

Donor Information Requests

Strategic delivery: Safe, ethical, effective treatment Consistent outcomes and support Improving standards through intelligence

Details:

Meeting	Authority
Agenda item	10
Paper number	HFEA (27/06/2018) 887
Meeting date	27 June 2018
Author	Sumrah Chohan, Donor Information Manager

Output:

For information or decision?	For information and decision
------------------------------	------------------------------

Recommendation	<p>The Authority is asked to note:</p> <ul style="list-style-type: none"> the update on OTR activity and performance the supportive way in which OTRs are handled by the team the positive feedback received about the support service, and the arrangements for its continuation the potential impact of DNA testing ancestral websites the steps the Donor Information Team is taking in planning for the future of the OTR service <p>The Authority is asked to agree:</p> <ul style="list-style-type: none"> that we continue the service on a rolling contract basis with PAC-UK
----------------	---

Resource implications	In budget
-----------------------	-----------

Implementation date	OTR service ongoing
---------------------	---------------------

Communication(s)	OTR service on website
------------------	------------------------

Organisational risk	<input type="checkbox"/> Low <input checked="" type="checkbox"/> Medium <input type="checkbox"/> High
---------------------	---

1. Introduction

- 1.1.** For some years now, we have provided the Authority with an annual report on the number and type of donor information requests (known as Opening the Register (OTR)) and associated counselling support. This paper updates the position to cover activity in 2017. The paper also highlights some policy areas affecting OTR requests the Donor Information Team is working on.

2. Background

- 2.1.** The Human Fertilisation and Embryology Act requires the Authority to keep a Register of information about donors and treatments involving the use of donor gametes and embryos in the UK. It also records the notified births resulting from these treatments.

- 2.2.** Donor-conceived people and donors have a statutory right of access to information held on the Register as follows:

- 16-year-old donor-conceived people can find out:
 - if they are donor-conceived
 - non-identifying information about their donor
 - the number, gender and year of birth of any donor-conceived genetic siblings
 - if their donor has removed their anonymity (since 2005)
 - if they might be related to an intended spouse or partner
- 18-year-old donor-conceived people can find out:
 - identifying information about their donor (if the donor is identifiable)
 - identifying information about their donor-conceived genetic siblings, if both sides consent (via Donor Sibling Link (DSL))
- Donors can:
 - find out the number, gender and year of birth of any children conceived from their donation
 - remove their anonymity - which is relevant to those who donated before the law changed on 1 April 2005

- 2.3.** Parents have no statutory rights to access Register information although in 2004 they were granted discretionary access rights to the following information:

- non-identifying information about their donor
- the number, gender and year of birth of any donor-conceived genetic siblings
- if their donor has removed their anonymity (since 2005)

- 2.4.** As noted above, applications by donor-conceived people, donors and parents for Register information are known as Opening the Register (or OTR). The HFEA has had a process in place for dealing with OTR applications by parents and donors since 2005, and donor-conceived people since 2007 (when the first cohort of donor-conceived people on our Register turned 16). Applicants

submit the relevant application form with proof of identity and address by post to us. We return their identity documents within 5 working days and respond to their application within 20 working days – both by special delivery post. We retain a copy of their identity documents for 5 years to enable applicants who wish to re-apply for updated information at a later date to do so with more ease.

- 2.5.** The OTR service is provided primarily by a small dedicated team (the Donor Information Manager and Donor Information Officer), with some additional support provided by two other members of the Register Team. All OTR staff have completed a 30-hour Introduction to Counselling Skills course. The current Donor Information Manager took over the role in May 2017. In addition to counselling skills training, she has attended Donor Conception Network conferences and also delivered presentations at various conferences to highlight the importance of issues affecting donor conception and to build good working relationships with clinics.

3. HFEA strategy 2017-2020

- 3.1.** The HFEA strategy 2017-2020, puts patients (including donors and donor-conceived people) and the quality of care and support they receive at the centre of our work. The following elements are relevant to this paper:

Vision: High quality care for everyone affected by fertility treatment

- Improve the emotional experience of care before, during and after treatment or donation
- Donors, parents and donor-conceived people to understand how their information is stored and how they can access it

What we will do:

- Focus efforts on support before, during and after treatment for patients, donors and donor-conceived people
- Make excellent support a core message

- 3.2.** The OTR service is fundamental in the achievement of these strategy objectives. The continued dedication to ensure all OTRs are handled to the highest quality and care contributes further to this aim.

Support and intermediary service

- 3.3.** In March 2014, as part of its commitment to providing improvements to the levels of support offered to people affected by donation, the Authority agreed a three-year 'pilot' service to provide enhanced support services at a national level. The contract to do so was awarded to PAC-UK in 2015, an adoption support agency with relevant expertise and suitably qualified staff.
- 3.4.** We currently fund a limited number of 1-hour contact sessions, which can be delivered flexibly, for:
- adult donor-conceived people who have or are considering applying for identifying information about their donor; or are considering joining DSL and making contact with their donor-conceived sibling(s)

- donor-conceived people over the age of 16 who have or are considering applying for non-identifying information about their donor
- donors considering re-registering to be an identifiable donor
- donors who are aware that an adult person conceived from their donation has applied for their identifying information
- we have also offered services to some donor-conceived adults who have found out they are donor-conceived via DNA testing websites (see section 5 below) and also donors who may have accidentally been matched with people conceived from their donation

3.5. Since the pilot was launched, 49 referrals (out of which 25 were made in 2017) have been made to the support service:

- 20 have been for donor-conceived adults who have applied for information about their donor and any donor-conceived siblings
- 6 have been for donors considering removing anonymity
- 5 have been for donors where their identifying details have been requested by people born as a result of their donation
- 1 referral has been made for a donor-conceived individual who found out they were donor-conceived via a DNA website
- 1 referral has been made for a parent who suspected that they had found out the identity of their donor
- 1 referral was made for the donor where the parent had found out their identity
- 6 were made for donor-conceived people who had matches on Donor Sibling Link
- 5 have been made for people considering joining Donor Sibling Link
- 4 have been made for other reasons where we felt support was needed

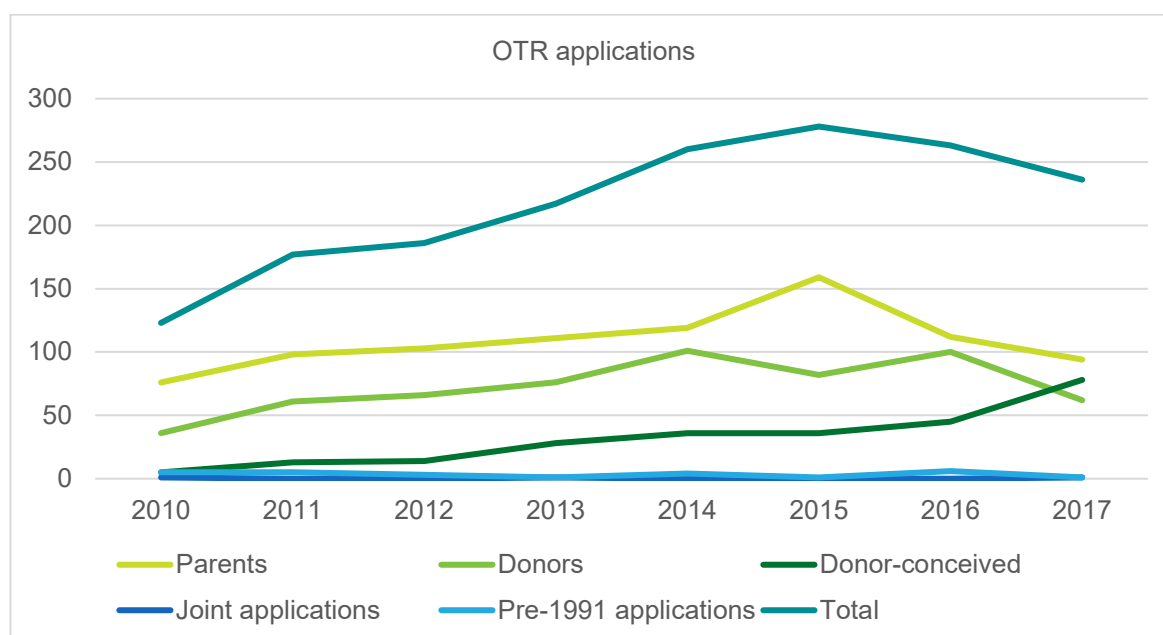
3.6. We survey service users as to their experience of the support service. All respondents rated the service as good or excellent, and all had appointments arranged within a week of the service user contacting the support service. The HFEA team is very satisfied that the service meets requirements, as well as service users.

3.7. Whilst the service was originally conceived a pilot service, given the modest numbers involved and the high quality of the service provided, we wish to provide PAC-UK with a commitment over the next few years at least, ensuring we support our 2017-2020 strategy commitments.

3.8. As noted above, our original intention was to run a three-year pilot. As above, all the evidence suggests users are happy with the current service provided by PAC-UK. In view of this, and the less than anticipated take up to date, we see little merit in a full-scale assessment of the three-year pilot at this stage and suggest instead to continue with a 'rolling' contract with PAC-UK with performance assessment at annual intervals. This is a specialist area, with few alternative providers available to us, and we are keen to provide certainty to PAC-UK.

4. Performance

- 4.1.** The number of OTR applications we receive is unpredictable but is driven by two principle factors: the increase in the number of donor treatments over time (which gives rise to more donors and donor conceived people who might wish to use the OTR service) and a greater openness among families (which gives rise to more donor conceived children being aware of their background). This is broadly supported in our figures: the number of donor-conceived applications has steadily risen since 2010, with a sharp rise to 78 applications in 2017 compared with 45 submitted in 2016.
- 4.2.** In looking at the number of OTR applications overall, there was a slight decrease in the number handled in 2017 compared to the previous year – largely as a result of fewer applications received from donors. Nevertheless, confirming the unpredictability, we have handled over 20 more OTR applications from donors, donor-conceived and parents to date in 2018 than for the same period in 2017.



	2010	2011	2012	2013	2014	2015	2016	2017
Parents	76	98	103	111	119	159	112	94
Donors	36	61	66	76	101	82	100	62
Donor-conceived	5	13	14	28	36	36	45	78
Joint applications	1	0	0	1	0	0	0	1
Pre-1991 applications	5	5	3	1	4	1	6	1
Total	123	177	186	217	260	278	263	236

- 4.3.** As of the end of 2017, 158 donor-conceived people have joined Donor Sibling Link, our voluntary contact register where people join to make contact with their donor-conceived genetic siblings. We have previously seen a steady but relatively low number of people joining each year, with 24 in 2015 and 27 in 2016. 41 registrants joined in 2017 which is in line with the rise in donor-

conceived applicants submitting OTR applications in 2017. We expect numbers to grow as we approach the 18 year anniversary of the lifting of anonymity in 2023 (see section 6 below). The first Donor Sibling Link match was made in 2015, with a further 4 matches in 2016 and 4 in 2017. A single match has been made so far this year which we are helping co-ordinate. In each case, support and intermediary assistance is offered.

- 4.4.** As of the end of 2017, 174 applications from donors wishing to remove their anonymity were received. These donors donated after the HFEA was set up and before the change in law in April 2005 whereby all donors would be identifiable to their donor-conceived once they turned 18 years old. We received 9 applications from donors to remove their anonymity in 2016 and 9 in 2017. We are aware with 2023 approaching, this may prompt interest from such donors to remove their anonymity and will be taking this into account when planning for the future (again see section 6 below).
- 4.5.** The first application for identifying information to be released to an adult donor-conceived child was received in 2013. In total, we have received 11 applications of this kind. Nine applicants have proceeded with receiving the identifying information, with the remainder deciding not to proceed with their application. In each case, support and intermediary assistance was offered where desired to the donor and donor-conceived person involved.

5. DNA testing websites

- 5.1.** We have been contacted by various people affected by donor-conception and interested stakeholders about the growing popularity of DNA testing websites and their potential impact on those affected by donor-conception.
- 5.2.** Websites of this nature are marketed at consumers wishing to discover their ancestral origins. A shared concern is that individuals using these websites may discover additional information (they may not have been expecting) such that they may be donor-conceived or donors seeing details of people born as a result of their donation. We are aware of parents who seek to use such websites in the hope of discovering their donors' identity and any donor-conceived siblings their children may have.
- 5.3.** This raises some wider issues about anonymity and we shall return to Authority with further advice in due course.

6. Preparing for 2023

- 6.1.** As noted above, the first cohort of adult donor-conceived people turn 18 in 2023. This, coupled with the steady increase in the number of OTR applications from donor conceived people, means that we are beginning to think about what impact this will have on the OTR service and the organisation.
- 6.2.** Currently the OTR service is delivered by a small team of two people with additional support from members of the Register Team. We will be monitoring the number of OTR applications received in the lead up to 2023 to evaluate whether the team will need expanding or further assistance.

- 6.3.** In line with planning for 2023, we will also be planning for an increase in the number of Donor Sibling Link applications which will involve evaluating the current software system that is used and its ability to meet the needs of registrants.
- 6.4.** In doing this work, we will also be taking into consideration the potential for media coverage which may highlight to donors donating prior to the change in law in April 2005, that they have the option to remove their anonymity if they wish, which could lead to an increase in the number of donors removing their identity.

7. Recommendations

7.1. The Authority is asked to note:

- the update on OTR activity and performance
- the supportive way in which OTRs are handled
- the positive feedback received about the support service, and the arrangements for its continuation
- potential impact of DNA testing ancestral websites
- the steps the Donor Information Team is taking planning for the future of the OTR service

7.2. The Authority is also asked to agree:

- That we continue the service on a rolling contract basis with PAC-UK