

# **WHO ARE THE DONORS?**

**- An HFEA Analysis of donor registrations  
and use of donor gametes  
over the last 10 years**

## Trends in the use of donor gametes (sperm and eggs)

Donor assisted conception is a relatively small, and declining, area of fertility treatment, particularly when compared to the fertility treatment carried out ten years ago

In 2002-2003:

- **1 in 5** of licensed treatments (19.8%) involved the use of donor sperm [*compared to almost half of treatments (46.9%) in 1994-95*]
- **1 in 20** licensed treatments (4.9%) involved the use of donor eggs [*compared to almost 1 in 35 of treatments (2.9%) in 1994-95*]
- **1 in 8** children born through licensed fertility treatment (12.2%) was born from donated sperm – this is equivalent to approximately 1 in 800 of all children born in the UK [*compared to 1 in 3 (33.1%) in 1994-95*]
- **1 in 16** children born through licensed fertility treatment (6.1%) was born from donated eggs – equivalent to approximately 1 in 1600 of all children born in the UK [*compared to 1 in 22 children (4.6%) in 1994-5*]

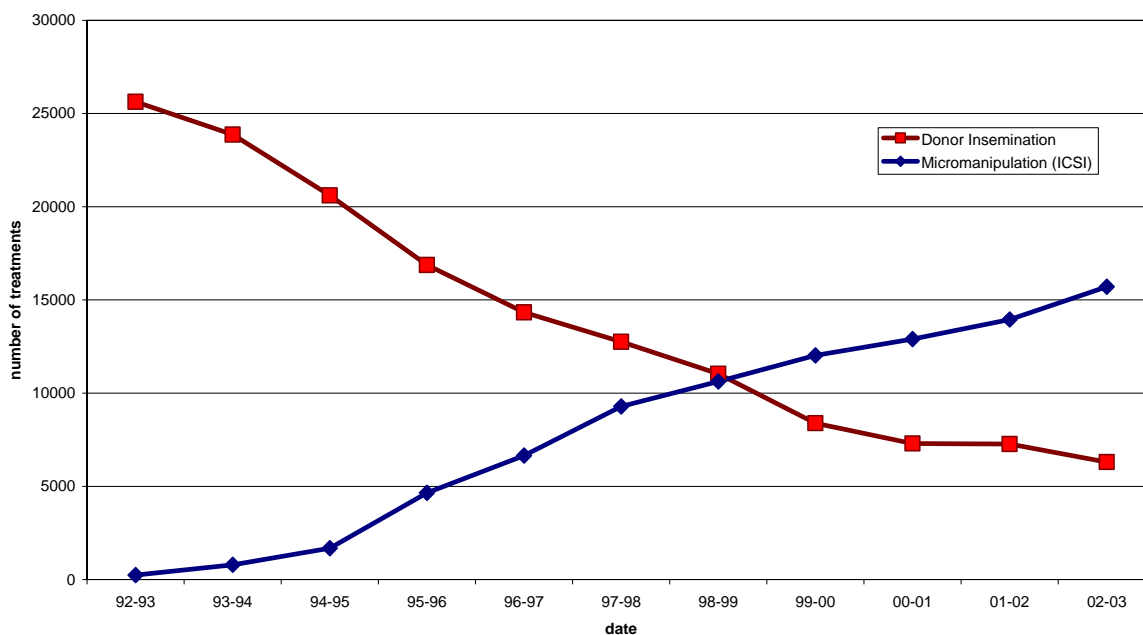
Advances in reproductive technology have meant that the demand for fertility treatment using donor gametes have declined considerably over the last 10 years.

For example, the development of ICSI (intra-cytoplasmic sperm injection) has led to a significant fall in the need for donor sperm. This involves injecting a single sperm directly into the centre of an egg which is then placed in a woman's body using conventional IVF methods.

ICSI is especially effective for men who have a low sperm count, have had a vasectomy or in cases where the sperm have difficulty swimming (low motility) or penetrating the egg. Prior to ICSI, couples where this problem had been identified would have been most likely to be treated using donor sperm. The graph below shows how the number of donor insemination treatments has fallen over the last 10 years, while the number of treatments using ICSI has risen steadily.

During 1992-93 there were more than 25,000 donor insemination treatments (using donor sperm), this had fallen to little over 6,000 treatments by 2003-03. While during this period the number of ICSI treatments had risen from nearly zero in 1992-93 to more than 15,000 in 2002-03.

DI and ICSI treatment numbers



### Treatment using donor gametes – who’s who in the system

A number of clinics across the UK have developed a particular speciality in recruiting sperm and egg donors (*referred to as the ‘recruiting centre’*) and it is common for sperm and egg donations to be made at a different clinic to the centre where a couple are receiving treatment using the donation (*the ‘treatment centre’*).

The recruitment of donors is the responsibility of recruiting centres, working within the law (the Human Fertilisation and Embryology Act 1990) and the detailed guidelines produced by the HFEA.

A national charity called the **National Gamete Donation Trust (NGDT)** exists to encourage people to come forward as donors, encouraging the supply of donated sperm, eggs and embryos and acts as a central reference point for donors, recipients and health professionals.

The **HFEA**, as fertility regulator, acts to ensure that donation and treatment using donor sperm eggs and embryos is carried out in a safe and appropriate way. Our role is also to make sure that the system is as simple and easy to administer as possible. We are also required to keep details of every donor and every treatment using donor eggs, sperm or embryos (*see below*). The HFEA has no responsibility for the supply of donor gametes.

## Information about donors

Since 1 July 1991, when the formal UK fertility regulation system was set up, details of all sperm, egg and embryo donors must be registered with the HFEA.

The HFEA's Register has been in place since the HFEA was set up in 1991 and contains information about all sperm, egg and embryo donors. Prior to April 2005, in accordance with the HFE Act 1990, people were permitted to ask the HFEA:

- *From the age of 18* - Whether they were born as a result of treatment with donor sperm, eggs or embryo and obtain non-identifying information about the donor
- *From the age of 16* - people could ask whether they could be genetically related to someone they intend to marry

The information that donors have given to the HFEA has included their name and address. They have also given a range of other information which *may* include

- sex, height, weight, ethnic group, eye colour, hair colour, skin colour, year of birth, country of birth, marital status, ethnic group of parents
- whether the donors were adopted, whether the donor has children of their own and if so, the number and sex of these
- screening tests carried out on the donor and information about their personal and family medical history
- the religion, occupation interests and skills of the donor, and their reason for donating
- a 'pen-portrait' of themselves as a person and a goodwill message to the future children

*Note: not all donors have supplied all of this information*

If the donor registered before 1 April 2005, the law says that the child born as a result of the donation is **NOT** allowed to know the name and address of the donor. This law is not retrospective. However, the donor re-registers as an identifiable donor after 1 April 2005; any child born as a result of their donation has the right to access identifying information about the donor when they reach the age of 18.

This new legislation was passed by Parliament in 2004 following two years of consultation with clinics, donors and voluntary organisations which highlighted that many donor-conceived people wanted the option of finding out their biological background.

From 1 April 2005 onwards, children born through donation are able to find out:

- The donor's name, name at birth if different and address
- The donor's date of birth and the town or district of birth
- The appearance of the donor

Treatment centres had until 1 April 2006 to use their stocks of non-identifiable donor eggs and sperm.

**Donors** themselves are able to apply to the HFEA to find out what happened following their donation. Donors can be told:

- How many children have been born as a result of their donation
- How many of these children are boys and how many are girls
- Which year the children were born in

## Donors – The UK Picture

Alongside the review of the Sperm, Egg and Embryo Donation system (the SEED review), the HFEA has carried out an initial analysis of the kind of people who are registering as sperm and egg donors.

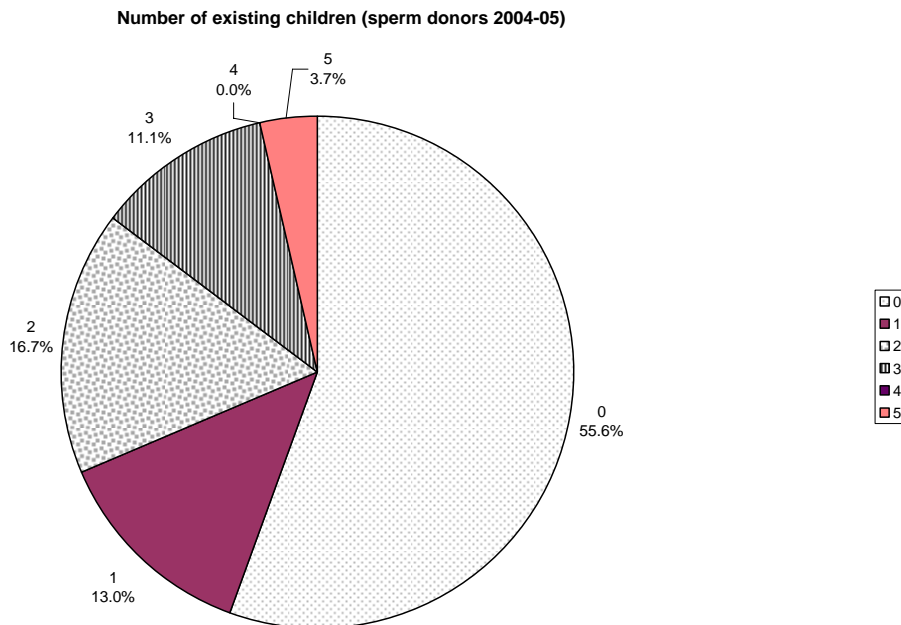
This has shown substantial change over the last 10 years with the stereotype of sperm donors being young students being far from the truth nowadays.

In 2004-05:

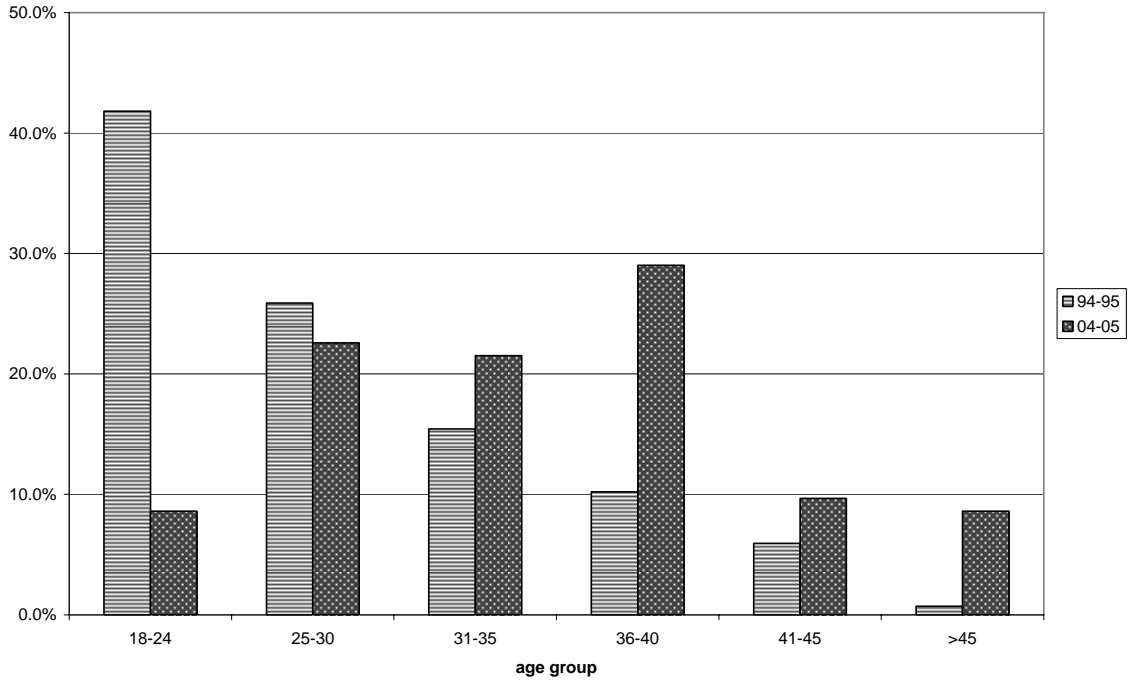
- more than 2 out of 3 sperm donors (69%) were aged over 30
- The most common age group for sperm donors is 36-40
- more than 2 out of 5 sperm donors (41.5%) already have children of their own
- just under a third of sperm donors (31.4%) have two or more children

While in 1994-1995:

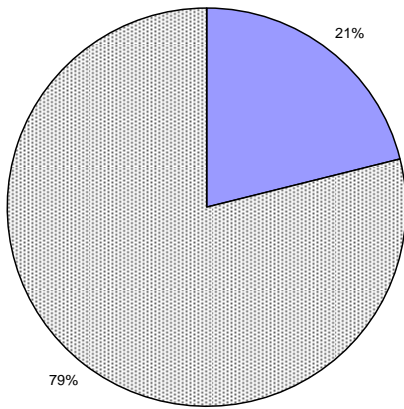
- Sperm donors were most commonly aged between 18 – 24 years.
- Less than a third (32.2%) of sperm donors were over the age of 30
- Only 1 in 5 (21%) of sperm donors already had children of their own.



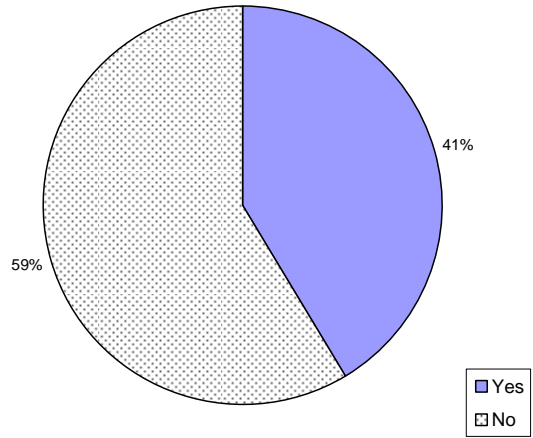
Age breakdown of sperm donors 94-95 and 04-05



sperm donors with own children 94-95

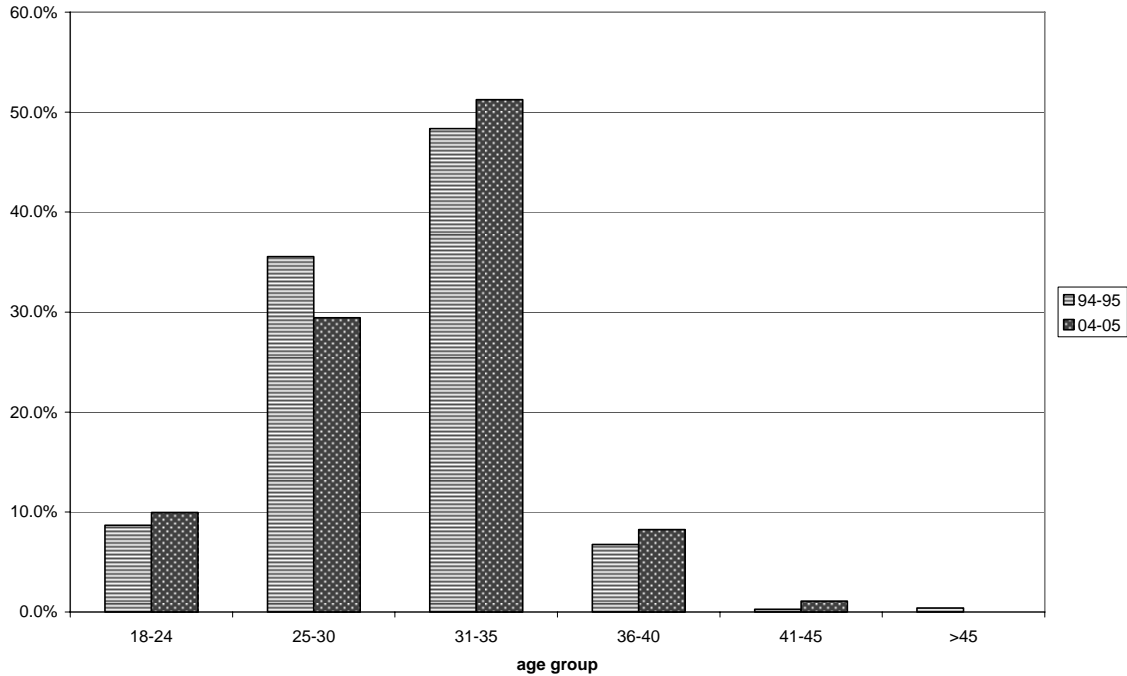


sperm donors with own children 04-05



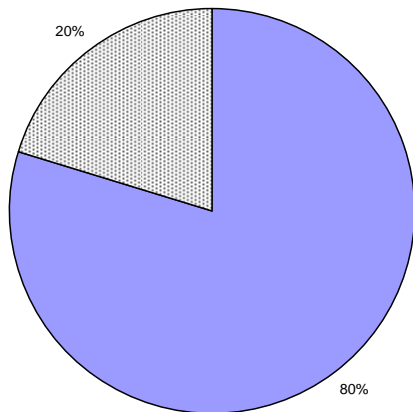
The changes have been less marked in egg donors, with the age distribution of egg donors remaining relatively unchanged over the last 10 years

Age breakdown of egg donors 94-95 and 04-05

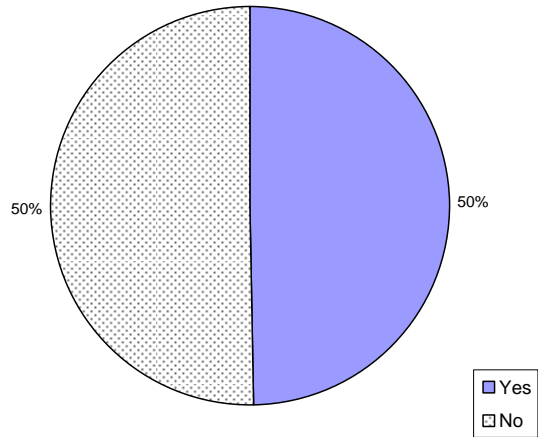


However, the number of egg donors with children of their own has fallen substantially. This is probably due to the rise in the number of 'egg sharing' schemes, where women donate their spare eggs at the same time as they receive fertility treatment themselves.

Egg donors with own children 94-95



Egg donors with own children 04-05



## **Key conclusions from the Sperm, Egg & Embryo Donation (SEED) Report**

### **Screening & selection of gamete donors**

The HFEA's current *Code of Practice* provides guidance to clinics on the screening of potential gamete donors and also informs clinics about sets of guidance from the relevant professional bodies in this area which clinics must adhere to.

One of the key conclusions of the SEED report is that the HFEA should move towards a reliance on professional guidance on the medical and laboratory screening of sperm, egg and embryo donors when revised guidance becomes available. The relevant professional bodies have formed a joint committee and will be working together to produce one set of professional guidance on donor screening for clinics.

This guidance will therefore be produced by those with the most expertise and direct experience, ensuring that donors continue to be screened to the highest possible standards.

The SEED Report also concluded that the HFEA will not provide prescriptive guidance on the selection of donors for the treatment of a particular recipient. Instead, the HFEA will provide guidance on issues to be taken into account during selection - this will give clinics more freedom in selecting donors for individual treatments whilst still ensuring the wishes of the patient and partner have been taken into account and ultimately, the welfare of the child who may be born as a result of treatment.

### **Compensation for donors**

The EU Tissue and Cells Directive sets out the underlying principle that all gamete donation should be voluntary and unpaid. Thus it was timely for the SEED Review to consider compensation for donors in the UK. With regard to issues of compensation and expenses the Authority has decided:

- Currently, donors may be reimbursed all reasonable, demonstrable out-of-pocket expenses incurred within the UK in connection with gamete or embryo donation – this policy remains the same
- In addition to the above, the Authority has concluded that donors may be compensated for loss of earnings up to a daily maximum commensurate with jury service (£55.19 per day) but with an overall limit of £250 for each 'course' of sperm donation (3-4 months) or each cycle of egg donation.
- Gamete donors may receive benefits in kind in return for supplying gametes for the treatment of others but these benefits should be limited to discounted treatment services.

## **The use of donor gametes**

Currently, an individual donor may only be used to produce '10 live birth events plus exceptions' Singletons, twins, triplets or greater births all count as one 'live birth event'. The most common exception is when there are more than 10 live birth events from a donor to provide genetically related brothers or sisters for children previously born from a donation. In addition, donors may set their own lower limits on the use their gametes which must not be exceeded.

The Authority concluded that this guideline should be simplified and clarified so that the gametes of an individual donor may not be used to produce children for more than 10 families in the UK. This change was intended to make it clearer for donors in terms of how many families will be created as a result of their donation. In addition, it was thought to be beneficial in that it would allow a genetic link between sibling and half siblings in donor conceived families. Donors are still able to set their own limits on the use of their gametes which must not be exceeded.

A new system of guidance has been introduced for clinics to help monitor the use of a donor's gametes to ensure better control on the use of the donation so the limits for their use will not be exceeded. As explained above, a donor can apply to the HFEA for details of the number of children born following their donation.

## **Import of donor gametes from abroad**

UK regulation has set a high standard of quality in terms of the screening criteria for gamete donation and the requisite information that must be provided for each donor.

The Authority felt that these standards should be maintained and that therefore the HFEA would expect to authorize the imports of gametes from abroad only where the same standards as are required in the UK can be met.

## **Conclusion**

The outcomes of the SEED Review, made in the light of the public consultation, are there to ensure that UK regulation is brought into line with new standards coming from Europe and to continue to ensure that donor assisted conception continues to be safe, fair and effective for donors, recipients and donor-conceived children alike.