Authority paper

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

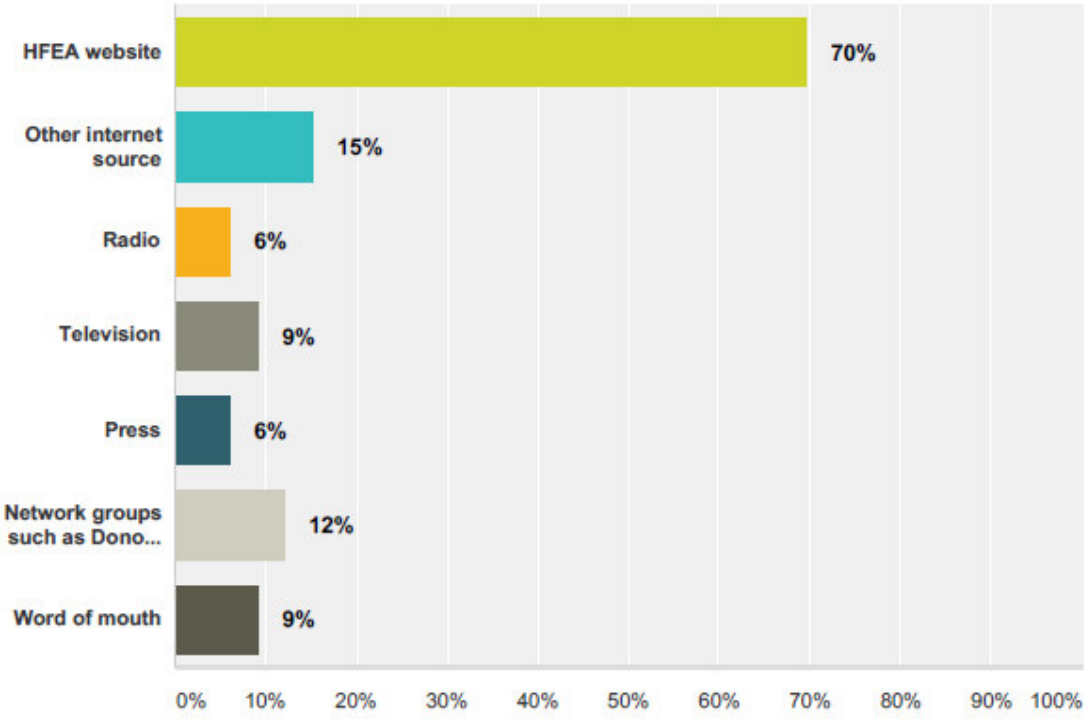
7.1. The Authority is asked to:

- 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

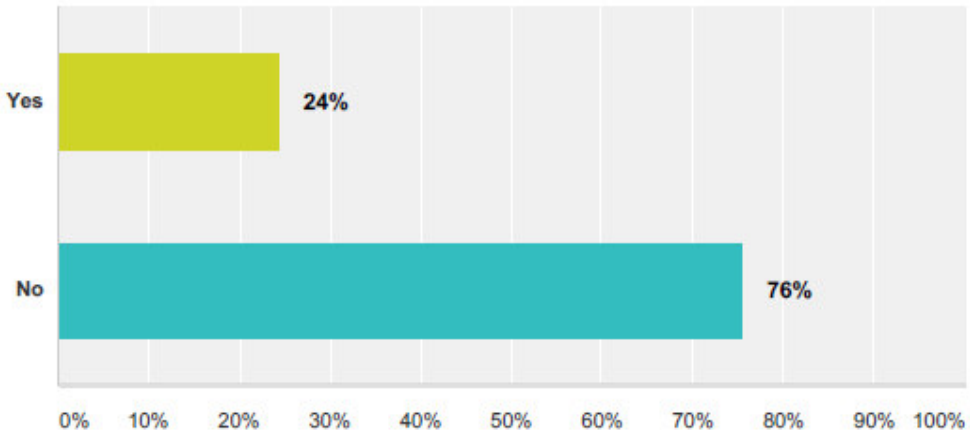
Q1 Where did you hear that you could apply for information from the HFEA register?

Answered: 33 Skipped: 13



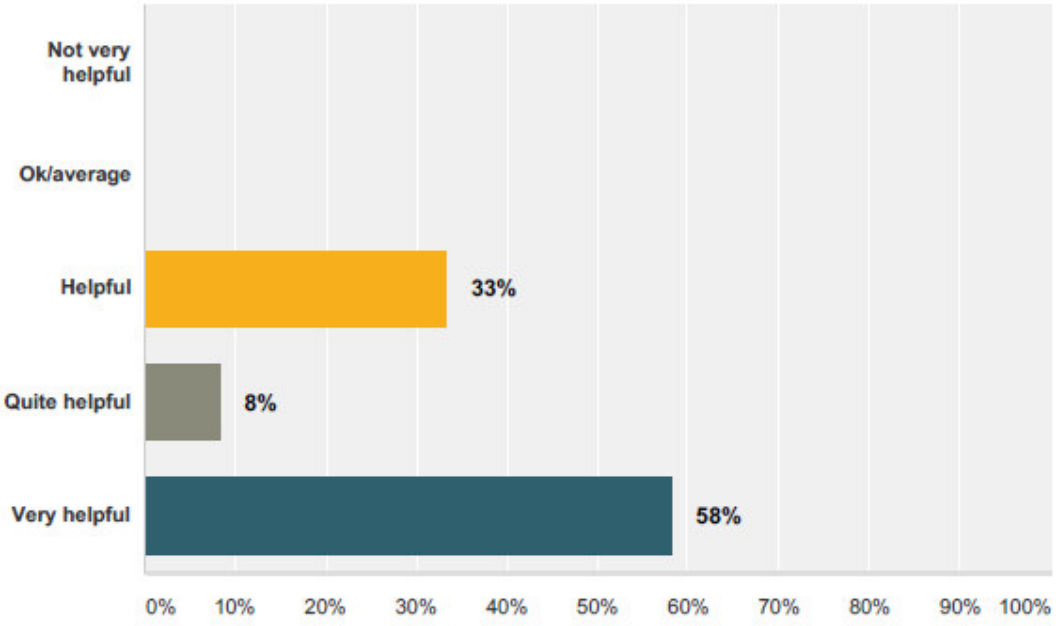
Q2 Did you speak to someone at the HFEA prior to applying for information from the HFEA register?

Answered: 45 Skipped: 1



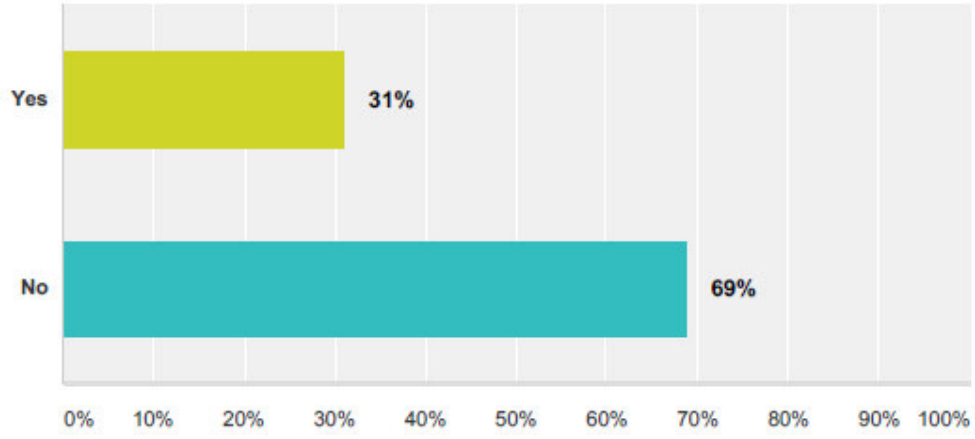
Q3 If you answered yes to the previous question, how would you rate the response ?

Answered: 12 Skipped: 34



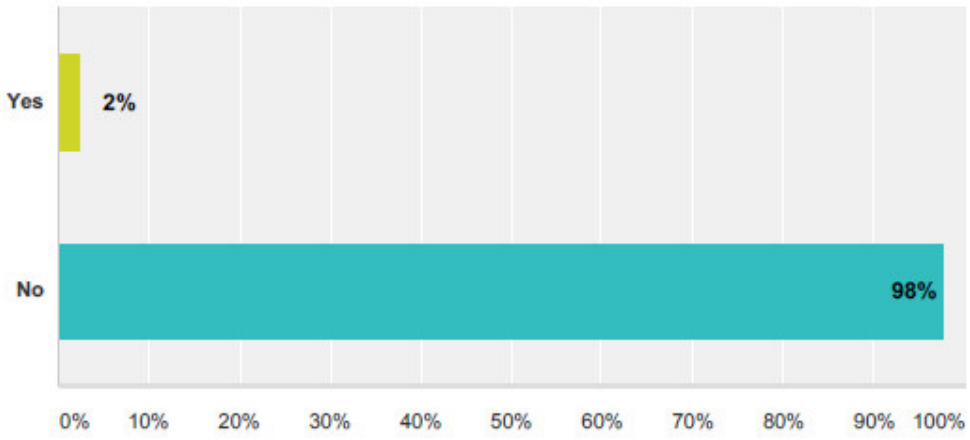
Q4 Did you discuss your decision to apply with someone external to the HFEA in advance ?

Answered: 45 Skipped: 1



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

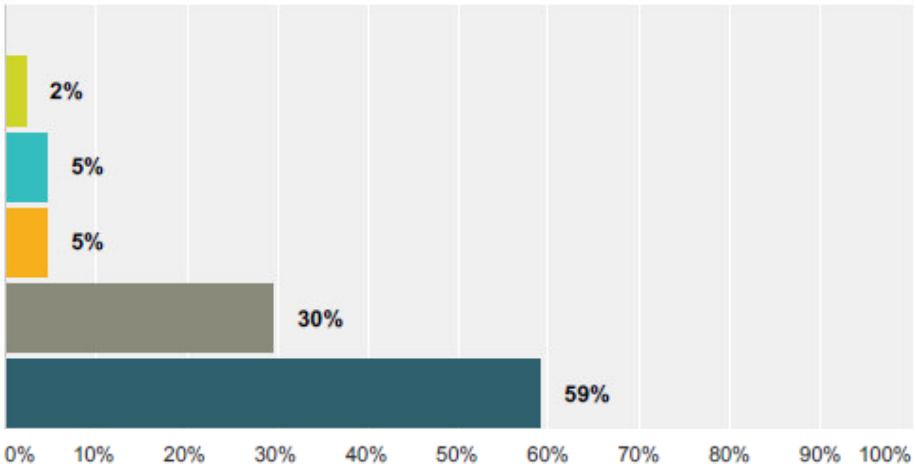
Answered: 45 Skipped: 1



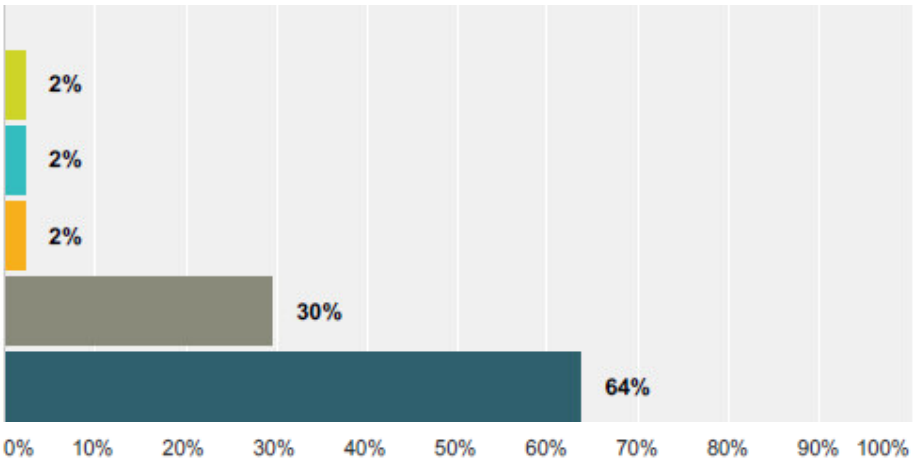
Q6 Thinking about the process to apply. How would you rate the following (1 being poor, 5 being excellent):

Answered: 44 Skipped: 2

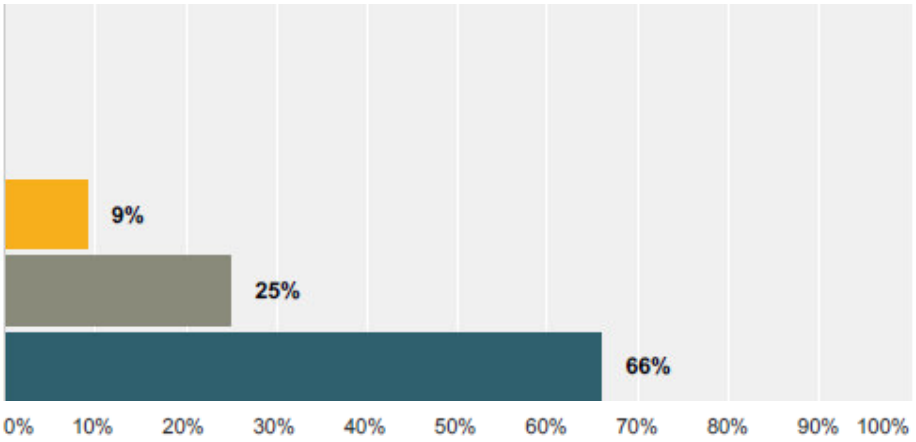
How easy was it to find the information you were looking for? (1-5 on ease)



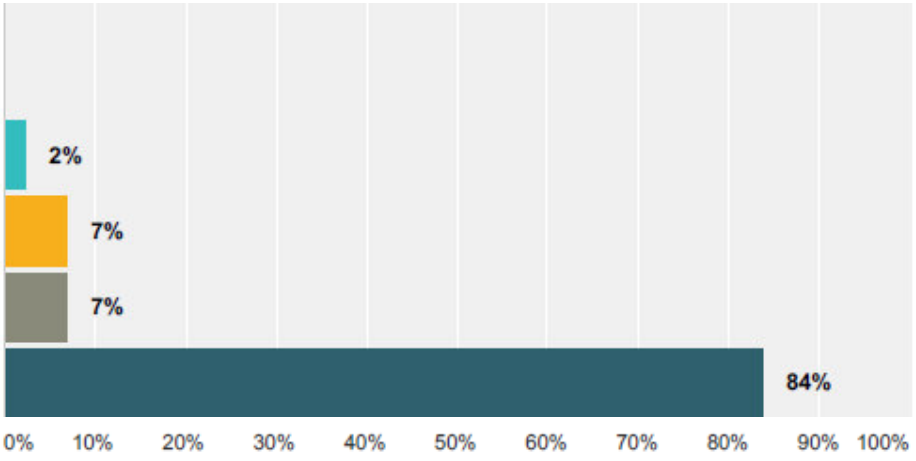
How clear was the information on the site? (1-5 on clarity)



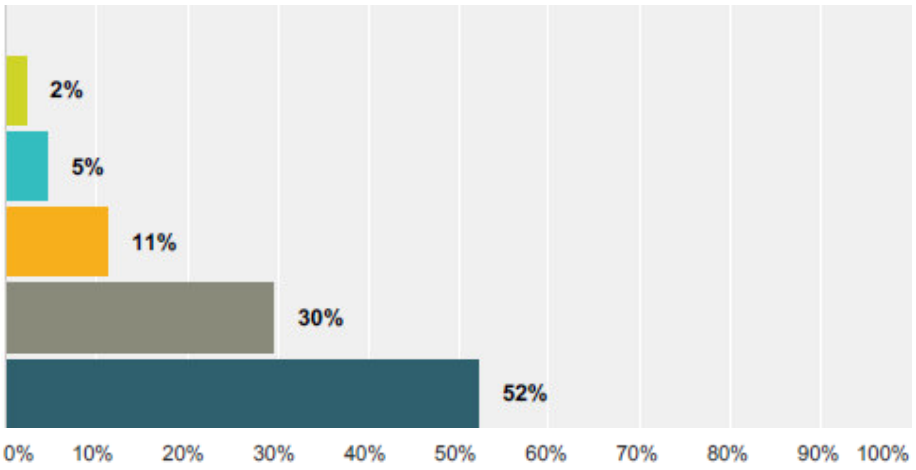
How clear were the instructions on the application form? (1-5 on clarity)



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

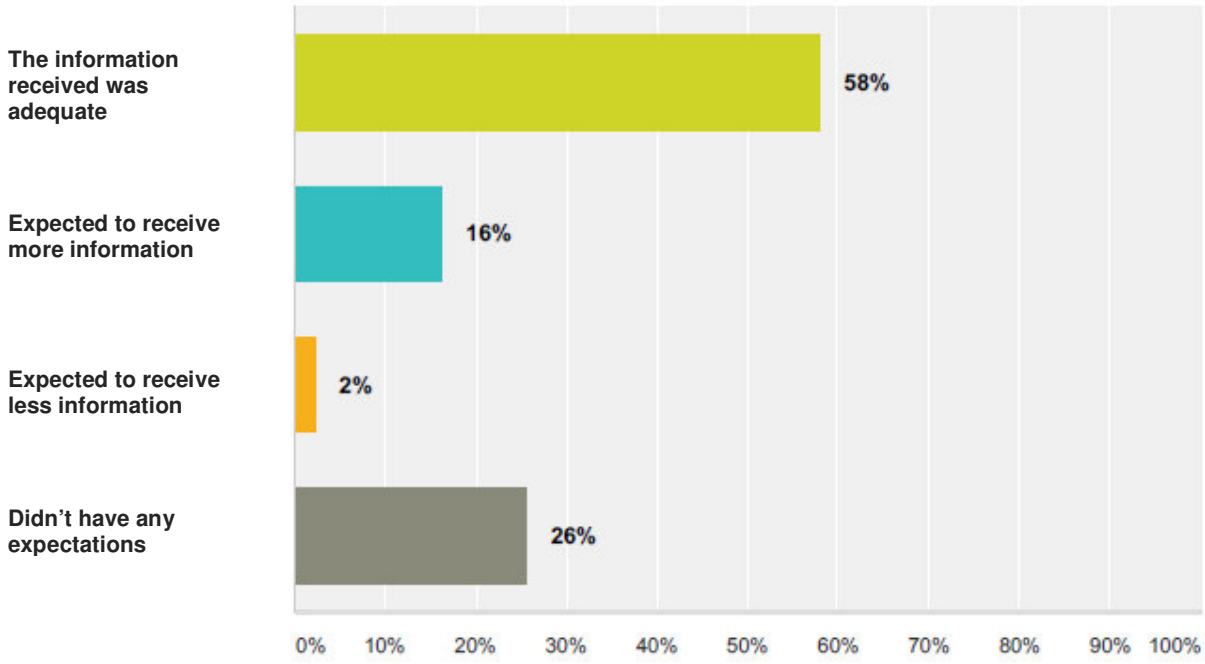


How would you rate the format of the letter you received ? (1-5)



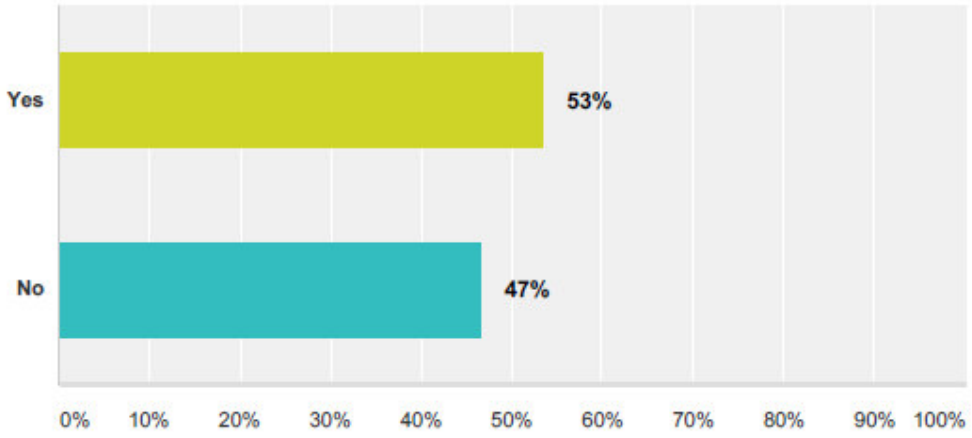
Q7 What were your expectations regarding the level of information you received from the HFEA?

Answered: 43 Skipped: 3



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

Answered: 43 Skipped: 3



Authority paper

Strategic delivery	**Setting standards**	☑	**Increasing and informing choice**	☑	**Demonstrating efficiency, economy and value**	☑
Paper title	**Information for Quality: update**					
Agenda item	**10**					
Paper number	HFEA (08/07/2015) 761					
Meeting date	8 July 2015					
Author	Nick Jones, Director of Compliance and Information					
For information or decision?	Decision and Information					
Recommendation	• Comment on, and approve, the vision for change which will guide our work • Note the progress as regards procurement of third party suppliers in line with corporate approval process, and associated costs; • Note that progression from Alpha stage is dependent on external approval (with an update report provided to Members at that point); • Comment on the arrangements informing organisational change resulting from the realisation of the IfQ Programme.					
Resource implications	Significant - within approved IfQ budget.					
Implementation	During 2015/16 business year					
Communication	Regular throughout 2015/16					
Organisational risk	High					
Annexes	N/a					

HUMAN FERTILISATION & EMBRYOLOGY AUTHORITY

1. Background

1.1. The IfQ programme encompasses:

- The redesign of our website and Choose a Fertility Clinic (CaFC) function. Recommended changes to CaFC will be presented at this meeting by the Director of Strategy and Corporate Affairs
- The redesign of the 'Clinic Portal' (used for interacting with clinics) and combining it with data submission functionality that is currently provided in our separate EDI (Electronic Data Interchange) system (used by clinics to submit treatment data to the HFEA)
- A revised dataset and data dictionary which will be approved by the Standardisation Committee for Care Information (SCCI)
- A revised Register, which will include the migration of historical data contained within the existing Register
- The redesign of our main internal systems that comprise the Authority's Register and supporting IT processes.

1.2. Given the importance of the programme to the Authority's strategy, updates on progress are provided to each meeting of the Authority and approval for direction and actions sought. This update, in particular, introduces the concept of a clear vision or 'offer' to guide us, addresses progress in procuring technical services and considers consequences for organisational change. We welcome comment, challenge and, as appropriate, endorsement of direction of travel.

2. Our vision for change

2.1. As the programme has evolved – from our initial thinking; engaging with stakeholders through a consultation exercise; establishing a business case; specifying contract requirements - we have established a set of objectives and expectations captured in various ways.

2.2. The Authority has been instrumental in that and informed it along the way (and will continue to do so, for example on the CaFC item later). The Authority has made a series of decisions about the shape of the IfQ programme. Those decisions are not simply technical in nature, they also embody the kind of information provider the Authority wants to be.

2.3. Other aspects are more operational – for example information technology architecture and detailed clinic portal development that the Authority will expect to be carried out carefully but would not expect to be across in the same way. The teams involved in the Programme see it as a whole and it's important that we establish a clear vision, or blueprint, for the change we (all) want to see.

2.4. The remainder of this section attempts to summarise those decisions into one easy to read description of our information offer to patients and clinics (and to our own way of working – particularly in relation to internal systems description) once IfQ is complete.

Website

2.5. This is our window to the world and will represent who we are – our personality, style, tone. It will embody our refreshed brand, not just visually but in our tone of voice. It will be fresh and current, with dynamic content - 'something new every day.' It will link to HFEA social media channels, giving a more human, active feel.

2.6. The website will be aimed at patients and the public, written in an upbeat,

personable style. Patient information will be organised along a typical patient or donor journey. Nothing old and out of date – with content owners defined and prompted to renew. This will be applied strictly – with incentives and sanctions in place. The site architecture will be designed so that content is easy to find and nothing is more than a few clicks away. The search will need to be used much less but, where it is used, the findings will be presented more clearly. Information will be presented as a mixture of infographics, charts, video and images as well as short, crisp text. It will be maintained with less text content than currently.

Choose a Fertility Clinic

2.7. The transition from website to CaFC will be seamless with all the website design principles applied. It will be a source of authoritative, trusted information – which will draw patients away from statistics on clinics' own websites. It will only be so if it is accessible and therefore consumed. Complex information will be presented clearly and unnecessary layers of detail will not appear. Success rates will not be privileged over other information such as inspection findings and patient feedback, but will be presented, in a comparable way, so that patients can make a choice based on different aspects of quality.

Clinic Portal

2.8. The clinic portal will be the key window to the HFEA by clinics – and there will be a seamless (if password-protected) transition from the public website to the portal. It will be attractive and intuitive to use – picking up corporate branding and functionality of the website. It will provide useful information about requirements placed on licensed clinics and their key staff. It will have the risk tool; other useful publications; and enable clinics to access information about their own performance and in comparison with all their peers or a selection – so they can improve their own performance.

2.9. Clinics' experience in submitting data to us will be easier and more pleasant. It will be an intuitive experience and users can adapt the system around their work rather than their processes being determined by our system. It will prevent simple errors by having a real-time verification facility. It will handle all transactions with us – clinics will make applications based on a simple interface that recognises who the clinic is with their core information already visible, only specific, new information will need to be inputted.

2.10. Like any good transactional system it will be intuitive and instructions will be helpful, provided at a few levels such as on-screen and videos or FAQs available on the portal that they use to submit data. Whether or not integrated systems are in place at a clinic we should work hard to ensure that the experience of users of such systems is similar. We will have a very clear data submission policy linked to Direction 0005, and a transparent approach for amending the data dictionary (with significant changes approved by the Authority). We may not be able to completely design out user input error – there will always be a need for checking and ultimately verifying - but this will be a much simpler time saving process than now. And we will look to get CaFC refreshed on a monthly basis, with data being more contemporary than now.

Internal Systems

2.11. We will implement an information technology strategy that supports all the IfQ developments and which provides economic and efficient hosting and storage arrangements, utilising the benefits of the 'cloud' (as appropriate); to provide business continuity and appropriate security; and desktop services meeting high service standards. All the 'business tools' the HFEA needs to operate whether

provided internally or externally function well - and based on simplicity and agile development principles. Once the development phase of IfQ is complete we will move to different ways of working. Contracts with suppliers may be in place to allow for minor improvements, and maintenance including bug fixes – but preclude improvements of a significant nature. Business leads will understand from their knowledge of user feedback what improvements to systems are needed and will bid for resource accordingly using business case approach.

3. Procurement

3.1. All design work will be provided by external suppliers. For development, we are adopting a mixed model - supplementing internal capacity with specific expertise further to a procurement exercise conducted on our behalf by the Crown Commercial Service.

3.2. The procurement process by way of competitive tender is almost complete. Nine suppliers were invited to make presentations to us. On the whole we were impressed by the quality of bids and presentations. Since the end of the evaluation period we have selected two preferred suppliers to enter in to further negotiations and agree contractual terms. One supplier was successful in five outward facing contracts relating to website and portal design and development (with some economies of scale secured as a consequence); and a further supplier in the delivery of 'internal systems' – that is the Register modernisation and technical architecture to enable the external systems to function efficiently and securely within the HFEA information technology framework. Contractual formalities need to be completed but we expect work to have started on-site week commencing 6 July 2015.

3.3. As regards costs, the Authority has approved an overall budget of £1.134m for 2015-16. This provides the overall approval and the Authority Standing Orders allow for subsequent approval at appropriate levels, Contract sums for the outward facing and internal systems work are c£500,000 and c£200,000 including VAT, respectively. It is important to note that the Authority's contractual position is protected. Payment at this level is made on the basis of the delivery of all requirements - with those requirements set out each phase (Alpha, Beta, Live). Of course, our expectation is a successful progression from one stage to the next but our overall exposure is protected. At this stage, the HFEA Chief Executive has approved the overall approach to the contract(s) and a financial commitment not exceeding £60,000 broadly aligned to the first part of the Alpha stage. The Chief Executive will subsequently approve progress to Alpha, Beta and Live on the basis of a recommendation from the IfQ Programme Board. In addition the Board will recommend approval to stages of expenditure within these phases and expenditure signed off by the Director of Compliance and Information and the Director of Finance These approvals will be reported to the Audit and Governance Committee on a post-hoc basis.

3.4. A substantial contingency is also available, c.20% of budget which is prudent as well as being considered good practice. The balance supports programme costs and 'backfill' for key personnel.

3.5. The Authority is reminded that 'approval' risks remain. That is, Department of Health and Government Digital Service must approve progression from Alpha to Beta stage. These relate to 18 measures (all of which must be met) such that the development of public service digital interface meet key standards including the appropriate involvement of users; appropriate agile methodologies are used for development and so on (https://www.gov.uk/service-manual/digital-by-default). To some extent our financial risks are mitigated given contractual protections set

out in 3.3 above. Moreover, our focus has been and remains on being very clear about our objectives and how those will meet 'digital by default expectations.

4. Organisational change

4.1. The aspects set out in section 3 above are the culmination of much work - in reviewing our extant systems and evaluating their fitness; undertaking substantial engagement with stakeholders and users; researching and establishing our requirements; specifying those to secure proposals from third parties and so on. We have now reached a significant milestone in moving from preparation to development.

4.2. The Gateway Review (highlighted in the previous meeting of the Authority) told us that we need to have increasing regard to the consequences for HFEA ways of working, and in turn the implications on our teams as we move from development to implementation. We agree, and having secured an affordable programme with the potential to transform how we and others who interact with us work, our attention can turn to the opportunities and challenges presented by change.

4.3. It is worth setting out a few key themes that will inform our approach to this over the next few months.

- Given the 'agile' nature of development we expect the first few weeks of the programme of development to discuss and finalise a detailed and resourced plan for the remainder of the year. That said, we expect the period between now and October/November 2015 to be intensive and focused on development activity. Those involved in the programme will in turn be energised, stretched, challenged in this period. As we go through these months and beyond we and our teams begin to appreciate the changes and potential for change that are emerging. In other words, it's a joint and shared experience.
- The period beyond that will be no less pressured but focused more towards refinement, preparation for implementation and delivery. This will be when teams will be starting to develop plans for new ways of working as a consequence of those changes.
- Beyond that we must hold in our minds that the ways of working we are adopting for this programme of change will become a way of working more generally. Agile development encourages us to move away from thinking we build a new set of systems and go back to normal. Instead, we must adopt a way of working that evaluates user experience, determines what changes are necessary and affordable, before building and testing out those changes, and then moves to implementation and so on. Clearly this will not be as intense as currently, but signals a new way of working.
- We will need to keep our stakeholders involved and informed with activities taking place between now and April 2016 - and subsequently as we return to more business as usual activities;
- The business case for the programme anticipated modest financial savings. That said we expect a change of focus in some teams and this will impact on some roles. Any such changes – expected to come into effect in the next financial year - will be accompanied by discussion and consultation with directly affected staff.
- Finally, our approach will be guided by our vision for the change set out in section 2 above.

5. Recommendation

5.1. The Authority is asked to:

- Comment on, and approve, the vision for change which will guide our work
- Note the progress as regards procurement of third party suppliers in line with corporate approval process, and associated costs;
- Note that progression from Alpha stage is dependent on external approval (with an update report provided to Members at that point);
- Comment on the arrangements informing organisational change resulting from the realisation of the IfQ Programme.

Authority paper

Strategic delivery	**Setting standards**	☐	**Increasing and informing choice**	☑	**Demonstrating efficiency, economy and value**	☐
Paper title	**Choose a Fertility Clinic**					
Agenda item	**11**					
Paper number	HFEA (08/07/2015) 762					
Meeting date	8 July 2015					
Author	Juliet Tizzard, Director of Strategy and Corporate Affairs					
For information or decision?	Information					
Recommendation	To comment on the progress on the Choose a Fertility Clinic review					
Resource implications	Within approved IfQ budget					
Implementation	During 2015/16 business year					
Communication	Regular throughout 2015/16					
Organisational risk	High					
Annexes	None					

HUMAN FERTILISATION & EMBRYOLOGY AUTHORITY

1. Background

1.1. Our patient information about treatments and clinics has changed significantly over the years. From 1996 onwards, we published 'The patients' guide to DI and IVF', which consisted of information about treatment options and success rates (see annex A), making us trailblazers in publishing outcome data. With increasing use of the web, in 2005 we launched an online version of the guide, which was relaunched in 2009 as Choose a Fertility Clinic.

1.2. Six years on, the design of Choose a Fertility Clinic is looking a little old and tired. We've always suspected that the statistics on the site were hard to understand, but our user research rammed the message home. Patients were confused – to the extent that some lost trust in the data and looked elsewhere.

1.3. So the design and the presentation of statistics need a refresh. But we've also been clear that we want Choose a Fertility Clinic to do much more than present success rates. We want it to be a tool that can help patients select the best clinic for them. To do that, they need to know what services the clinic offers, but they also to get a feel for the quality of those services.

1.4. We came to the Authority in January 2015 with recommendations from the Information for Quality (IfQ) advisory group about the website, Choose a Fertility Clinic and the clinic portal. At that meeting, members agreed that the quality of a clinic should be measured in a multi-dimensional way: through patient feedback, inspection findings *and* success rates.

1.5. Wider developments in the IfQ programme are reported in a separate paper from the Director of Compliance and Information. This paper updates members on our progress on the review of Choose a Fertility Clinic. We would welcome members' views and comments to make sure that we are going in the right direction.

2. What we've already decided

2.1. Taking most of the recommendations from the IfQ Advisory Group on board, the Authority agreed in January that it wanted Choose a Fertility Clinic to offer:

- a better balance between statistical and non-statistical information
- easier comparison between clinics
- non-statistical information that includes inspection findings, patient reviews and the availability of donated eggs, sperm or embryos
- patient reviews which should not consist of free-text feedback – the executive should think further about how else to do it
- information about the availability of donated eggs, sperm or embryos consisting of types of donors available, the source (ie, imported or UK) and waiting times for treatment
- top-line statistical information consisting of births per embryo transferred, followed by the cumulative success rate (ie, births per egg collection and all subsequent transfers).

2.2. Members asked the executive to think about how this could work in practice.

3. What we've done since January 2015

3.1. We set up two work streams, one on statistical information and one on non-statistical information, to take this work forward. The two groups have drafted a comprehensive set of recommendations which have recently been approved by the IfQ programme board. Here we present the key issues.

Statistics: cumulative birth rates

3.2. The IfQ advisory group recommended that, after births per embryo transferred, the second success rate should be births per egg collection (or cumulative birth rates). Births per *embryo transferred* enables patients to understand how good the clinic's success rates are across all services (IVF, ICSI, PGD, fresh and frozen cycles), getting above patient case-mix to an extent. Births per *egg collection* shows how likely patients at the clinic are to conceive over a full cycle of treatment – ie, one egg collection and all fresh and frozen embryo transfers which follow.

3.3. Our statisticians and analysts recommend that once a patient is successful, any further transfers from the same egg collection are excluded from the analysis, so that they are not double counted.

Statistics: sample sizes

3.4. One big issue with clinic-by-clinic data is that some clinics carry out very few cycles of treatment each year. That alone makes the statistics we present less reliable. Once the data tables are split into age band, the numbers (or sample size) get even lower and the statistical reliability decreases further.

3.5. To date, we have tried to overcome this problem by showing data in ranges (see the middle column below) and showing how the clinic's rates compare with the national average (right hand column). But, as you can see, the smaller the sample size, the more meaningless the ranges are.

Age	Live births per treatment cycle	Predicted chance of an average patient having a live birth Why this range?	How does this clinic compare to the national average? What does this mean?
Under 35	44 out of 213	Predicted chance between: **13% - 30%** most likely around: 20.7%	Below national average live birth rate of 32.5%
35-37	15 out of 112	Predicted chance between: **6% - 26%** most likely around: 13.4%	Below national average live birth rate of 28.5%
38-39	7 out of 75	Predicted chance between: **3% - 24%** most likely around: 9.3%	Consistent with national average live birth rate of 21.1%
40-42	3 out of 41	Predicted chance between: **2% - 29%** most likely around: 7.3%	Consistent with national average live birth rate of 14.0%
43-44	0 out of 11	Predicted chance between: **0% - 46%** most likely around: 0.0%	Consistent with national average live birth rate of 6.0%
Over 44	0 out of 3	Predicted chance between: **0% - 76%** most likely around: 0.0%	Consistent with national average live birth rate of 1.7%

3.6. One way of addressing this is to increase the sample sizes. This could be done by presenting data over more than one year or for a minimum number of cycles. This, however, would be difficult to achieve and potentially confusing for users.

3.7. Instead, we recommend that we change the age bands from the six we currently have to two: under 38 years and 38 years and over. This would give us a larger sample size: in the example above, this would mean a sample size of 325 for the under 38s and 130 for the 38 and over. The national data, because it aggregates all clinics should continue to display in six age bands and it will be easy for patients to see that data.

3.8. We chose 38 as the cut-off point because this is already a threshold between two age bands and it marks the point where the success rate declines more significantly. This banding would have the effect of greatly increasing the size and therefore the reliability of the sample, without significantly impacting on the accuracy of the results. And, with the births per embryo transferred calculation including fresh and frozen transfers, the sample sizes will be even bigger and more reliable.

Statistics: ranges

3.9. We have also reconsidered using ranges to convey statistical reliability. In our user testing, people found them confusing, partly because we call them 'predicted chance…' and also because a very small sample size results in a range so wide as to be meaningless.

3.10. By the same token, abandoning ranges altogether in favour of a single percentage point could be equally misleading, as the following example shows:

- Clinic A carries out 50 cycles a year resulting in 25 births, and has a 50% birth rate. But if they'd got just 5 more or 5 fewer births, the birth rate would be 60% or 40%.
- Clinic B carries out 2000 cycles a year resulting in 1000 births, and also has a 50% birth rate. But 5 more or 5 fewer births for this clinic would have a negligible impact on their birth rate: 50.25% or 49.75%.

3.11. Bad luck or good luck for Clinic A dramatically changes their result, so relying on a single percentage point is unwise. However, Clinic B's results are much more reliable.

3.12. So, single percentage points are easy to understand but ranges are more statistically reliable. Given the need to balance understanding and accuracy, we think this should come down to what works best for users, knowing a better visual design will help enormously. We have come up with three approaches to test on users:

- Stick with the ranges but improve the design (using visual rather than typographic display) and the data explanations (with simple text or an animation, video or suchlike)
- Show clinic-specific statistics, unless the sample size is below a particular threshold, in which case we would show the national data
- Show a single percentage point with percentage increase or decrease on either side, for example: 25% (+/- 10%). This could be done graphically.

Patient reviews: ratings

3.13. The Authority has already decided that we should not allow free-text feedback. We have considered ways of seeking more structured feedback and think that a

1-5 rating is the best approach.

3.14. We considered using the friends and family test question to generate an overall score: 'Would you recommend this clinic to a friend of family member who needed it?'. We could then have five further questions to give more detail., the downside of the friends and family test is that it is very general. The advantage is that it is used across the health service and is therefore recognisable.

3.15. We think that the best approach is to ask five questions covering customer service, decision-making, emotional support, information and transparency of costs (for self-funded patients). We would display the 1-5 rating for each question and then an overall average score for that clinic, derived from the five questions. However, we recommend testing out both approaches on users.

Patient reviews: honesty and representativeness

3.16. Some clinic staff have a legitimate concern about patient feedback: that it won't be representative of patient views at that clinic. They worry that:

- reviewers won't actually be patients at the clinic, but staff giving false, negative reviews of other clinics or false, positive reviews of their own;
- only the very unhappy (or very happy) patients will give their views;
- hardly anyone will give reviews at all.

3.17. One way of addressing false reviews is to make reviewers identify themselves by registering – even cross-checking to our register. Setting aside the potentially insurmountable confidentiality issues, our research shows that this will deter patients from giving feedback. They need anonymity to be frank.

3.18. One way of achieving a more representative set of views is to ask the clinic to contact a sample of patients and ask them to submit a review or forward their details to us for follow-up contact. There are confidentiality concerns with this approach, but the anonymity point bites here too: our research shows that patients don't feel able to be frank if their clinic is involved in review process. The administration needed might be prohibitive too.

3.19. We think we can address these in the follow ways:

- Remind clinics that it is an offence (under the Consumer Protection from Unfair Trading Regulations 2008) for businesses to falsely represent themselves as consumers.
- Invest time and money (though less than £5000) in marketing the patient review service, so that clinics without marketing departments avoid being disadvantaged and patients with mixed experiences give feedback.
- Use the close relationships we have with our clinics through inspectors to apply moral pressure to not 'game' the system. A simple phone call prompted by unusual activity in their patient reviews will have an impact.
- Remind clinics that successful patients won't necessarily give a positive review – and the contrary for unsuccessful patients.

3.20. With a free-text option, patients may feel frustrated that they can't say more. We will obviously point them to the complaints channel if they have that kind of problem with the service they received at the clinic. But we will also give reviewers the chance to click through to the fuller survey that inspectors use to assess patient satisfaction, letting them know they can give more expansive feedback that will be seen by the inspector and the clinic only.

Availability of donated eggs, sperm or embryos

3.21. In January, the Authority asked the executive to look further at this feature. We think it should be possible clinics to say whether they have egg, sperm or embryo donors available within broad timeframes (ie, immediately available, one to six months, more than six months). We have yet to test this concept on clinic representatives, but will do so in the next month with the formation of a stakeholder group which will meet for the first time in July.

Comparisons

3.22. Patients want to compare clinics. As we saw in our research, when thwarted from doing so on our current website, they simply create multiple tabs in their web browser to do it. IfQ advisory group members had misgivings about facilitating comparisons, largely because they think comparing success rates can be misleading. We agree. We think a better approach would be to allow users to short-list clinics, then display them in a table showing inspection findings, patient feedback *and* success rates. A carefully designed layout will discourage users from relying on one factor on its own.

4. Recommendation

4.1. We would welcome members' views and comments on the progress with Choose a Fertility to make sure that we are going in the right direction.

Annex A: Excerpt from 'Patients' guide to DI and IVF'

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Licensed for

In Vitro Fertilisation - Donor Insemination - Storage of Sperm - Storage of Embryos - Egg Donation

In Vitro Fertilisation Treatment

(For treatments carried out during the period 1.4.93 to 31.3.94)

Number of patients	360
Number of cycles	448
Number of stimulated cycles	389
Number of unstimulated cycles	0
Number of frozen embryo transfers	57
Adjusted live birth rate	13.5% (+/- 4%)
(Unadjusted live birth rate 15.5%)	
Multiple birth rate	28.6%
Triplet birth rate	4.3%
Abandoned cycles	36

Donor Insemination Treatments

(For treatments carried out during the period 1.4.93 to 31.3.94)

Number of patients	15
Number of cycles	23
Number of stimulated cycles	23
Number of unstimulated cycles	0
Adjusted live birth rate	42.6% (+/-22%)
(Unadjusted live birth rate 26.1%)	
Multiple birth rate	50.0%
Triplet birth rate	12.5%

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In Vitro Fertilisation - Donor Insemination - Storage of Sperm - Storage of Embryos - Egg Donation

In Vitro Fertilisation Treatments

(For treatments carried out during the period 1.4.93 to 31.3.94)

Number of patients	49
Number of cycles	74
Number of stimulated cycles	67
Number of unstimulated cycles	5
Number of frozen embryo transfers	2
Adjusted live birth rate	16.8% (+/- 10%)
(Unadjusted live birth rate 17.6%)	
Multiple birth rate	23.1%
Triplet birth rate	7.7%
Abandoned cycles	16

Donor Insemination Treatments

(For treatments carried out during the period 1.4.93 to 31.3.94)

Number of patients	56
Number of cycles	263
Number of stimulated cycles	180
Number of unstimulated cycles	83
Adjusted live birth rate	3.2% (+/- 3%)
(Unadjusted live birth rate 3.4%)	
Multiple birth rate	10.0%
Triplet birth rate	0.0%

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