

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.

The British Infertility Counselling Association

## Consultation questions

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In order to inform and support the Working Party's deliberations, the Council would like to invite anyone with an interest (personal, professional or general) in this field to contribute views, examples and evidence within the scope of the terms of reference. The questions on which the Council is particularly interested in hearing your views are set out below. **Please feel free to answer any or all of these questions, or to give your views in any other way on the issues within the scope of the terms of reference.** Where possible, it would help us if you could explain the reasoning behind your answers.

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

#### 1a Establishing children's rights as paramount

Primary ethical concern is the welfare of any children born through donor conception. Historically the needs of donor-conceived offspring have not been paramount when compared with for example the needs of donors and parents. This urgently needs addressing to bring this area of family building in line with the rest of UK legislation concerning children – i.e. that the emotional and physical well being needs of children – who did not choose to be conceived in this way - are paramount. The current situation of being careful not to infringe the rights of the donors and parents is unique when compared to other forms of family building e.g. adoption. The right of donor offspring to information about their genetic background needs to be established in law.

#### 1b Support Services for those affected

The second ethical issue regarding disclosure is the lack of support services for all parties in a 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 do need support and some do need counselling. 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 don't offer counselling, due to the continual lack of certainty regarding 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 there is no suitable opportunity to receive this support, as 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 and widely accepted by the sector following the publication of the British Infertility Counselling Services Report 'Opening the Record'. Again, the lack of support services for people affected by donor conception is an anomaly and needs addressing.

#### 1c Secrecy

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The historical premise established in donor conception is that parents have had a choice about whether or not they inform their donor-conceived offspring of their genetic origins. This has led to many parents choosing to keep this a secret with sometimes the unintended consequence of offspring finding out later in life – with associated emotional harm, or of relationship difficulties when one parent wants to tell and the other doesn't. There is also anecdotal evidence that the discomfort regarding not telling becomes particularly acute for some parents and causes a lot of distress when couples separate and are faced with individually continuing to 'live a lie'. It has long been established that secrets are damaging to relationships and it seems inconceivable that the current legislation still allows for deception regarding a person's origins.

#### 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. 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, must be remedied. If it is established that donor-conceived offspring have a right to origin information, then ethically this right must be established for all donor-conceived people – not confined to those conceived after a certain date. I.e. either all people or none have this right. There is evidence now of others e.g. the Australian Victoria Law Reform Committee recommending retrospective disclosure of donor's identity with appropriate safeguards in place.

#### 1e Support for Parents

In some Licensed Treatment Centres, people undergoing treatment with donor gametes can either opt in or opt out of counselling on the implications of this treatment. This is not in the best interests of children that might be born, or families that may be formed and is unethical. This approach is difficult to comprehend when compared with the preparation for parenthood required in adoption. It is acknowledged that there are different and more complex issues involved in preparing parents for adoption, but there should be proportionate preparation for parents undergoing donor-conception treatment. Counselling on the social, ethical, medical, legal etc. implications of this treatment should be mandatory. This is another example of where the needs of clinics providing such a service and those seeking treatment has had supremacy over the needs of those affected by donor conception. Counselling for donors should also be mandatory in order to prepare them for the life-long implications of donation.

#### 1f Donor consent

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 is not what donors consented to. Donors may have to be contacted to vary their consent with the associated resource

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implications. There is precedent to this in adoption in England and Wales, 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 the right to see their original birth certificate and obtain other information related to their biological parents. There is no evidence that this retrospective legislation has been detrimental to those involved. However, the issue remains the same, is it ethical to retrospectively enable anonymous donors to be identified?

### **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. Infertility counsellors based in licensed centres usually have the role of exploring the issue of disclosure with recipients of donor gametes. However in many centres it is not mandatory that recipients take up what is essentially an offer of counselling. Their practice experience suggests that:

- Where there isn't a fertility issue, e.g. with lesbian parents, there is desire and intention to be open
- 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 reeling from discovering 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

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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 point of presenting this infertility counselling practice evidence is that

- 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.
- v. It seems reasonable to conclude that it is often the lack of opportunity for this support at the time of diagnosis, pre-treatment, after successful treatment and on going, that leads to parental decisions not to disclose. There are still many instances of men discovering their infertility at their GP surgery and not given any support to help them deal with this devastating news.
- vi. Disclosure should be the norm and mandatory, rather than a decision that parents need to make. Exemptions could be granted in rare exceptional cases where it can be demonstrated that a child could experience significant harm if their donor conception was disclosed. However, mandatory disclosure cannot be enforced without the necessary support services available to help parents come to terms with their infertility and manage the process of telling their child, family and friends.

2c Disagreement within families emerges because currently parents have a choice. It is well documented that early disclosure leads to the best outcomes for donor-conceived offspring and therefore most parents make the decision about whether or not to be open even before treatment outcome is known so that they are prepared to announce pregnancies with or without the information that donor gametes were used. Clearly 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 inevitably leads to conflict that can be lifelong. If people started donor gamete treatment with the knowledge that they must disclose, and the appropriate support to enable them to do this well, disagreements and conflict within families about disclosure wouldn't arise.

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2d It is important not to neglect so called 'known sperm donors' in this discussion. The issues are often far more complex especially when donation of sperm has taken place outside a 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 enforced 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 disclosure should apply unless as previously stated there is a case for exemption from this.

In conclusion, disclosure should be mandatory except in exceptional circumstances.

### **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. Again, clinical evidence from infertility counselling practice 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 s/he a 'weirdo'?
- vi. Is there any family history of inheritable diseases?
- vii. How old is s/he?
- viii. Does s/he have any children?
- ix. How big is his/her family?
- x. What does s/he do for a living?
- xi. What sort of traits has s/he inherited from his/her family?
- xii. What level of education?
- xiii. 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?
- xiv. How many other people has s/he donated to?

3b 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.

3c Even prospective parents who at this stage either do not intend to disclose, or are undecided, want information for themselves so that they can feel more comfortable about having a donor-conceived child – particularly women who are concerned about actually having a developing child inside them whose genetic makeup is half (or more) unknown.

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3d Prospective parents are anxious about characteristics that their child may have that are so different to the rest of the family and whether they would be able to relate to a child that is perceived to be 'different'. They also report a concern that if the child is particularly difficult or doesn't match their family's level of intelligence etc., that they will possibly blame all these so called 'negative' characteristics on the donor's genetics and not their own. Having good information about the donor helps to allay these fears.

3e In sperm donation, issues also arise, for couples in pre treatment counselling, about the female partner physically having someone else's sperm inside their body. Some patients have reported that it helps to know that the donor is someone that they feel positively about in order to make this part of the process more acceptable.

3f Consanguinity between donor offspring is a predominant concern for parents particularly when they intend to continue to live in the area near the clinic where they are being treated. This is a particular concern to people living in small towns and cities where the donors are also more likely to live in the same area. Although there can never be any certainty about this, if it is an issue, then information about the donor at the point of choosing can help to allay concerns about this at the time of treatment and in the future.

3g 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. Most single 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 be deteriorating. Good biographical information is very important to these women in choosing a sperm donor.

3h 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 See all points in Q3. There have been a number of research studies in this area that list the above items of information as being significant to donor-conceived people. It is important to recognise that donor offspring's need for information changes over time. For example, medical and family history will not be so important for a child, but will become more important when the donor-conceived person is considering having a family of his or her own, or if they develop medical problems.

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Some donor-conceived people have additionally said that they would like to see a photograph of the donor. Knowing about donor-conceived half siblings, their gender and age, is particularly important as these children have a linked experience and shared genetic heritage. However it is also important to have access to information on the donor's own children, even if there were none at the time of donation.

#### **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 This is very significant. UK Donor link reports that the historical prevalence of non-disclosure has had detrimental affects on the health and decision-making of donor-conceived offspring. For example where the 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. This is becoming increasingly important, as more developments in genetic causes or propensity of particular genes to increase the likelihood of disease, become known. There are already cases where donor-conceived offspring have undergone invasive tests based on their social father's medical history, which were unnecessary. Now that egg donation is a more common way of family building for women post cancer/chemotherapy, this is increasingly likely to affect egg donor-conceived individuals too. The knowledge that a person is donor-conceived is absolutely essential, as is accurate and up to date knowledge about the donor and his/her family's medical history.

#### **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 should be drawn up and all donors should 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 have been diagnosed with life limiting

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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.

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

### ***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, i.e. over and above the needs of parents, donors etc., then there is only one conclusion to be drawn – children must be told about their donor conception at an early age.

7b There is much documented evidence that the disclosure of genetic origin information (whether concerning donor conception, step mothers/fathers or adoption etc.), is best carried out during infancy. This is now established as best practice and has for example been incorporated into the HFEA Code of Practice (8th edition):

**‘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’

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7c There is also plenty of evidence, particularly from the work carried out by UK Donor Link and the Donor Conception Network, of significant psychological distress to donor-conceived people who either were told later in life or who discovered that they were donor-conceived by accident.

7d It has also been well documented that parents rarely regret telling their children in infancy, 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.

7e From a medical point of view, as referred to 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. However, as with adoption, 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. 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.

8b Evidence from the adoption field indicates that distress to both donors and donor-conceived people can be considerably ameliorated when intermediary services are used and professional support is available 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. Evidence is emerging that many sperm donors, especially those who donated prior to 2005, did not tell their families that they had donated and therefore there is much that we do not know about their interests.

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

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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 children must also be considered. Again there is little research evidence in this area.

9c There has been little investment in research on the post donation wellbeing needs of donors. 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 Evidence 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 so-called '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 also needed into what on-going information should be available for surrogates about the child 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?)***

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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 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 responsibility of fertility clinics is also arguably to share the financial burden of providing support services and there are various ways in which they could do this such as paying a fee to a central authority to provide post donor conception services based on the number of donor conception treatment cycles carried out.

10c Individuals may also have a responsibility to contribute to support services that they or their children may need to access in the future. Rather than services being chargeable at the time of access, all patients having donor conception treatment could pay a small fee as part of their treatment charge to contribute to the on-going costs of the provision of information from the Registers, and associated professional support services.

10d The primary responsibility, however, 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, as is the case with adoption, 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. If the principle that children have the right to information about their genetic origin is accepted in the UK, then the rights of children conceived in foreign clinics are the same and provision must be made for the collection of donor information for them in the future.

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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, and also birth outcome data, to the appropriate UK Authority.

10h It should be noted that disclosure is not a one-off event; it is an evolving process that takes place within families and will inevitably be different in every family, as parents have varying amounts of information to disclose.

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

- i. A professional national support network for all who are affected by donor conception to include intermediary services, professional support workers and counsellors.
- ii. Mandatory pre-treatment/donation counselling in fertility clinics to prepare people for the life long responsibilities they are considering.
- iii. Funding for peer support organisations such as the Donor Conception Network
- iv. Funding for a professionally led voluntary Register for people affected by donor conception prior to 1991
- v. Official 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 – similar to the US based Donor Sibling Registry, which currently has in excess of 36,000 registrants.
- vi. Access to support for those who seek information from the Registers – currently applicants are just signposted to non-specialist counselling services.

#### ***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.***

It seems as if over the last few years there have been great leaps in the thinking about donor conception and the needs of all those affected. The historical focus has been on the needs of donors and the importance of recruiting and retaining them to meet the demand for donor gametes, but this has sometimes been at the expense of the needs of resulting children for information. For example, some clinics have been reluctant to ask too much of their donors such as attending for counselling, or providing good quality information on the Donor Information Form for fear of putting them off. There has also been a prevailing culture of almost playing down the longer-term implications of donating, again in case donors were put off. Australia now 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 affected. The UK needs to catch up and there is a great opportunity to do this now, particularly in the light of the compensation for donors that has recently been introduced to help to address the shortage of donors in the UK.

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In addition to clinical experience, particularly of infertility counsellors, the following reference material provides some of the evidence supporting this response:

1. 'Opening the Record' 'Planning the provision of Counselling to people applying for information from the HFEA Register – Report of the HFEA Register Counselling Project Steering Group' Oct 2003 BICA Publications
2. The Donor Sibling Registry website: [www.donorsiblingregistry.com](http://www.donorsiblingregistry.com)
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