

Authority Paper

Committee:	Authority
Meeting date:	21 January 2009
Agenda item:	10
Paper number:	486
Paper title:	Disclosure of donor codes to gamete and embryo recipients: evaluation and review of HFEA policy
Author:	Information
For information or decision?	Decision
Resource implications:	None
Implementation	By 1 October 2009
Communication	Communication to licensed centres via a Chair's letter and revised Code of Practice guidance. Communication to recipients via HFEA information.
Organisational risk	High
Recommendation to the committee:	To accept the recommendation that the HFEA stops disclosing donor codes and strongly advises centres against doing so.
Evaluation	Monitor through clinic and stakeholder contact
Annexes	None

1 Background

- 1.1 The disclosure of information provisions in the Human Fertilisation and Embryology Act 1990 lay out which information on the HFEA Register should and should not be disclosed to donor-conceived individuals upon request. However, the Act is silent about information which could be disclosed to donors or to recipients of donated eggs, sperm or embryos.
- 1.2 The HFE Act 2008 will add to the provisions in the 1990 Act regarding disclosure of information to donors (they will be able to request information about the number of children born of their donation, as well as their year of birth and their sex). However, the Act continues to make no mention of disclosure of information to the recipients of donor gametes. This means that the HFEA needs to continue to use its discretion about whether information can be disclosed under circumstances not provided for in the legislation. One example of such a disclosure is when parents of donor-conceived children ask whether children have been born to other recipients using the same donor. Current HFEA policy is that we will disclose the number, sex and year of birth of such children, in line with the statutory disclosure provisions governing the disclosure of such information to donors.

- 1.3 The HFEA's current policy regarding disclosure of information to recipients is to take a permissive approach. Through a Chair's letter published in October 2004 (CH(04)07), the HFEA informed centres that certain information about donors could be disclosed to recipients as long as such disclosure could not lead to the identification of the donor. This included the disclosure to recipients of non-identifying information about donors *and* the codes assigned to donors by licensed clinics.
- 1.4 The reasons for taking this permissive approach to the disclosure of non-identifying information about donors were:
- to help parents to be open with their children about the circumstances of their conception: giving parents as much information as possible about the donor enables them to help their child make sense of their genetic history and to prepare them for possible contact with the donor in the future.
 - to help donor-conceived individuals make contact with genetically related siblings: permitting the disclosure of donor codes enables parents, or their children, to make contact with children in different families who were born as a result of the same donor.
- 1.5 Most requests for donor codes are made directly to the clinics concerned. However, many parents also contact the HFEA for such codes. It is estimated that of all requests for information about donors made to the HFEA by parents, about half also seek the donor code.

2 Reasons for the review of current policy

- 2.1 The current policy of disclosing donor codes to recipients of donated gametes or embryos is being reviewed for two reasons.
- 2.2 The first reason is an amendment to the 1990 Act which, from 1 October 2009, will place a duty upon the HFEA to disclose information to genetically-related siblings born of donor gametes or embryos. Section 31ZE of the Act will require the HFEA to disclose identifying information to donor-conceived individuals of 18 years or older about any genetically-related siblings who have given consent to their identity being released. Given that the purpose of requesting clinic donor codes is to forge this kind of contact, a review of the practice is timely.
- 2.3 The second reason for reviewing the policy is because some stakeholders have identified a number of problems with the existing policy, both in terms of its operation and its potential risks. Those problems are:
- Donor codes are not unique identifiers: different donors can be issued with the same code (because centres tend to use similar numbering systems), creating the potential for erroneous matches between siblings.
 - The Code of Practice does not mention the disclosure of clinic donor codes. However, information for recipients on the HFEA website mentions the fact that they can request their donor's code from the clinic at which

they received treatment or from the HFEA. As a result of this lack of clarity, some clinics are unsure about releasing donor codes and many prospective donors are not informed that their code may be released to recipients.

- Not all donor codes can be released, even under the current policy. Some clinics use potential identifiers in the code (such as the donor's date of birth) and therefore disclosure could be regarded as a potential breach of the Act.
- If donors are given their codes, they may be able to discover the identity of the children born of their donation if they are part of the same networks as children seeking genetically related siblings. This is particularly problematic since the children may not have consented to this contact.
- If recipients of donor gametes obtain the code for their children's benefit and then go on to become an embryo donor, they may be able to discover the identity of the children born of their donation if they are part of the same networks as children seeking genetically related siblings.

3 Policy options

3.1 The operational problems with the existing system of allocating and disclosing donor codes – that donor codes are not unique identifiers and therefore erroneous matches may occur – mean that continuing with the status quo is not an option. Two possible courses of action are therefore:

- to continue with the current policy of permitting the disclosure of donor codes to recipients, but to overhaul the donor code allocation system; or
- to stop handing out donor codes when applications are made to the HFEA Register for non-identifying information on donors and to also tell clinics not to disclose donor codes in future. This could be done via a Chair's Letter, outlining the policy change and adding guidance to the Code of Practice.

4 Stakeholder views on the policy options

4.1 Staff from the Policy team have met representatives from the Donor Conception Network and the National Gamete Donation Trust, as well as officials from the Department of Health and a number of individuals involved in adoption. Those who support the disclosure of donor codes in principle still agree that the practice of disclosing donors codes can only continue if the system of allocating them is improved in order to avoid the risk of erroneous matching. This could mean either bringing the allocation of codes under HFEA control or requiring clinics to add something to the code which distinguishes it from codes allocated in other clinics (the HFEA centre number, for instance).

4.2 Some stakeholders argued that the practice of disclosing donor codes should stop because of

- the risks of identification of donors to donor-conceived individuals or vice versa; and
- the discrepancy between the new provisions in the Act regarding voluntary contact between genetically-related siblings and the current practice of facilitating contact between siblings under the age of 18.

4.3 However, from discussing the disclosure of donor codes with these and other stakeholders, a number of arguments for retaining the policy have also emerged:

- The ability of siblings to make contact with one another enhances family networks and benefits many donor-conceived individuals, particularly those born to single mothers. Anecdotal evidence shows that donor-conceived 8-14 year olds are interested in knowing who their siblings are.
- Limiting potential contact between donor-conceived genetically related siblings until those siblings are aged 18 or over might prevent them from developing a close, life-long relationship.

5 Recommendations of the Opening the Register Working Group

5.1 The Opening the Register Working Group discussed the disclosure of donor codes to recipients in October 2008. The Group was concerned that the disclosure of donor codes allows parents of donor-conceived individuals effectively to bypass the legal restrictions that apply to donor-conceived people themselves: donor-conceived people cannot trace their siblings until they reach the age of 18 and tracing is done on the basis of mutual consent.

5.2 The Working Group supports the Authority's wider policy of being permissive about the disclosure of non-identifying information not provided for in the Act. For instance, it thinks that parents of donor-conceived children should continue to be able to access information about the number, sex and year of birth of other children born to the donor. However, it felt that in the particular instance of donor codes, the risk of identifying the donor (or of the donor identifying themselves to the offspring), combined with the concern about bypassing the statutory scheme, tipped the balance against continued disclosure. The Working Group therefore recommends that donor codes should not be disclosed to parents of donor-conceived children, to donor conceived individuals or to donors themselves.

6 Recommendation to the Authority

6.1 There are a number of operational reasons for stopping the disclosure of donor codes. The operational problems could, however, be solved. From an ethical point of view, the most compelling reason for continuing to disclose these codes is the benefit which is derived from some donor-conceived teenagers contacting their genetically-related siblings. This argument tipped the balance towards disclosure when the Authority last reviewed the policy in 2004.

- 6.2 However, with voluntary contact between genetically-related siblings now coming into the statutory scheme, the balance may tip towards stopping further disclosure. If parents continue to obtain the donor's code, they may share it with their children at a relatively young age. Continued disclosure of codes to parents of teenage (or younger) children would, from October 2009, effectively bypass the Act, which requires that siblings reach adulthood before contact can be facilitated.
- 6.3 Further, since the practice of disclosing all other non-identifying information to parents of donor conceived children would continue, the emphasis on (and facilitation of) open communication with donor conceived children would remain. The only possible use of donor codes is to make contact with other donor conceived individuals or donors themselves. As stated above, this contact is now set out in statute.
- 6.4 It is therefore recommended that the Authority:
- stop the practice of disclosing donor codes to parents of donor-conceived individuals and donors themselves; and
 - strongly advise centres not to disclose such codes.

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