Choose a fertility clinic - evaluation of patient rating trial

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

Details:

Meeting	Authority
Agenda item	9
Paper number	HFEA (14/03/2018) 873
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Author	Yuba Bessaoud, Media and Stakeholder Relations Manager

Output:

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For information or decision?	For decision
Recommendation	Approve the continuation of the patient ratings scheme and free text function and further work around understanding and encouraging participation
Resource implications	
Implementation date	Work on encouraging participation to begin in Spring 2018
Communication(s)	To be developed in light of research
Organisational risk	☐ Low ☒Medium ☐ High
Annexes	Annex A: Patient and clinic case studies

1. Background

1.1. The views of patients are an increasingly important element in the provision of modern health care services in the UK and elsewhere. It has been central to our thinking since the publication of our strategy for 2017-20 and it is a direction which was further emphasised at the last Authority meeting when we approved our first Intelligence strategy, with its proposals for a national patient survey and the development of a voluntary patient charter mark for clinics.

1.2. This paper provides an evaluation of one discrete element of our work on patient voice: the patient ratings function that was launched last year as part of the re-vamped Choose a Fertility Clinic (CaFC) section of the website. The decision to trial the rating system, taken by the Authority in March 2017, envisaged a six-month trial focused on the operation, rather than the principle, of the system. We wanted to ensure that the rating system was fair and robust, and, crucially, that it provided data that was helpful to us, clinics and patients.

1.3. The rating system has two distinct elements: a set of five questions the answers to which are then made available on our website; and a free text feedback mechanism which allows patients to make private comments direct to the clinic's HFEA inspector (a similar feedback feature has been part of our inspections for some time).

1.4. The five questions, each with a five-point range, are:

1. How likely are you to recommend this clinic to friends and family if they needed similar care or treatment?
2. To what extent did you feel you were treated with privacy and dignity?
3. To what extent did you feel you understood everything that was happening throughout your treatment?
4. What was the level of empathy and understanding shown towards you by the clinic team?
5. Did you pay what you expected?

1.5. The answers given are used to generate a five-star rating for the first four answers. The average of the four ratings is used to create an overall star rating for the clinic, or what we term a 'patient rating', which is displayed on the relevant clinic page on the CaFC section of our website. We also show the total number of ratings submitted, so patients can see the number of reviews a rating is based on.
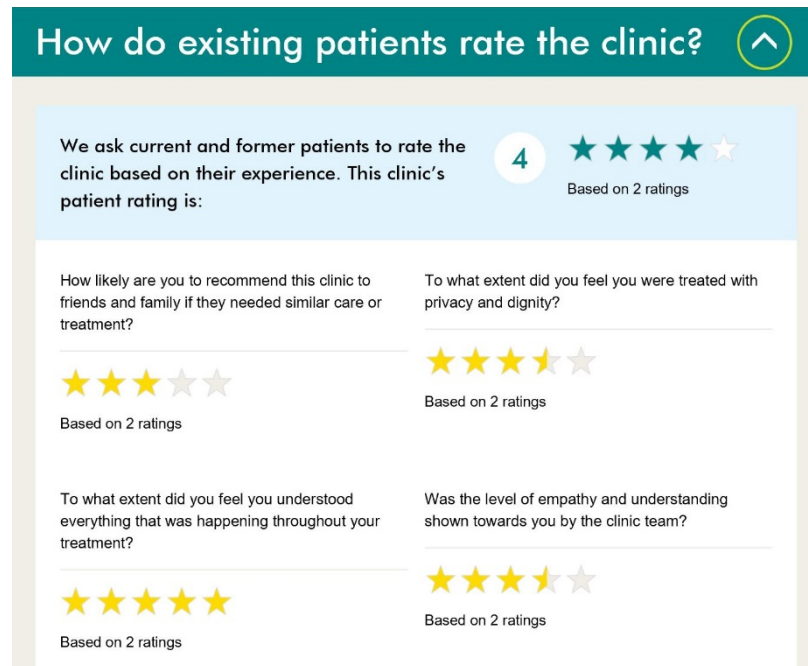
1.6. The question about the cost of treatment is not included in the overall score, as around 40% of patients are publicly funded, but patients are still able to access that data.

1.7. The plan approved by the Authority in March 2107 for the trial included a range of elements for the effective promotion, implementation and monitoring of the new system.

1.8. This paper sets out the results of the trial and provides an analysis of how the patient system could be improved going forward.

2. The trial period

2.1. In any new feature it is important to generate awareness and interest. To that end, from its launch in July 2017 we undertook a range of different activities to raise awareness of the new ratings system: direct patient contact; contact through clinics; contact through stakeholder publications.

Direct patient contact

- We used a range of different social media content to promote the system (Twitter and Facebook), with the biggest push coming in November around National Fertility Awareness Week. On average, such messages have reached around a thousand people per month over the course of the trial period, with a peak of 200 per day – or over 6,000 per month – in November. Social media work is continuing, with paid-for promoted to content to go out on Facebook in the near future.

- We published a "rate your clinic" page with simple instructions on how to rate a fertility clinic which has been visited 1900 times since it was introduced in November 2017, and we can see its positive impact in that 55% of page visitors move directly on to the clinic search page where they can rate their clinic.

- We handed out leaflets at the London Fertility Show to raise awareness among patients of the new ratings feature.

Contact through clinics

- We designed and printed 175 posters and 5,000 leaflets promoting the ratings system. We initially sent one poster and 30 leaflets to each UK clinic, and have subsequently had requests from a dozen clinics for more leaflets.

- The ratings system has been the subject of two Clinic Focus articles, in September and November 2017, which encouraged clinics to raise awareness of the scheme with patients. The November article also set out best practice hints and tips about how to promote the scheme to patients in a fair and neutral manner.

Contact through stakeholders

- We wrote content promoting both the new website, and the patient ratings system specifically, for FNUK magazine (September 2017 and January 2018), BICA magazine (September 2017) and The Embryologist (August 2017). The system has also been raised at stakeholder meetings.

Security concerns

2.2. A key concern in establishing the rating system was that it was not open to abuse. If patients and clinics are to get the greatest value out of the system they need to be confident that it reflects the views of real patients. However, the system also needed to be easy to use and we were concerned that too many security checks might put off patients from giving their views. Therefore, we took a decision not to add a verification check before launching the trial.

2.3. At the beginning of February 2018, the ratings of 46 clinics were affected by an 'automated bot', which randomly added 40-50 ratings on to their CaFC pages (totalling around 2,200 ratings overall) in just over five minutes. The clinics were informed within hours of this being identified and the ratings were removed. It did not affect the genuine ratings submitted before or after

this event. Given this recent event, a verification tool has been added to prevent a recurrence of this.

Assessment and evaluation

2.4. A range of assessment and evaluation exercises have been undertaken:

Patient survey (survey of the ratings system)

- In line with the plan set out to Authority, we set up an online survey for those patients who had filled in the ratings and wished to provide their feedback of the system. To date, we have had 23 responses, the details of which are set out in Annex A.

Patient interviews

- Of the patient survey submissions, six people left their details for future contact. Of those, two patients have been interviewed for their views, details of which are set out in Annex A.

Clinic interviews

- Two clinics were contacted for their views of the ratings system, details of which are set out in Annex A.

2.5. Taken all together, the qualitative and quantitative data so far gathered provide the beginnings of a more rounded understanding of what the patterns of adoption, by both patients and clinics, have been to this scheme.

3. Evaluation

3.1. Any patient rating system takes time to become known. For that reason, we did not approach this six-month trial with an expectation that a specific proportion of patients would complete the questions. Rather our aim was to see whether we could establish a simple and workable system for capturing patient opinion reliably and securely. We also wanted to see whether patients, clinics - and ourselves - found the data useful.

3.2. The total number of patient ratings received each month is set out overleaf (as of 15 January 2018, six months from the launch of the new website).

Table 1: Monthly patient feedback submissions

Month	Monthly total - ratings	Monthly total – free text
July	N/A	N/A
August	97	31
September	200	70
October	150	59
November	223	107
December	148	76
January (Mid-month)	147	47
Total	965	390

- By mid-January 2018, 965 patient ratings had been submitted across all clinics, representing around 1 rating for every 30 treatment cycles performed nationally over the same period.

- Of these 965, the ratings for just five clinics accounted for half (482), with the top two clinics receiving over a third (347) alone.

- Only one of the top five most rated clinics is classified as a large clinic (1,000+ treatments per year), the other four are all medium-sized.

- All the top five clinics had a minimum rating of four and a half, with the top two clinics scoring five.

- Drawing the data out further, we see that only 16 clinics out of the 116 rateable clinics on CAFC had 10 or more ratings submitted over the first six months.

- Of those 16 clinics, seven were large, five were medium and four were small.

- With one exception, the average scores for all 16 were 4.5 and above.

- Combined, the top 16 clinics accounted for 698 (72%) of all ratings submitted.

- Of the remaining 100 clinics, 46 had no rating at all, meaning the remaining 267 ratings were spread across 54 clinics at an average of five ratings per clinic.

- Of the 22 clinics classified by the HFEA as large (1,000+ treatments per year), 16 had five ratings or fewer.

- The free text system appears to be working better than before in terms of the quality and number of responses. Under the previous system inspectors received around 300 free text submissions per year, that

figure now looks set to more than double under the new system, with 390 received under the new system in the first six months.

3.3. What conclusions can we draw from this? In terms of the overall numbers of responses, the patient rating system has made slow but steady progress. As noted above we received 965 reviews in total

3.4. For the system to work most effectively to the benefit of patients, it would be hoped that the number of ratings being received per clinic would be more or less proportionate to the number of treatments provided; i.e. the larger the clinic, the greater the number of ratings. However, our findings so far show medium-sized clinics buying into the new system most eagerly as they received the highest number of ratings.

3.5. Without further research it's difficult to know precisely why the number of ratings varies so widely, or why so few clinics have ten or more ratings. The data suggests that our most intensive period of direct-to-patient promotion of the scheme via social media – in November 2017 around National Fertility Awareness Week – coincided with a spike in submissions, which suggest that further promotional work may help to get the patient ratings firmly established among clinic staff and patients.

Conclusions and next steps

3.6. Discussions with staff from clinics with the most ratings (see Annex A) supports the idea that the difference between those with only a few ratings and those with a significant number is the level of promotion being done by the clinics themselves.

3.7. For example, we know some clinics have tablet computers in their waiting rooms. Such active promotion is clearly working in terms of achieving high numbers, but it is not without risks around the potential for pressure, however unintentionally, to be placed upon patients. **We may wish to provide more best-practice guidance for clinics looking to encourage patients to provide their ratings in-house.**

3.8. It does seem clear that, perhaps inevitably, in-house clinic promotion of the scheme to patients is currently the most effective mechanism for raising awareness and securing participation. **We may wish to consider whether more time and funding be deployed so that we can do more direct marketing to patients.**

3.9. Further, with a disproportionate number of ratings being submitted in relation to medium-sized and small clinics, and with comparatively few ratings to the larger clinics, the system is not yet working to the full benefit of patients, and more needs to be done to ensure that ratings are more evenly and proportionately spread across the sector. **Specifically, work should be done to improve our understanding of why larger clinics have not, in the main, embraced the scheme as readily as others. We may wish to attempt to shift attitudes towards participation, in part by explaining**

that as more ratings are entered on the system larger clinics may begin to feel left behind.

4.   Outstanding technical issues

Epicentre spreadsheet

4.1. All the patient ratings, including the free text comments, are available to the HFEA inspectors via a spreadsheet in Epicentre. Whilst we know that the free text feedback element of the system is working well , the HFEA inspectorate is looking for improved functionality so that they can access ratings data more easily and in more readily digestible format. IT are aware of this and will work on it as priorities and resources permit.

Gaming and IP addresses

4.2. When the system was being designed, consideration was given to gaming by clinics, spamming by robots, and the rare actions of very disgruntled patients, with plans to minimise the potential for abuse in each case put in place accordingly. In designing the ratings system, the decision was taken to collect IP addresses as a means of identifying issues around potential problems and abuses. The use of IP addresses was useful, for example, in assisting the removal of spambot ratings.

4.3. The usual method for recording IP addresses is recording them through the use of cookies. However, under the General Data Protection Regulation (GDPR), IP addresses are considered identifying information, and the new regulations will allow people to opt out of supplying their IP address, which may have an impact on our ability to fully monitor issues around gaming, duplication, and spambot interference.

4.4. Consideration by IT colleagues will be given as to how this may impact upon the system, and what might be put in place to replace any monitoring deficit that results.

5.   Recommendations

5.1. When the Authority agreed to this trial in March 2017, we undertook to develop and implement mechanisms for the promotion, by ourselves and clinics, of the new ratings system, and to monitor and evaluate the results both quantitively and qualitatively. Though more patient and clinic views would be helpful, we have begun to achieve these aims, identify patterns of behaviour, outstanding issues to be resolved, and possible next steps to further improve the system.

5.2. Moreover, all the patients and clinic staff consulted as part of this trial period felt it was a welcome and useful addition to the website, and very much in-

keeping with modern healthcare and consumer methods for incorporating the patient/consumer voice.

Authority are asked to:

- Approve continuation of the patient rating scheme;
- Approve continuation of the free text mechanism for providing views to inform our inspection activity

Approve further work to:

- Develop best-practice guidance for the promotion of the scheme by clinic staff, and what is acceptable practice in terms of encouraging completion of the ratings scheme in-house;
- Consult with large UK clinics to understand why take-up of the scheme has been slower, and to encourage greater participation.

Annex A

1. Qualitative data – patient survey and case study findings

1.1. As part of the trial we set up a small online survey asking patients who had used the system to give us their views (see below). To date, 23 patients, each treated at a different clinic, have responded.

1.2. To understand how the ratings system had been raised, discussed and completed, we also undertook four qualitative interviews; two with patients and two with staff working in clinics with good ratings numbers.

1.3. The relatively small number of survey responses and interviews mean that the findings should be treated with caution, but they offer a starting point for understanding the perspectives of patients and clinic staff, and raise issues that we may wish to consider in the future.

2. Patient survey

2.1. The patient survey consisted of nine questions:

1. Are you about to start treatment/had some treatment/stopped having treatment/an egg or sperm donor?
2. Which clinic did you rate today?
3. What motivated you to give your rating? Information from HFEA/My clinic told me/I heard about it from another patient/Heard about it from another organisation/Looking for somewhere to make a complaint
4. Do you understand how the rating feature works and how the patient ratings are calculated?
5. What did you think of the questions you were asked?
6. How confident are you that the ratings have been provided by real patients, partners and donors at this clinic (very – not at all)?
7. NHS Choices asks people to give their email address and name before they can give feedback. If we had asked you to register your email address and name would you still use the tool to give your views?
8. If you needed to request a token from your clinic to prove you were a patient partner or donor (they could not identify your feedback from this) before you could give your feedback then would you still have given your views?
9. Please give any other feedback about the ratings feature.

The highlights were

- Most people (39%) said they had heard of the ratings system directly, through our website or social media , while (34%) said they had learned

about it from their clinic. 17% found the survey while searching how to make a complaint about their clinic.

- 70% of respondents felt the questions asked were the right ones, 30% did not. Of those that did not, suggestions included a question on professional/clinical expertise; more space for free text; and greater specificity in the questions asked, especially in relation to the emotional, "psychological" support given.

- 74% were very confident/confident that the ratings they saw had been put there by other patients. 17% were somewhat confident, while 9% were not confident. Those who lacked confidence tended to be concerned about the capacity for clinic staff to rate themselves, and for patients to submit repeated ratings.

- Most patients were unconcerned about being identifiable to the HFEA. When asked if they would still have given feedback if they had received a 'token' from a clinic that would have proven they were genuine patients, but that might link them to their rating, 91% said they would still have rated their clinic as long as the clinic could not identify them.

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3. Interviews:

Patient 1

3.1. Patient 1 is currently having treatment with donor eggs. She had more than one cycle, at the same clinic. She was made aware of the patient ratings system by the HFEA posters in the clinic and clinic staff. The nurse at the clinic, which has many tablet computers in the waiting room, asked Patient 1 to give her rating while she was waiting to go in for the embryo transfer of her first cycle. She completed the ratings form, but in the briefest of terms. The patient feels that the clinic took advantage of this moment of vulnerability to ask for feedback.

3.2. Although no-one at the clinic asked her to rate them again, the patient did so of her own accord, from her own home, after having had some negative experiences at a later date that she wished to give her views about.

3.3. She is a supporter of the ratings system overall, and wants it to stay, but believes the current questions focus too much on the emotional journey and that there should be a question relating to whether the clinic displayed professional expertise. She felt the clinic was focusing on those aspects of treatment covered by the ratings and a question about expertise would ensure they worked hard on all areas of their service.

3.4. While she was aware what would happen to the feedback she gave she was concerned that, in giving the specifics of her case as part of the free text submission, such information would somehow become available to the clinic in a way that would make her identifiable. She felt this might be reflected in the services she received.

Patient 2

3.5. Patient 2 had treatment at two clinics. Having chosen her first clinic because it was close, but then having an unpleasant experience, she next chose a clinic much further away. She is now pregnant following treatment.

3.6. She came across the patient ratings system from her research into the HFEA, it was not mentioned at either clinic. She used it to rate both her first clinic (very negatively) retrospectively and her second (positively) during treatment.

3.7. She felt the questions were the right ones, and captures was what the patient needs, although she too was in favour of a question around clinical expertise. She understood what the purpose of the ratings system was, and felt that "in her mind's eye" she was speaking both to future patients and HFEA staff as she gave feedback.

3.8. As she had complained directly to the first clinic, she had no concerns about being identifiable to them. She was firmly in favour of the system continuing, as "in a world where you pay so much money clinics should be accountable".

Clinic 1

3.9. Clinic 1 is a large London clinic, the only one to appear in the top five for ratings submitted. They were very conscious of the system going live, and the low number of ratings they would have to start with, so they took action to address that through promotion. They felt the HFEA website could have more prominently promoted the scheme in its early stages; and that more should be done by us in terms of general promotional materials.

3.10. The clinic has installed tablet computers in waiting rooms and other places in the clinic. They have created a home page featuring the HFEA ratings page that patients can access at any time they wish. Patients are asked to complete their rating at various points across the 20 or so contact points the clinic has with them over the course of their treatment. It forms part of the broader feedback they ask for their own purposes.

3.11. The most common time for completion is the egg collection, or embryo transfer stages, which require long waiting times. Clinic staff mention the possibility of rating (anonymously) - there is no attempt to influence the patients in any way.

3.12. They feel this approach has worked as they have quite a high number – sufficiently high for them to have stopped promoting the HFEA rating. Unless or until the ratings score drop they won't promote it again.

3.13. They feel the questions are the rights ones, framed in the right way. Patients have no trouble understanding what is required of them. When asked, they were unsure about the usefulness of a possible clinical expertise question, as they're not sure the patient would be able to answer it They also wonder

whether patients will answer the question on cost intuitively, or based expressly around the costed treatment plan.

3.14. They would "certainly" recommend that the ratings system stays, as they want the opportunity to direct as many people to the HFEA as possible, and their research with patients shows that patients want that too.

Clinic 2

3.15. Clinic 2 is a medium sized clinic with a high number of ratings. They have placed the leaflets and posters around the clinic so that the ratings system is well promoted. At the beginning they found promotion hard work but that it has got easier now that momentum is there. Trying to get the message across that it is for the benefit for all patients.

3.16. The ratings scheme is raised by various staff across the treatment journey from open evenings and consultations onwards, but the theatre manager ensures that a tablet is always passed to patients at the end of their treatment - generally after embryo transfer. They feel this is the best time because patients have completed their journey.

3.17. They feel the questions are the right ones – "the ones patients ask themselves". Patients don't tend to ask about clinical expertise. Cost and the commitment of time they'll need to spend in the clinic is important to patients.

3.18. They combine the feedback received directly from patients with that on the HFEA website and have quarterly meetings about the sort of feedback they are getting.

3.19. They are in favour of the system remaining as it's an important tool for promoting patient voice.