



A review of the HFEA's sperm and egg donation policies - 2011

(Text sourced from www.hfea.gov.uk/donationreview)

The changing landscape of donation

The ethics of sperm and egg donation capture the public imagination. The issues are rarely out of the press which is unsurprising given what donation involves: making children who will not be genetically related to their parent(s). As the fertility watchdog, it is our job to regulate sperm and egg donation and treatment. We last looked at our rules in 2005, but even in this short time the landscape of donation has changed and we want to make sure our rules are up-to-date.

To do this, we need to hear your views and understand what you think are the most important ethical principles around donation.

Many aspects of donation are beyond our remit but they impact on the areas we do regulate – namely compensation for donors, the family limit and donation within families.

Find out about the wider context of donation to inform your response to our consultation and then have your say by responding to our questionnaire.

The wider donation context:

- Social and technological changes
- Shortages of egg and sperm donors
- Possible solutions to the donor shortage
- The ethical principles and concerns of donation

Social and technological changes

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.

This mirrors 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.

Text sourced from www.hfea.gov.uk/donationreview

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

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 open up a number of fertility options for people who a generation ago would not have had the choice.

Shortages of egg and sperm donors

Demand for donor treatment in the UK is greater than the supply of donors. Although this has been an issue since we were established in 1991, it is often argued that the shortage was exacerbated by the removal of anonymity by parliament in 2005. [link to legislative changes since 2005]

As the regulator, it is not our role to ensure the supply of donors: that is for fertility clinics. However, this shortage impacts on aspects of donation where we do have some control: 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.

Long waiting times for suitable donors 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.

However, people conceived in clinics abroad will not be able to benefit from the safeguards which exist in the UK, including the right to information about their donor and siblings.

Rising number of online donation sites

There has been an emergence of web-based matching services where donors advertise their willingness to donate to potential recipients.

We are concerned about the safety of patients and the quality of care if donation does not take place within a licensed clinic. There are 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 trends

Infertility affects around 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 are having donor insemination, the demand from couples with an infertile male partner has decreased over the past decade. This is because of ICSI (intracytoplasmic sperm injection) which has become widespread in treatment since it was introduced in 1992. ICSI involves the injection of one sperm into an egg, so it can be used when men 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 we need 500 sperm donors a year to meet demand in the UK.

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. (Link to NGDT)

Improving the current system

Many people make initial enquiries about donation, but they don't 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.

Our 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 us that the current system for compensation (INSERT link to compensation background info) 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.

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. (INSERT: link to family limit section)

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.

Outlined below are the principles we think 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 donor conceived 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 not full human status) and should be afforded legal protection; in part, it is the role of the regulator to ensure this protection is provided.

We would like your views about the changing landscape of donation in the UK and the most important principles engaged in donation.

Compensation, reimbursement and benefits in kind

What do you think about compensation for sperm, egg or embryo donors?

Should donors be compensated for the time and inconvenience involved with the process of donation? If so, **what is a fair amount**? Is the current system working well or does it need to be changed?

We'd like to know what you think a fair and moderate compensation scheme looks like and what ethical principles the scheme should be based on.

Before completing our questionnaire, you can read up on the background issues to help you form your own view.

Donor compensation: the issues

- What is the current policy on donor compensation?
- What changes would be possible within the law?
- What does sperm and egg donation involve?
- What does egg sharing involve?
- What motivates people to donate?
- What principles should we keep in mind?
- How could the current system change?

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.

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

Our 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



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requirements as UK donors (eg, screening tests, identifiability), including the amount of compensation for expenses and loss earnings that they can receive.

We 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.

Read more about current policy [link to Direction 0001 and guidance notes 12 and 13 of Code of Practice.]

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.

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.

When we last considered donor compensation, in 2005, we 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 we do not currently allow donors to be compensated for the inconvenience associated with donation.

We are seeking your views on whether these policies should be changed.

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.

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Occasionally there can be a potentially dangerous over-reaction to the hormones, called ovarian hyperstimulation syndrome. This occurs in about 1% of egg donation cycles (according to one US study) and this figure is higher for fertility patients.

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 egg 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 they may not.

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Egg sharing differs from egg donation, as it is an option for women undergoing their own treatment. Some believe the benefits in kind 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. However, these concerns have not been borne out in the small number of studies on the experience of 'unsuccessful' sharers. Overall, the limited knowledge about egg sharers' experiences of treatment suggests that they feel adequately prepared and the majority are satisfied with their treatment.

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.

Comments from clinicians included:

"I don't think that most donors are doing it for the money but we would probably get more donors if they felt valued and the reimbursement was more proportionate."

And

"The amount is part of the whole jigsaw of what encourages a donor to donate."

During this consultation, we will be talking further to donors, recipients and clinics about what motivates people to donate and what might encourage more people to do so.

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.

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?

Our 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't prove their loss of earnings to the clinic), but also that the system is more complex than it needs to be.

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Some clinic staff tell us 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. We'd like to know what you think the ideal compensation scheme would look like and what principles such a scheme would be based on.

Family donation

What are your thoughts on sperm and egg donation between family members? How should this form of donation be regulated? We want to know what you think.

Before responding to our questionnaire, discover the issues and the ethics behind this type of donation.

Family donation: the issues

- Within a family, who can donate?
- Why donate sperm and eggs to family members?
- Creating embryos between family members – how it works
- Is family donation legal?
- What is our current policy on family donation?
- How should family donation be regulated?

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

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- can avoid long waiting lists at the fertility clinic
- overcomes the uncertainty of using an unknown 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 our current policy on family donation?

We do not currently have specific rules on donation between family members. We don't 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, we issue general guidance on donation which covers the welfare of the future child, consent and counselling. [link to COP8 guidance on donation]

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

- We could ban the mixing of sperm and eggs between close relatives (those who would otherwise be banned from having sex with each other); or
- We 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

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

Leave things as they are

- we 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.

The various different options are laid out in the questionnaire – please tell us what you think.

Text sourced from www.hfea.gov.uk/donationreview

Family limit for donated sperm and eggs

Do you think the number of families created with sperm or eggs from a single donor should be capped? **Should the current limit of 10 families be raised? Or should it be lowered?**

Before **answering our questionnaire**, you can read up on the background issues to help you form your own view.

Family limit – the issues

- What is the current policy on the family limit?
- How do fertility clinics keep to the family limit?
- What do we know about donors and how their donations are used?
- Is the family limit ever reached?
- Should the family limit be changed?

What is the current policy on the family limit?

- 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).

We set a family limit to minimise the possibility of two children from the same donor having a 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.

Text sourced from www.hfea.gov.uk/donationreview

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 our 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.

Text sourced from www.hfea.gov.uk/donationreview

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.