

The HFEA Register

The HFEA is required by law to keep a Register of information which records details of regulated assisted reproductive treatment services in the UK. The HFEA has recorded this information since 1 August 1991, which is the date the Human Fertilisation and Embryology Act 1990 came into force. The Register contains all births resulting from treatment services, including those where donated gametes were used. The Register also records information regarding gamete donors, including a physical description, ethnicity and any additional information they wish to provide, for example occupation and interests. Since donor anonymity was removed in April 2005, the Register also records the donor's name and address. Donors who donated prior to April 1 2005 can elect to remove their anonymity retrospectively.

Government regulations introduced in 2004 specify what information the HFEA should collect about donors, and subsequently provide to donor-conceived individuals. As a result, in July 2004, the HFEA introduced new donor registration forms which ask for the following information from donors:

- the donor's parents' ethnic group
- whether the donor was adopted
- the donor's marital status
- how many children the donor already had (if applicable) and the gender of those children
- details of donor screening tests and medical history
- a goodwill message
- a description of themselves as a person (pen-portrait)¹

Current information access rights

Donor-conceived individuals, statutory access rights

Currently only donor-conceived people have a statutory right to information from the HFEA Register. Any person, born after 1 August 1991 who is over the age of 18 can contact the HFEA to find out whether they are donor conceived. The HFEA is required to provide the following information to donor-conceived individuals, aged 18 or over, upon request:

- identifying information about the donor (if donor donated after 1 April 2005 or retrospectively removed anonymity)
- anonymous information about the donor (if donated under conditions of anonymity)

The law also makes the provision that allows donor-conceived offspring under the age of 18, who intend to marry, to submit a joint application to establish whether they are genetically related.

A further important feature of the current legislation, which is retained under the revised law, is the requirement on the HFEA to provide a "suitable opportunity to receive proper counselling about the implications of compliance with the request." This requirement is in recognition of the fact that the information contained on the Register is highly sensitive and has the potential to have a significant impact on the recipient.

HFEA Policy decisions

¹ This is not an exhaustive list of the information collected on donors

The HFEA has taken the policy decision to grant some further discretionary access rights to the Register to parents of donor-conceived individuals and to donors. It has also taken the decision to allow donor-conceived people to access information about donor-conceived genetic siblings.

Discretionary access rights

Parents of donor-conceived individuals

Parents are provided with non-identifying information about the donor by the clinic when they receive treatment. Upon request, the HFEA can then provide them with the following additional information:

- number, sex and year of birth of other offspring with the same donor

Donors

Donors can receive the following non-identifying information about their donor-conceived offspring:

- number, sex and year of birth

Donor-conceived individuals

Donor-conceived individuals can receive non-identifying information about their donor-conceived genetic siblings, including the number, sex and year of birth.

Statutory information access rights, from October 2009

Donor-conceived individuals

- 16 year-olds will be entitled to:
 - non-identifying information about their donor
 - non-identifying information about donor-conceived genetically related siblings
- Anyone who intends to marry, or enter into a civil partnership, may submit a joint application to establish whether they are genetically related
- 16 year-olds who intend to enter into an intimate physical relationship can find out whether they are genetically related
- 18 year-olds will be able to find out identifying information about donor-conceived genetic siblings, if both sides consent (sibling register), and will be able to find out identifying information about their donor, if applicable.

Donors

- Will have a new statutory right to access the following anonymous information about their genetic offspring: the number, sex, and year of birth of people born as a result of their donation.
- The HFEA is expected to contact and forewarn a donor of the fact that that a donor-conceived person has requested identifying information about him or her.

Donors will be able to contact the clinic where they donated or the HFEA for this information.