

Authority paper

Strategic delivery	Setting standards	<input type="checkbox"/>	Increasing and informing choice	<input checked="" type="checkbox"/>	Demonstrating efficiency, economy and value	<input type="checkbox"/>
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					

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 	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 or 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'

Centre0024 University of Bristol IVF Service	Centre0032 Southmead General Hospital
Address	Address
UNIVERSITY OF BRISTOL IVF SERVICE BUPA HOSPITAL REDLAND HILL DURDHAM DOWN BRISTOL AVON BS6 7JJ	DEPARTMENT OF INFERTILITY SOUTHMEAD GENERAL HOSPITAL WESTBURY-ON-TRYM BRISTOL AVON BS10 5NB
Telephone	Telephone
0117 973 2562 ext 247	0117 959 5102
Licensed for	Licensed for
In Vitro Fertilisation - Donor Insemination - Storage of Sperm - Storage of Embryos - Egg Donation	In Vitro Fertilisation - Donor Insemination - Storage of Sperm - Storage of Embryos - Egg Donation
In Vitro Fertilisation Treatment	In Vitro Fertilisation Treatments
(For treatments carried out during the period 1.4.93 to 31.3.94)	(For treatments carried out during the period 1.4.93 to 31.3.94)
Number of patients 360	Number of patients 49
Number of cycles 446	Number of cycles 74
Number of stimulated cycles 389	Number of stimulated cycles 67
Number of unstimulated cycles 0	Number of unstimulated cycles 5
Number of frozen embryo transfers 57	Number of frozen embryo transfers 2
Adjusted live birth rate 13.5% (+/- 4%)	Adjusted live birth rate 16.8% (+/- 10%)
(Unadjusted live birth rate 15.5%)	(Unadjusted live birth rate 17.6%)
Multiple birth rate 28.6%	Multiple birth rate 23.1%
Triplet birth rate 4.3%	Triplet birth rate 7.7%
Abandoned cycles 36	Abandoned cycles 16
Donor Insemination Treatments	Donor Insemination Treatments
(For treatments carried out during the period 1.4.93 to 31.3.94)	(For treatments carried out during the period 1.4.93 to 31.3.94)
Number of patients 15	Number of patients 58
Number of cycles 23	Number of cycles 263
Number of stimulated cycles 23	Number of stimulated cycles 180
Number of unstimulated cycles 0	Number of unstimulated cycles 83
Adjusted live birth rate 42.6% (+/- 22%)	Adjusted live birth rate 3.2% (+/- 3%)
(Unadjusted live birth rate 26.1%)	(Unadjusted live birth rate 3.4%)
Multiple birth rate 50.0%	Multiple birth rate 10.0%
Triplet birth rate 12.5%	Triplet birth rate 0.0%