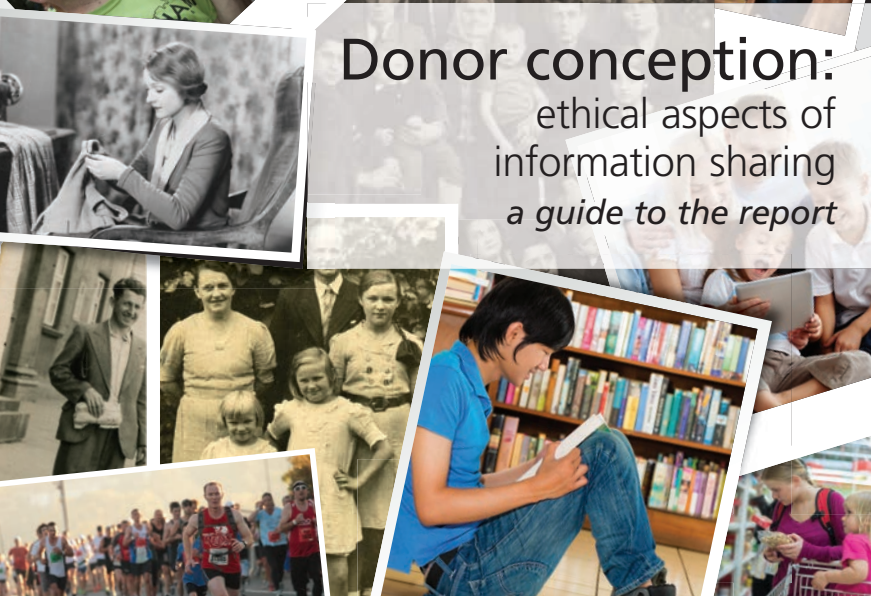




**Donor conception:**  
ethical aspects of  
information sharing  
*a guide to the report*

**NUFFIELD  
COUNCIL ON  
BIOETHICS**



In April 2013, the Nuffield Council on Bioethics published a report, *Donor conception: ethical aspects of information sharing*. The report considers the interests of the many parties affected by donor conception (donor-conceived people, parents, donors, and all their wider family and social networks), and the role of the state in promoting or encouraging particular approaches to the providing and sharing of information. This guide sets out some of the conclusions and recommendations that are discussed in more detail in the report.

The report was produced by an expert Working Party. In coming to its conclusions, the Working Party invited contributions from a wide range of people, including donor-conceived people, parents, donors, professionals involved in fertility services, professionals working with donor-conceived people and families, those involved in regulating donation, professionals involved in genetic medicine, academics and researchers, faith groups, and members of the wider public.

Throughout this guide we use the word 'parents' inclusively, to mean either a single parent, or parents. References to 'donation' include both gamete and embryo donation.

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# Families created through donor conception

The donation of eggs or sperm ('gametes') or embryos makes it possible for many people, who would otherwise not have been able to have children, to create families of their own.

People may consider using donor gametes or embryos to conceive because they have fertility problems, or because they want to avoid passing on a serious genetic condition to their child. Donor gametes or embryos may also be used to help create 'non-traditional' families, such as those created by same-sex couples or single people.

Since the introduction of regulation in 1991, over 35,000 donor-conceived children have been born in the UK as a result of their parents having treatment in a licensed clinic. These figures do not include those donor-conceived people born as a result of unlicensed sperm donation (sperm donation arranged privately without involving a clinic), or of treatment in overseas clinics.

Some donors ('known donors') choose to donate in order to help a friend or relative have a child. Others ('unknown donors') decide to donate to help someone they don't know. Sometimes donors may themselves be having fertility treatment – for example in 'egg-sharing' arrangements, women donate some of their own eggs in return for free or reduced-cost treatment.

Families come in all shapes and sizes, and include single parent and adoptive families, as well as families with step-children. While 'blood' relationships are seen as important in families, so too are relationships created through love, care and nurture.



# Law and practice in the UK

The parents of a child born as a result of donated gametes or a donated embryo are the child's legal parents from birth, as long as they had treatment in a UK licensed clinic.

## Information about donors

Donors who donate through a licensed clinic are not legally considered to be a parent and have no parental rights or responsibilities in respect of any children born as a result of their donation.

However, information about donors is collected by a regulatory body, the Human Fertilisation and Embryology Authority (HFEA), so that this can be provided later to donor-conceived people on request. Brief descriptive information such as the donor's eye and hair colour is always collected, and donors are also encouraged, although not required, to provide biographical information about themselves, for example in the form of a 'pen portrait'. They are also encouraged to write a message for the future donor-conceived person or persons. This information (in an anonymised form) is also available to parents so that they can share it with their children during childhood, if they wish.

Unless a 'known donor' is used, parents and their donor-conceived children will not know the identity of the donor during the donor-conceived person's childhood. However, as a result of a change in the law in 2005, in the future donor-conceived adults will be able to find out the identity of their donor if they wish. The amount of information available will depend on when they were born because the change in the law does not apply to past donations.

|   |   |
|---|---|
| <b>People conceived with gametes donated after April 2005</b>                   | At age 18 can obtain identifying information about the donor.   |
| <b>People conceived with gametes donated between August 1991 and April 2005</b> | No identifying information available unless the donor chooses to become identifiable, although the HFEA can supply non-identifying information.   |
| <b>People conceived before regulation began in 1991</b>                         | No access to any information via the HFEA, although limited information may be available from clinics.<br>The voluntary Donor Conceived Register offers the possibility of being 'matched' through DNA testing if donor and donor-conceived person both choose to join. Matches between donor-conceived siblings are also possible. |

## Telling people they are donor-conceived

In the past, most clinics encouraged prospective parents to forget about their treatment as soon as it was over. It was thought to be unnecessary, and potentially harmful, to tell children about how they were conceived. However, social and professional attitudes have changed, and now parents are strongly encouraged to tell.

Some people feel that the state should do more to make sure that donor-conceived people know of the circumstances of their birth, so that they are in a position to ask for the information held on their behalf by the HFEA. For example, birth certificates could include a note that the person is donor-conceived. It has also been suggested that the law should change retrospectively so that all donor-conceived people, not just those born after 2005, can find out the identity of their donor.

The UK Government has not accepted the need for any further change in the law. There are significant differences in approach to these issues across Europe and around the world. Many countries, for example, think it is important for donors to remain completely anonymous.

### Support

Under UK law, potential donors and prospective parents must be given a “suitable opportunity” to receive counselling about the implications of donation or treatment before they decide to go ahead. Clinics vary in how much they encourage people to take part in counselling sessions.

Donor-conceived adults applying to the HFEA’s Register for information about their donor should also be given a “suitable opportunity” to receive counselling about the implications of this, before the HFEA provides the information.

However, at present there are no dedicated specialist services for those in this position.

Apart from the support provided by clinics at the time of donation and treatment, the main sources of support for people affected by donor conception, particularly for families, are voluntary sector organisations such as the Donor Conception Network and the National Gamete Donation Trust.





## Medical information and family history

Potential donors undergo careful medical screening before they are allowed to donate. However, information about the medical history of the donor is still a source of concern for some donor-conceived people and their parents.

In most cases, information about a donor's personal and family medical history will not, in fact, be medically useful for the donor-conceived person. This is because of the screening and assessment that potential donors undergo before they are accepted as donors, and because family histories of particular medical conditions often have 'low predictive value' – they play only a very small part in determining whether or not a person develops a particular condition.

However there are some medical conditions that are strongly heritable: if the donor has the condition, then their offspring are also likely to develop it. Current guidelines make clear that potential donors who are known to have a strongly heritable condition – or have a close family member with such a condition – are not allowed to donate.

Occasionally there may be something in the donor's own medical or family history that is not serious enough to prevent the donor from donating, but could still be relevant information for the donor-conceived person to know for their own health care. More guidance is needed for health professionals as to what information might be relevant to the future health care of the donor-conceived person so that, if useful, information can be passed on appropriately.



Also, some heritable conditions only appear relatively late in life ('late-onset' conditions). If a donor is diagnosed with a serious strongly heritable condition after donation, it is important that this information can be passed on to the donor-conceived person and their family. Similarly, if a donor-conceived child is born with a serious inherited condition, it is important that there is a way of passing this information back to the donor.

## We conclude...

- It is important that all health professionals, in their day-to-day practice, ask themselves why they are seeking information about a person's family history, and only do so where this might genuinely be useful for the person's care.
- Parents need clear information about the screening procedures that the donor has undergone, so that they can be reassured that the risk of their child developing a serious strongly heritable condition is very low. Where no additional information about the donor's health is available, it should be clear that this is because there is no relevant information to provide – not because the donor was unwilling to provide it.
- Medical information about the donor or the donor's family is only useful if it is likely to have an effect on the donor-conceived person's health or health care, and should not be made available otherwise.



# Knowledge of donor conception and access to donor information

Evidence about the views and experiences of donor-conceived people, parents, and donors with respect to the sharing of information is patchy, but some tentative conclusions can be drawn. Inevitably though, some things cannot be known – in particular the views of those who do not know that they are donor-conceived.

## Disclosure in donor conception

Until relatively recently, parents were advised not to tell their children that they were donor-conceived, and most parents followed this advice. However, the number of parents who do share this information with their children is now increasing. The latest figures suggest that over three quarters of parents intend to tell their child about how they were conceived, although not all actually go on to do so. Solo mothers and same-sex couples are more likely to tell their children about the way they were conceived than heterosexual couples.

Both ‘disclosing’ and ‘non-disclosing’ families seem to function well up to early adolescence. Not much is known about families with older children.

Children who are told that they are donor-conceived when they are very young appear to absorb this information without difficulty. However, some adults who found out later in life that they were conceived through sperm donation have reacted negatively. It is not known how often people discover in unplanned circumstances that they were donor-conceived.

Parents who do tell their children about the way that they were conceived rarely appear to regret this decision. Most non-disclosing parents also appear not to regret their decision, although some non-disclosing parents have described finding ‘secrecy’ in the family to be a burden, and some wish that they had disclosed when their child was younger.

The evidence points to the conclusion that it will usually be better for children to be told, by their parents and at an early age, that they are donor-conceived. However, every family is different and there can be no hard and fast rules.



## Access to information

Some donor-conceived people are interested in knowing more about their donor. Their reasons include:

- finding out what kind of person the donor was, and why they chose to donate
- finding out whether they look like their donor, or have characteristics in common
- obtaining medical or family history information about their donor

Information about the donor may help some donor-conceived people fit their donor into their existing life story. The evidence in this area is currently limited to those conceived through sperm donation – little is yet known about the experiences of adolescents or adults conceived through egg or embryo donation.

Some donor-conceived people (and also some parents of younger children) are very interested in contacting both their donor and any donor-conceived siblings. Most people who search for their donor do not wish to form a 'parental' relationship with them. However, some do wish to form a family-like relationship with their donor-conceived siblings. Experiences of contact between donor-conceived people, donors, and donor-conceived siblings are generally reported to be positive, although not much is yet known about how such contact develops over time.

When the law changed in 2005, so that in the future donor-conceived adults would be able to find out the identity of their donor, there were concerns that this would prevent people from offering to be donors. However, clinics that actively recruit donors do now appear to be successful in finding a sufficient number of donors.



# Ethical considerations

When thinking about the issue of information sharing between people affected by donor conception, we should start with a focus on *people and relationships*.

## Interests and rights

Everyone involved in donor conception has interests in how information is shared. These interests may include:

- the importance placed by many on knowledge of (and contact with) people with whom they have close biological links
- the value placed on having children and bringing them up without undue interference by others
- the privacy associated with personal information
- the importance placed on keeping promises and honouring contracts

These interests are often expressed in terms of 'rights'. However, by using instead the language of 'interests', we can first think about what we know about those interests, and then consider separately whether others have responsibilities to make sure those interests are protected and promoted.

It is not the role of this Working Party to make any judgment as to how important these interests ought to be in any given situation. However, the extent to which these interests are widely shared is relevant to the degree of responsibility that they may create in others. In turn, this is relevant in determining what action may be demanded on the part of public bodies to protect or promote these interests.

## Values

These interests arise in the context of relationships, and values that are widely regarded as important in contemporary family relationships in the UK include trust and honesty. 'Openness' in families is also valued by many. Openness, however, is not necessarily the same as honesty. In particular, choosing not to disclose private information is not usually considered to be dishonest.

Difficulties arise when talking about openness in donor conception because information may at the same time be *both* private information about the parents or donor, and information about the donor-conceived person.

## We conclude...

Openness about donor conception should not be regarded as valuable in itself, but rather as important in so far as it improves family relationships, and adds to the well-being both of parents and of donor-conceived people.



## Weighing interests

Where interests come into conflict, the interests of one person in the relationship (whether donor-conceived person, parent or donor) should not automatically be given priority over another. The interests of the different people involved in the relationship always have to be weighed.

In practice, it will fall to the parents of donor-conceived children to weigh the interests in any particular decision regarding disclosure, unless exceptionally there is a serious risk of harm to others. Such power on the part of parents should be exercised responsibly.

## Responsibilities

The parents of donor-conceived children have a responsibility to:

- avoid, where reasonably possible, any harmful consequences that may follow for their children from the fact that they were donor-conceived
- be willing to consider the evidence about the impact of disclosure on family relationships (see pages 6 and 7)
- be willing to engage with professional support, when determining what is likely to be best for their child

Donors have a responsibility to:

- think carefully about the consequences for themselves, for their own families, for the recipients of the donated gametes, and for the resulting person

Donor-conceived people have a responsibility to:

- do their best to understand the reasons why their parents chose to create a family through treatment with donated gametes, and why they made the decisions they did about disclosure

If the question of contact arises, each party has a responsibility to be sensitive to the needs of the other, including the potential impact on the other's family.

# Ethical considerations (continued)

## Responsibilities of professionals

Health professionals who provide fertility services, and those who regulate these services, also have responsibilities. These include:

- taking account of the welfare of any future child, before fertility treatment is provided
- providing non-judgmental support to prospective parents and potential donors
- taking their role as an 'information collector/information provider' seriously

When taking account of the welfare of any future child, professionals may only justifiably refuse treatment if there is a risk of significant harm or neglect to future children. There is not sufficient evidence about the risks of harm to donor-conceived people who do not know they are donor-conceived (and who may or may not find out inadvertently later in life) to justify a refusal to provide treatment to prospective parents who do not propose to inform their child.

## The stewardship role of the state

The state has a 'stewardship' role in providing conditions that support and enable people in making their choices. In the UK, the state has endorsed and encouraged donor conception as a means of creating a family. It should also be willing to take action to promote the welfare of people affected by donor conception, where this can be achieved without unreasonably interfering with the interests of others. This should include encouraging a social environment where the creation of families through donor conception is seen as unremarkable: as one way among a number of others of building a family.



# Implications for regulation in the UK

The Working Party took the approach that, wherever possible, measures that aim to support, encourage and empower those making decisions are preferable to measures that limit or remove choice.

On policy affecting prospective parents, we conclude...

- It would be inappropriate to introduce any form of additional 'screening' of prospective parents in connection with their plans to tell, or not tell, their children that they are donor-conceived.
- It is not the role of the Government to intervene (for example through indications on the birth certificate) to ensure that all donor-conceived people know of the circumstances of their conception.
- As a matter of good professional practice, clinics should present counselling sessions as a routine part of the series of appointments that prospective parents attend before beginning treatment with donated gametes, in order to ensure the best possible support for those contemplating treatment.
- Information should be provided in a non-judgmental and understandable way that helps prospective parents to engage with the issues of disclosure and non-disclosure.
- Clinics should routinely offer parents an additional support session later in pregnancy or after the birth of the child.
- The option of anonymous donation should not be reintroduced.





## Implications for regulation in the UK (continued)

### On policy affecting parents and donor-conceived people during childhood and into adulthood, we conclude...

- Information about donor conception, and about organisations that support donor-conceived people and their families, should be included in materials routinely available to pregnant women and new parents.
- While most support for donor-conceived families is provided by the voluntary sector, the state retains a responsibility to ensure that donor-conceived people and their families are able to access the support they need.
- The state should take an active role in ensuring that an appropriate counselling and intermediary service is in place for those who, in the future, may contact the HFEA for identifying information about their donor. The future of the voluntary register connecting pre-1991 donor-conceived people and donors should be secured on a long-term basis.
- Parents should be provided with clear and comprehensible information about the significant heritable conditions that have been 'screened out' in the donor assessment process, so that they may be reassured that the risk of their child inheriting such a condition is very low.
- A multi-disciplinary group should review and update current guidance on the screening and assessment of donors. It should also recommend what further medical information about the donor (if any) should be recorded on the donor information form for the future use of the donor-conceived person.
- A clear, well-publicised mechanism should be set up so that any significant medical information that emerges after donation may be shared between donors and donor-conceived people.



## On policy affecting donor-conceived adults who do not have access to information, we conclude...

- The rules about anonymity for donors who donated before 2005 should not be changed. However, the state should take action to increase awareness among past donors that a willingness on their part to become identifiable would be highly valued by some donor-conceived adults.
- The HFEA should issue guidance to clinics setting out what is expected of them with respect to making information from pre-1991 records (where such records exist) available to donor-conceived adults.
- The HFEA should ensure – for example through the creation of a dedicated donor conception website – that factual information about the implications of seeking treatment with donor gametes abroad, or through unregulated methods, is readily accessible to those contemplating these routes to parenthood.

## On policy affecting donors, we conclude...

- Clinics should ensure that sessions with a counsellor are scheduled as part of the routine series of appointments that donors attend before deciding whether or not to go ahead with donation. Where donors have partners, clinics should strongly encourage partners to attend these sessions.
- Donors have a responsibility to think seriously about how they provide information about themselves, and clinics have a responsibility to provide appropriate support in doing so where required. Filling in the donor information form should not be seen as a brief administrative task.
- The HFEA's National Donation Strategy Group should consider further the question of how much, and what kind of, information would be likely to be helpful to the recipient parents and, in time, the donor-conceived person, so that this is routinely recorded on the donor information form. In doing so, it should draw on the expertise of a range of interested parties.



# Summary

The donation of sperm, eggs and embryos makes it possible for many people, who would otherwise not have been able to have children, to create families of their own.

In contrast with practice in the past, parents of donor-conceived children are now strongly encouraged to tell their children about the way they were conceived. Donors are also encouraged to provide biographical information about themselves, so that donor-conceived people can find out more about them, if they wish. Donor-conceived people born as a result of donations made after April 2005 will be able to contact their donor, if they wish, when they reach the age of 18.

People have different interests when it comes to sharing, or not sharing, information about donor conception. Some people feel strongly that information about a donor is essential for a donor-conceived person, while others feel information about the use of fertility services, or about the donor, is private to the parents or donor.

This report suggests what responsibilities parents, donors, donor-conceived people and health professionals have in connection with sharing information, and makes recommendations to clinics, the Human Fertilisation and Embryology Authority, and to the Government.

**Copies of the report and this guide are available to download or order from the Council's website:  
[www.nuffieldbioethics.org](http://www.nuffieldbioethics.org)**

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