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Date: 8 April 2011 – The Human Fertilisation and Embryology Authority

The changing landscape of donation - Social and technological changes

Consultation response on behalf of the Scottish Council on Human Bioethics:

The **Scottish Council on Human Bioethics** (SCHB) is an independent, non-partisan, non-religious registered Scottish charity composed of doctors, lawyers, biomedical scientists, ethicists and other professionals from disciplines associated with medical ethics.

The principles to which the Scottish Council on Human Bioethics subscribe are set out in the **United Nations Universal Declaration of Human Rights** which was adopted and proclaimed by the UN General Assembly resolution 217A (III) on the 10th of December 1948.

The SCHB is very grateful to the Human Fertilisation and Embryology Authority for this opportunity to respond to the consultation entitled **The Changing Landscape of Donation**. It welcomes the Authority's intention to promote public consultation, understanding and discussion on this topic.

Scottish Council on Human Bioethics Response:

The changing age of fertility treatment patients

The average age of women having fertility treatment in UK clinics with donated sperm, eggs or embryos has increased from 31.9 years in 1991 to 35.1 years in 2007. These results mirror the average age of mothers giving birth, which has been gradually increasing since the mid 1970s, from 26.5 years in 1975 to 29.4 years in 2009.

In the last decade the number of women giving birth at age 35 or older has increased by a third: from 15% in 1999 to 20% in 2009.

Who is having fertility treatment?

The structure of the family is changing and so too are patterns of personal behaviour. The percentage of births outside marriage has risen dramatically in the last 30 years: 11% in 1979, 39% in 1999 and 46% in 2009.

Same sex couples and single women are increasingly seeking treatment with donor sperm. Up to 30% of clients at London Women's Clinic – a major donation clinic in London - are lesbian couples, representing an increase of about 10% from 10 years ago.

Since 2009 it has been possible for two women to register as the parents of a child and the law no longer requires clinics to consider the 'need for a father' before offering treatment. It is also now possible for two women or two men to become parents following surrogacy.

New technologies in fertility treatment

Today IVF is commonplace; it has proved itself to be a safe and mainstream clinical technique. Many additional treatments and techniques have been developed since 1991, such as ICSI (intracytoplasmic sperm injection) and egg freezing. These techniques open up a number of fertility options for people who would have been consigned to infertility a generation ago.

Shortages of egg and sperm donors

Demand for donor treatment in the UK exceeds the supply of donors. Although this has been an issue since the HFEA was established in 1991, it is often argued that the shortage was exacerbated by the removal of anonymity by Parliament in 2005.

As a regulating body, the HFEA does not have responsibility to ensure the supply of donors. Fertility clinics have this responsibility. Nevertheless, the current shortage does touch aspects of donation within the HFEA's purview, e.g., donor compensation, the family limit and family donation.

What are the consequences of donor shortages?

The shortage of donors results in long waiting times for treatment; there are reports of waiting times of three to five years for donor eggs in the UK. A delay in treatment is one of the main reasons people give for going abroad, where it can be easier to access donor treatment. Rules on donation differ across Europe. It is possible, for example, to travel within the EU to access sperm from an anonymous donor, which is illegal in the UK.

The danger of this fertility tourism, however, is that children conceived in clinics abroad will not be able to benefit from the safeguards which exist in the UK. For example, children conceived abroad do not have the right to information about their donor and siblings. As noted below, this lack of connection to genetic relatives raises important questions about a person's identity and the challenges he or she may face later in life.

Rising number of online donation sites

Web-based matching services have emerged as major players in the fertility business. Through these websites, donors advertise their willingness to donate. The HFEA is concerned about the safety of patients and the quality of care if donation does not take place within a licensed clinic. Internet donation services raise real risks that:

- The sperm sample received is not safe;
- The donor is not who they say they are;
- Women in a vulnerable situation are exploited;
- The safeguards that the law offers to parents, to donors and to those who are born do not apply.
- There have also been media reports of donors being paid directly by the recipient for their donation.

Fertility treatment and donation trends

Fertility treatment trends

Infertility affects roughly one in six UK couples – approximately 3.5 million people. Whilst the world's first IVF baby was born in 1978, it is likely that sperm donor insemination has been going on for centuries. As well as being a treatment for couples where the male partner has fertility problems, donor insemination is also used for single women, same-sex couples and those who want to avoid passing on genetic disorders.

While more single women and same sex couples seek donor insemination, the demand from couples with an infertile male partner has decreased over the past decade. As noted above, this is due largely to the increased use of ICSI (intracytoplasmic sperm injection). Introduced in 1992, ICSI is now a common treatment. It involves the injection of one sperm into an egg in the laboratory, and is particularly effective for men who have a low sperm count or poor quality sperm.

As a result of ICSI, the number of women undergoing donor insemination is now less than a third of the number treated in the early 1990s (around 2,000 in 2007, compared with 9,000 in 1991). About 4% of IVF and ICSI treatment in the UK involves donated eggs.

Donation trends

The number of sperm and egg donors has risen in the UK in recent years. In 2005, when donor anonymity was removed, 251 people registered as sperm donors and 921 as egg donors. In 2008, 396 people registered as sperm donors and 1,150 as egg donors.

Despite this increase in donors, the number of people receiving treatment has dropped since 2005: 825 patients were treated with donor sperm in 2005, compared with 651 in 2008. Meanwhile, 1635 patients were treated with donor eggs in 2005, compared with 1306 in 2008. It is not clear why there has been an increase in donor numbers, at the same time as a decrease in donor treatment. One explanation could be an increase in known donors (friends or family of the patient), who donate to one family only. Increasingly donated sperm is imported from other countries. Currently about 20% of donors are from overseas, compared to 12% in 2005.

Demand for treatment with donated eggs or sperm continues to outstrip supply, resulting in long waiting times at some clinics, particularly when patients want a donor from a minority ethnic group. The **British Fertility Society** estimates that the UK needs 500 sperm donors a year to meet demand.

Possible solutions to the donor shortage

One way to increase donor numbers is to increase awareness of donation. The **National Gamete Donation Trust (NGDT)**, a government-funded charity, works to achieve this, though it is a small charity with limited funds.

Improving the current system

Many people make initial enquiries about donation, but they do not go on to become donors. This may be because they change their mind after finding out about what donation involves (eg, lack of anonymity, the screening process, the time involved and lack of payment) or they are not accepted because of medical reasons.

The HFEA's discussions with donor and patient organisations so far suggest that donors are sometimes lost because of inadequate customer service.

Some clinics fail to return donors' phone calls or to let them know if they have been accepted as donors following screening.

More donors could be retained through better customer service and improved information.

Clinics have told the HFEA that the current system for compensation is a burden to administer and may leave some donors out of pocket. Making the process for claiming expenses easier (eg, not being required to submit receipts) may increase donor numbers. Other considerations for maybe increasing numbers are:

- Compensation, reimbursement and benefits in kind for sperm and egg donation
- Access to sperm donor treatment might be increased by raising the number of families an individual donor can donate to - this limit is currently set at 10.
- Putting systems in place to make it easy for clinics to monitor the maximum family limit set by donors could also improve access to treatment.
- Family limit for donated sperm and eggs.

There are factors outside of HFEA policy - such as UK and European law - that affect the availability of donated sperm and eggs in the UK.

The ethical principles and concerns of donation

There is a greater demand for donor treatment in licensed clinics than the supply of donors, yet there is a perception that unlicensed donor/recipient matching websites are on the increase.

This suggests that there are people who are willing to donate, but do not do so through licensed clinics.

These issues force us to consider our values and principles regarding the nature of giving, the value of life, how life should come about and the proper place of regulation.

There is not a clear 'right' answer; there are competing principles and concerns.

These are the principles the HFEA believes are relevant to the issues surrounding donation:

- **Welfare of the future child** - not doing anything which could result in serious harm to any child born as a result of assisted reproduction with donor eggs or sperm.
- **Safety of donors, patients and donor conceived people** – safety of all those affected by donation is paramount, for example, donors are carefully screened for transmittable diseases.

- **Respect for family life** – concerns the intrinsic value of forming a family. For some, donated sperm, eggs or embryos represents the only chance, other than adoption, of forming a family. In order for such people to form a family, there needs to be an adequate supply of donated gametes; posing unjustifiable barriers to donation may be seen to impinge some people’s ability to form a family.
- **Altruism** – is acting in the interests of others, rather than through self interest. Anything that would benefit the donor directly – such as a financial reward – might be seen to undermine altruistic motivation.
- **Fairness** – relates to treating people equally and not benefiting one party over another. It may be perceived as unfair for donors to be out of pocket as a result of donation, especially if clinics benefit financially from their donation.
- **Informed consent** – in order to consent to treatment or donation, full information about the procedure, risks and any consequences must be provided in an accessible and easy to understand way.
- **Free choice** – family pressure, or financial incentive, to donate may impinge an individual’s ability to make a free choice.
- **Importance of counselling** – patients and donors must, by law, be offered counselling to discuss their donation/treatment, before it takes place. This helps ensure consent is fully informed, free and properly thought through.
- **Pragmatism** – any change in policy should be easy for clinics to implement and pose minimum burden on donors, patients and clinics.
- **Openness** – it is believed to be in the best interests of the child conceived for them to have information about their origins; clinics must, by law, give patients information about how to inform their children of their donor conception.
- **Special status of the human embryo** – human embryos have special moral status (although a majority may not give full human status) and should be afforded legal protection; in part, it is the role of the regulator to ensure this protection is provided.

Questions:

1. What action, besides amending HFEA policy, do you think could be taken to increase the availability of donated sperm and eggs in the UK? (please select more than one if appropriate):

- A change to the law to enable donors to be paid for their donation, which is currently prohibited
- A change to the law to allow donors to be anonymous, which is currently prohibited
- A change to the law - other (please specify)
- A change to professional guidance on donor screening
- A change to professional guidance - other (please specify)
- Increasing people’s awareness of and educating people about donation
- Carrying out national donor recruitment campaigns
- Other (please specify)
- None

2 a) Do you think we have accurately captured the principles relevant to donation?

- Yes
- X No

2 b) Do you think there are other relevant principles that should be considered?

- X Yes (please specify)
- No

SCHB Comment:

Relationships between children resulting from donor gametes and their parents

1. In addressing the issues raised by the regulation of donor-assisted conception, the SCHB believes that it is very important to examine the deep bonds that exist between parents and their offspring. For example, many parents, as the responsible partners in the creation of life, know intuitively that they belong to the child and that the child, in receiving life, belongs to them, i.e., there exists a sort of mutual belonging.

The deep sense of loss or incompleteness felt by parents who are unable to be directly responsible for the creation of life in their child is an underlying reason that many seek assisted reproduction rather than adoption. In other words, the fact that prospective parent even consider, let alone undergo, expensive procedures for artificial conception indicates the importance they attach to the biology of creation. Such parents are aware, even if subconsciously, that the lack of biological connection may prevent them from feeling a sense of belonging with the child or the child with them.

2. This apprehension is also reflected in published reports which suggest that when Assisted Insemination by Donor (AID) has been used, the commissioning (non-genetic) father is significantly more reticent than the commissioning (genetic) mother to inform the child of its biological origins. Illustrative of this reticence is a report from the Netherlands about the willingness of parents to inform their children about conception procedures. The report in question notes that only 21% of parents who used AID to conceive have also decided to inform their child about the procedure. In contrast, 94% of parents who did not use AID have informed their children about the origin of the child's life¹.

A more recent study of 46 AID families in England found even lower transparency about their children's conception procedures. In each case, the family had a child up to age 8 who had been conceived through sperm donation. Only 13% of parents had already told their child, while 26% said they intended to. But 43% had decided against it, and 17 % were still unsure what they would do^{2,3}.

An earlier European study of donor insemination families in the UK, Italy, the Netherlands and Spain found that only 12% of the mothers had planned to tell the child about his or her conception procedure, while 75% had decided not to do so. By the time the children reached 11-12 years old, only 8.6% of parents had actually told their children about their conception procedure⁴.

This is all the more worrying since 50% of donor insemination children suspect, when growing up, that their social father may not be their genetic one before being told⁵.

But why do so few parents inform their children of the manner in which they were conceived? Exploring the deep and important bonds parents and their children may turn up an answer. This is a topic that is sorely under-researched and that may prove fruitful in light of the present discussion about gamete donation.

Other examples of the importance of the biological parent-child bonds:

The following examples illustrate the strength of the parent-child bond:

3. In 2003, Natallie Evans and Lorraine Hadley lost a High Court battle to use the frozen embryos created with the help of their respective, estranged partners. In both cases the use of the embryos would countered the wishes of the former partners⁶. Both men refused to grant permission in large part because they felt that some kind of bond would exist between them and the child. Since they did not want this bond, they denied consent to their previous partners, Evans and Hadley, to use the embryos.

¹ Brewaeys, A., Golombok, S., Naaktgeboren, N., de Bruyn, J.K., Van Hall, E.V., Dutch parent's opinion about confidentiality and donor anonymity and the emotional adjustment of their children, *Human Reproduction*, Vol.12, No.7, (1997)

² Sperm donation — should you tell your child?, Reuters, <http://www.msnbc.msn.com/id/6866305/>

³ Poor couples 'want IVF anonymity', BBC News, 26 January 2005, <http://news.bbc.co.uk/1/hi/health/4205661.stm>

⁴ Golombok *et al*, The European Study of Assisted Reproduction Families: The transition to adolescence, *Human Reproduction*, Vol. 17(3): 840-40 (2002)

⁵ Mary Braid, Your daddy was a donor, *The Observer*, 20 January 2002, <http://observer.guardian.co.uk/review/story/0%2C6903%2C636020%2C00.html>

⁶ Women lose embryo battle - BBC - 1 October 2003, <http://news.bbc.co.uk/1/hi/health/3151762.stm>

4. Many gamete donors fear the removal of anonymity, suggesting that there is an assumed strength of the biological parent-child bond. For example, in 2004, 90% of UK clinics reported a shortage of donors,⁷ but fertility experts suggest that when new donors lost their right to anonymity in 2005, an even greater shortage resulted.

5. Recent research shows that more than four out of five US children conceived using donor insemination with an identifiable sperm donor would be likely to ask the identity of their donor and try to contact him. This would happen as early as age 18 when the donor's information became legally available. Many said that they would also like to contact any other children of the donor⁸. While fascinating, this research raises the poignant question of why children—and such a high percentage at that—want contact with their biological fathers. Is this because of a feeling of mutual belonging or for another reason? Again, this is a question that may prove fruitful for future research, particularly in light of the present HFEA report.

6. When possible, UK clinics are expected to match the ethnic background and physical characteristics of gamete donors to those of an infertile partner, thus ensuring that the possible child is seen (in a visual sense) to 'belong' to its parents.⁹ In this regard, Olivia Montuschi from the Donor Conception Network, which represents families of children conceived after sperm or egg donations, insisted that it was vital for children to share physical characteristics with their parents. She also indicated that *"If a child is significantly different in any way, either in physical characteristics or intellectual attainment, then it can make it harder for them to feel part of that family"*¹⁰. But why is it so important that children feel part of the family? Does this not reflect a deep sense of bonding or communality which should exist between the biological parents and the child?

7. Some persons such as previous UK Home Secretary, Mr. David Blunkett, go to extremes in order to prove their paternity. But what do these people feel towards the child they claim is 'theirs' and why do they go to such lengths? Moreover, it is interesting to note that, in Mr. Blunkett's case, the judge indicated that it was in the child's best interests to have his parentage determined at the earliest opportunity. And the court ordered scientific tests to ensure this¹¹.

8. At present more than 116,000 frozen human embryos leftover from IVF treatments are stored in UK clinics. This has arisen because parents may^{12,13}:

(1) want to implant these embryos at a later date into the biological mother,

(2) be unsure of the moral status of these human embryos and therefore not want to see them destroyed either outright or in research,

(3) not want to give these embryos up for adoption because of the 'bonds' that exists between them and the embryos. In the UK, despite the high number of left-over embryos, only around 190 embryos/year are donated to infertile couples who cannot create their own¹⁴.

⁷ A. Frean, Couples may get chance to design the 'ideal' IVF baby, TIMESONLINE, 12 November 2004: <http://www.timesonline.co.uk/article/0,,2-1355182,00.html>

⁸ Children Positive about Sperm donors, BioNews No. 284, 15 November 2004

⁹ This is also reflected in paragraph 18 of a previous HFEA consultation which states that: Clinics usually offer recipients gametes or embryos from donors who are a close physical match to the people receiving treatment. This is thought to be in the interests of the family concerned so that donor-conceived members of that family do not 'stand out' and risk becoming socially stigmatised as a result. Additionally, some recipients want donors with a certain background for non-genetic reasons, for example because they want a donor who shares their religion.

¹⁰ A. Frean, Couples may get chance to design the 'ideal' IVF baby, TIMESONLINE, 12 November 2004: <http://www.timesonline.co.uk/article/0,,2-1355182,00.html>

¹¹ Blunkett wins right to seek access, BBC NEWS, 3 December 2004: http://news.bbc.co.uk/1/hi/uk_politics/4065177.stm

¹² Sarah-Kate Templeton, Spare embryos 'should be donated to infertile couples', The Sunday Herald, 21 September 2003: <http://www.sundayherald.com/36912>

¹³ Couples' feelings mixed about extra embryos, 14 October 2003 (Reuters Health): <http://www.stjudemedicalcenter.org/healthnews/reuters/20031014elin022.htm>

¹⁴ G Fuscaldo, J Savulescu, *Spare embryos: 3000 reasons to rethink the significance of genetic relatedness*, *Reproductive BioMedicine Online*, Volume 10, No 2 February 2005, <http://www.rbmonline.com/4DCGI/Article/Detail?38%091%09=%201550%09> Studies reviewing the fate of surplus human embryos reveal that close to 90% of couples choose to discard their excess embryos and that hundreds of embryos are disposed of annually. It has been argued that human embryos are a valuable resource and that there is a need to consider educational programmes to encourage couples to donate spare embryos to other infertile couples, rather than discard

In this respect, Professor Ian Craft, director of the London Fertility Centre, said: *“It surprises me that so few couples agree to donate spare embryos if you consider the desperation of infertile couples to have children.”* Adding that *“there are very few babies to adopt and so I would have thought these couples, who have been through infertility treatment themselves and who have completed their families, would be more sympathetic to others”*. He also indicated that society should be making people more aware of the benefits that these supernumerary embryos may represent to childless couples¹⁵.

Concerns of the SCHB relating to Donor-Assisted Conception

1. The SCHB notes that Donor-Assisted Conception is not risk-free for the woman giving the eggs since egg retrieval procedures may risk ovarian hyperstimulation syndrome following aggressive hormonal treatments¹⁶.
2. It remains the Council’s concern that some media-highlighted cases of obvious gamete insemination and embryo implantation errors have taken place. This has arisen when obvious racial differences were noticed. Of course, it is not known how often other true mistakes have occurred when racial characteristics were not present.
3. The SCHB notes that parents who use donor insemination often bring a child into the world for their own sakes without fully considering what the wishes of the future child may be. That is, the child may want to have a relationship with his or her genetic parents. Though the parents may concede to tell their child the truth when they are older, they would then have to understand that the child may wish to see and know his or her biological parents (the donors) and express a sort of a ‘love’ or affection which he or she may already experience. The child may also experience difficulties towards his or her biological or social parents with the possibility of feeling a sense of rejection.
4. Therefore, the SCHB is of the opinion that the possibility of promoting donated gametes in order to address infertility should not be envisaged until two following issues have been satisfactorily addressed:
 1. the important bonds that exist between the biological parents and the child, and
 2. the unease the general population has concerning donor insemination.

Accordingly, the SCHB cannot reply to the other questions posed by the HFEA in its consultation entitled **‘The changing landscape of donation’**. Any response to these consultation questions would undermine the stance of the SCHB that such procedures should not proceed until further investigations are undertaken and the serious doubts concerning these procedures are addressed.

2 c) Do you think there are principles outlined that should not be considered?

- Yes (please specify)
- No

them. Surveys show that one reason that so few embryos are donated is that couples attach great significance to genetic parenthood. Advances in reproductive technology may necessitate a review of biological definitions of family and the importance of genetic relatedness. It can be argued that it is unreasonable to conclude that genetic ties are so significant that embryos should be discarded rather than donated and raised by non-genetically related parents. It is suggested that education programmes should encourage reflection on people’s beliefs about the importance of genetic relatedness with regard to what makes a family. Open embryo donation or directed embryo donation programmes might cause couples to change their minds, or alleviate their anxiety about donating embryos to others.

¹⁵ Sarah-Kate Templeton, Spare embryos ‘should be donated to infertile couples’, The Sunday Herald, 21 September 2003: <http://www.sundayherald.com/36912>

¹⁶ Delbaere, A., G. Smits, O. Olatunbosun, R. Pierson, G. Vassart, and S. Costagliola. New insights into the pathophysiology of ovarian hyperstimulation syndrome. What makes the difference between spontaneous and iatrogenic syndrome? Human Reproduction 19: 486-489, 2004.

Donor compensation, reimbursement and benefits in kind

What is the current policy on donor compensation?

The law prohibits the payment of donors but allows them to be compensated for expenses and for the inconvenience of donation. It is the HFEA's job to decide what kind of compensation should be given to donors within these legal limits.

The HFEA last looked at its rules on donation in 2005. Since then there have been significant legislative and social changes which may impact on the ethics of donation.

The HFEA's current policy allows sperm and egg donors to claim reasonable expenses in connection with their donation (eg, travel costs). Donors may also be compensated for loss of earnings up to £61.28 for each full day (as for jury service), with a limit of £250 for each course of sperm or egg donation.

Clinics must keep a record of the expenses and compensation they pay, including receipts.

Clinics can only give donors compensation for expenses incurred within the UK. So, clinics cannot currently bring in donors from other countries. However, they can import eggs or sperm from abroad.

Currently about 20% of sperm donors and 2% of egg donors are from overseas, compared to 12% and 4%, respectively, in 2005. Overseas donors whose sperm or eggs are imported to the UK must meet the same requirements as UK donors (eg, screening tests, identifiability), including the amount of compensation for expenses and loss earnings that they can receive.

Benefits in kind

The HFEA allow egg or sperm sharing, which is a 'benefits in kind' system:

- **Egg sharing** is where a woman receiving IVF treatment donates some of her eggs at the same time as undergoing treatment. In return, the clinic can offer a significant reduction in the cost of her treatment (commonly half or the full cost of treatment, which is about £5000 per cycle).
- **Sperm sharing schemes** are offered by some clinics. Couples can get a reduction in treatment costs, or are moved up the waiting list, in return for the male partner (or another person they provide as a donor) donating their sperm.
- **Freeze sharing schemes** have become available at a small number of clinics more recently, allowing women to store their eggs for future treatment (free for about 5 years) in exchange for donating some of these eggs.

What changes would be possible within the law?

The law on the donation of sperm, eggs and embryos is set both by UK legislation and by a European directive which was implemented in 2007. This legal framework means that the UK has a responsibility to ensure that:

- donation is voluntary and unpaid;
- donors act from altruistic motives;
- donation is in the spirit of contributing to a wider social good ('solidarity between donor and recipient' is the term used in law);
- there's an adequate supply of donor tissues and cells.

Outright payment for donation is not allowed by law. The essence of donation is the act of giving. Because the act of giving is generous and humane, the law does allow donors to receive compensation for inconvenience. This is different from and additional to compensation for expenses and loss of earnings.

Those who donate are under no obligation to do so and they make adjustments to their daily lives and go significantly out of their way to help others who, without their help, might be unable to have the chance to have children through fertility treatment. The law on compensation for inconvenience is a way of allowing clinics to recognise the disruptive and out-of-the-ordinary impact of donation on donors' lives.

When the HFEA last considered donor compensation, in 2005, it had concerns that offering compensation for the physical inconvenience or risk of donation may encourage some people to donate without thinking sufficiently about the consequences of donation. Therefore the HFEA did not currently allow donors to be compensated for the inconvenience associated with donation.

The HFEA is seeking views on whether these policies should be changed.

Donor compensation in Europe

Different countries have interpreted the European legislation differently:

Denmark

Sperm donors receive 50-150 Euros (around £45-135) for the examination and use of their time and travel expenses (egg donation is illegal).

Spain

Egg donors are compensated 900 Euros (around £765); sperm donors are compensated 45 Euros (around £40) per valid sperm sample they produce. This is a blanket fee for expenses, loss of earnings and inconvenience.

France

Donors receive no compensation besides the reimbursement of travel expenses.

What does sperm and egg donation involve?

Egg donation

Clinics must offer counselling to all donors; many insist that donors undergo counselling before donation takes place.

Egg donation is an invasive procedure. Before starting, donors are tested for infectious and genetic diseases. They are then given a series of hormone injections to help develop and mature eggs within the ovaries.

Once the eggs are matured, they are collected, under anesthetic, by inserting a needle into the ovaries through the vagina. Donors will probably need at least the day after the operation off work.

Although serious side effects are rare, common side effects include:

- tiredness;
- abdominal pain;
- bloating;
- mood swings;
- headaches.

Occasionally there can be a potentially dangerous over-reaction to the hormones (about 5% of women develop some symptoms and 1-2% experience severe symptoms).

Sperm donation

Clinics must offer counselling to all donors; many insist that donors undergo counselling before donation takes place.

Sperm donation is less invasive than egg donation, but usually more time consuming. It starts with blood tests for infectious and genetic conditions, as well as giving a semen sample so that sperm quality can be checked.

Sperm donors are then asked to produce semen samples over several weeks or months. The donor needs to abstain from sex and alcohol for at least two days prior to each donation. Sperm donors have to go back to the clinic six months after their last donation to have further screening tests, before their sperm samples are released for use in treatment.

After the donation

- Both sperm and egg donors are asked to provide biographical information and a message to any child born from their donation.

- Since the law was changed in 2005, children born from a donation will be legally entitled to access identifying information about the donor once they reach the age of 18, which means that anyone who donated after this change in the law, might, in the future, be contacted by children conceived as a result of their donation.
- Donors have no financial or legal obligations towards the child.

What does egg sharing involve?

Women donating eggs in an egg sharing arrangement undergo the same procedures and are subject to the same requirements as egg donors.

Some of the eggs collected from the egg sharer are used for her treatment and some are donated for use in another woman's (or sometimes for two women's) treatment. The egg sharer and the egg recipient do not meet each other.

Many clinics insist that eggs sharers have counselling to ensure that they have considered the implications; including the possibility that the recipient may become pregnant and have a child, but that they may eventually remain childless.

Egg sharing differs from egg donation, as it is an option for women undergoing their own treatment.

In return for their donation, some donors in the UK receive 'benefits in kind'. This is usually fertility treatment at a reduced cost, which is known as 'egg sharing' or 'sperm sharing'.

Some believe the benefits in kind, such as a substantial reduction in the IVF £ 5000 fee, provide a powerful incentive to donate and are, in fact, no different from paying donors

Others see it as improving access to treatment for women who might not otherwise be able to afford IVF and improving access to donated eggs for women who are unable to use their own eggs in treatment.

Concerns have been raised that egg sharing may cause psychological harm to the donor if she is unsuccessful with her treatment, but the recipient conceives, and, upon reaching 18 years of age the child then eventually contacts the donor. She may then realise that she has remained childless all her life while another woman has had a child with her egg. However, these concerns have not been borne out in the small number of studies on the experience of 'unsuccessful' sharers.

What motivates people to donate?

Little is known about what motivates people to donate sperm or eggs, but what is known suggests that:

- some donors want to help a friend, family member or stranger to have a family;
- in other countries some wish to receive financial compensation;
- most egg sharers would not donate if there were no incentive to do so;
- many egg sharers want to both help themselves and to help someone else.

Certainly in relation to egg donation the benefits in kind are part of the reason why people donate, but the main motivator appears to be a desire to help others. Outcomes of a survey we carried out with UK fertility clinics and interviews with some sperm and egg donors support this.

What principles should we keep in mind?

The question of whether donors should be financially compensated and, if so, how much, evokes strong views.

The issue forces us to consider our values and principles on the nature of giving, the value of life, and how life should come about.

There are competing principles and concerns. Some of the principles relevant to the issue of financially rewarding donors include:

- **Altruism (selflessness)** – anything that would benefit the donor directly – such as a financial reward – might be seen to undermine altruistic motivation and informed consent.
- **Fairness** – it may be unfair for donors to be out of pocket as a result of donation, especially if clinics benefit financially from their donation, and recipients are charged for their donated gametes.

- **Free choice** – family pressure or incentives to donate may impact on an individual’s ability to make a free choice.
- **Welfare of the future child** – financial rewards to donors may have an emotional and psychological impact on future children, who may believe they were “bought”.
- **Safety of donors, patients and donor conceived people** - donors are screened for diseases but financial rewards may encourage donors to lie about their health.
- **Respect for family life** – for some, donated sperm, eggs or embryos represents the only chance, other than adoption, of forming a family. In order for such people to start a family, there needs to be an adequate supply of donated gametes; imposing barriers to donation may affect some people’s ability to form a family.
- **Pragmatism (a practical solution)** – any compensation scheme must be straightforward to implement with minimum burden on donors, patients and clinics.

It may not be possible to reach a solution that respects each principle equally. **For example:** to emphasise altruism we could insist that donors do not receive financial compensation, not even for expenses or loss of earnings. This would mean, however, that donors could end up out of pocket, while clinics may make money from their good will, which could, in turn, conflict with the principle of fairness.

How could the current system change?

The HFEA’s current policy tries to ensure that donors do not benefit from their donation but allows for compensation for loss of earnings and expenses.

Feedback from clinics, however, shows that not only do some donors end up being out of pocket (eg, if they can not prove their loss of earnings to the clinic), but also that the system is more complex than it needs to be.

Some clinic staff tell the HFEA that losing out on income or expenses can deter potential donors. Ensuring donors are not out of pocket or paying some sort of compensation for inconvenience may remove a barrier to donation, rather than provide an incentive.

This would result in more donors and allow more people to have treatment with donated sperm and eggs. However, different people will be motivated by different amounts of money - a removal of a barrier to some, may be an incentive to others.

People will weigh these various principles differently and reach their own solutions. The HFEA would like to know what the public thinks the ideal compensation scheme would look like and what principles such a scheme would be based on.

This questionnaire will ask separate questions on expenses, earnings, inconvenience and benefits in kind.

Expenses

Questions:

1a) In principle, do you think donors should be compensated for expenses they incur during the process of making a donation (e.g., the cost of a train fare to the clinic)?

Sperm donors

Yes

X No

Egg donors

Yes

X No

If you answered ‘No’ for both sperm and egg donors above > go to next page

If you answered 'Yes' for either sperm or egg donors please tell us more about this > go to question 1b

1b) In practice, how do you think a donor's expenses should be compensated (select a scheme for sperm donors and a scheme for egg donors)?

Sperm donors

- A fixed amount of money that is the same for all sperm donors (please specify an amount in £)
- A variable amount of money according to the donor's actual expenses
- Other (please specify)

Egg donors

- A fixed amount of money that is the same for all egg donors (please specify an amount in £)
- A variable amount of money according to the donor's actual expenses
- Other (please specify)

It's important for us to understand the reason(s) why you chose the sperm and/or egg donor scheme(s) above. Please give a brief explanation below:

1c) Do you think donors should be compensated for expenses they incur outside the UK (eg, the cost of travel to a clinic in the UK from Asia or Europe)?

Sperm donors

- Yes
- X No

Egg donors

- Yes
- X No

Please give an explanation of your answer or provide any further comments, including how compensation should apply to overseas donors, whose eggs or sperm are imported in to the UK.

Earnings

Questions

2a) In principle, do you think donors should be compensated for earnings they lose during the process of making a donation (eg, for time off work to attend clinic appointments)?

Sperm donors

- Yes
- X No

Egg donors

- Yes
- X No

If you answered 'No' for both sperm and egg donors above > go to next page
If you answered 'Yes' for either sperm or egg donors please tell us more about this > go to question 2b

2b) In practice, how do you think a donor's loss of earnings should be compensated for (select a scheme for sperm donors and a scheme for egg donors)?

Sperm donors

- A fixed amount of money that is the same for all sperm donors (please specify an amount in £)
- A variable amount of money according to the donor's actual earnings lost
- Other (please specify)

Egg donors

- A fixed amount of money that is the same for all egg donors (please specify an amount in £)
- A variable amount of money according to the donor's actual earnings lost
- Other (please specify)

It's important for us to understand the reason(s) why you chose the sperm and/or egg donor scheme(s) above. Please give a brief explanation below:

Inconvenience

Questions:

3a) In principle, do you think donors should be compensated for the disruption and discomfort associated with the process of making a donation (eg the inconvenience and side effects of hormone injections for egg donors and the inconvenience of numerous clinic visits for sperm donors)?

Sperm donors

- Yes
- X No

Egg donors

- Yes
- X No

If you answered 'No' for both sperm and egg donors above > go to next page
If you answered 'Yes' for either sperm or egg donors please tell us more about this > go to question 3b

3b) In practice, how do you think a donor should be compensated for the routine disruption and discomfort associated with the process of making a donation (select a scheme for sperm donors and a scheme for egg donors)?

Sperm donors

- A fixed amount of money that is the same for all sperm donors (please specify an amount in £)
- A variable amount of money according to the donor's actual disruption and discomfort experienced
- Other (please specify)

Egg donors

- A fixed amount of money that is the same for all egg donors (please specify an amount in £)
- A variable amount of money according to the donor's actual disruption and discomfort experienced
- Other (please specify)

It's important for us to understand the reason(s) why you chose the sperm and/or egg donor scheme(s) above. Please give a brief explanation below:

Benefits in kind

Questions

4a) In principle, should donors be offered benefits in kind for their donation?

Sperm donors

- Yes
- X No

Egg donors

- Yes
- X No

Comment from the SCHB:

It would appear that any 'egg-sharing' arrangement being considered is on the basis of the woman in question having an inducement such as reduced fees (or perhaps something more subtle such as a shorter waiting time) for her infertility treatment. The SCHB regards this as tantamount to the commodification of human body parts because human tissue has been obtained in exchange for financial gain or comparable advantages.

Concerns related to the commodification of body parts are the coercion and exploitation of more vulnerable members of society.

The SCHB notes that the following national and international legal instruments have addressed the topic of compensation in the context of the donation of human organs, tissue and cells (including eggs):

1. United Kingdom - Human Fertilisation and Embryology Act 1990 (as amended)

Section 12 General conditions

*(1) The following shall be conditions of any licence granted under this Act -
 ...(e) that no money or other benefit shall be given or received in respect of any supply of gametes, embryos or human admixed embryos unless authorised by Directions...*

Section 41 Offences

...(8) Where a person to whom a licence applies or the holder of the licence gives or receives any money or other benefit, not authorised by Directions [from the HFEA], in respect of any supply of gametes, embryos or human admixed embryos, he is guilty of an offence.

2. European Union - Directive 2004/23/EC of the European Parliament and of the Council of 31 March 2004 on setting standards of quality and safety for the donation, procurement, testing, processing, preservation, storage and distribution of human tissues and cells^{17,18}

¹⁷ This includes haematopoietic peripheral blood, umbilical-cord (blood) and bone-marrow stem cells, reproductive cells (eggs, sperm), foetal tissue and cells and adult and embryonic stem cells. The Directive does not include organs or parts of organs if it is their function

Article 12 (Principles governing tissue and cell donation), paragraph 1:

Member States shall endeavour to ensure voluntary and unpaid donations of tissues and cells. Donors may receive compensation, which is strictly limited to making good the expenses and inconveniences related to the donation. In that case, Member States define the conditions under which compensation may be granted.

3. Council of Europe - Additional Protocol to the European Convention on Human Rights and Biomedicine concerning transplantation of organs and tissues of human origin (ETS No. 186)^{19,20}

Article 21 (Prohibition of financial gain), paragraph 1:

The human body and its parts shall not, as such, give rise to financial gain or comparable advantage. The aforementioned provision shall not prevent payments which do not constitute a financial gain or a comparable advantage, in particular:

- compensation of living donors for loss of earnings and any other justifiable expenses caused by the removal or by the related medical examinations;*
- payment of a justifiable fee for legitimate medical or related technical services rendered in connection with transplantation;*

In this respect the official Explanatory Report²¹ of the **Additional Protocol on transplantation of organs and tissues of human origin** indicated that Article 21 should be interpreted in the following manner:

113. It states in particular that the human body and its parts must not, as such, give rise to financial gain or comparable advantage. Under this provision, organs and tissues should not be bought or sold or give rise to direct financial gain for the person from whom they have been removed for a third party. Nor should the person from whom they have been removed, or a third party, gain any other advantage whatsoever comparable to a financial gain such as benefits in kind or promotion for example. A third party involved in the transplant process such as a health professional or a tissue bank may not make a profit from organs or tissues or any products developed from them (but see paragraph 115 below).

114. However, Article 21 states that certain payments that a donor may receive are not to be treated as financial gain within the meaning of this article. Essentially, apart from the last indent, these provide examples of expenses that may be incurred during or as a result of donation or other parts of the transplant process. This paragraph does not make exceptions to the principle laid down but gives examples of compensation to avoid possible financial disadvantage which may otherwise occur. In the case of the donor it allows for compensation for loss of earnings and other justifiable expenses.

115. The second indent of the first paragraph refers to payment of a justifiable fee for medical or technical services performed as part of the transplant process. Such acts might include the cost of retrieval, transport, preparation, preservation and storage of organs or tissues, which may legitimately give rise to reasonable remuneration.

On 1 July 2003, Belgium began providing full reimbursement for up to six cycles of IVF. An article by Pennings and Devroey (2006) in **Reproductive Biomedicine Online** compared the numbers of egg sharers before and after this date. The main finding was a drop of approximately 70%. This seems to confirm the

to be used for the same purpose as the entire organ in the human body. After receiving EU legal advice it is also thought to cover human embryos but only with respect to their quality and safety aspects.

¹⁸ Came into force on the 7th of April 2006.

¹⁹ The provisions of this Protocol, applicable to tissues, also apply to cells, including haematopoietic stem cells. However, the Protocol does not apply (1) to reproductive organs and tissue (comprising ova, sperm and their precursors); (2) to embryonic or foetal organs and tissues including embryonic stem cells; (3) to blood and blood derivatives.

²⁰ Additional Protocol to the European Convention on Human Rights and Biomedicine concerning transplantation of organs and tissues of human origin (ETS No. 186):
<http://conventions.coe.int/Treaty/Commun/QueVoulezVous.asp?NT=186&CM=8&DF=12/10/04&CL=ENG>

²¹ Explanatory Report²¹ of the Additional Protocol on transplantation of organs and tissues of human origin:
<http://conventions.coe.int/Treaty/en/Reports/Html/186.htm>

belief that the majority of egg sharers donate to obtain a benefit in kind and because of restricted financial means.

Thus, the SCHB notes that, in the light and in the spirit of the legislation mentioned above, there should never be any risk of a donation taking place (even once) as a result of compensation being considered by a person as a financial incentive or *“any other advantage whatsoever comparable to a financial gain such as benefits in kind or promotion for example”*. In other words, no compensation should ever be given to a donor if he or she can perceive this compensation as a financial incentive to donate.

For the same reasons, any benefit in kind, such as the reduction of fertility treatment costs encouraging the donation of eggs for research or the treatment of others would be completely unethical.

The SCHB is, therefore, of the opinion that egg sharing amounts to coercion (albeit an indirect form of coercion), and that the alleged harm is likely or significant enough to amount to a sufficient and compelling reason to prohibit egg sharing.

The SCHB is therefore in agreement with the statement of the 1998 HFEA consultation on the **Implementation of Withdrawal of Payments to Donors**: *“In order to ensure beyond doubt that donors were not motivated by financial gain, it would be necessary to abolish all payments and benefits (other than necessary expenses).”*²²

If you answered ‘No’ for both sperm and egg donors above > click ‘Next’ at the bottom of this page and proceed to end of questionnaire

If you answered ‘Yes’ for either sperm or egg donors please tell us more about this > go to question 4b

4b) In practice, what do you think benefits in kind should include (select more than one if necessary)?

Sperm donors

- Reduced waiting time for treatment
- Reduced price or free fertility treatment
- Reduced price or free storage of sperm
- Other (please specify)

Egg donors

- Reduced waiting time for treatment
- Reduced price or free fertility treatment
- Reduced price or free storage of eggs
- Other (please specify)

4c) In practice, do you think the value of benefits in kind should be limited and if yes, how should it be limited?

Sperm donors

- No, the value should not be limited
- Yes, the value should not exceed other types of compensation (expenses, loss of earnings, routine disruption and discomfort)
- Yes, the value should not exceed that of an average cycle of fertility treatment, eg, £5000 for a cycle of

²² The Regulation of Donor-Assisted Conception, HFEA, 2003, paragraph 8.

IVF

X Yes, the value should be limited (please specify an amount in £)

Egg donors

No, the value should not be limited

Yes, the value should not exceed other types of compensation (expenses, loss of earnings, routine disruption and discomfort)

Yes, the value should not exceed that of an average cycle of fertility treatment, eg, £5000 for a cycle of IVF

X Yes, the value should be limited (please specify an amount in £)

Family limit

Within a family, who can donate?

Donation between family members – for example egg donation to a sister – is relatively common in the UK and is thought to be increasing.

Family donation includes many different types of donation relationships, some more common than others. From what we know, donation between sisters, cousins and brothers are the most common donation relationship. But we have had reports of:

- mother to daughter (usually when the daughter is known from a young age to be infertile);
- daughter to mother;
- niece to aunt;
- father to son, son to father.

Some people think donation between different generations heightens social and ethical concerns because they are a further step removed from the types of relationships that could occur 'naturally' – ie, without the aid of assisted reproductive technology.

Why donate sperm and eggs to family members?

Receiving sperm or eggs from a family member is an attractive option for some as it:

- maintains a genetic link between the donor recipient and their subsequent child;
- can avoid long waiting lists at the fertility clinic;
- overcomes the uncertainty of using an anonymous donor in treatment.

It can also raise additional ethical and social issues, such as:

- confusing genetic/social relationships for children (if a woman donates an egg to her sister, she will be the genetic mother and social aunt of any child born as a result);
- how to tell the child about their origins and managing non-traditional relationships throughout life;
- the potential for pressure to be placed on donors by family members to give their eggs or sperm.

Creating embryos between family members – how it works

Potentially, there are two ways to conceive through family donation:

- **Creating an embryo with eggs and sperm from family members who are genetically related**
For example: Rita and Paul are first cousins. Rita's husband Mike cannot produce his own sperm, so

Paul offers to donate his sperm to Rita and Mike to help them have a baby. They use Paul's sperm and Rita's eggs in the treatment and Rita falls pregnant. Here, the sperm and eggs of male and female cousins (Rita and Paul) are used to create a baby.

- **Creating an embryo with eggs and sperm from family members who are not genetically related**

For example: Wil's brother Bob cannot produce his own sperm. Wil donates sperm to Bob and his partner Helen. Bob and Helen use Wil's sperm and Helen's eggs to conceive. Here, the sperm and eggs of two genetically unrelated people (Wil and Helen) are being used to create a baby.

Is family donation legal?

The mixing of sperm and eggs between genetically related people is more controversial than between genetically unrelated people. This is because it involves mixing family genes which creates a risk of disorders for the future child. The mixing of donated sperm and eggs between relatives is legal, although no mixing between close relatives (eg brother and sister or father and daughter) has known to have occurred. A clinic would not allow such a donation, due to the strict legal duty they have to prevent treatment which could result in serious harm to any future child.

What is the HFEA's current policy on family donation?

The HFEA does not currently have specific rules on donation between family members. The HFEA does not say who can donate to who or what special considerations clinics take into account when they are presented with requests for donation between family members. Instead, the HFEA issues general guidance on donation which covers the welfare of the future child, consent and counselling.

HFEA guidance on donation - Code of Practice

Clinics which see a lot of these types of donation requests have developed models of good practice. For example, some clinics require both donors and recipients to undergo counselling, both separately and together, before treatment commences. This ensures that both parties are comfortable with the arrangement and have fully thought through the potential consequences.

Some clinics have introduced 'pooling schemes'. If a brother, for example, wishes to help his infertile sister, but cannot donate to her directly, he could donate to an unknown woman and, in exchange, his sister would be prioritised for sperm from an unknown donor.

How should family donation be regulated?

There are a number of possible options for the regulation of family donation:

Bans

- The HFEA could ban the mixing of sperm and eggs between close relatives (those who would otherwise be banned from having sex with each other), or
- The HFEA could only ban the mixing of sperm and eggs between close genetic relatives (incest laws are broader than genetic relatives, for example it is illegal for an adoptive father and daughter to have sex together) as only the mixing of their sperm and eggs poses a medical risk to the future child.

Additional guidance to clinics

- The HFEA could issue best practice guidance to clinics, or
- The HFEA could ask clinics to have a strategy in place to handle cases of family donation; or
- The HFEA could instead encourage the counselling profession to issue best practice guidance to clinics.

Leave things as they are

- The HFEA could leave things as they are, as clinic staff have been dealing with family donation for several years with no reported problem and no mixing between close relatives (eg brother and sister or father and daughter) is known to have occurred.

Questions:

1. What do you think should be the maximum number of families that can be created using one donor's sperm or eggs?

- X A limit lower than 10 families (please specify a number):
- A limit of 10 families
- A limit of more than 10 families (please specify a number)
- No family limit

It's important for us to understand the reason for your answer above. Please give a brief explanation below:

SCHB Comment:

The SCHB is of the opinion that until the following questions are answered satisfactorily concerning:

- (1) the important bonds that exist between the biological parents and the child, and
- (2) the unease the general population has concerning donor insemination,

then the possibility of promoting donated gametes in order to address infertility should not be envisaged.

Family donation

What is the current policy on the family limit?

At present in the UK:

- Clinics must ensure that sperm or eggs from a donor are used to create no more than 10 families.
- Donors can specify a lower limit if they wish.
- There is no limit on the number of children within each family.
- Sperm imported from abroad may be used for more than 10 families worldwide (ie, the family limit only applies in the UK).

The HFEA set a family limit to minimise the possibility of two children from the same donor eventually having a sexual relationship with each other without knowing they are genetically related. This is a concern both because of the emotional effect of the couple discovering they are related and because of the increased risk of them having children with health problems.

The current family limit is also based on the perceived social and psychological interests of donor conceived people and their parents in maintaining a relatively small number of siblings.

In practice, the family limit is only relevant to sperm donation. Sperm can be donated relatively easily and in larger quantities than eggs and it can be frozen and moved around the country efficiently. Because of the medical intervention associated with egg donation and the relatively low number of eggs that can be collected each time, women are unlikely to donate their eggs more than a few times.

How do fertility clinics keep to the family limit?

Keeping within the family limit is straightforward if a clinic recruits donors and uses the sperm or eggs for their own patients. However, some clinics – particularly sperm banks - recruit many donors and pass the sperm onto other clinics within the UK. These recruiting clinics are responsible for ensuring that the 10 family limit is not exceeded and have procedures in place to do so, based on guidance in our Code of Practice. We know that there are some operational difficulties with how clinics monitor and enforce the limit. This will be addressed with clinic staff and other stakeholders alongside this consultation. Addressing these difficulties may help clinics to maximise the use of donations.

What do we know about donors and how their donations are used?

The majority of egg and sperm donors registered since the removal of donor anonymity in 2005, are happy for up to 10 families to be created from their donation.

In 2008:

- around 80% of newly registered donors did not specify a lower limit
- 16% of newly registered donors limited the use of their donation to just one family - this is likely because they donated to help a friend or family member
- the proportion of egg and sperm donors limiting their consent follows a similar pattern.

The majority of donation clinics think that most donors (apart from those donating to a friend or family member) would be prepared to donate to more than 10 families, a view supported by the HFEA's own interviews with a small number of donors.

Is the family limit ever reached?

Less than 1% of donors create 10 families. On average sperm donors create one or two families, with one or two children in each family (based on donors who are happy for 10 families to be created, who registered between 2006 and 2008).

The number of families created may be affected by the following:

- 19% of sperm donors registered with the HFEA are never used, perhaps because donors withdraw their consent or patients do not choose them;
- a lot of donor sperm does not result in pregnancy. The success rates for IVF and DI (donor insemination) are around 32% and 14% respectively for women under 35 (and less for older women);
- on average, clinics use sperm from one donor to treat only six patients, with an average of two cycles of treatment per patient;
- sperm is sometimes imported from overseas sperm banks to treat specific patients (around 20% of sperm donors) - these donors may be happy for 10 families to be created with their sperm, but their sperm may only be imported for one patient.

Should the family limit be changed?

The majority of sperm donations rarely result in 10 families. Any rise in the family limit would unlikely lead automatically to an increase in donor supply unless operational difficulties are addressed.

There are two main considerations when thinking about whether the limit should be raised, lowered or kept the same:

- the risk of two children from the same donor having a relationship with each other without knowing they are genetically related;
- the psychological effects on donors and donor conceived people.

Risk of two children from the same donor having a relationship with each other without knowing they are genetically related

It is possible for anyone, from the age of 16, who intends to enter into an intimate physical relationship, marry or enter into a civil partnership, to find out, from the HFEA, whether they are genetically related to one another. But this depends on the person knowing or suspecting they are donor conceived.

The family limit is important to minimise the risk of two people born from the same donor, who do not know they are donor-conceived, having a relationship with each other.

Other countries approach this risk in a different way:

In the Netherlands there is a 25 children limit based on the principle that children from sperm donors may have, at most, a similar risk as children in the general population for having a relationship with a naturally conceived unknown half-sibling. This was calculated on the basis of specific data about the Dutch population and included figures on chance of having an unknown half-sibling, the average number of children parents have, the chance for donor conceived children to have children themselves, age and geographical factors

determining the likelihood of meeting a partner in the district of a donor bank, and the size of the population being served by the donor bank

The American Society for Reproductive Medicine recommends that the limit should be based on the population from which the donor is selected and the catchment area that might be served by a particular donor. For example, in a population of 800,000 a donor should be used for no more than 25 pregnancies to avoid an increased risk of unintentional relationships between two genetically related individuals.

The risk depends on:

- how widely sperm from one donor is used (ie, if all samples are used at one clinic or at a number of clinics across the UK);
- the population of the area where the donor treatment is provided;
- how mobile the population is (sperm from one donor may be used just at one clinic in a low population area, but this only presents an increased risk if the children born from that donor reside in the same area).

Outcomes of treatment with donor sperm in the UK, from donors who have reached the 10 family limit in the last few years, indicates that:

- families created from the same donor live a median of 36 miles away from each other;
- children have been born as far as Atlanta, Calvados, Florida, Islamabad and Sydney;
- the median number of families per town is 2.7 and a maximum of five families live in the same town (by which we mean the same town as where the donation took place) – there are three such cases: London (population over seven million), Bristol (population 421,300) and Glasgow (population 580,690);
- it is not known whether children from these families will remain in the same place as they get older.

It appears that risk of unintentional relationships between donor conceived children is low, and it may also be reduced with increased openness around donor conception. It is likely that the risk would probably remain low unless the limit was increased greatly.

Psychological effects on donors and donor conceived people

Some people feel that it is in the interests of donor conceived people (and their parents) to have a small number of genetic siblings and that the limit should be in line with the number of people a donor can have a meaningful relationship with. This is based upon the assumption that all people born in these circumstances know that they are donor-conceived.

As part of this consultation we will aim to find out more about the impact of donor conceived people having multiple siblings and the impact this has on donors' own children.

Questions:

1. Which of the following approaches do you think we should take towards mixing sperm and eggs between family members? (Please select one option)

- No further regulatory control
- X Prohibit the mixing of gametes between close relatives who are either genetically related or unrelated
- X Prohibit the mixing of gametes between close relatives who are genetically related

2. Which of the following approaches do you think we should take towards donation between family members? (Please select more than one if necessary)

- No further regulatory control
- Issue guidance to clinics on handling donation between family members
- X Invite the counselling profession to produce guidance for clinics on handling donation between family members
- X Require clinics to have a strategy in place to deal with cases of donation between family members

It's important for us to understand the reason for your answer above. Please give a brief explanation below:

SCHB Comment:

As noted in an earlier comment, the SCHB is of the opinion that the possibility of promoting donated gametes in order to address infertility should not be envisaged until two issues have been addressed:

1. the important bonds that exist between the biological parents and the child, and
2. the unease the general population has concerning donor insemination.