different expectations of contact will dictate whether the resulting contact is perceived as a positive, neutral or negative experience. The BFS has long supported the idea of setting up of a nationally funded intermediary service to provide professional support to all parties involved.

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?

9a Contact is not just desired by donor-conceived people. Sometimes the donors and families of donors will have an interest and this can carry on through future generations of the family. There is little evidence available about the attitudes of donors' families towards receiving information about donor offspring.

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9b Currently, the donor's own children are not allowed to register on the HFEA administered Donor Sibling Register. Although this does protect the right of the donor not to be identified if s/he donated prior to 2005, it does not take into account the information needs of the donors' children to make contact with their half siblings. In the context of decisions and recommendations about the information needs of all those affected by donor conception, the needs of the donor's own children must also be considered. Again there is little research evidence in this area.

9c There has also been little research on the post donation information needs of donors. One study looked at donors' experiences of donating anonymously and deciding subsequently to become identifiable to their offspring²⁷. Another elucidated some of the on-going information needs of donors in the context of their views on the use of a Voluntary Register²⁸. There is evidence in Australia that Public Awareness Campaigns result in a significant interest in past donors wanting to become identifiable, which gives an indication that donors are interested in the outcome of their donations.

9d The small numbers of donors in the past who engaged in pre-donation counselling on the implications of donating has led to many being unaware that they have a right to know about the existence of children born from their gametes. Donors also do not have readily accessible support services available to them if they need help to tell their family at a later date e.g. when they enter into a long term partnership and are considering having children of their own.

9e Feedback from infertility counselling practice suggests that most altruistic egg donors do want to know the outcome of donation and have an interest in future contact. Women who egg share on the other hand can feel quite differently: many express a wish pre-treatment not to know the outcome and to not have any further involvement in the recipient's life. Inevitably their primary concern is to have a child of their own and at the pre-treatment stage, they often cannot accommodate any feelings they may have towards resulting donor-conceived offspring.

9f The issues are far more complex when the recipient knows the donor. Recent legal cases have highlighted that some 'known donors' do have an interest not only in receiving information about donor-conceived children, but being involved in their life. Parents also need guidance and support on how to manage the known donor situation both in terms of the needs of the donor for information about the child and vice versa.

9g The information needs of surrogates and their families must also be considered whether or not the child was conceived with the surrogate's eggs. Further research is needed into what on-going information should be available for surrogates about the child

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British Fertility Society

they carried and also what reciprocal information about the surrogate should be available for the child. With an increase in surrogacy arrangements with women living outside the UK, and the legal complexities associated with this, there could be a situation developing where the long term interests of children being born from a foreign surrogacy arrangement are not being attended to.

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?)

10a In terms of child welfare, family welfare and adult mental health, there is a case to be made for the government to acknowledge the responsibility it has to all people affected by donor conception. Fertility Clinics also have a responsibility to acknowledge the life-long implications of family creation through donor conception and to ensure that processes are in place at the donation and treatment stage to assist patients and donors in meeting the long term needs of all who are affected. This includes proper access to pre-treatment and to time limited post-treatment counselling for everyone involved in donor conception, and support and guidance to donors to assist them in providing good quality information.

10b The primary responsibility rests with parliament to legislate to bring donor conception into line with all other UK children's legislation in determining children's rights to information about their identity as paramount. From this, government agencies would be primarily responsible for setting up the systems and processes required to collect, maintain and enable access to the information required for disclosure to parents, donor-conceived people, donors and their families, and surrogates, and for ensuring that appropriate support services are available.

10e It makes sense for UK fertility clinics to continue to be responsible for the collection of information about donors and recipients and for passing this on to the appropriate authority. Donors need to be given information about how to update their medical, social and family history and under what circumstances it would be appropriate to do this. Subsequent updates from donors could be collected centrally to bypass further contact with the fertility clinic.

10f Consideration must also be given to the information needs of children conceived as a result of assisted donor conception treatment in non-UK fertility Clinics, but who are born in the UK.

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10g There may be a role in the future for ante natal services to be involved in advising pregnant women of their responsibility to submit any information they have about their non-UK donor conception treatment to a central Register.

The BFS would support debate on how the needs of all stakeholders could be met in the future.

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

- i. The BFS feel that the introduction of a national support network delivered by appropriately trained professionals for all who are affected by donor conception to include intermediary services, professional support workers and counsellors is required.
- ii. The BFS feel that fertility clinics should be given adequate support to ensure people undertake mandatory pre-treatment/donation counselling in preparation for the lifelong responsibilities they are considering.
- iii. The BFS feel that there should be funding for a professionally led voluntary Register for people affected by donor conception prior to 1991
- iv. The BFS feel that the following support should be made available:
- v. The BFS feel that the setting up of networks for the growing number of families who want to make contact with donor-conceived half siblings as their children are growing up rather than after the age of 18 should be supported – similar to the US based Donor Sibling Registry, which currently has in excess of 36,000 registrants.
- vi. The BFS feel that there should be publicising of where to get information from Donor Registers
- vii. The BFS feel that there should be appropriate support available for people seeking information from the Registers.

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.

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British Fertility Society

Australia seems to be leading the way in reviewing how the whole field of donor conception can be developed to improve the life long experiences of all who are affected⁹. The UK needs to review the evidence that is being produced and capture good practice to ensure every child born as a result of donated gametes or embryos has the best outcome. In addition to clinical experience, particularly of infertility counsellors, the following references were cited:

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