



HUMAN FERTILISATION AND EMBRYOLOGY AUTHORITY

RESPONSE TO THE DEPARTMENT OF HEALTH'S CONSULTATION ON 'DONOR INFORMATION: PROVIDING INFORMATION ABOUT SPERM, EGG AND EMBRYO DONORS'

INTRODUCTION

1. The HFEA welcomes the Department of Health's consultation exercise on 'Donor Information: providing information about sperm, egg and embryo donors'. The issues discussed in this document raise complex social and ethical questions that warrant careful discussion. In responding to the document it was felt to be essential to take into account the possible effects of any changes on people seeking treatment, licensed clinics and those who have donated or intend to donate gametes or embryos for the treatment of others.

2. Also, as the organisation charged by Parliament with the regulation of infertility services, including the provision of donor information, the outcome of this consultation may have significant implications for the HFEA. It was important, therefore, to explore the possible practical and financial consequences for the HFEA of any changes that are introduced.

3. The consultation document poses the following questions:

- Q1 - Should Regulations be made to specify that offspring that are conceived using sperm, eggs or embryos provided by a donor should be able to obtain non-identifying information about that donor?

- Q2 - Should offspring be able to obtain identifying information about future donors?

- Q3 – An option would be for donors to say whether identifying information should be made available, with the agreement of the donor or in all cases?

4. These questions are considered below, in the context of a broader discussion of the ethical, clinical and practical implications of potential changes in access to donor information.

CURRENT POSITION

5. The HFEA began recording information on its register on August 1, 1991, when the relevant provisions of the 1990 Act came into force. Prior to this, information was collected independently by clinics and may or may not be available - the register contains a small amount of information about "transitional donors": prior donors who registered with the HFEA at its inception.

6. Decisions on the information to be collected took account of discussions of the Committees of both Houses of Parliament in their scrutiny of the Human Fertilisation and Embryology Bill, and took further evidence from those with experience of treatment provision.

7. At present, the HFEA can only release information about donors under a limited number of exceptional circumstances:

- if it is to a member or employee of the Authority;
- if it is to someone to whom a licence applies for the purposes of their functions as a licensee;
- if the information provided does not identify those individuals to whom it relates;
- if it is in pursuance of an order made by a court in proceedings to establish whether a person is or is not the parent of a child by virtue of s.27-29 the HFE Act;
- if it is for the purposes of instituting court proceedings under section 1 of the Congenital Disabilities (Civil Liability) Act 1976;
- if it is following a request from the Registrar General to establish whether a man is or is not the father of a child; or
- if it is to provide information to applicants as defined in s.31 of HFE Act 1990.

8. S.31(5) of the HFE Act 1990 prohibits retrospective identification of donors to donor-conceived offspring. This means the new regulations could only require the HFEA to release non-identifying information to any applicant who had been conceived with gametes that had been donated up to that point. The consultation document appears to rule out any change in this position.

9. The HFEA currently collects the following information about gamete donors:

- General information: recruiting clinic, date of completion of form;
- Personal information: name at time of donation, name at birth, place of birth, own children (Yes/No), sex;
- Physical characteristics: height, weight, ethnic group, eye colour, hair colour, skin colour;
- Optional additional information: religion, occupation, interests;
- Pen portrait: optional information provided by the donor, the level of detail of which varies greatly between donors.

10. The HFEA currently recommends that when people seeking treatment are assessed certain factors are taken into account. These include:

- a child's potential need to know about their origins;
- whether or not the prospective parents are prepared for the questions which may arise while the child is growing up; and
- the possible attitudes of other members of the family towards the child, and towards their status in the family.

11. The HFE Act also requires that people seeking treatment be given a suitable opportunity to receive proper counselling about the implications of taking the proposed steps before they consent to treatment.

12. Further information is collected by licensed clinics that are not recorded by the HFEA. This includes details of donors' consent, results of screening procedures and certain background information. At present, clinics are advised to encourage donors to provide as much other, non-identifying biographical information about themselves as they wish, to be made available to prospective parents and any resulting child. Clinics may disclose this additional information to people seeking treatment.

ETHICAL FRAMEWORK FOR THE CONSIDERATION OF DONOR INFORMATION

13. The following principles informed the HFEA's discussion of the ethical issues and they address two different aspects of the debate:

- the value of giving information; and
- the need to balance the interests of the different individuals involved.

The value of information

14. Information about the circumstances of one's conception can play an important role in the formation of an individual's personal identity. More importantly, however, the deliberate concealment of such information can have an injurious effect on an individual's familial and social relationships and sense of self-worth, particularly if that information is later discovered in an unplanned manner.

15. The importance of information about a donor's medical and family history in the healthcare of donor offspring should be acknowledged, as well as its potential value in informing the donor offspring's lifestyle choices in order to compensate for genetic predispositions to disease. Therefore, it is felt that the principle of openness should be encouraged in order to promote the welfare of the prospective child.

Balancing interests

16. The interests that are engaged by the question of information provision are primarily those of existing offspring and donors and, as the HFE Act requires, the interests of unborn children who may be affected in the future, and parents of donor offspring. These interests are not necessarily the same and the possibly conflicting needs should be explored in considering any changes.

17. In this regard, some concern attaches to possibility of instituting a two-track system, since this would seem to give a determining role to the decisions of the parents, who would be able to choose whether to use donated gametes where there was no identifying information.

18. It is felt that the starting point for the consideration of any change should be:

- **those who have previously donated gametes under legal guarantees of anonymity should not have these removed;**
- **any anticipated effect on the supply of donor gametes and embryos of removing anonymity from those donating in future does not in itself constitute a sufficient reason for not allowing donor offspring the possibility of obtaining identifying information about the donors who contributed to their conception;**
- **for past treatments, and also in future if anonymity is not lifted, the interests of those concerned would be promoted by the establishment of a 'voluntary contact register' whereby donors and donor offspring could register their willingness to be contacted and their consent to the mutual disclosure of identifying information.**

The interest of offspring and the interests of the family

19. Before considering information to donor offspring, it seems necessary to establish the likelihood of offspring being aware of the circumstances of their birth. Because of the stigma attached to infertility by some people (particularly male infertility where the male partner may feel less involved because of a lack of direct involvement in pregnancy and birth) it has been assumed that the parents of donor conceived offspring had a natural interest in maintaining secrecy surrounding donor conception. Consequently, the interests of donors and of parents of donor offspring were generally thought to be allied for the preservation of secrecy. At the very least it was felt that telling donor offspring of the circumstances of their conception was something that the State, and hence the HFEA, could not and should not enforce.

20. Disclosure of the use of donor gametes to resulting offspring has been subject to intense investigation in Europe, the USA and Australia. This is due, in part, because it was known that many people do not tell their child that donor gametes were used in their conception. All studies found that a majority of parents, up to 90% in some studies, had not disclosed to the child and some studies showed that there was no intention to disclose.

21. A recent study investigating the reasoning behind parental disclosure of their children's genetic origins found that of 70 men and 86 women who had children through donor insemination treatment, 30% said they would disclose this to their children, but a larger percentage (54%) would not, or remained undecided (16%)¹. The reasoning behind the decision to tell was to be 'honest', whereas reasons not to tell were seen as 'confidentiality' issues. This unwillingness to disclose persists even though there is a greater public understanding of, and openness about, infertility than ten years ago.

22. The literature on the counselling needs of people receiving donor gametes highlights some of the issues surrounding disclosure.

- a third of people in one study did not know how or when to disclose;
- there was a lack of post-donation guidance.

23. It is suggested that parents of donor conceived offspring often do not disclose this information because they know their child will only be able to access a limited amount of information about the donor. It is argued, therefore, that if donors could be identified more parents would be willing to disclose to their children. However, the reality may not be so clear cut. Despite the availability of identifying information for donor conceived offspring conceived in Sweden, it has been found that the majority of parents (89%) who had received treatment with donor sperm had not informed their children². In the U.S. a similar trend was found.

24. It has also been suggested that parents do not tell because they do not know how to go about it. It is argued that without giving parents access to the necessary information about how to tell they do nothing, although other studies have revealed that willingness to tell does appear to depend on what type of donation has been received and who has received it.

25. Many couples seem not to have been offered adequate counselling to explore the issue, and work to some resolution. It may therefore not be surprising that, without information, many people tend to do nothing, even though this may not be in their own, or their child's, best interests.

26. This highlights the importance of providing in-depth information and counselling for people considering treatment using donor gametes. The HFEA would strongly recommend that counselling provision be given a high priority in guidance resulting from any change in donor information.

¹ Nachtigall *et al.*, 1998

² Gottlieb *et al.*, 2000

Interests of donor offspring

27. The expansion of infertility treatment means that there are significant numbers of donor conceived children. Also the context in which these children are growing up is changing.

28. The dramatic steps made by the science of genetics have led to a very different importance becoming attached to genetic inheritance; the role of specific gene sequences in conditioning features of an individual's health, and possibly even certain aspects of their behaviour, has given knowledge of genetic background a privileged status.

29. Attention is often drawn to the value of information about a donor's medical and family history in the healthcare of offspring, and in informing their lifestyle choices in order to compensate for genetic predispositions to disease, is now widely acknowledged.

30. Perhaps more subtly than the developments discussed above, there has been a perceptible development in attitudes to individual human rights and a similar growth in willingness to claim those rights through legal action. This has been codified in law following the passing into law of the Human Rights Act 1998.

31. Whilst research suggests that openness has been shown to be beneficial, evidence that secrecy is harmful has not been reported in young DI offspring. However, other studies have suggested that harm is likely when a child finds out by accident or when they find out in later life.

Interests of donors

32. The rights and claims of offspring to knowledge of their genetic background must be carefully weighed against those of donors who might have an interest in protecting their anonymity. At the time of donation, donors are made aware of what information may be released and the limits to which the protection of information is guaranteed. Although donors are encouraged to remain in contact with their recruiting clinic for purposes of varying consent or feeding back health-related information, they cannot be required to do so, and in practice few do.

33. It has been suggested that if donors were identified in the future this could result in a severe shortage of donors. The research is very contradictory, some of the evidence supports this concern, with studies showing that less than half of oocyte donors would be happy with the release of identifying information. However, evidence to the contrary is also available. Several studies have shown that sperm donors would be happy to have identifying information about them provided to any possible children conceived as a result of their donation(s); and that more sperm donors were happy with the possibility that their offspring would attempt to contact them in later life than is generally assumed^{3 4}.

34. Swedish law changed in 1985 allowing all donor insemination offspring the right to obtain identifying information about the donor providing the sperm for their conception, followed by Austria in 1992 and Victoria, Australia in 1995. Although initially there was a reduction in donors in Sweden, the numbers of prospective donors coming forward increased again some time later to its original numbers.

35. However inconclusive the research, as stated earlier, the HFEA does not believe this potential practical consequence should override any potential right to information.

Payment to Donors

36. The Report of the Committee of Inquiry into Human Fertilisation and Embryology, the "Warnock" report, recommended a gradual move towards a system where semen donors should be given only their expenses. The HFEA has also been keen to encourage a culture of altruism with respect to donation, however it was agreed three years ago that the withdrawal of payments to donors may negatively impact on the supply of donors.

37. There are a number of pieces of published work discussing the costs associated with the recruitment of donors and this subject was discussed at length following the HFEA's consultation on 'Payment for Donors'. One notable UK study⁵ attempted to recruit altruistic gamete donors. Despite extensive use of a wide range of initiatives including the distribution of posters and leaflets and radio and newspaper advertising campaigns, the number of donors successfully recruited was limited. This study resulted in about 25% of women who had initially shown interest successfully donated oocytes, but <1% of the men went on to donate sperm. This was a very expensive exercise, which resulted in the recruitment of a limited number of donors.

³ Kirkland *et al.*, 1992

⁴ Baetens *et al.*, 2000

⁵ McLaughlin *et al.*, 1997

Arguments by analogy

38. Due to the limited amount of rigorously collected evidence and the intrinsic difficulties of conducting studies in this area, analogies with other relevantly similar situations are helpful to a limited extent in allowing inferences to be drawn about the effects of providing or withholding information. In considering the interests of donor offspring evidence relating to the following situations should be taken into account:

- **Adoption:** Whilst there are some similarities between gamete donation and adoption there are certainly many differences (for example, gamete donation is supposedly altruistic whereas adoption is often the result of complicated life-choices).
- **Step families:** This analogy was felt to be most close to the present circumstances and was used by *Warnock* in preference to adoption. It was acknowledged that there were relationships in which one parent is not genetically related to the child that work extremely well.
- **Natural conception:** Although they are hard to quantify, there are many cases of natural conception where the offspring are unknowingly not related to those whom they believe to be their parents. In a number of cases one or both parents may also be unaware of this.
- **Surrogacy:** Cases of surrogacy also offer an analogy to donor treatments, although the maternal relationship might be expected to differ in these cases owing to the fact that the mother has not undergone pregnancy and birth.
- **Known / related donors:** Known donation is permitted in the UK under the same treatment circumstances as anonymous donation. However, the legal position is unclear with respect to legal fatherhood following this type of arrangement for single women and no systematic studies of known donors exist in the UK context. The practice of using donors related to the infertile partner is known to be relatively common in other cultures, particularly in cases of male infertility where a relative of the infertile male donates sperm. Again no systematic studies exist in a UK context.
- **Self insemination:** A number of people resort to self insemination for a variety of reasons, for example because of the law regarding donor anonymity, the medical nature of the procedure, the cost, etc. Again, no reliable systematic studies are available.

39. Openness and disclosure of identifying information or the identity of donors in gamete donation, is still a contentious issue. The research does not show an overwhelming desire to tell in recipients or donors, although the majority of offspring do prefer more rather than less information about their heritage.

40. Evidence from surrogacy and adoption indicates that relinquishing mothers would like openness and contact, as do adoptive offspring, which is accepted by a majority of recipient mothers.

PROPOSALS FOR CHANGE

41. It seems essential that some changes emerge from this consultation exercise. Expectations have been raised that further information would be available and the potential for legal challenge of not doing so seems significant. This section looks at the implications of the possible alternatives.

RETROSPECTIVE CHANGE

42. Both s.31(5) of the HFE Act 1990 and paragraph 1.3 of the consultation document itself have ruled out retrospective identification of donors to donor-conceived offspring. The HFEA would strongly support the principle that any change should apply **only** to future donors.

PROSPECTIVE CHANGE

Option A

Regulations are drafted specifically allowing non-identifying information to be released to donor conceived offspring

43. If new regulations were drafted, they could permit those aged 18+, who approached the Authority to:

- establish whether they were born as a result of licensed treatment services or not; and
- obtain access to certain non-identifying information about the donor.

44. However, this option does not meet the central principle of openness in promotion of the welfare of the child set out in paragraph 16 above. Nor is it likely to meet the growing demands for information from donor offspring.

45. There may be challenges relating to the principle of only releasing a limited amount of information to donor conceived children, when it is known that more information was being held either in clinics or on the HFEA's register.

46. In addition, there may be further challenges that relate to the age at which donor conceived offspring may obtain access this information. At present, people seeking treatment with donated gametes may be given access to an anonymised version of the donor information form, which contains non-identifying information about the donor, by the licensed clinic prior to receiving treatment with that donor's gametes. It could be considered unreasonable that prospective parents can have access to this information before treatment commences, but donor conceived offspring would be denied access until they were 18.

Option B

Ending anonymity for prospectively recruited donors

47. This option would meet the principles of openness, and it is the one supported by the HFEA. The HFE Act does not differentiate between permitting the release of identifying or non-identifying information through regulations, so providing regulations were drafted to state that identifying information could be released prospectively this could be implemented.

48. It is acknowledged that ending donor anonymity does involve some risk to the future availability of donors. However, the Authority does not feel that this practical consideration should outweigh the more fundamental right of donor offspring to knowledge of their genetic origins.

Option C

A two-track system where some donors would be willing to be identified and give their consent to this, whereas others would be anonymous, as in the present system

49. Superficially, this option appears to offer the best of both worlds. It would provide for those people who wished to have treatment with donors willing to be identified in the future, but would also allow those donors who wished to be anonymous the opportunity to donate. However, the Authority feels this proposal presents significant ethical and practical problems.

50. There is a strong argument that such a system would be highly discriminatory, as one group of donor conceived offspring would have full access to identifying information about the donor, whereas a second group would only be given a limited amount of non-identifying information. Based on the evidence already cited, it is possible to envisage problems arising in the future, when some donor conceived offspring discover that their parents selected a donor who wished to remain anonymous, rather than one who was willing to be identified.

51. This option introduces considerable complexity by creating two different categories of donors. It also creates two different categories of donor-conceived offspring who will have access to differing amounts of information. It would be a very complex system for clinics to operate, and would rely on them having systems in place to ensure that donors were correctly recorded as those who wished to be anonymous, or those who were willing to be identified.

52. It is also possible that this arrangement may fall foul of Articles 8 and 14 of the European Convention for the Protection of Human Rights and Fundamental Freedoms (as enshrined in UK law by the Human Rights Act 1998).

VOLUNTARY CONTACT REGISTER

53. The possibility has been raised of a non-statutory, voluntary contact register. This would enable donors and donor conceived offspring to get in contact if they wished to do so. It is felt that this would have to be run by a third party, working outside of the restrictions of the HFE Act. One difficulty with this option would be verification of details to allow the matching of donors with donor conceived offspring, as neither the HFEA nor licensed clinics would be allowed to verify the details. This approach relies on both parties coming forward and providing enough information to allow a match to be made.

54. An alternative approach would be the development of a mechanism that would give donors, who had legally assured anonymity, the option of revealing their identity should any offspring who had been born as a result of their donation come forward requesting it. This approach would also present a number of practical and legal difficulties that would need to be overcome.

55. One of the major differences between the analogous scenarios set out in paragraph 37 above, and the situation that relates to donors is the potential number of offspring that could be involved. For each donor recruited there could have been ten children (plus additional full siblings) born. This would need to be taken into account by a donor before they agreed to be identified as contact from a large number of donor conceived offspring could prove to be very disruptive to not only the donor, but also to their family.

IMPLICATIONS FOR THE HFEA

56. Any of the options for change would be dependant on comprehensive and reliable information being collected and monitored by the HFEA and licensed clinics. This underlines the importance of the modernisation of the regulatory and information systems already begun by the HFEA. The resource implications of these developments are set out in the Authority's Business Plan.

57. Completion of donor information forms varies considerably, and as a result the amount of non-identifying information available to donor conceived people is similarly uneven. It has also been shown that 94% of egg donors do not complete the space on the donor information form that allows them to give additional information about themselves⁶.

58. Any possible changes in the right to donor information must be supplemented by systems, both in clinics and the HFEA, which ensure that the information promised can be delivered. This would include:

- robust HFEA audit of clinical data collection and processes;
- reliable, comprehensive data on the outcome of licensed treatment;
- ensuring appropriate information is given to people seeking treatment by donor gametes, and those wishing to become donors.

CONCLUSIONS AND RECOMMENDATIONS

58. The HFEA has considered the different issues raised in the consultation document and the implications of the different outcomes. Whilst there are differing views about the impact of the loss of anonymity we have concluded that a move to greater openness would best serve the welfare of donor offspring. The Authority would therefore recommend:

- a) there should be a move toward the removal of donor anonymity;**
- b) any change in donor anonymity should not be applied retrospectively;**
- c) the rejection of the two track system on the grounds of the ethical and logistical problems set out above; and**
- d) stronger guidelines should be developed on the counselling needs of those considering treatment with donor gametes, and donor offspring seeking information on donors.**

⁶ Abdalla *et al.*, 1998

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