

Authority Paper

Committee:	Authority Meeting
Meeting Date:	21 January 2009
Agenda Item:	9
Paper Number:	485
Paper Title:	Opening the Register Policy – a principled approach
Author:	Information
For information or decision?	For decision
Resource Implications:	Pending Authority's of policy recommendations, potential implications in terms of staff time and resources.
Implementation	October 2009
Communication	Consultations with external stakeholders Revision of HFEA web information
Organisational Risk	High: The consequences of the HFEA not agreeing and implementing a robust and sensitive policy by October 2009 could impinge donor's and donor-conceived people's statutory rights to access information. This is also a media sensitive area and there is subsequently a high reputational risk to the HFEA.
Recommendation to the Committee:	The Authority is invited to: <ul style="list-style-type: none"> • Review the issues raised by Opening the Register • Approve the recommendations of the Opening the Register Policy Working Group contained in Section J of this paper. • Approve the illustrative policies attached in Annexes 1-4 of this paper
Annexes	Annex 1 – An Illustrative Policy. Donor-Conceived People – Access to Donor Information Annex 2 – An Illustrative Policy. Donor-Conceived People – Access to Voluntary Sibling Contact Register Annex 3 - – An Illustrative Policy. Parents of Donor-Conceived People – Access to Information about their Children's Donor and Siblings Annex 4 – An Illustrative Policy. Donors – Access to Information about Donor-Conceived Offspring Annex 5 – HFEA Interim Policy. Processing requests for information from the HFEA Register for donor-conceived applicants: a three stage process Annex 6 – Code of Practice consultation questions regarding access to donor information.

Section A: Overview

1 Introduction

- 1.1 The purpose of this paper is to outline the issues involved in Opening the HFEA Register (OTR) to people affected by gamete and embryo donation, including donor-conceived people, their parents and donors themselves. Members are asked to discuss and approve the recommendations outlined in Section J and to sign off the draft processes contained in Annexes 1-4 to this paper.
- 1.2 Section 31 of the Human Fertilisation and Embryology Act 1990 (as amended) requires the HFEA to maintain a Register of information obtained by it which relates to the provision of regulated assisted reproductive services and the use and storage of gametes and embryos, in the UK. The Register contains information about all notified births resulting from treatment services, including those where donated gametes and embryos were used. The Register also records information regarding gamete donors, including a physical description, ethnicity and any additional information donors wish to provide. Where people go abroad for treatment, details of their treatment will not be included on the HFEA Register.
- 1.3 Since 1991 people born as a result of donation have had statutory access rights to some information about their donor from the HFEA Register. In 2004, the HFEA also granted information access rights to parents of donor-conceived children and donors. Under the Human Fertilisation and Embryology Act 2008, which is due to come into force in October 2009, statutory access rights to people affected by donation have been considerably expanded. Current and future access rights are outlined in Section B.
- 1.4 An Authority Policy Working Group was established in September 2008 to support the Executive in developing a set of principles and top level policy recommendations for handling applications to the HFEA Register. Members of the group were: Anna Carragher (Chair), Jennifer Hunt, David Archard and Ruth Fasht. The Executive Membership was: Danielle Hamm (Secretary), Charlotte Augst, Richard Martin and Emer O'Toole.
- 1.5 It is expected that the policy recommendations, to be approved by the Authority, will become operational in October 2009, alongside the changes contained in the new Human Fertilisation and Embryology Act 2008.
- 1.6 An interim policy was drafted by the Executive and signed off by the Authority Chair and Working Group in October 2008, which applies to donor-conceived applicants to the Register before October 2009. The interim policy will then be superseded by the policy adopted in light of this paper. The interim policy is discussed in Section B and attached in Annex 5.

2 Structure of the paper

- 2.1 Section B of this paper outlines the legislative and policy context surrounding access rights to information from the HFEA Register. Current and future access rights are outlined and relevant parts of the legislation are summarised.
- 2.2 Section C of this paper introduces and discusses the principles considered by the Working Group to be appropriate to underpin the OTR policy. In addition it provides a suggestion for a public statement of intent, which should accompany the OTR policy. *Members are asked to approve the principles and public statement of intent.*
- 2.3 Section D of this paper introduces and summarises the issues involved in accessing information from the HFEA Register by donor-conceived people, or people wishing to find out whether they are donor-conceived. It outlines the Working Group's recommendations on how to handle these issues.
- 2.4 Section E of this paper introduces and summarises the issues involved in the establishment of a Voluntary Contact Sibling Register. It outlines the Working Group's recommendations on how to handle these issues.
- 2.5 Section F of this paper introduces and summarises the issues involved in accessing information from the HFEA Register by parents of donor-conceived people. It outlines the Working Group's recommendations on how to handle these issues.
- 2.6 Section G of this paper introduces and summarises the issues involved in accessing information from the HFEA Register by donors. It outlines the Working Group's recommendations on how to handle these issues.
- 2.7 Section H of this paper discusses the outputs the Executive will produce, following the approval of the policy recommendations. These include various issues surrounding implementation and the revision of HFEA guidance to clinics. It outlines the Working Group's recommendations on how to handle these issues.
- 2.8 Section J of this paper summarises all the Working Group's policy recommendations. *Members are asked to approve these recommendations.*

Section B: Current and Future Access Rights

3 Introduction

- 3.1 The HFEA is required by law to keep a Register of information which records details of regulated assisted reproductive treatment services in the UK. The HFEA has recorded this information since 1 August 1991, which is the date the Human Fertilisation and Embryology Act 1990 came into force. The Register contains all births resulting from treatment services, including those where donated gametes were used. The Register also records information regarding gamete donors, including a physical description, ethnicity and any additional information they wish to provide, for example occupation and interests. Since donor anonymity was removed in April 2005, the Register also records the donor's name and address. Donors who donated prior to April 1 2005 can elect to remove their anonymity retrospectively.
- 3.2 Government regulations introduced in 2004 specify what information the HFEA should collect about donors, and subsequently provide to donor-conceived individuals. As a result, in July 2004, the HFEA introduced new donor registration forms which ask for the following information from donors:
- 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
 - details of donor screening tests and medical history
 - a goodwill message
 - a description of themselves as a person (pen-portrait)¹

4 Current Statutory Access Rights

- 4.1 Currently only donor-conceived people have a statutory right to access information from the HFEA Register. Any person, born after 1 August 1991 who is over the age of 18 can contact the HFEA to find out whether they are donor conceived. The HFEA is required to provide the following information to donor-conceived individuals, aged 18 or over, upon request:
- identifying information about the donor (if donor donated after 1 April 2005 or retrospectively removed anonymity)
 - anonymous information about the donor (if donated under conditions of anonymity)
- 4.2 The law also makes the provision that allows donor-conceived offspring under the age of 18, who intend to marry, to submit a joint application to establish whether they are genetically related.
- 4.3 A further important feature of the current legislation, which is retained under the amended legislation, is the requirement on the HFEA to provide a "suitable opportunity to

¹ This is not an exhaustive list of the information collected on donors

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.

5 HFEA Policy Decisions

- 5.1 In 2004 the HFEA decided to grant additional access rights to the Register to parents of donor-conceived individuals and to donors. It also took the decision to allow donor-conceived people to access some information about donor-conceived genetic siblings.

HFEA Policy Decisions

Parents of donor-conceived individuals

Parents are provided with non-identifying information about the donor by the clinic when they receive treatment. Upon request, the HFEA can then provide them with the following additional information:

- Donor code (if non-identifying)
- Number, sex and year of birth of other offspring with the same donor

Donors

Donors can receive the following non-identifying information about their donor-conceived offspring:

- number, sex and year of birth

Donor-conceived individuals

Donor-conceived individuals can receive non-identifying information about their donor-conceived genetic siblings, including the number, sex and year of birth.

6 Statutory Access Rights from October 2009

- 6.1 Statutory access rights to information from the HFEA Register have been considerably expanded under the Human Fertilisation and Embryology Act 2008. These rights will be operational from October 2009, when the Act comes into force.

New Statutory Access Rights

Donor-conceived individuals

16 year-olds will be entitled to:

- non-identifying information about their donor
- non-identifying information about donor-conceived genetically related siblings

Anyone who intends to marry, or enter into a civil partnership, may submit a joint application to establish whether they are genetically related

16 year-olds who intend to enter into an intimate physical relationship can find out whether they are genetically related.

18 year-olds will be able to find out identifying information about donor-conceived genetic siblings, if both sides consent (sibling register).

Donors

Will have a new statutory right to access the following anonymous information about their genetic offspring:

- the number, sex, and year of birth of people born as a result of their donation.

Donors will be able to contact the clinic where they donated or the HFEA for this information.

The HFEA is expected to contact and inform a donor of the fact that that a donor-conceived person has requested identifying information about him or her.

6.2 It is noteworthy that most of the HFEA's policy decisions regarding information access rights have been translated into primary legislation, with the exception of parental access rights. The HFEA, however, retains the power to grant access rights to parents of donor-conceived people.

7 Who currently accesses the HFEA Register?

7.1 All requests to date have come from parents and donors. Under 18 year-olds who intend to marry may access information from the HFEA Register to establish whether they are genetically related, however no such applications have been made to date.

7.2 There have been 66 requests for information from the HFEA Register over the past year; 43 of these requests were from parents, 20 from donors and 2 from egg-sharers (who can submit a combined parent/donor request) and 1 from a pre-1991 donor-conceived individual.

7.3 The following summarises the nature of these requests:

- Donors wishing to know how many children have been born as a result of their sperm or egg donation. [20 requests]
- Parents wishing to know how many donor-conceived half-siblings their children have. [35 requests]
- Parents wishing to know how many donor-conceived full-siblings (i.e. a sibling conceived using the same egg and the same sperm donor) their children have. [1 request]
- Parents requiring access to non-identifying information about the donor(s) used in the conception of their children. [39 requests]
- Parents wishing to know whether the donor(s) used in the conception of their children have re-registered as an identifiable donor since the law change in April 2005. [17 requests]

7.4 Many requests combine several of these questions. In addition, we know that 90 previously anonymous donors have re-registered as identifiable since the 2004 Regulations came into force in April 2005.

8 Interim Policy

- 8.1 The HFEA has established processes in place to handle requests from parents of donor-conceived people and donors. These processes ensure that identity and proof of address is verified and that requests are processed in a timely and accurate manner.
- 8.2 There is an additional statutory requirement on the HFEA to ensure that donor-conceived people have a suitable opportunity to receive counselling on the implications of receiving information from the HFEA Register. The HFEA policy builds in time for applicants to receive counselling and offers some signposting to counselling services. The policy has been signed off by the Chair of the Authority.
- 8.3 The interim policy, attached in Annex 5, will apply to requests from donor-conceived people until October 2009.

Section C: Principles and Statement of Intent

9 Introduction

- 9.1 The Policy Working Group was established in recognition of the fact that opening the Register involves complex policy work and, because of the potential impact information on the Register has on people's lives, needs to be handled extremely sensitively and robustly.
- 9.2 The first task of the Working Group was to establish and agree the appropriate principles to underpin the OTR policy. This section outlines the Working Group's thinking on these principles. The Working Group also agreed that the OTR work should be underpinned by a public statement of intent, on behalf of the HFEA. This is also outlined in this section.

10 Background

- 10.1 We know that people born as a result of donation may want to know about their genetic origins and may wish to find out what their donor was like and their reasons for donating. Donor-conceived people can also feel a sense of empathy and connection with any genetically related siblings conceived as a result of donation, and wish to be able to make contact with them. Such information and contact can help people complete a picture of their identity and it is natural to seek it. Equally, people born as a result of donor conception may not wish to seek information about their donor or any genetically related donor conceived siblings.. Donors also may wish to seek information about the number of people born as a result of their donation, and parents may wish to have information about their children's donors so that they can pass this onto their children in a manner which is easy for them to understand.

11 Statutory Compliance

- 11.1 The first principle the Working Group considered in its analysis of the OTR policy, was that of statutory compliance. The HFEA has a statutory duty to implement the changes brought about by the Human Fertilisation and Embryology Act 2008. In addition, it also must abide by other legal requirements, for example that of confidentiality.
- 11.2 The principle of legal compliance underpinned the Policy Working Group's deliberation around its policy recommendations and the Group sought legal advice when necessary.
- 11.3 Notably, the Working Group felt that, in the case of parental access rights, the HFEA should go further than its duty to implement legislative requirements. The law permits the HFEA to grant parents' access rights to information about their child's donor. The Group felt that an extension of access rights was in the best interests of donor conceived children and their families. This would enable parents to manage the process of telling their child about their donor conception, the donor and the possible existence of siblings early in the child's life and in age appropriate ways.

12 Enhancing the right of applicants to access information

- 12.1 This principle concerns the right of people affected by donation to receive accurate information from the HFEA in timely, secure and sensitive manner. It also concerns the HFEA's duty to be open about the type of information it holds on the Register.
- 12.2 Several of the Policy Working Group's recommendations are underpinned by this principle. One of the core recommendations which stems from this principle is that the HFEA publishes good quality information to those affected by donation, on the implications of donor-conception and receiving information from the HFEA's Register

13 Duty of Care

- 13.1 The third principle salient to the HFEA policy around OTR is the duty of care the HFEA owes to donor-conceived individuals. This duty of care is partly incurred by virtue of the sensitive nature of the information and its potential to have a significant impact on the recipient. The personal nature of this information puts the HFEA in a close relationship with the applicant. There is also a statutory duty of care placed on the HFEA, towards donor-conceived individuals, to provide a "suitable opportunity to receive proper counselling about the implications of compliance with the request."
- 13.2 The Working Group felt that a primary duty of care is owed to donor-conceived people. This is due to the lack of control this group have over the circumstances of their birth and the potential significant impact the release of information could have on their sense of identity. This primary duty is also reflected in the legislation, which only imposes a duty to provide a suitable opportunity to receive counselling to this group of applicants.
- 13.3 The Group emphasised, however, that the HFEA also has some duty of care to parents and donors. The principle of duty of care underpins several of the Group's recommendations outlined in this paper.

14 Statement of intent

- 14.1 The Group recommends that the HFEA's OTR policy should be underpinned by a public statement of intent which conveys a message to people affected by donation that the HFEA is committed to OTR. The Group suggests the following.

Statement of Intent

The HFEA is mindful that the information contained in its Register can be of crucial importance to donor conceived individuals, their parents and donors. We are aware that the confidentiality requirements of the information need to be carefully balanced with the rightful expectation of applicants to the Register to be given all the information that relates to them.

The HFEA will safeguard the privacy of the information we hold on our Register and release it to those entitled to see it in a consistent, timely and confidential manner. We will work with all those concerned to realise the potential of the Register to meet the information needs of those affected by donation.

The HFEA will treat applicants with respect and sensitivity ~~and~~ and will provide good general information about its processes, about the data it holds and about the possible impacts register information can have on the lives of applicants and their families. We are committed to regularly reviewing and evaluating our opening the register policies and processes.

Section D: Donor-conceived people – access to donor information

15 Introduction

15.1 In considering the principles which should apply to the opening of the Register, the Working Group identified several issues that need to be resolved when opening the Register to donor-conceived applicants.

15.2 These issues include how the HFEA can fulfil its duty to provide a suitable opportunity to receive counselling, the information needs of applicants, whether a fee should be charged for the provision of information and the implementation of a quality assurance process.

16 Counselling and support

16.1 In light of the potentially complex psychological and social issues related to donor conceptions², the Working Group concluded that the HFEA should strongly recommend counselling, or similar support services, to donor-conceived Register applicants.

16.2 In strongly recommending counselling to this group, the Working Group concluded that there is a subsequent duty to provide donor-conceived applicants with effective signposting to qualified counsellors with expertise on the implications of donor-conception.

16.3 Currently the only organisation within the UK which has counselling expertise with donor-conceived people is UK Donor Link (UKDL). UKDL is a voluntary organisation run by After Adoption Yorkshire and funded by the Department of Health. It maintains a voluntary contact register for people affected by donation prior to 1990. Based on mutual consent, UKDL establish links between donors and their offspring and genetically related donor conceived siblings through DNA tests. UKDL provide free counselling support to applicants upon request.

16.4 The other notable group with relevant and transferable expertise in this area is adoption counsellors.

16.5 The Working Group believes that, that as the demographic group of donor-conceived people grows and begins to start accessing information from the Register, there will be an emerging opportunity and need for the counselling and voluntary sector to address the counselling and support needs of this group. The Working Group recommends that the HFEA engage with the sector to maximise the provision of counselling and support available to people affected by donation, by October 2009.

17 ‘Suitable opportunity’

17.1 Thought was given to ensuring donor-conceived applicants have time to consider counselling and retain maximum control over when their information is released.

² British Infertility Counselling Association. *Opening the Record. Planning the Provision of Counselling to People applying for Information from the HFEA Register.* January 2003.

17.2 The approach of the interim policy is to give donor-conceived individuals information on counselling services upon first contact with the HFEA. Applicants are then asked to get back to the Authority in their own time, when they are ready to receive information from the Register. Further, it is pointed out to applicants that they can change their mind at any time regarding their application. The Group decided that the approach of the interim policy should be followed in the long-term policy.

17.3 In addition, a mandatory tick-box should be included on the application form to ensure applicants have received and understood the recommendation to receive counselling and a list of suitable support services.

18 Sensitive handling

18.1 Whilst the HFEA will not be providing counselling to applicants to the Register, all requests must be dealt with sensitively and some applicants may have high-support needs.

18.2 The Group concluded that front-line Register staff should be equipped with adequate skills to deal with applicants who are distressed or have high support needs. The handling of first contacts with applicants needs to be monitored and evaluated.

19 Provision of information

19.1 The Group agreed that the provision of information on the implications of donor-conception may aid donor-conceived applicants to think through accessing information from the Register.

19.2 A US based, on-line, voluntary organisation, *The Donor Sibling Registry* (TDSR), provides assistance to donor-conceived individuals who wish to make links with people who share genetic ties. As part of their service TDSR provides detailed web-based information on the implications of making contact with donor-conceived relatives, what to expect and advice to parents on how to tell their children they are donor-conceived. The Infertility Treatment Authority in Victoria, Australia, also provides similar written support to people affected by donation.

19.3 The Group recommends that the HFEA publishes written information on the implications of donor conception, to donor-conceived individuals and their families, learning from best practice nationally and internationally.

20 Fees

20.1 The HFEA is permitted by law to charge a fee to donor-conceived applicants to access the Register.

20.2 The Group considered that, since donor-conceived applicants bear no responsibility for the circumstances of their conception, such applicants should not be charged a fee.

20.3 The longer-term implications of providing information without a charge was discussed by the Group. The Group felt strongly that we should resist charging donor-conceived

people. If processing requests within the HFEA's current budget becomes unmanageable, we should call on the Department of Health to increase grant-in-aid.

21 Quality Assurance

21.1 The Group believe that it is important for the HFEA to implement a quality assurance system as part of the implementation of the OTR policy, to minimise room for errors in the information we provide to applicants and to evaluate the OTR policy.

21.2 One suggestion was that two people independently process Register requests and then agree on the outcome. This would clearly be resource intensive, but it was considered imperative that some such system is introduced as the potential harm in providing applicants with inaccurate information is too high to allow room for error in the processing of requests.

22 Summary of Working Group recommendations

22.1 A summary of the Working Group's policy recommendations with regard to OTR to donor-conceived applicants is provided below.

22.2 An illustrative policy on providing information to donor-conceived applicants, which reflect these recommendations, is provided in Annex 1.

Working Group recommendations:

- The HFEA should strongly recommend that donor-conceived people wishing to access the Register seek counselling or similar support services before making a formal application.
- The HFEA should ensure that donor-conceived people receive information on counselling before they make an application to the HFEA. This information should include adequate signposting to counselling services. Once an application has been lodged, the applicant must be told that they are free to change their mind at any point before the information is released.
- Currently there are a limited amount of people with the specialist counselling skills to address the emerging needs of donor-conceived people. The HFEA has a role in engaging with the sector to ensure there is adequate provision of appropriate counselling expertise available to donor-conceived applicants.
- Front-line Register staff should have adequate training and skills to enable them to deal sensitively with applicants.
- The HFEA should make clear, good-quality, information on possible implications of seeking information from the HFEA Register publicly available.
- No charge should be made for the release of information to donor-conceived people. This policy should be reviewed in light of demand and resources to meet demand.

- The HFEA must ensure that adequate quality assurance processes are built into the implementation of OTR, to safeguard against errors and the release of inaccurate information and to evaluate the OTR policy.

Section E: Donor-conceived people – Access to the Voluntary Sibling Contact Register

23 Introduction

- 23.1 As outlined in Section B, the revised legislation permits the HFEA to establish and run a voluntary sibling contact register (VSCR) for people born as a result of gamete donation. The VSCR would enable donor-conceived genetic siblings to make contact with each other, provided both sides consent. Individuals would have to make contact with the HFEA to add their details to the VSCR. The HFEA would make the genetic sibling matches and inform applicants if a match occurs.
- 23.2 The Working Group agreed that the HFEA should exercise the power granted by the amended legislation and establish a VSCR.
- 23.3 The Working Group considered that many of the same issues involved in policy around providing donor information to people born as a result of donation are salient to the VSCR policy.
- 23.4 The same recommendations, for example, around counselling and the provision of information apply equally to policy around the VSCR. In addition the Working Group considered issues around confidentiality and the inclusion of the donor's naturally conceived children on the Register.

24 Confidentiality

- 24.1 In thinking through the scope of the information applicants should be permitted to place on the VSCR, the Working Group identified issues around the protection of third party confidentiality.
- 24.2 The Group questioned whether the HFEA could act as a forum for information exchange between siblings through permitting applicants to place personal information about themselves on the VSCR. The Group concluded that, in doing so, there is a risk applicants may inadvertently disclose identifying third party information, for example in describing family and friends. It was suggested that this is a good area of work for a voluntary organisation to take on, but in the Group's view it was not appropriate/possible for the HFEA to run such a service.
- 24.3 The Group concluded, therefore, that applicants should only be permitted to leave their name and how they wish to be contacted on the VSCR.

25 Naturally conceived children

- 25.1 The Group noted that amended legislation specifies that the sibling register is designed to facilitate contact between donor-conceived siblings, but excludes naturally conceived children of the donor. The Group felt that naturally conceived children of the donor also have a legitimate interest in joining the VSCR.
- 25.2 The Group sought legal advice on this point and was advised that the inclusion of the naturally conceived children of donors on the VSCR goes beyond the statutory remit of the HFEA. To do so would raise the risk of inadvertent disclosure of personal data and

other information relating to anonymous donors which would be in breach of the Authority's duties under section 33 of the Human Fertilisation and Embryology Act 1990 (as amended).

26 Provision of information

26.1 The Group agreed that the provision of information on the implications of joining the VSCR was important to help donor-conceived applicants think through the implications of joining the VSCR.

26.2 In addition, the Group concluded that information on the VSCR should be provided to donor-conceived applicants when they apply to the HFEA for information about their donor, however, applicants for HFEA Register information should not be told of sibling matches on the VSCR if they have not made a formal application to the VSCR.

27 Summary of Working Group recommendations

27.1 A summary of the Working Group's policy recommendations with regard to the VSCR is provided below.

27.2 An illustrative policy on accessing the VSCR, which reflect these recommendations, is provided in Annex 2.

Working Group recommendations:

- The HFEA should establish a VSCR.
- The HFEA should strongly recommend that donor-conceived people wishing to access the VCSR, seek counselling or similar support services before making a formal application.
- The HFEA should ensure that donor-conceived people receive information on counselling before they make an application to the HFEA. This information should include the importance of considering counselling and adequate signposting to counselling services. Once an application has been lodged, the applicant must be told that they are free to change their mind at any point before the information is released.
- Currently there are a limited amount of people with the specialist counselling skills to address the emerging needs of donor-conceived people. The HFEA has a role in engaging with the sector to ensure there is adequate provision of appropriate counselling expertise available to donor-conceived applicants.
- Front-line Register staff should have adequate training and skills to enable them to deal sensitively with applicants.
- The HFEA should make clear, good-quality, information on possible implications of seeking information from the HFEA Register publically available.
- No charge should be made for the release of information to donor-conceived people. This policy should be reviewed in light of demand and resources to meet demand.

- The HFEA must ensure that adequate quality assurance processes are built into the implementation of OTR, to safeguard against errors and the release of inaccurate information and to evaluate the OTR policy.
- The HFEA should facilitate only the exchange of names, contact details and a preference for how people wish to be contacted between donor-conceived siblings on the VSCR.
- Donor-conceived people should be told about the Voluntary Sibling Contact Register when they contact the HFEA seeking information about their donor. Information should not, however, be provided about genetically related donor-conceived siblings, unless the applicant makes a formal application.

Section F: Parents – Access to Information about their Donor-Conceived Children

28 Introduction

- 28.1 As noted in Section C, the decision to permit parents access to information from the Register about their children's donor is not a statutory requirement, although it is legally permitted.
- 28.2 The reasoning behind the Working Group's decision to grant access rights to parents is outlined below. In addition the Working Group has made several policy recommendations around how such requests should be handled.
- 28.3 It should be noted that question 12 of the current HFEA consultation on the 8th Code of Practice (attached in Annex 6) relates to the amount and type of information patients seeking treatment with donated gametes and embryos, and parents of donor-conceived children, should be able to access about their donor. With this in mind, the Working Group has not made any recommendations around the amount of donor information which should be disclosed to parents.

29 Parental access rights to information from the Register

- 29.1 The Working Group had a detailed discussion around whether parents should have access rights to non-identifying information about their children's donor. HFEA guidance stipulates that patients seeking treatment with donated gametes and embryos are entitled to all non-identifiable information available about the donor. In theory, therefore, it is unlikely that there will be any additional information to provide to parents after the child's birth, but granting parents access to this information would allow for instances where this information was lost and cases where they were not given full information at the time of treatment.
- 29.2 In addition, it is current HFEA policy to provide parents, upon request, with information about the number, sex and year of birth of any genetically-related donor-conceived siblings of their child.
- 29.3 It was felt that it is likely to be in children's best interests to receive information about their conception, donor and donor-conceived siblings from their parents. The Working Group therefore concluded that parents should continue to be entitled to receive information about their children's donor and anonymous information about any genetically-related donor-conceived siblings their child has.

30 Sharing information with the child

- 30.1 The Working Group concluded that, because the release of information to parents is based on the child's best interests, it should be made clear to parents that it is recommended that the information will be shared with their child.

31 Where to access the information

31.1 Currently parents can access information about their children's donor from the HFEA or the clinic where they received treatment. The Working Group concluded that this should remain the case.

32 Donor codes

32.1 It is current HFEA policy to provide parents of donor-conceived children with their children's donor's donor code. A donor code is a code allotted to donors by the clinic, as part of an internal auditing system. Clinics devise their own system of donor code allocation and as a result donor codes may not uniquely identify donors (where two or more clinics happened to allocate the same code to different donors).

32.2 Donor codes are used by parents of donor-conceived children to establish contact with families who have children conceived from the same donor. This is done through comparing donor codes with other parents of donor-conceived children.

32.3 It is the belief of the Working Group that parents should not be able to access information which allows them to effectively bypass the legal restrictions that apply to donor-conceived people themselves, i.e. donor-conceived people can not trace their siblings until they reach the age of 18 and tracing is done on the basis of mutual consent. It is therefore the recommendation of the Working Group that donor codes should not be released to parents of donor-conceived children.

32.4 A separate paper on the release of donor-codes to parents of donor-conceived children is being brought to the Authority for decision; the Working Group's recommendation may contribute to this debate.

33 Counselling

33.1 Parents may have ongoing counselling needs related to the impact of donor-conception on their child's life. They may also need support in telling their children that they are donor conceived and dealing with the impact of this revelation on their children and the wider family.

33.2 In light of these potential ongoing counselling needs, the Working Group recommends that counselling is suggested to parents of donor-conceived children seeking information from the Register. This approach is in line with the recommendations contained in the British Infertility Counselling Association (BICA) 2003 Report *Opening the Record Planning the Provision of Counselling to People applying for Information from the HFEA Register*.

34 Information

34.1 As with the provision of information to donor-conceived people (see Sections D and E), the Working Group felt it was important to make available good quality general information to parents on the implications of donor conception, and signpost to useful resources on how to tell children they are donor-conceived.

35 Fees

- 35.1 The HFEA is permitted by law to charge a fee to parents to access the HFEA Register. The Group was reluctant to charge fees to parents of donor-conceived people, as the provision of this information is in the best interests of the child. The Group felt, however, that there needs to be some mechanism in place to protect against vexatious requests.
- 35.2 The Group recommends that parents should be permitted one free Register request per year. If they want to apply to the Register more frequently, then they should be charged a fee for each subsequent application. The amount they are charged should be determined by the Fees committee.

36 Summary of the Working Group's Recommendations

- 36.1 The summary of the Working Group's policy recommendations with regard to OTR to parents is provided below.
- 36.2 An illustrative policy on accessing the Register, which reflects these recommendations, is provided in Annex 3.

Working Group Recommendations

- Information access rights should go beyond the mandatory provisions and parents should have access rights to information about their children's donor and the number, sex and year of birth of their children's genetically related donor-conceived siblings.
- It should be made clear to parents that it is recommended that the information will be shared with their children.
- It should be suggested to parents that they may find counselling on the implications of seeking information from the HFEA Register helpful.
- Parents can access donor information either from the clinic where they received treatment or the HFEA. Only the HFEA will be able to provide information about their children's genetically related donor-conceived siblings.
- Information to parents should not bypass legal restrictions that apply to donor-conceived people themselves; therefore donor codes should not be released to parents of donor-conceived people.
- The HFEA should make clear, good-quality general information on possible implications of seeking information from the HFEA Register and the importance of telling children about their origins publicly available.

Section G: Donors – Access to Information about their Donor-Conceived Offspring

37 Introduction

- 37.1 As noted in Section B, gamete and embryo donors are granted statutory access rights to anonymous information about their donor offspring under the amended legislation.
- 37.2 Donors are legally entitled to receive information about the number, sex, and year of birth of anyone born as a result of their donation. The legislation prohibits charging for the provision of this information.
- 37.3 The Working Group considered several issues in relation to policy regarding the provision of information to donors. These are outlined below and include counselling, the primary point of contact for donors, provision of information in different languages, the maintenance of up-to-date contact details.

38 Place of contact

- 38.1 Under current HFEA policy, donors can contact clinics or the HFEA for anonymous information about their donor-conceived offspring. The Working Group recommends that this is maintained under the revised OTR policy.

39 Counselling

- 39.1 Although the HFEA is not obliged by law to provide a suitable opportunity to receive counselling to donors, it is the belief of the Working Group that some donors may have counselling requirements. The Group concluded that counselling should be suggested to donors.

40 Information

- 40.1 As with the provision of information to donor-conceived people and parents (see Sections D,E and F), the Working Group felt it was important to make available good quality information to donors on the implications of accessing the Register.
- 40.2 The Working Group noted the use of imported donor gametes and recommends that the Authority considers the provision of donor information in several different languages.
- 40.3 The Working Group noted the lack of any major publicity campaign to inform donors who donated under the conditions of anonymity that they are entitled to retrospectively remove their anonymity.
- 40.4 The Working Group recommends that donors are provided with information about the possibility to re-register as identifiable when they make enquiries about their donor-conceived offspring. It is important, however, that the HFEA is not seen to encourage donors to remove their anonymity.

41 Summary of Working Group Recommendations

- 41.1 The summary of the Working Group's policy recommendations with regard to OTR to donors is provided below.
- 41.2 An illustrative policy on accessing the Register, which reflects these recommendations, is provided in Annex 4.

Working Group Recommendations

- Donors should be able to contact either the clinic where they donated or the HFEA for information about their donor-conceived offspring.
- Donors should be given information about the right to re-register as identifiable when they make enquiries about their donor-conceived offspring.
- It should be suggested to donors that they may find counselling on the implications of receiving information from the HFEA Register helpful.
- The HFEA should make clear, good-quality information on possible implications of donation publicly available.

Section H: Executive Outputs

42 Introduction

- 42.1 Following the approval of the OTR policy recommendations there will considerable work to do within the Executive in order to implement the policies contained in this paper.
- 42.2 The Working Group has agreed the following actions as appropriate to take the OTR policies forward.

43 Guidance

- 43.1 The HFEA policy team to revise the 8th Code of Practice to reflect the revised OTR policy and the results of Code of Practice consultation (See Annex 6 for Code of Practice consultation questions on the release of donor information).

44 Donor Information Forms

- 44.1 The Working Group believes that the donor information forms should document evidence of donor consent to the sharing of the information provided with anyone born as a result of their donation.
- 44.2 The HFEA policy team to revise the donor-information forms to include written consent from the donor. The Working Group also believes that clinics and prospective donors need better information on how to fill in donor information forms. The policy should therefore liaise with the sector and stakeholders to explore how this information need can be met.

45 Stakeholder event

- 45.1 The Working Group recommends that a stakeholder event is held in the first quarter of 2009, to inform the sector of the OTR policy framework and consult on the details of the policy implementation.
- 45.2 The HFEA policy team to organise and run a stakeholder event in the first quarter of 2009.

46 Information

- 46.1 The policy team to ensure that good quality information on the implications of donor-conception is published and is accessible to people affected by donation.

47 Summary

- 47.1 The above actions and all the recommendations are summarised in Section J, Summary of Recommendations to the Authority.

Section J: Summary of Recommendations to the Authority

48 Introduction

48.1 The following provides a summary of the Working Group Recommendations detailed in this paper. The Authority is invited to discuss and approve these recommendations.

49 Principles and statement of intent

49.1 The following principles should support the HFEA's OTR policy:

- Statutory compliance
- Protection of the right of applicants to access information
- Duty of care

49.2 The OTR policy should be underpinned by the following public statement of intent:

The HFEA is mindful that the information contained in its Register can be of crucial importance to donor conceived individuals, their parents and donors. We are aware that the confidentiality requirements of the information need to be carefully balanced with the rightful expectation of applicants to the Register to be given all the information that relates to them.

The HFEA will safeguard the privacy of the information we hold on our Register and release it to those entitled to see it in a consistent, timely and confidential manner. We will work with all those concerned to realise the potential of the Register to meet the information needs of those affected by donation.

The HFEA will treat applicants with respect and sensitivity and will provide good general information about its processes, about the data it holds and about the possible impacts register information can have on the lives of applicants and their families. We are committed to regularly reviewing and evaluating our opening the register policies and processes.

50 Donor-conceived people accessing information about their donor

50.1 The HFEA should strongly recommend that donor-conceived people wishing to access the Register seek counselling or similar support services before making a formal application.

50.2 The HFEA should ensure that donor-conceived people receive information on counselling before they make an application to the HFEA. This information should include signposting to counselling services. Once an application has been lodged, the applicant must be told that they are free to change their mind at any point before the information is released.

50.3 Currently there are a limited amount of people with specialised counselling skills to address the emerging needs of donor-conceived people. The HFEA has a role in engaging with the sector to ensure there is adequate provision of appropriate counselling expertise available to donor-conceived applicants.

- 50.4 Front-line Register staff should have adequate training skills to enable them to deal sensitively with applicants.
- 50.5 The HFEA should make clear, good-quality, information on possible implications of seeking information from the HFEA Register publicly available.
- 50.6 No charge should be made for the release of information to donor-conceived people. This policy should be reviewed in light of demand and resources to meet demand.
- 50.7 The HFEA must ensure that adequate quality assurance processes are built into the implementation of OTR, to safeguard against errors and the release of inaccurate information and to evaluate the OTR policy.

51 Donor-conceived people access to the Voluntary Sibling Contact Register

- 51.1 The Working Group believes that recommendations 50.1-50.6 should apply to OTR policy around donor-conceived people accessing the VSCR.
- 51.2 The HFEA should facilitate only the exchange of names and a preference for how people wish to be contacted between donor-conceived siblings on the VSCR.
- 51.3 Donor-conceived people should be told about the Voluntary Sibling Contact Register when they contact the HFEA seeking information about their donor. Information should not, however, be provided about genetically related donor-conceived siblings, unless the applicant makes a formal application.

52 Parents of donor-conceived people

- 52.1 Information access rights should go beyond the mandatory provisions and parents should have access rights to information about their children's donor and the number, sex and year of birth of their children's genetically related donor-conceived siblings.
- 52.2 It should be made clear to parents that it is recommended that the information will be shared with their children.
- 52.3 It should be suggested to parents that they may find counselling on the implications of seeking information from the HFEA Register helpful.
- 52.4 Parents can access donor information either from the clinic where they received treatment or the HFEA.
- 52.5 Information to parents should not bypass legal restrictions that apply to donor-conceived people themselves; therefore donor codes should not be released to parents of donor-conceived people.
- 52.6 The HFEA should make clear, good-quality information on possible implications of seeking information from the HFEA Register and the importance of telling children about their origins publicly available.

53 Donors

- 53.1 Donors should be able to contact either the clinic where they donated or the HFEA for information about their donor-conceived offspring.
- 53.2 Donors should be given information about the right to re-register as identifiable when they make enquiries about their donor-conceived offspring.
- 53.3 It should be suggested to donors that they may find counselling on the implications of receiving information from the HFEA Register helpful.
- 53.4 The HFEA should make clear, good-quality information on possible implications of donation publicly available

54 Executive Outputs

- 54.1 The Working Group recommends that a stakeholder event is held in the first quarter of 2009, to inform the sector of the OTR policy framework and consult on the detail of the policy implementation.
- 54.2 The HFEA policy team to revise the 8th Code of Practice to reflect the revised OTR policy and the results of Code of Practice consultation (See Annex 6 for Code of Practice consultation question on the release of donor information).
- 54.3 The HFEA policy team to revise the donor-information forms to include written consent from the donor.
- 54.4 The policy team to ensure that good quality information on the implications of donor-conception is published and is accessible to people affected by donation

Annex 1

An Illustrative Policy

Donor-Conceived People – Access to Donor Information

1. All front-line Register staff must have adequate training and skills to deal sensitively with Register applicants.
2. Applicant makes initial contact with the HFEA, either via the website or by telephone or in writing. Information on the process of accessing information from the Register is given to the applicant. This information can either be sent in writing or applicants can be directed to the HFEA website.

The information will include the following on counselling:

The HFEA strongly recommends that you receive counselling or similar support services on possible implications of receiving information from the HFEA Register. Below are some organisations you may choose to contact for advice about counselling services:

The British Association for Counselling and Psychotherapy (www.bacp.co.uk)

Your local GP may also be able to refer you to a counsellor

Action: engage with sector to improve signposting to appropriate counselling services.

The applicant will be informed that they need to complete and submit an application form once they have had the opportunity to consider counselling, and have made a decision that they are ready to pursue an application for information from the Register. The applicant will be advised that they need to include proof of identity and address with the request.

3. HFEA receives a completed application, along with proof of identity and address. The application form will include a mandatory tick box for people to indicate whether they have received and understood information on counselling. The applicant is told that it will take a minimum of 5 working days to process the application and a maximum of 20 working days. This is to allow a full week for the applicant to change his or her mind and postpone the release of the information. The request is processed as soon as possible, within a maximum of 20 working days. No charge is made for the release of this information
4. Proof of identity and address is scanned and returned to applicant within X working days of receiving the application.
5. The requested information is sent by special delivery to the applicant at least two days before the time limit expires.
6. Copies of identity documents and proof of address are destroyed after a period of six months.

Annex 2

An Illustrative Policy

Donor-Conceived People – Access to the Voluntary Sibling Contact Register

1. All front-line Register staff must have adequate training and skills to deal sensitively with Register applicants.
2. Applicant makes initial contact with the HFEA, either via the website or by telephone or in writing. Information on the process of accessing information from the Register is given to the applicant. This information can either be sent in writing or applicants can be directed to the HFEA website.

The information will include the following on counselling:

The HFEA strongly recommends that you receive counselling or similar support services on possible implications of receiving information from the HFEA Register. Below are some organisations you may choose to contact for advice about counselling services:

The British Association for Counselling and Psychotherapy (www.bacp.co.uk)

Your local GP may also be able to refer you to a counsellor

Action: engage with sector to improve signposting to appropriate counselling services.

The applicant will be informed that they need to complete and submit an application form once they have had the opportunity to consider counselling, and have made a decision that they wish to register their details on the VSCR. The applicant will be advised that they need to include proof of identity and address with the request.

3. HFEA receives a completed application, along with proof of identity and address. The application form will include a mandatory tick box for people to indicate whether they have received and understood information on counselling. The applicant is told that it will take a minimum of 5 working days to process the application and a maximum of 20 working days. This is to allow a full week for the applicant to change his or her mind and postpone the release of the information. The request is processed as soon as possible, within a maximum of 20 working days. No charge is made for the release of this information.
4. Proof of identity and address is scanned and returned to applicant within X working days of receiving the application.
5. Written confirmation that details have been placed on the VCSR is sent to the applicant.
6. As and when sibling matches are made, details are sent to all affected applicants. Information will included the name, contact details and the preferred method of contact.
7. Copies of identity documents and proof of address are destroyed after a period of six months.

Annex 3

An Illustrative Policy

Parents of Donor-Conceived People – Access to Information about their Children’s Donor and Siblings

1. All front-line Register staff must have adequate training and skills to deal sensitively with Register applicants.
2. Applicant makes initial contact with the HFEA, either via the website or by telephone or in writing. Information on the process of accessing information from the Register is given to the applicant. This information can either be sent in writing or applicants can be directed to the HFEA website.

The information will include the following:

- *What information parents can access about their children’s donor.*
- *The importance of being open with children about their donor-conceived origins.*
- *Signpost to sources of information about how to share information with their children (Donor Conception Network)*

You may find counselling or similar support services on the possible implications of receiving information from the HFEA Register. Below are some organisations you may choose to contact for advice about counselling services:

The British Association for Counselling and Psychotherapy (www.bacp.co.uk)

Your local GP may also be able to refer you to a counsellor

Action: engage with sector to improve signposting to appropriate counselling services.

The applicant will be informed that they need to complete and submit an application form to receive information from the Register. The applicant will be advised that they need to include proof of identity and address with the request.

3. HFEA receives a completed application, along with proof of identity and address. The applicant is told that it will take a minimum of 5 working days to process the application and a maximum of 20 working days. This is to allow a full week for the applicant to change his or her mind and postpone the release of the information. The request is processed as soon as possible, within a maximum of 20 working days. No charge is made for the release of this information if the number of requests does not exceed one per year.
4. Proof of identity and address is scanned and returned to applicant within X working days of receiving the application.
5. The requested information is sent by special delivery to the applicant at least two days before the time limit expires.
6. Copies of identity documents and proof of address are destroyed after a period of six months.

Annex 4

An Illustrative Policy

Donors – Access to Information about Donor-conceived Individuals

1. All front-line Register staff must have adequate training and skills to deal sensitively with Register applicants.
2. Applicant makes initial contact with the HFEA, either via the website or by telephone or in writing. Information on the process of accessing information from the Register is given to the applicant. This information can either be sent in writing or applicants can be directed to the HFEA website.

The information will include the following on counselling:

You may find counselling or similar support services on the possible implications of receiving information from the HFEA Register. Below are some organisations you may choose to contact for advice about counselling services:

The British Association for Counselling and Psychotherapy (www.bacp.co.uk)

Action: engage with sector to improve signposting to appropriate counselling services.

The applicant will be informed that they need to complete and submit an application form to receive information from the Register. The applicant will be advised that they need to include proof of identity and address with the request.

3. HFEA receives a completed application, along with proof of identity and address. The applicant is told that it will take a minimum of 5 working days to process the application and a maximum of 20 working days. This is to allow a full week for the applicant to change his or her mind and postpone the release of the information. The request is processed as soon as possible, within a maximum of 20 working days. No charge is made for the release of this information.
4. Proof of identity and address is scanned and returned to applicant within X working days of receiving the application.
5. The applicant is informed that he can re-register as an identifiable donor.
6. The requested information is sent by special delivery to the applicant at least two days before the time limit expires.
7. Copies of identity documents and proof of address are destroyed after a period of six months.

Annex 5

HFEA Interim Policy

Processing requests for information from the HFEA Register for donor-conceived applicants: a three stage process

1. Applicant makes initial contact with the HFEA, either via the website or directly by telephone or in writing. Information on the process of accessing information from the Register is given to the applicant. This information can either be sent in writing or applicants can be directed to the HFEA website to download it.

The information will include the below on counselling:

The HFEA strongly recommends that you receive counselling or similar support services on the implications of you receiving information from the HFEA Register. Below are some organisation details you may choose to contact for advice about counselling services:

- *The British Association for Counselling and Psychotherapy (www.bacp.co.uk)*
- *Your local GP may also be able to refer you to a counsellor*

The applicant will be informed that they need to contact the HFEA again in writing once they have had the opportunity to consider counselling, and have made a decision that they are ready to pursue an application for information from the Register. The applicant will be advised that they need to include proof of identification and address with the request.

2. HFEA receives a request to access to information from the Register in writing, along with proof of identification and address. The request is processed as soon as possible, within a maximum of 20 working days.
3. The requested information, along with proof of identity and address, is sent by special delivery to the applicant at least two days before the time limit expires.

Annex 6

Code of Practice consultation questions regarding access to donor information

COP8 – consultation questions

Information for patients undergoing donor treatment

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.

12a. What information do you think those who are choosing a donor should be allowed to access about the prospective donor, as long as this has been made clear to the donor beforehand?

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).

I don't have a view

Please tell us why

12b. What information do you think should be made available to parents of donor-conceived individuals about the donor?

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).

I don't have a view

Please tell us why

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