

Authority paper

Strategic delivery	Setting standards	<input checked="" type="checkbox"/>	Increasing and informing choice	<input checked="" type="checkbox"/>	Demonstrating efficiency, economy and value	<input checked="" type="checkbox"/>
Paper title	Opening the Register Update					
Agenda item	9					
Paper number	HFEA (08/07/2015) 760					
Meeting date	8 July 2015					
Author	Rosetta Wotton, Donor Information Manager					
For information or decision?	Information					
Recommendation	Note developments to the Opening the Register service					
Resource implications	In budget					
Implementation	OTR service ongoing					
Communication	OTR service on website					
Organisational risk	Low					
Annexes	Annex A – Opening the Register Questionnaire Responses					



1. Introduction

- 1.1. This paper brings the Authority up to date on developments in the Opening the Register (OTR) service over the last three years, particularly in the areas of policy, number of applications and feedback received on the service.

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 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, a 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
- 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 a recently recruited 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 4 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 numerous Donor Conception Network conferences.

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.

4. Policy developments

- 4.1. Since the last substantive update to the Authority on the OTR service several significant policy and process developments have taken place:

Operational issues

- 4.2. In June 2012 the Authority provided a steer on key operational issues. Further to Committee deliberations and legal advice, the Authority determined we could
- provide applicants with donor information in the donors own handwriting
 - translate foreign language in donor information
 - disclose messages containing concerning content
 - disclose details of the donor's family history.

Redaction framework

- 4.3. We also developed a redaction framework to support OTR staff in making more confident decisions on what donor information to redact to protect donor anonymity whilst also retaining as much information as possible to the applicant.

Information on donor re-registration for past applicants

- 4.4. A number of donors who donated anonymously before 1 April 2005 have since chosen to remove their anonymity – many have not but may choose to do so in the future.
- 4.5. 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. Website content was created in 2013 enabling previous applicants to check using a unique reference code provided to them.
- 4.6. 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 and fully consider the implications of their decision first.

Improving the sharing, quality and disclosure of donor information

- 4.7. Following a workshop held at the HFEA Annual conference in 2014, we developed a guidance pack for clinics to support their disclosure of non-identifying donor information, including goodwill messages and pen portraits, with patients.
- 4.8. This pack was available to clinics in March this year along with the redaction framework and a good practice case study.
- 4.9. Following publication 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.
- 4.10. A workshop was also held at the HFEA Annual Conference this year 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

- 4.11. Support for Register applicants was identified as a high priority by a group of key stakeholders in June 2013. This followed the Nuffield Council on Bioethics report 'Donor conception: ethical aspects of information sharing' published in April 2013, which made recommendations relating to donor information and support for applicants to the Register, and the McCracken review of the HFEA in 2013 which also recognised the importance of this work.
- 4.12. 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 in 2015 to PAC-UK, an adoption support agency with relevant expertise and suitably qualified staff.
- 4.13. 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 service which launched on 1 June 2015.
- 4.14. 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.

5. Performance

5.1. We have seen a steady rise year-on-year in the number of OTR applications handled, with a 20% increase in 2014 compared to the previous year (see table below).

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

5.2. In addition, and since launching in 2010, 79 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 but increasing to 21 per year in 2013 and 2014 – but will likely grow significantly in the coming years.

5.3. We have also received 149 applications from anonymous donors (those who donated after the HFEA was set up but before 1 April 2005) to remove their anonymity. Over the last 3 years there have been slight increases year-on-year in such applications; however numbers are disappointingly low with only 12 doing so in 2014.

5.4. In 2013 a first application for identifying information from an adult donor-conceived individual with an identifiable donor was received. In total six applications of this nature have been received; two each year so far, and earlier this year we made the first DSL match.

5.5. In each case we offered and coordinated (where desired) support and intermediary assistance to the donor-conceived individuals and donors concerned.

Future policy

5.6. The Opening the Register domain is an ever changing and fluid area with

complex issues coming to light on a regular basis. New issues for consideration include: disclosing identifying information for safeguarding purposes; and our responsibilities where a donor or donor-conceived genetic sibling has died or is mentally incapacitated.

- 5.7. We also want to ensure the smooth running of the new support service together with evaluating quantitative and qualitative feedback from PAC-UK and the users of the service.

6. Questionnaire feedback

- 6.1. As part of the OTR service, applicants are provided with a link to an online confidential feedback questionnaire. Annex A sets out the responses received over the last 3 years - a summary is shown here.
- The majority of respondents discovered they could apply for information from the HFEA through our website, with others finding out through sources such as their clinic.
 - Only a quarter of respondents said they had spoken to someone at the HFEA prior to applying, however 100% of these rated this experience as helpful or very helpful.
 - A third of respondents stated they had discussed their decision to apply with someone external to the HFEA in advance and the majority had not considered using a formal counsellor first.
 - Where the ease of finding the information on our website and the clarity of it were concerned, 89% and 93% of respondents respectively rated these as very good or excellent. Similarly 91% rated the clarity of the instructions on the application form just as highly.
 - Our speed of response to applications was also rated well by respondents, with 89% considering it very good or excellent, and 82% also rated the format of the response letter just as highly.
 - Expectations among respondents varied in terms of the amount of information they received from us; 58% considered it adequate, 26% didn't have any expectations, 16% expected to receive more and only 2% expected to receive less information.
- 6.2. Respondents were also invited to add any further comments they had on the letter or the process and the majority stated that they found the process straightforward, efficient and speedy, and are grateful for both the existence of the OTR service and the high level of service received.

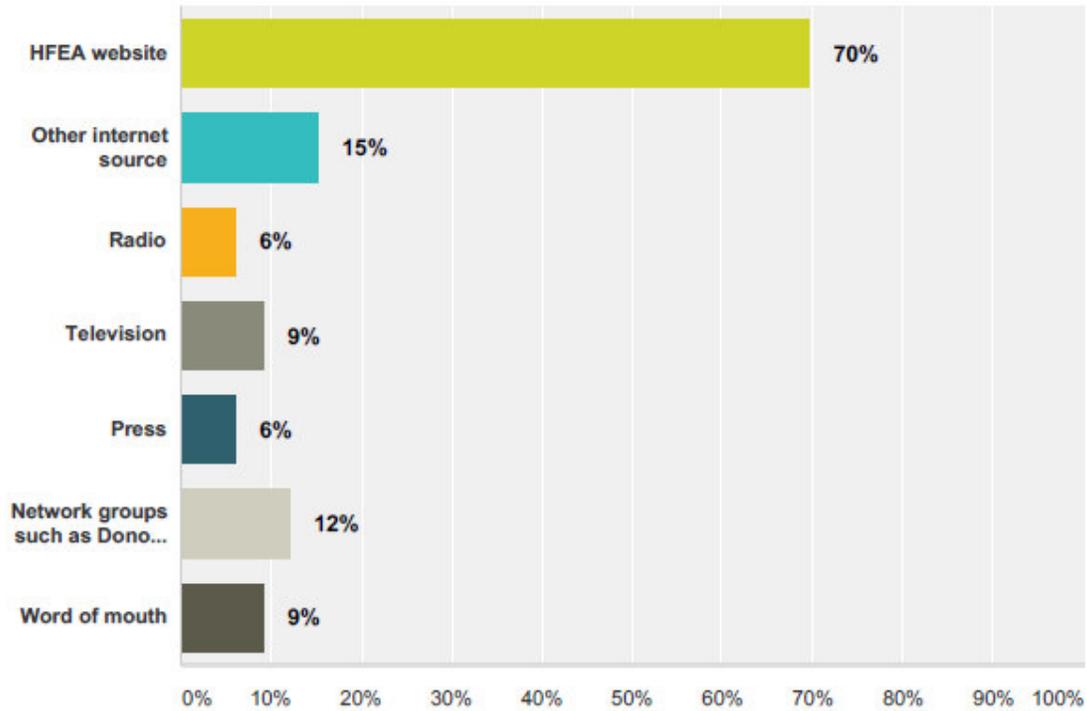
7. Recommendation

- 7.1. The Authority is asked to:
- Note the significant policy and process developments over the last 3 years to Opening the Register, which are in line with delivering the HFEA 2014-2017 strategy.
 - Note the trend showing increases in the number of applications, timely and sensitive way in which they are handled.
 - Note the positive feedback we have received about the Opening the Register service provided by the HFEA.

Opening the Register Questionnaire

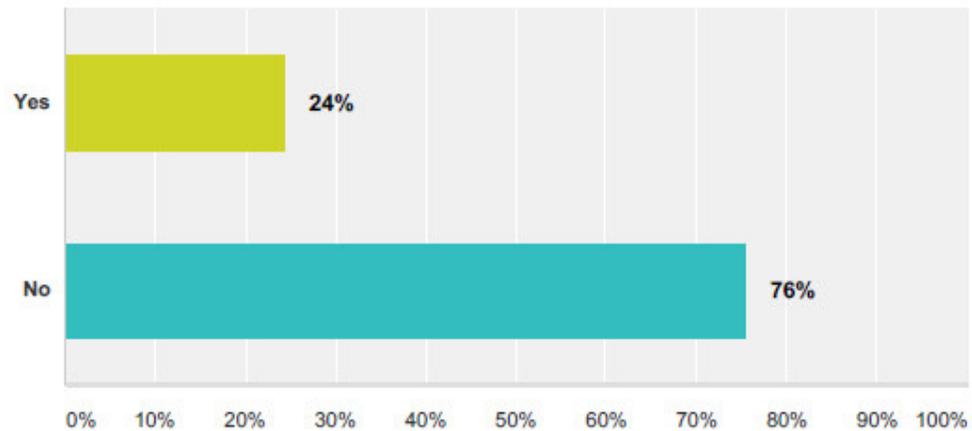
Q1 Where did you hear that you could apply for information from the HFEA register?

Answered: 33 Skipped: 13



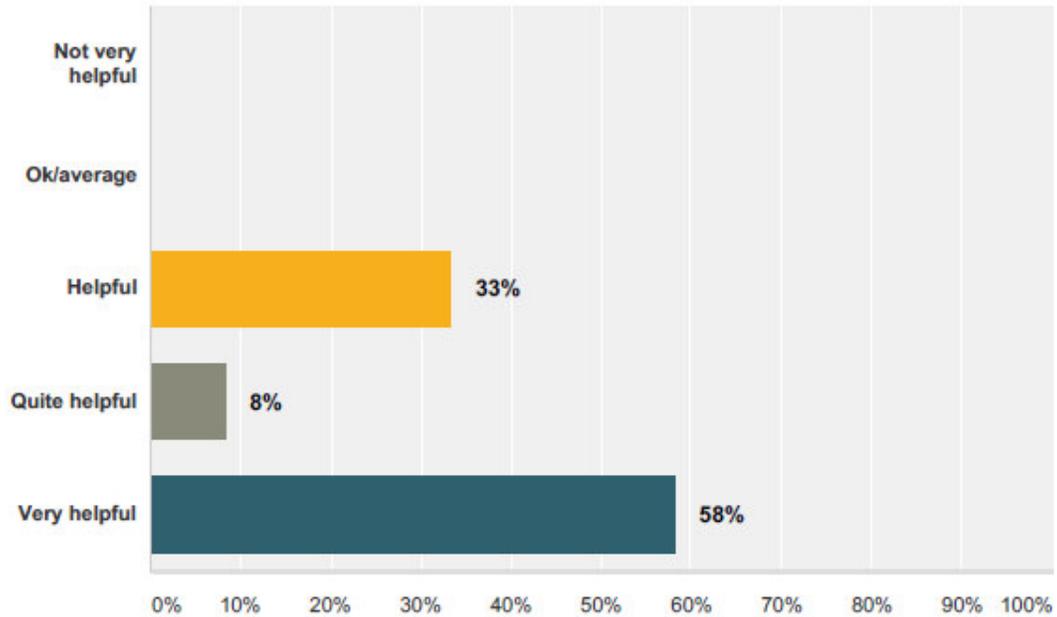
Q2 Did you speak to someone at the HFEA prior to applying for information from the HFEA register?

Answered: 45 Skipped: 1



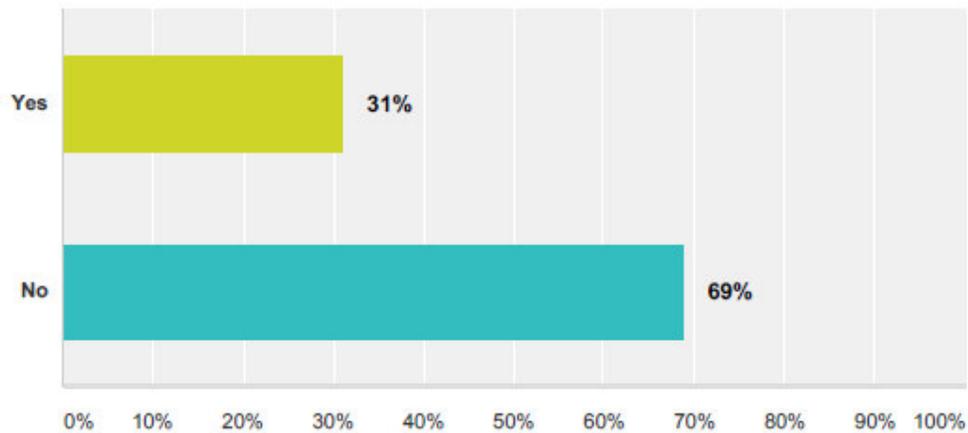
Q3 If you answered yes to the previous question, how would you rate the response ?

Answered: 12 Skipped: 34



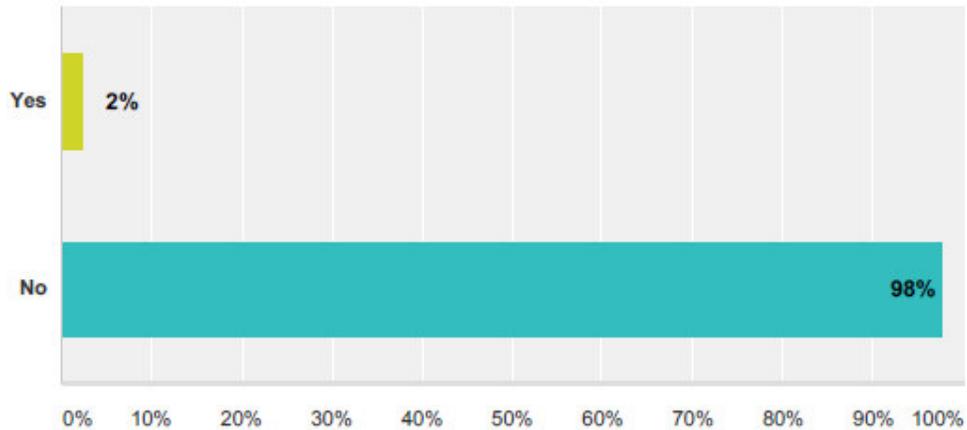
Q4 Did you discuss your decision to apply with someone external to the HFEA in advance ?

Answered: 45 Skipped: 1



Q5 Did you consider using a formal counsellor before applying for information from the HFEA register ?

Answered: 45 Skipped: 1

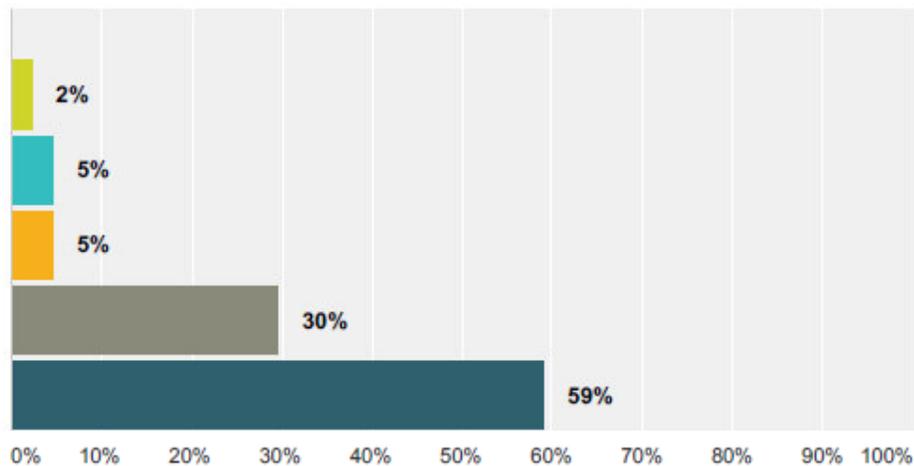


Q6 Thinking about the process to apply. How would you rate the following (1 being poor, 5 being excellent):

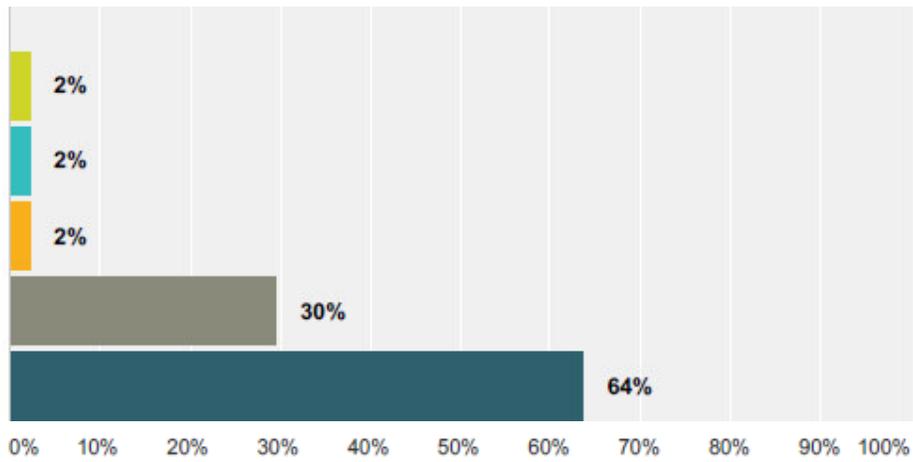
Answered: 44 Skipped: 2

1 (poor) 2 3 4 5 (excellent)

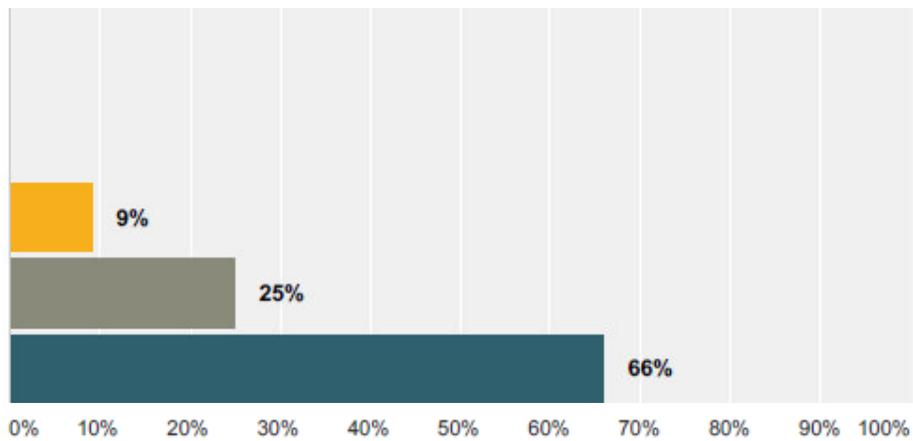
How easy was it to find the information you were looking for? (1-5 on ease)



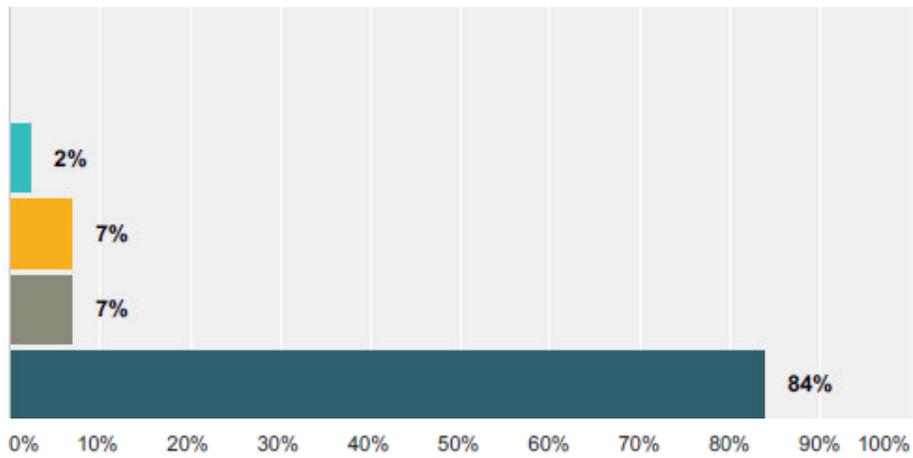
How clear was the information on the site? (1-5 on clarity)



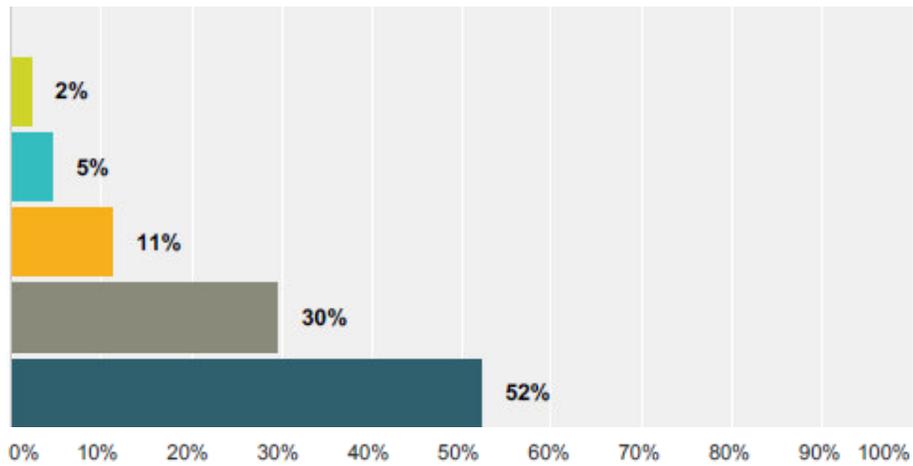
How clear were the instructions on the application form? (1-5 on clarity)



How would you rate the speed of the response? (1-5 as expected, better etc.)

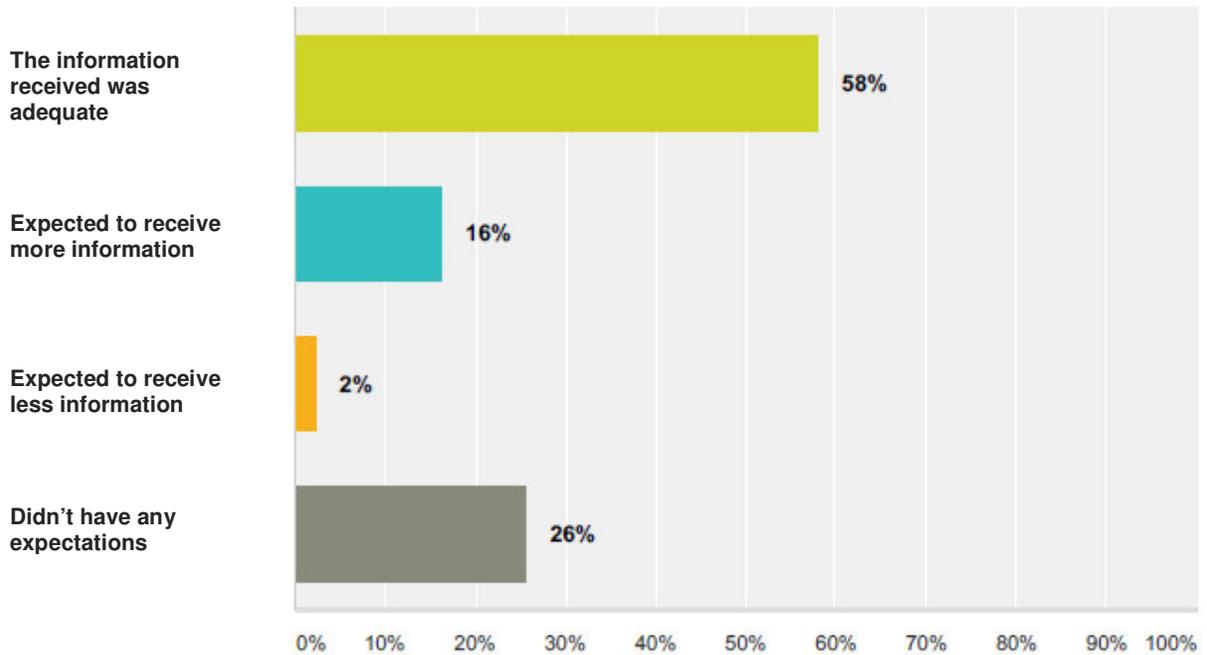


How would you rate the format of the letter you received ? (1-5)



Q7 What were your expectations regarding the level of information you received from the HFEA?

Answered: 43 Skipped: 3



Q8 Are you aware of the Donor Sibling Link (DSL)?

Answered: 43 Skipped: 3

