

# Opening the Register report

**Strategic delivery:**       Setting standards       Increasing and informing choice       Demonstrating efficiency economy and value

## Details:

Meeting	Authority
Agenda item	10
Paper number	HFEA (06/07/2016) 803
Meeting date	6 July 2016
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## Output:

For information or decision?	For information
Recommendation	<p>The Authority is asked to note:</p> <ul style="list-style-type: none"> <li>• the significant OTR policy and process developments over the last three years, which are in line with delivering the HFEA 2014-2017 strategy</li> <li>• the prospect of the first cohort of post-2005 donor-conceived children turning 18, and developments in genealogy DNA testing sites that will impact on anonymity more generally</li> <li>• the trend showing increases in the number of applications, and the timely and sensitive way in which they are handled</li> <li>• the first-year evaluation of the pilot support service and the informal positive feedback received from service users.</li> </ul>
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

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## 1. Introduction

- 1.1.** This paper brings the Authority up to date on the activity in the Opening the Register (OTR) service over the last year and, in particular, the pilot support and intermediary service.

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## 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.<sup>1</sup>

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

- 16-year-old donor-conceived individuals can find out:
  - if they are donor-conceived
  - non-identifying information about their donor
  - the number, sex and year of birth of any donor-conceived genetic siblings
  - if their donor has removed their anonymity
  - if they might be related to an intended spouse or partner
- 18-year-old donor-conceived individuals 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, our voluntary contact register)
- Donors can:
  - find out the number, sex 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

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<sup>1</sup> There is also a Donor Conceived Register specifically for people conceived before the HFEA register was set up in August 1991. It links these individuals through DNA matching and offers advice and support. It can also bring people into contact with others in the same situation. Since 2013 it has been run by the National Gamete Donation Trust.

- the number, sex and year of birth of any donor-conceived genetic siblings
- if their donor has removed their anonymity

- 2.4.** Applications by donor-conceived individuals, donors and parents for Register information are known as Opening the Register (OTR). 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 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 Donor Information Manager has worked in the OTR team for 5 years and, in addition to counselling skills training, she has completed an accredited mediation course and Samaritans training on handling challenging contacts. She has also attended BICA study days and a number of Donor Conception Network conferences.

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### **3. HFEA strategy 2014-2017**

- 3.1.** The HFEA strategy 2014-2017, puts patients (including donors and donor-conceived people) and the quality of care they receive at the centre of our work.

*Vision: High quality care for everyone affected by assisted reproduction*

- Support for patients, donors and donor-conceived people
- Excellent service and information from the HFEA

*What we will do:*

- We will improve the lifelong experience for donors, donor-conceived people, patients using donor conception, and their wider families.

*How we will work:*

- We will make the quality of care experienced by patients, donors and donor-conceived people our central priority and the primary consideration in our decision making.

- 3.2.** The OTR service is fundamental in the achievement of these strategy objectives. Recent developments and improvements contribute further to this aim.

#### **Information on donor re-registration for past applicants**

- 3.3.** A number of donors who donated anonymously before 1 April 2005 have since chosen to remove their anonymity. However, many more have not but may choose to do so in the future.

- 3.4.** We want to enable people who have already made applications and been told that the donation was made anonymously to be able to check whether the donor has since removed their anonymity. To this end, website content was created in 2013 enabling previous applicants to check using a unique reference code provided to them.
- 3.5.** We have also improved the information and guidance on all our application forms and, for donors in the process of re-registering, we have added in steps to ensure they have the opportunity to discover the outcome of their donation first and fully consider the implications of the decision to re-register.

#### Improving the sharing, quality and disclosure of donor information

- 3.6.** Following publication in 2013 of the 'Lifecycle' leaflet to give donors an idea of what they can write about themselves we expect donor-conceived people will receive better information about their donor in future.
- 3.7.** Following a workshop held at the HFEA Annual Conference in 2014, we developed a guidance pack for clinics to support their disclosure of all non-identifying donor information to patients. This pack was provided to clinics in March 2015 along with the redaction framework and a good practice case study.
- 3.8.** A workshop was also held at the HFEA Annual Conference in 2015 focusing on how clinics can look after their donors and highlighted the importance of supporting donors properly, not only throughout their donation, but afterwards too.

#### Support and intermediary service

- 3.9.** In April 2013 the Nuffield Council on Bioethics report 'Donor conception: ethical aspects of information sharing' made recommendations relating to donor information and support for applicants to the Register. The McCracken review of the HFEA in 2013 also recognised the importance of this work.
- 3.10.** Support for Register applicants was also identified as a high priority by a group of key stakeholders in June 2013 as no established, professional practice existed for providing support to those accessing donor identifying information from the HFEA Register, and potentially making contact with a donor.
- 3.11.** The Authority approved scoping work in July 2013 and in March 2014 agreed a three-year pilot to provide enhanced support services at a national level. A contract to deliver such a service to people affected by donation was awarded to PAC-UK in 2015, an adoption support agency with relevant expertise and suitably qualified staff.
- 3.12.** We delivered a two-day training event to PAC-UK in May 2015 and developed a suite of leaflets to compliment, or act as an alternative to, the support service which launched on 1 June 2015.
- 3.13.** The HFEA funds 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 Donor Sibling Link 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.

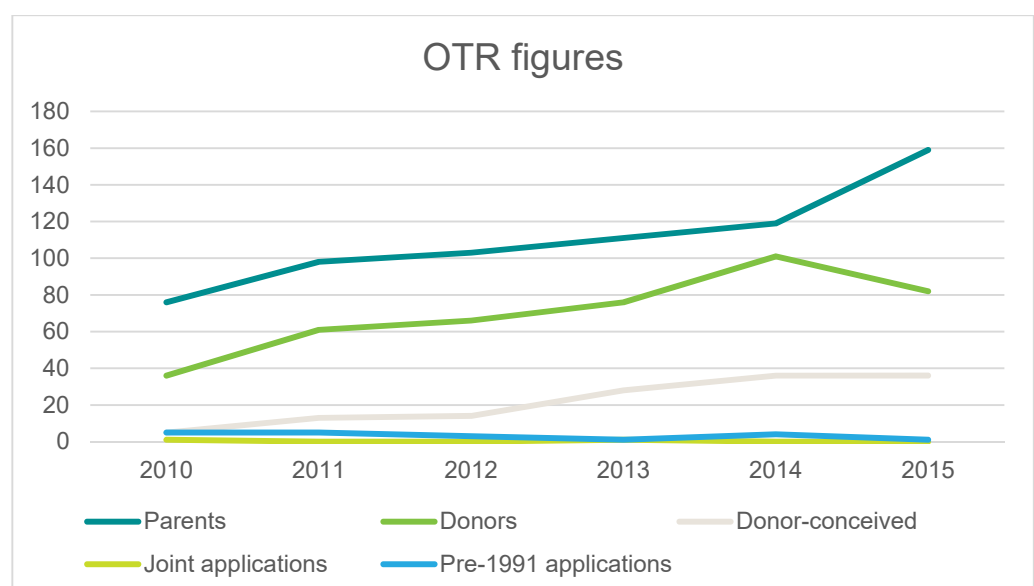
### Looking ahead

**3.14.** The Authority will soon be thinking about the HFEA Strategy for 2017-2020. It is worth noting that the strategy after that will need to take into account the coming of age of the post-2005 donor-conceived cohort. There were approximately 1,250 to 1,500 donor-conceived births per year following the April 2005 law change so it will be necessary to keep an eye on the support service in this light.

**3.15.** In any event this could all be somewhat immaterial given the huge growth of DNA testing sites for genealogy purposes. There are significant implications for donors and donor conception families in terms of how this affects the notion of donor anonymity.

## 4. Performance

**4.1.** We have seen a steady rise year-on-year in the number of OTR applications handled, with over double the amount in 2015 compared to 2010 (see table below).



	2010	2011	2012	2013	2014	2015
Parents	76	98	103	111	119	159
Donors	36	61	66	76	101	82
Donor-conceived	5	13	14	28	36	36
Joint applications	1	-	-	1	-	-
Pre-1991 applications	5	5	3	1	4	1
<b>Total</b>	<b>123</b>	<b>177</b>	<b>186</b>	<b>217</b>	<b>261</b>	<b>278</b>

- 4.2.** In addition, since launching in 2010, 99 adult donor-conceived individuals have joined Donor Sibling Link (DSL). This is our voluntary contact register, whereby registrants agree to us sharing their name and contact details with any of their donor-conceived genetic siblings who have also joined. Numbers registering are still small - 11 per year in 2011 and 2012, increasing to 21 per year in 2013 and 2014, and 24 in 2015 – but will likely grow significantly in the coming years. In 2015 we made the first DSL match and there have been two further matches so far this year.
- 4.3.** We have also received 157 applications in total from anonymous donors (those who donated after the HFEA was set up but before 1 April 2005) to remove their anonymity. Over the last four years there have been slight increases year-on-year in such applications however; numbers are disappointingly low with only 14 doing so in 2015.
- 4.4.** In 2013 a first application for identifying information from an adult donor-conceived individual with an identifiable donor was received. In total seven applications of this nature have been received; two per year in 2013, 2014 and 2015 and one so far this year.
- 4.5.** In each case we offered and coordinated support and intermediary assistance to the donor-conceived individuals and donors concerned.

### Feedback

- 4.6.** As part of the OTR service, applicants are provided with a link to an online confidential feedback questionnaire. A summary of the feedback received since the last update to the Authority in July 2015 will be provided in a presentation when the Authority meets on 6 July 2016.

## 5. Support service evaluation

- 5.1.** At the time of agreeing the three-year pilot support and intermediary service in 2014, the Authority asked that the HFEA retained control over the quality of any service provided and evaluated the service during the course of the pilot.

- 5.2.** We developed an evaluation framework for this purpose and an evaluation of the service will be presented to the Authority on an annual basis in July 2016 (here), July 2017 and a final paper in January 2018.
- 5.3.** The evaluation of the first year of the service covers:
- The cost of the service
  - The level of demand for the service and its value to users
  - The quality of the service provided by the contractor

### Cost

- 5.4.** The Authority set aside a capped budget of £50,000 for the duration of the pilot. This amount covers the cost of PAC-UK's initial service set up and training, and from then on a 'pay as you go' arrangement for each session provided at a fixed rate (£99 + VAT). The initial set up and training cost was £7248 and the total charge for sessions (inclusive of VAT) provided over the first year (period 1 June 2015 – 31 May 2016) was £594. This second sum would indicate that the amount set aside for the pilot will be more than sufficient for its duration.

### Demand

- 5.5.** In the first year of the service we referred a total of just seven cases for HFEA-funded support to PAC-UK.
- A sperm donor following an application for his identifying details
  - Two egg donors – one whose identifying details were requested and one who was considering removing her anonymity
  - An embryo donor couple considering removing their anonymity
  - Three donor-conceived adults – one who had requested their donor's identifying details, one following a sibling match on Donor Sibling Link and the other following the provision of non-identifying information from us.

Out of the seven cases, six contacted PAC-UK within its first year and four received support (several of these cases are ongoing).

- 5.6.** Looking ahead, it is difficult to assess the level of demand for the service in the next two years, but given demand so far it is not expected to be high.
- 5.7.** In 2015 there were nearly 19,000 children aged 16 or above conceived following donor treatment between 1991 and 2005, and who had therefore reached the age where they could access non identifying information about their donor(s) and donor-conceived genetic siblings from the Register.
- 5.8.** There were also nearly 4,500 additional individuals aged 18 or above in 2015. Out of this number of adults, only the small percentage whose donor(s) had removed their anonymity could access identifying information about them, and only those who have donor-conceived genetic siblings would be eligible to join Donor Sibling Link. The rate of donors re-registering is also very low.

- 5.9.** The cohort of people eligible to seek funded services is therefore small and many may not know they are donor-conceived. Of those who do know, some may not be interested in accessing information at all and some may not feel a need for professional support. Where anonymous donors are concerned, many who contact the HFEA are not aware that they can request information on the outcome of their donation, let alone re-register as identifiable.
- 5.10.** The support service is also available on a self-funded basis to those who are not eligible for HFEA-funded support (e.g. parents etc.) but there has not been any demand in this area. This may be down to several factors including; a lack of awareness of the existence of the service, the cost to those self-funding (£89 per session) and the availability of free informal support from charitable organisations such as Donor Conception Network.

### Quality

- 5.11.** All service users are invited to fill in a feedback form, which is then sent to both PAC-UK and the HFEA. The form also states that if there is anything the user would like to tell the HFEA in confidence, they can contact us directly.
- 5.12.** We have not received any feedback forms so far, which may be because some referrals are ongoing and some have not begun yet. Despite a lack of formal feedback, the informal feedback received from users in correspondence with the HFEA has been positive. Users have expressed gratitude that such a service exists and have found it helpful.
- 5.13.** We have not received any formal complaints from users regarding the service, although we did receive an informal complaint from the first person we referred to the service who, at the time, had yet to receive any sessional support. The complaint concerned the difficulty and delay the user was experiencing with accessing support from PAC-UK and distress at a request from a support worker for sensitive personal information by email. PAC-UK acted very quickly once we brought the complaint to their attention. The user chose to proceed with a different support worker and reported it had been a positive experience.
- 5.14.** Although PAC-UK did not meet the KPI for providing support within the required timeframe to the above user, since then they have met all their KPIs where users are concerned.
- 5.15.** The quality of the relationship between the HFEA and PAC-UK has improved significantly in recent months (e.g. ease of interactions, PAC-UK's level of engagement and commitment; whether we have had to chase information). However; there has been some cause for concern at times particularly with late submission of information and a frequent need to chase up any information requested.
- 5.16.** PAC-UK took a little time to adjust to providing a support service which required the unavoidable, and integral, involvement of the HFEA to (a) refer funded people to PAC-UK and (b) hold PAC-UK accountable to the same standards of service delivery as the HFEA holds for itself.



- 5.17.** Furthermore, our contract with PAC-UK only represents a tiny percentage of the work their organisation does, given the cohort of eligible users is small and the service uptake has been low.
- 5.18.** As noted above, the support service is a pilot scheme and, as with any pilot, it will inevitably involve some trial and error. It's clearly preferable that any teething problems occur while the number of service users is low rather than when numbers rise and any issues could potentially have a wider impact.
- 5.19.** It is very encouraging, however, that all informal user feedback has been positive following support sessions. The outcome of the HFEA's meeting with PAC-UK earlier this year was also very reassuring. Both the HFEA and PAC-UK share a common goal of providing an excellent service to all concerned and the HFEA looks forward to further collaborative working as the pilot proceeds.

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## 6. Recommendation

- 6.1.** The Authority is asked to note:
- the significant OTR policy and process developments over the last three years, which are in line with delivering the HFEA 2014-2017 strategy.
  - the prospect of the first cohort of post-2005 donor-conceived children turning 18, and developments in genealogy DNA testing sites that will impact on anonymity more generally.
  - the trend showing increases in the number of applications, and the timely and sensitive way in which they are handled.
  - the first-year evaluation of the pilot support service and the informal positive feedback received from service users.