

**This response was submitted to the evidence call held by the Nuffield Council on Bioethics on Donor conception: ethical aspects of information sharing between 21 March 2012 and 15 May 2012. The views expressed are solely those of the respondent(s) and not those of the Council.**

## **Human Fertilisation and Embryology Authority (HFEA)**

15 May 2012

### **Consultation Response: Nuffield Council on Bioethics, Donor conception: ethical aspects of information**

In response to the call for evidence on disclosure of information we submit the following information to assist the Nuffield Council on Bioethics on its exploration of the ethical aspects of information. Our submission includes:

- The role of the HFEA;
- Legislative framework;
- What information we collect;
- Current and future work on information disclosure;
- Questions you may wish to explore;
- Useful links; and
- Annex A: Information provision to donors, patients and the donor-conceived regarding donor conception processes.

The information enclosed in this document addresses the areas outlined in the terms of reference for this enquiry.

#### **1. The role of the HFEA**

- 1.1. The HFEA is required by Section 31 of the Human Fertilisation and Embryology (HFE) Act 1990 (as amended) to maintain a Register of Information which records details of regulated assisted reproductive treatments and the use and storage of gametes and embryos.
- 1.2. The Register contains information about all notified births resulting from treatment services, including those where donated gametes and embryos were used. The Register also contains information on gamete donors, including a physical description, ethnicity and any additional information donors wish to provide. Since donor anonymity was removed in April 2005, the Register also contains the donor's name and address. Donors who donated prior to 1 April 2005 can also elect to lift their anonymity retrospectively.
- 1.3. In 2009 the HFEA developed its Opening the Register (OTR) policy which sets out a broad framework for processing requests for donor information, who can receive what information and the core principles which should underpin the release of such information.
- 1.4. The Authority has trained OTR staff who deal with applications for Register information and discloses information on the basis of the statutory access rights and the HFEA's OTR policy.

## 2. Legislative Framework

### *Statutory requirements*

- 2.1 The legislative framework which underpins the disclosure of donor information was established in 1991 with the introduction of the Human Fertilisation and Embryology (HFE) Act 1990. Information provisions under the Act were amended in 2004 and in 2008 with the introduction of the Human Fertilisation and Embryology (Disclosure of Donor Information) Regulations 2004 ('The Donor Disclosure Regulations') and the Human Fertilisation and Embryology (HFE) Act 2008. Annex A sets out the current information access rights for donors, patients and the donor-conceived.
- 2.2. Originally the 1990 Act envisaged no contact between the donor and the donor-conceived person. People born as a result of donation could only access non-identifying information about the donor once they were over the age of 18. This changed in 2005 with the introduction of the Donor Disclosure Regulations which removed donor anonymity thereby making it possible for donor-conceived people to make contact with their donor.
- 2.3. Following the 2008 amendments to the Act, the statutory access rights were extended to allow donor-conceived people aged 16 and above to apply for non-identifying information about the donor. The amendments also made it possible for the HFEA to establish the Donor Sibling Link (DSL), a service to help donor-conceived siblings contact each other.
- 2.4. An important feature of the current legislation 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 making*

- 2.5. Over time the HFEA has developed its thinking and policy around information disclosure. With the introduction of the Donor Disclosure Regulations in 2004 the HFEA shifted its approach, recognising the importance of information disclosure to people affected by donation. The HFEA gave donors non-statutory access rights to anonymous information about their genetic offspring, including the number, sex, and year of birth of people born as a result of their donation (now a statutory right following the 2008 amendments to the Act).
- 2.6. The HFEA also gave parents of donor-conceived people access to non-identifying information about the donor from the Register. This was to enable parents to share information about the donor with their child as they grew up. This was reaffirmed by the HFEA in the 2009 OTR policy which further extended access rights to allow patients to access non-identifying information about the donor from the clinic where they received treatment.
- 2.7. In making these policy decisions the Authority considers finely balanced arguments of protecting the confidentiality of donors and the importance of information about donors to people affected by donation. In 2009 the Authority

agreed core principles which should underpin the release of such information, which include:

- Protection of the right of applicants to access information – to be open about the type of information the HFEA holds and to provide people with accurate information in a timely, secure and considerate manner.
- Duty of Care – to treat all applicants sensitively and provide good general information about the possible impact information can have on people's lives. To provide meaningful signposting to appropriate counselling and support services.
- Statutory Compliance – to implement the changes brought about by amendments to the Human Fertilisation and Embryology (HFE) Act 1990.

2.8. In addition, in light of the potentially complex psychological and social issues related to donor conception, the HFEA strongly recommends that donor-conceived people wishing to access the Register seek counselling or similar support services before making a formal application. We provide signposting on our website to professional support groups who can provide counselling or similar support to donor conceived people on the implications of seeking donor information from the HFEA.

2.9. We have also taken steps to encourage the sector to provide adequate provision of appropriate counselling to donor-conceived applicants.

### **3. What information we collect**

3.1. There are statutory limits to what information the HFEA can disclose and to whom. The Donor Disclosure Regulations specify both what information the HFEA is required to give about donors and what information should not be given ie, information which would identify the donor.

3.2. Clinics collect donor information on donor registration forms<sup>1</sup> which are submitted to the HFEA. The current donor registration form ask the donor for non-identifying information, including:

- 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
- any physical illness or disability, history of mental illness or learning difficulties and any known medical conditions within the donor's biological family
- a goodwill message
- a description of themselves as a person (pen-portrait)

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<sup>1</sup> Donor Registration form: <http://www.hfea.gov.uk/2505.html>

#### 4. Number of Requests

4.1. To give an idea of the number of requests we receive per year for information from the Register, please see the table below:

##### Requests for information: October 2010 to September 2011

Type of applicant	Number of requests
Donor-conceived individuals	12
Donors	57
Parents	99
Total	168

4.2. Although relatively small in number, applications for information from the Register are rising steadily. The above numbers represent over a 30% increase on the previous 12 months. This increase may be a result of more people reaching the age at which they are eligible to access information (the first donor-conceived people on the HFEA register had their 18<sup>th</sup> birthdays in May 2010). It may also be that an increase in applications is a result of a greater openness about donation within families and more generally within society. For example, HFEA staff have seen slight increases in applications when television programmes about donation are aired.

4.3. There are now 19 people registered to share their contact details with their donor-conceived genetic siblings, should any of them join the register. To date there have been no matches on the DSL, but all the processes and protocols are in place for future use. This service gives donor conceived people the opportunity to share experiences with someone in the same position as they are, and as more donor conceived people register the likelihood of finding a match will increase.

#### 5. Current and future work on information disclosure

5.1. Since 2009 the number of requests for information from the Register has increased and some complex operational issues have emerged, which could not have been foreseen.

5.2. As a result we are carrying out work to develop a framework for guiding the staff through complex decisions regarding the release of Register information. On 16 May we are seeking advice from our Ethics and Law Advisory Committee (ELAC) on a number of operational issues, including: how we judge what is potentially identifying (whether of a donor or their family members) and should therefore be withheld; how we deal with goodwill messages written in a foreign language; and whether to inform past applicants when donors re-register as identifiable. Often these operational issues require staff to balance their statutory duty to protect the

donor's confidentiality with the right of the applicant to access information. The ELAC paper can be viewed at: <http://www.hfea.gov.uk/7212.html>

- 5.3. The work we have been carrying out on OTR requests has highlighted the fact that donor information, which is collected by centres and held on the HFEA Register is of varying quality. This includes goodwill messages containing identifying information, poor spelling and grammar, possibly problematic content, or foreign language.
- 5.4. We therefore plan to carry out future work with the sector to improve the quality of donor information and this work will be a core aim of the HFEA's new National Donation Strategy Group. We will be happy to keep you updated with this work as it progresses over the year.

## 6. Questions you may want to explore

- What role should the Regulator play in information disclosure, should the Regulator go beyond the statutory minimum to provide information and if so, how far should the Regulator go?
- What role should centres play in helping donors provide better information about themselves for future families? Do centres have a responsibility to submit good quality donor information to the HFEA?
- What role should the professional bodies play in providing guidance on information disclosure to people affected by donation?
- What is the role of the Regulator in ensuring good practice in:
  - Good quality donor information
  - Good counselling
  - Emphasis on "openness"

### Useful links:

- 2009 Opening the Register Policy <http://www.hfea.gov.uk/535.html>
- Information we provide to donor-conceived people accessing information about their donor <http://www.hfea.gov.uk/112.html>
- Information we provide to parents who can find out about their child's donor and donor-conceived genetic siblings <http://www.hfea.gov.uk/118.html>
- Information we provide for parents on talking to their child about their origins <http://www.hfea.gov.uk/116.html>
- Donor Registration form: <http://www.hfea.gov.uk/2505.html>
- Code of Practice, information to be provided to donors: <http://www.hfea.gov.uk/498.html#guidanceSection4290>