

Response to the HFEA Consultation on the 8th Code of Practice on donor information by the committee of the Donor Conception Network

There are two strands to this HFEA consultation. There is the draft of the 8th Code of Practice on which consultation is invited, and there is the online questionnaire which asks a number of specific questions. With respect to the issue of donor information with which this response is concerned however, the two strands are not consistent one with the other.

We begin with an analysis of the viewpoint and rights of those involved.

Patients, parents, donors and donor conceived individuals

The issues that arise in the provision of donor information can be considered from the perspective of

- people seeking treatment (who we will refer to as *patients*)
- people who have donor conceived children (who we will refer to as *parents*)
- donors and potential donors, and
- donor conceived children under 16, and
- donor conceived individuals over 16 and 18.

Patients are facing decisions as to whether to go ahead with treatment by a particular donor offered by a clinic and use donor information to help them decide. The Act does not provide specific rights to donor information for those seeking treatment.

Donor parents have the task of preparing an actual child for life as part of their donor conception family, telling the child about his or her conception, and telling the child about the donor. The legislation does not give them specific rights to donor information.

Donors now accept the responsibility that their identity can be disclosed to their donor conceived children at the age of 18, and that non-identifying information about them can be disclosed to children at 16. Before they donate they must be given an opportunity to receive proper counselling so that they can understand the implications of what they are proposing to do. The 8th Code of Practice at para 11.6 requires that prospective donors be given up-to-date advice about the nature and extent of the information that centres and the HFEA hold about donors; and the circumstances in which this information, identifying and non-identifying, may or must be disclosed; and at para 11.7 those actually donating are to be told about the extent to which the centre or the HFEA (or both) may disclose non-identifying information about them, for example to prospective recipients or to the parents of donor-conceived children.

Donor conceived children under 16

The HFE Act does not give children under 16 specific rights to information. However children have rights under the general law and under human rights law. In the 2002 case of *R (Rose and another) v Department of Health and HFEA* which decided that the right to respect for private and family life of donor conceived people was engaged in circumstances where their donors were anonymous, the claimants were a donor conceived adult Joanna Rose and EM, a donor conceived child acting by her parents.

Donor conceived individuals over 16 and 18

The Act provides for specific access to both non-identifying and identifying information about their donor.

Consultation on the draft 8th Code of Practice

Background

Some years ago when there was a more than adequate supply of (sperm) donors, patients were offered a choice of donors, based on non-identifying information supplied by the clinic. It is fair to say that practice varied as to how much non-identifying information was gathered by recruiting clinics, and how much was supplied to patients. The 2004 Disclosure of Donor Information Regulations have done much to standardise the gathering of non-identifying information.

Many UK patients contrast what often seems to them the limited information about donors compared to the apparent wealth of information provided about the wide selection of sperm donors on offer from American sperm banks, and some decide to import US sperm for this reason. These sperm banks are clearly in a commercial and competitive market, and know that they would lose business if the donor information they provided was less full than that offered by their rivals. Patients use the information to make a selection of a donor.

Development of HFEA practice and policy

By virtue of the Disclosure of Donor Information Regulations, the information to be disclosed to a donor-conceived person, and therefore (following G.5.4.1) currently to patients must include:

- a) the sex, height, weight, ethnic group, eye colour, hair colour, skin colour, year of birth, country of birth and marital status of the donor;
- (b) whether the donor was adopted;
- (c) the ethnic group or groups of the donor's parents;
- (d) the screening tests carried out on the donor and information on his personal and family medical history;
- (e) where the donor has a child, the sex of that child and where the donor has children, the number of those children and the sex of each of them;
- (f) the donor's religion, occupation, interests and skills and why the donor provided sperm, eggs or embryos;
- (g) matters contained in any description of himself as a person which the donor has provided;
- (h) any additional matter which the donor has provided with the intention that it be made available to an applicant.

Chair's letter 2004

Following the passing of the Regulations, the HFEA adopted a policy set out in Chair's letter CH(04)07 dated 28 October 2004 on the disclosure of information relating to gamete donation. In addition to the information to be provided to donors, it set out the donor information that centres should give to both patients and parents. The letter explained that "providing information may benefit those concerned, for example by allowing parents to make informed decisions about the controlled disclosure of information to their children". It specified that centres should respond as fully as possible to patients' requests for non-identifying donor information, and this was to include any non-identifying codes or designations assigned by clinics to donors. The Chair's letter also indicated that the HFEA itself would provide this information to parents.

The 7th Code of Practice told centres to give patients “relevant non-identifying information about donors whose gametes are made available to them for treatment, including any information that may be disclosed to a donor-conceived person born as a result of treatment using that donor’s gametes when they reach the age of 18”. (G.5.4.1) The wording “are made available” seems to encompass both patients and parents.

8th Code

The draft 8th Code at para 20.3 requires centres to inform patients that their children will have access to non-identifying information about the donor from the age of 16. Then at para 20.5 the draft Code requires centres to give anyone seeking treatment with donated gametes or embryos the same non-identifying information as that which can be accessed by a donor conceived person at 16. The information is listed at 20.3 is in plainer English and broadly, but not entirely, covers the list in the Regulations.

The regulations mention the donor’s skills and reasons for donating, but these are not reproduced in the 8th Code. Under (g), the regulations specify a description of himself as a person, often referred to in the sector as a “pen portrait”, but this is not mentioned in the draft Code. Under (h) the regulations mention additional matter intended by the donor for a donor conceived person, referred to in the Code as “a goodwill message”.

We regard it as important that all these aspects about donors should be recorded, and, while there will be some variation in the style and operation of donor recruitment practice, they should be recorded as consistently as possible. Donors may need support and assistance in thinking how to record information about themselves in a meaningful way. We believe that the goodwill message donors are encouraged to record helps to focus the attention of donors on their responsibilities to the donor conceived children. Its primary purpose of course is to be a message to the donor conceived individuals who will have a right to access it at 16, whether or not their parents have been able to obtain it earlier and have shown it to them. The message may help the donor children to prepare for the possibility of contacting the donor. The question of whether, contrary to the policy set out in the draft 8th Code, the pen portrait and goodwill message should be made available on a more limited basis is addressed below in the response to the “online questionnaire”.

In the attempt to “plain English” the Code, some significant elements of the information specified in the regulations have been lost - in particular the donor’s reasons for donating. These will be really important to patients, parents and donor children. **We recommend that the wording of paragraph 20.3 of the Code be revised to include all the matters specified in the regulations, and in particular the donor’s reasons for donating.**

Donor codes and sibling tracing

In addition to the non-identifying information required by the regulations, the 8th Code proposes that “the code assigned to the donor (as long as this is not identifying)” should also be disclosed to donor conceived people at 16. Para 20.5 then requires centres to give patients relevant non-identifying information about donors whose gametes may be available to them, and this information is to include information to which a donor conceived person can access at 16. Thus the 8th Code proposes to embody the HFEA policy and practice that has obtained since October 2004, i.e. that patients should be provided with non-identifying donor codes. This policy is also reproduced in para 30.14 of the draft Code.

Since the 2004 policy was adopted, a number of donor parents have sought to make links with other families who have used the same donor, so that their children can be brought together with their (half) siblings. They believe that this linking will be beneficial for their children, both in helping them to understand some of the implications of being donor conceived, but also may offer them the chance to make a life-long relationship with a blood relative.

Siblings: messages from the world of adoption

There are very significant differences between donor conception and adoption, but there are also some parallels. The law on both now ensures that at 18 adopted and donor conceived individuals can identify their genetic parents.

Many donor parents will not see or want to see their children's half-siblings as in any way "family", in the way that cousins are. On the other hand some donor parents do see a valid family-like potential connection that is not dissimilar to the situation of adopted, but parted, siblings. Some donor conceived individuals see their situation in a similar light and are more interested in pursuing sibling connections than in contact with the donor.

What is clear from the world of adoption is that it is widely recognised that the welfare of children is enhanced if siblings are enabled to make contact with each other, even if they are not placed together. According to one study, *"Sibling relationships are likely to last a lifetime and can be an integral part of a child's sense of identity, whilst potentially also providing support, companionship, continuity, annoyance, competition and conflict"*. (Edwards et al, 2005)

Most local authorities have implicit or explicit policies that siblings should remain together where possible in permanent placements. The Children Act 1989 s23(7)(b) places a duty on local authorities to accommodate a child with his/her siblings so far as is *'reasonably practical and consistent with his welfare'* This was followed by the Adoption and Children Act 2002 s1(4) which requires the court to consider a child's relationships with relatives. The Local Authority circular, 'Adoption - Achieving the Right Balance' (LAC(98)20), states 'In the exceptional case where siblings cannot be placed together with the same family, it is important for agencies to ensure that contact arrangements with other siblings are given very careful attention and plans for maintaining contact are robust'.

The British Association for Adoption and Fostering has guidelines 'Siblings: Together or Apart' (Lord and Borthwick 2001), which reflects the common assumption that separating siblings into different placements should only take place in exceptional circumstances (to do with the children's experiences in their birth family). A BAAF book by Hedi Argent, 2008, *'10 Top Tips for Placing Siblings'*, has as Tip No. 9, *'Ensure that parted siblings can share their lives'*.

These provisions for ensuring links between siblings in state sponsored family creation and placement arrangements contribute to compliance with the respect for the private and family life, demanded under human rights law, of adopted children. Not only is the right of adopted individuals at 18 to identify genetic relations enshrined in law, but law and practice aims to ensure that contact between siblings can be maintained below that age.

Donor conception practice has traditionally intended that gametes will be donated to different families who will have no knowledge of each other. As half siblings are being brought up in separate families the concept of the avoidance of unnecessary parting of siblings is inappropriate. On the other hand while parting is inherent in the process, routes to linking of siblings should be left open, particularly if the potential benefits may include “an integral part of a child’s sense of identity.”

Donor codes: the viewpoint of donors

Donors should know that their donor conceived children will not only be able to make contact with them when they reach 18, but will, by mutual consent, be able to make contact with each other. Since October 2004 donors should also have been told that patients and parents will have had access to non-identifying donor codes, and it is important that donors understand the use to which some parents may want to put them in enabling their children under 18 to make links with siblings. Provided that the identity of donors is protected (assuming that it what they want), there seem to be no reasons why donors would want to object to their offspring being enabled to make contact with each other, either before or after the age of 18.

We support the continuation of the 2004 policy of supplying donor codes to patients; and the inclusion of donor codes in the list of information in the 8th Code to be provided to patients.

The online questionnaire: questions 12a and 12b

In parallel with the consultation on the Draft 8th Code of Practice, an online questionnaire has been issued which at questions 12 a and 12b touches on donor information for patients. The introduction to the questions is as follows:

Patients undergoing treatment with donated gametes or embryos are given relevant non-identifying information about prospective donors such as their eye and skin colour, ethnic origin and reasons for donating.

Many donors also provide a more detailed description about themselves (pen portrait) and a goodwill message for children born as a result of the donor treatment. Based on current guidance it is not clear who should have access to this more personal information.

Donor conceived individuals, once they reach the age of 16, are entitled to access this information. But it can also be argued that the parents of such donor conceived children should have access to this information earlier so that they can have meaningful conversations with their children about their origins.

Some even think that all the non-identifying information should be made available to people who are choosing a donor. However, very personal information about the donor would then be made available to people who might not choose to be treated with the donor’s gametes.

Some of these statements are inconsistent with provisions in the draft 8th Code. For instance paras 20.3 and 20.5 which make clear the information (including pen portraits and goodwill messages) which should be supplied to anyone seeking treatment, is hardly consistent the statement “*it is not clear who should have access to this more personal information*”. And the tone of shocked surprise in the statement that “*some even think that all the information should be made available to people*

who are choosing a donor” is inappropriate, since this is the policy set out in the draft 8th Code.

Questions 12 a and 12b address the issues as to whether and how much non-identifying donor information should be made available to parents of donor conceived children, and also to patients – always subject to the position being made clear to donors beforehand.

There are good arguments for letting donors decide how much information about themselves they wish to release and to whom, in the same way that donors can choose the number of families to whom they wish to donate. But we recognise that this would not be easy to administer. Clinics need standard procedures for gathering information from donors, and standard ways of explaining to them how much information can be released and to whom. So in completing information forms about themselves, donors will need to be conscious of who their readers may be. There is a risk that this will inhibit them from expressing themselves as fully as they otherwise might. Support and guidance from clinic staff is vital in this process.

The questions

The options for both patients and parents are set out:

- only basic characteristics, such as ethnic origin, eye and skin colour
- basic information, but also the donor’s pen portrait
- all non-identifying information that donor conceived individuals will be able to access once they are 16 (including the good will message)

These options do not do justice to the full list of non-identifying information that the regulations require to be recorded. In our view “basic characteristics” to be disclosed to patients seeking treatment and to parents should include the following information about the donor

- parents’ ethnic group,
- year and country of birth,
- marital status,
- occupation, religion, skills and interests,
- reasons for donating,
- details of family medical history,
- and whether donor already has children.

We think it is not unreasonable for donors to expect that this information would be available to patients seeking treatment.

The pen portrait

We believe that a pen portrait written by a donor about him or herself is relevant as it may give a revealing indication of the donor’s values in life. At the risk, alluded to above, of possibly inhibiting the donor’s self expression, we favour making this available to patients seeking treatment and to parents.

The goodwill message

While the argument can similarly be made about the possible revealing indication about the donor’s values, we do see this message as properly relevant only for parents – or indeed for those for whom it is intended, that is the donor conceived children.

The way that this will be drafted by donors will, or should, entirely depend on who is to be able to access it. If it is to be accessed by parents with the intention that it

should be conveyed by them to their young children, it will be written in a style appropriate for them. If on the other hand it is aimed at 18 year olds, it should or is likely to have a very different style and content.

We favour the goodwill message being made available to parents of donor conceived children if they choose to have it. Donors should be encouraged to think about the possible ages at which they intend their message to be received. Parents should then use their discretion in how to use the message in conveying information to their children about the donor.

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