

Authority meeting - agenda

10 May 2017 Venue: Church House, 27 Great Smith Street, London SW1P 3NZ

Agenda item	Time
1. Welcome, apologies and declaration of interests	1:00pm
2. Minutes of 15 March 2017 HFEA (10/05/17) 834 For decision	1:05pm
3. Chair's report (verbal)	1:10pm
4. Chief Executive's report (verbal)	1:20pm
5. Committee chairs' updates (verbal)	1:30pm
6. Performance report HFEA (10/05/17) 835 For information	1:45pm
7. Information for quality: update on closure HFEA (10/05/17) 836 For information	2:00pm
8. Pre-HFEA Voluntary Contact Register HFEA (10/05/17) 837 For decision	2:25pm
Break	2.50pm
9. Communication strategy 2017 - 2020 HFEA (10/05/17) 838 For information	3.00pm
10. Any Other Business	3:45pm
11. Meeting Close	3.50pm

Minutes of Authority meeting

15 March 2017

Strategic delivery:

- Safe, ethical effective treatment
- Consistent outcomes and support
- Improving standards through intelligence

Details:

Meeting	Authority
Agenda item	2
Paper number	HFEA (10/05/17) 834
Meeting date	10 May 2017
Author	Erin Barton, Governance Manager

Output:

For information or decision?	For decision
Recommendation	Members are asked to confirm the minutes as a true and accurate record of the meeting

Resource implications

Implementation date

Communication(s)

Organisational risk Low Medium High

Annexes

Minutes of the Authority meeting on 15 March 2017 held at Church House, 27 Great Smith Street, London SW1P 3NZ

Members present	Sally Cheshire (Chair) Dr Andy Greenfield Kate Brian Dr Anne Lampe Anthony Rutherford Bishop Lee Rayfield	Yacoub Khalaf Margaret Gilmore Anita Bharucha Bobbie Farsides
Apologies	Ruth Wilde	
Observers	Steve Pugh (Department of Health)	
Staff in attendance	Peter Thompson Nick Jones Juliet Tizzard Paula Robinson Richard Sydee Catherine Drennan	Chris Hall Joanne Anton Helen Crutcher Joanne McAlpine Erin Barton

Members

There were 10 members at the meeting, 7 lay members and 3 professional members

1. Welcome, apologies and declarations of interest

- 1.1. The Chair opened the meeting by welcoming Authority members and members of the public to the second meeting of 2017. As with previous meetings, it was audio-recorded and the recording was made available on our website to enable interested members of the public who could not attend the meeting to listen to our deliberations.
- 1.2. Apologies were received from Ruth Wilde.
- 1.3. Declarations of interest were made by:
 - Anthony Rutherford (Person Responsible at a licensed centre)
 - Kate Brian (Regional organiser for London and the South East for Infertility Network UK)
 - Yacoub Khalaf (Person Responsible at a licensed centre)

2. Minutes of Authority meeting held on 18 January 2017

- 2.1. Members agreed the minutes of the meeting held on 18 January, for signature by the Chair of the meeting.

3. Chair's report

- 3.1.** The Chair gave an update on the events that she attended since the Authority meeting on 18 January 2017.
- On 18 January, the Chair and the Chief Executive had an introductory meeting with Clara Swinson, our new senior sponsor at the Department of Health
 - On 7 February, the Chair attended the ALB Chairs & NED's Compassionate Leadership Seminar at the Department of Health
 - On 8 March, she chaired an interview panel to select a new Chair for our Independent Appeals Committee and appointed Peter Freeman.
- 3.2.** The Chair also talked about the HFEA Annual Conference the following day, at which we planned to launch our new strategy for 2017-20 and set out some new expectations of the cultural and ethical leadership needed to improve services.

4. Chief Executive's report

- 4.1.** The Chief Executive advised members that on 3 February he attended our quarterly accountability meeting with Department of Health colleagues and on 6 February he attended our Scientific and Clinical Advances Advisory Committee.
- 4.2.** On 21 February, the Chief Executive, along with the Director of Compliance and Information, met with a legal officer from the West Indies University who is providing advice to the Jamaican government on the regulation of IVF.
- 4.3.** On the 24 February, the Chief Executive attended the Healthcare Leaders scheme graduation and engagement event.

Organisational change

- 4.4.** At the meeting on 18 January, the Chief Executive set out our proposals for organisational change in the light of the Authority agreeing its new strategy for 2017-20 and the near completion of the Information for Quality programme (IfQ). The Chief Executive informed members that a draft proposal was sent to staff at the end of January for consideration, closing in late February. The responses were analysed and a revised organisational structure was published. All staff that were directly affected received a letter setting out how the changes will impact on their role. That letter was supported by a 1:1 meeting with the relevant Director.
- 4.5.** The new organisational structure will be phased in between April and September. Members were reassured that staff will be supported through this uncertain time and any redundancies will be approved by the Remuneration Committee.

Press coverage

- 4.6.** The Chief Executive informed members that it had been a quiet couple of months in the press office, with relatively few mentions of the HFEA in the press. However, he highlighted two developments relevant to research and responsible innovation.

- 4.7.** There had been a series of stories around genome editing, beginning with the relatively positive assessment in the report from the US National Academies, the outcome of the patent dispute over who owns the Crispr-Cas9 technology, and the work being done by the House of Commons Science and Technology Select Committee into genomics and genome editing. It is too early to tell whether the use of gene editing in treatment will become a serious public policy possibility, but the picture is changing rapidly.
- 4.8.** A new study was published by researchers from the University of Cambridge, which involved the creation of an artificial mouse embryo using stem cells. The researchers were reported to have claimed an intention to try and repeat the procedure with human cells. We were contacted by a few members of the press for our views on whether this would be legal and declined to comment as we had not had the chance to study the paper in detail. Again, this is likely to require consideration in the future.

5. Committee Chairs' updates

- 5.1.** The Chair of the Statutory Approvals Committee (SAC) reported that the committee met on 23 January and 23 February. It considered four preimplantation genetic diagnosis (PGD) applications in January and three requests for Special Directions, all of which were approved. At the February meeting, three PGD applications were considered, all of which were approved.
- 5.2.** The Chair of the Licence Committee advised members that the committee met on 9 March to consider one new research licence application, one research licence renewal, and one application to vary a centre's licence to permit mitochondrial donation. The minutes have not yet been published.
- 5.3.** The Director of Strategy and Corporate Affairs advised members that the Executive Licensing Panel (ELP) met three times; on 27 January, and 10 and 24 February. The panel considered three treatment and storage renewal applications, two of which were approved and one of which was adjourned; three interim inspection reports, including two where the licence was continued and one which was adjourned; one additional inspection report where the licence was continued; and one voluntary licence revocation which was approved. The Licensing Officer considered two applications to change the Licence Holder which were both approved.
- 5.4.** The Chair of Scientific and Clinical Advances Advisory Committee (SCAAC) advised members that the committee met on 6 February, and considered the following items:
- Developing a traffic light system for treatment add-ons which will be published when the new website launches in Spring 2017, and will be reviewed annually as part of the horizon scanning process
 - New technologies in embryo testing
 - Prioritisation of issues identified through the horizon scanning process
 - The implementation of audit recommendations. The following issues were considered as high priority for the coming year:
 - Use of ICSI
 - Mitochondrial donation
 - Genome editing

- Fertility preservation
- Embryo culture media
- Health outcomes in children conceived by ART
- Alternative methods to derive embryonic and embryonic-like stem cells
- New technologies in embryo testing
- Treatment add ons.

6. Strategic performance report

- 6.1.** The Chair introduced this item, advising that the strategic performance report was a general summary of our performance measures, the progress towards implementation of the strategy, our programmes and their status, and generally the wider performance of the Authority.
- 6.2.** The Director of Finance and Resources gave an overview of our income and expenditure for 2016/17 and introduced the draft budget for 2017/18. He apologised to members that some of the figures in the strategic performance report they had received were incorrect and not consistent between different pages and tables. The figures contained within the PowerPoint presentation were accurate.
- 6.3.** Members heard that our budgeted income for 2016/17 assumed that there would be around 55,000 IVF treatment cycles. The number of cycles had already surpassed this figure, and was predicted to reach 62,000 cycles by the end of the financial year. An underspend of just under £620k at year-end was forecast, primarily due to the additional income we received from activity. Legal costs were above our original budget but this included a conservative reserve against costs relating to a judicial review, and these costs will fall significantly should we receive a favourable judgment. There may also be some provision for the organisational restructure in this financial year.
- 6.4.** The draft budget for 2017/18 was similar to that of the previous year. As the IfQ programme finishes and we recognise the asset from an accounting perspective, we will begin to depreciate it which will increase our costs. We are also taking on the running of the donor conceived register from the Department of Health (DH) which will increase costs.
- 6.5.** The Director of Finance and Resources informed members that a new piece of work is planned to study any correlation between the demand for treatment and demographics, as well as other socio-economic factors, in order to predict our future income more accurately and to gain a better understanding of the treatment market more generally. The following areas will be explored to understand how changes within them might impact on activity:
- NHS Commissioning
 - Providers
 - Patient behaviour
 - Economic outlook
 - Scientific advances.

- 6.6.** The Director of Strategy and Corporate Affairs reminded members that our annual conference was taking place the following day. The focus was the new Strategy for 2017-2020 but other themes included: good care for transgender patients; facilitating research; medicines management; reducing multiple births; emotionally safe treatment; and responsible innovation.
- 6.7.** The Director of Strategy and Corporate Affairs informed members that we are working with NHS England and a number of partners including the BFS, to develop a benchmark IVF price and commissioning guidance, to help commissioners to make fair and cost effective decisions about fertility services for their local population. Guidance and a benchmark price is expected by the next financial year. Members will be kept up to date with our progress.
- 6.8.** Following discussion, members noted the latest strategic performance report.

7. Information for Quality: update

- 7.1.** The Director of Compliance and Information reminded members that the IfQ programme is a comprehensive review of the information that we hold, the systems that govern the submission of data, the uses to which it is put and the ways in which the information is published. It includes:
- The redesign of our website and Choose a Fertility Clinic (CaFC) function
 - The redesign of the 'clinic portal' used for interacting with clinics
 - Combining data submission functionality
 - A revised dataset and data dictionary which will be accredited
 - A revised Register of treatments, 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.
- 7.2.** The Director of Compliance and Information advised members that the new Clinic Portal was launched on 19 January. The launch went well but there were queries from some clinics, most of which were dealt with quickly and effectively. The focus was now on embedding business-as-usual practices.
- 7.3.** Since the launch of the Clinic Portal, the priority has been completing the website and preparing for the Government Digital Service (GDS) gateway assessment, which took place on 8 March 2017. The assessment identified a few issues which needed to be addressed before going live, including testing the speed and ensuring we have the resources and structure in place to maintain a secure service after the website has gone live.
- 7.4.** As outlined to the Authority at the previous meeting, we were expecting the judgment on the judicial review relating to proposals for publishing performance measures within CaFC, by the end of January 2017. To date, this had not been received, and the impact of this on plans to launch the website is unclear.
- 7.5.** In December 2016, we asked clinics to undertake a verification exercise relating to their performance data in respect of CaFC. This differed from previous years' exercises due to the new focus on cumulative birth rates, but was necessary to enable us to start the new CaFC with a high

quality dataset. We extended the deadline a month to the end of March 2017, to ease the burden on clinics.

- 7.6.** Members heard that data migration was planned to take place over five stages, which will become progressively easier, and that the team has made good progress. Data cleansing has taken place for all errors with the potential to prevent migration. We commissioned an external specialist to audit our process and ensure that our approach conforms with our data migration strategy. Feedback from their preliminary audit in January 2017 was very positive. Further audits were scheduled for May 2017, one as we move to the third stage, and one final audit prior to migration.
- 7.7.** The Director of Compliance and Information informed members of the intention to close the formal aspects of the Programme on 31 March and scope the outstanding work as a project of activity within our business plan commitments for 2017-18.
- 7.8.** Members noted:
- the Clinic Portal is now live
 - the intention to launch the HFEA website and choose a fertility clinic as live, in April 2017
 - the intention to close the programme at the end of March 2017
 - the arrangements for securing completion of the programme components in 2017/18.
- 7.9.** Members agreed that the programme should not close after a set date, but after the amendments to the website and CaFC. Members also requested that the Audit and Governance Committee continue to receive regular updates on progress. The Chair thanked all staff and stakeholders who have contributed to the programme.

8. Draft information policy

- 8.1.** The Head of Information advised members that, with the IfQ programme drawing to a close, we need to revisit the rules and expectations which are currently set out in a mixture of policy, directions and guidance in the Code of Practice, in order to agree a new information 'bargain' between ourselves and the bodies we regulate. In doing so, we aim to:
- ensure that clinics hold treatment information safely and securely, and submit high quality information to us on time
 - drive better performance
 - facilitate conversations between our inspectors and clinics about performance
 - enable patients and donors to make more informed choices about their options.
- 8.2.** The Head of Information summarised the specific areas under review which included:
- The foundations of the Register
 - Register data submission: quality and timeliness
 - Publishing data on Choose a Fertility Clinic
 - Clinics' websites and marketing
 - Information security
 - Accessing anonymised and identifying HFEA register data for research and understanding

- Opening the Register.

8.3. Members heard the proposal for a ‘mixed-model’ approach to consultation, using a range of approaches to gather views, including:

- gathering feedback from users on the new data dictionary and submission system further to user testing
- seeking the views of stakeholder using our existing framework of licensed centres’ panel, professional stakeholder organisation group and so on
- focused pieces in Clinic Focus, including links to e-survey tools
- engagement through the new Clinic Portal – which now provides the mechanism for gathering views more quickly
- face-to-face events, for example workshops.

8.4. Members thanked the Head of Information for his very comprehensive paper outlining the draft information policy. Some members stressed the importance of incentivising the timely submission of data, and others were interested in exploring the regulatory levers that could be used to sanction the minority of centres who do not comply with our policy, especially regarding their own websites and marketing. After some discussion, the Authority noted:

- The areas of focus for consultation regarding the HFEA policy on information
- That following consultation a revised Information Policy together with General Directions and revisions to the Code of Practice will be presented to the Authority for approval.

9. Governance and transparency

9.1. The Director of Strategy and Corporate Affairs gave an overview of the committees’ annual reviews. All committees are working well with good quoracy and effective chairing, although technical issues involving telephone systems had disrupted some meetings. The use of external members, expert advisors and peer reviewers is working well, and the additional patient perspective provided to the Statutory Approvals Committee is greatly appreciated when considering applications for preimplantation genetic diagnosis.

9.2. Following discussion, members noted the committees’ annual reviews and agreed that the Standing Orders remain unchanged.

10. Facilitating research and responsible innovation

10.1. The Head of Regulatory Policy gave an overview of our planned work on embryo, data and clinical research, and sought a wider discussion about our role on emerging issues within the context of our new Strategy.

Embryo research

10.2. Members heard that a wide-ranging project on embryo research had commenced, focussing on giving patients greater opportunity to donate embryos to research if they so wish, and improving access to donated embryos for research projects. Early feedback from the sector presented a complex picture with different issues affecting different types of clinics.

10.3. Further work is planned for the coming months to explore potential barriers to embryo research and develop ways to overcome these barriers. This includes gathering feedback through clinic and patient surveys on consent and ways to encourage more collaboration between clinics and researchers. A paper will be presented to Authority in June to incorporate changes into the Code of Practice for October 2017.

Data research

10.4. Members heard that around 70% of patients give their consent to data research which, although an improvement on previous years, could be higher. Over the coming months further work is planned to increase patient awareness of data research, and to understand the potential reasons for the fluctuation of consent rates across the sector, including a clinic-led research workshop at the annual conference. Other possible actions include:

- Developing a patient leaflet on data research to provide patients with more information about the types and benefits of research.
- Exploring the advantages and disadvantages of setting a minimum target for consent to disclosure rates (similar to the way we introduced a minimum target for reducing multiple births) to help the inspectorate measure the effectiveness of the clinic.
- Making data research a key part of our information strategy which will be developed by the new Intelligence team. This will set out how we plan to work differently to carry out and facilitate data research to improve the quality of fertility services.

Responsible innovation for new treatments

10.5. In January, the Authority noted its concerns about the apparent proliferation of fertility treatment add ons that have not been rigorously tested in a clinical trial setting before being offered to patients. We want patients to have access to good quality treatments which maximise their chance of a pregnancy, but we must be careful not to stifle innovation in the fertility sector.

10.6. The following steps aim to encourage more robust clinical research:

- Our Scientific Clinical Advances Advisory Group have produced clear, honest information for patients about add ons; how safe they are, whether they work to increase pregnancy and birth rates, and how much they are likely to cost.
- We will encourage more clinics to participate in clinical trials by publishing on the new HFEA website information about which clinics are carrying out clinical trials and providing information to patients on how to get involved.
- We will use our new Intelligence Team to carry out a thorough analysis of our data and encourage clinics to carry out studies and publish their findings – all carried out through collaboration with scientific and clinical professional bodies, patient organisations and perhaps scientific publications.
- We will develop a consensus about responsible innovation in fertility treatment that we could agree with stakeholders and encourage clinics to sign up to. Our success with changing professional and patient attitudes towards single embryo transfer suggests ways that we could make progress, utilising the same style of collaborative working, coupled with an effective public education campaign.

10.7. Members heard that they will be presented with a plan for the above work later this year and were invited to discuss our role on emerging issues, in particular how we balance our regulatory

responsibilities with our strategic ambition to promote high-quality research and responsible innovation.

Our role on emerging issues

- 10.8.** Some members felt that we should engage more with existing clinical trials and research projects. Randomised controlled trials are expensive and there is a general lack of funding in this area, worsened by problems with participation. Greater participation in current trials would increase interest and drive funding in future.
- 10.9.** Members stressed that we should encourage evidence-based medicine consistently across all areas of practice, and not just in relation to novel techniques. Members were keen for us to play a greater role in highlighting where research is lacking or would be most beneficial, which could be questions relating to everyday practices. The IfQ programme provides the opportunity to share data trends and analysis more easily, in order to produce hypotheses. Some members also felt that we could do more in setting standards by ourselves collecting more outcome data, for example in relation to PGD, which could be used by researchers.
- 10.10.** Members noted that patients may have differing views towards data research and embryo research, and therefore different views on consent. This requires us to take a different approach to consent for embryo and data research. Some members felt that a target rate for consent would be inappropriate because it implies that consent to research is desirable, when this should be a personal choice. Instead, members wanted to raise awareness amongst patients of the different types of research and their potential benefits which may, in turn, increase the rate of consent.
- 10.11.** Members were keen to establish a dialogue with the sector about research through collaboration with professional stakeholders. Members noted the important role that we played in facilitating the debate around mitochondrial donation, and felt that we could similarly create a space for discussion of other topics. Members stressed that we can be engaged whilst still being impartial, and recognised that, as the regulator, our input can have a big impact.
- 10.12.** Following discussion, members agreed that we should continue with the planned work and return to the Authority later in the year with an update.

11. Choose a Fertility Clinic – patient rating trial and evaluation

- 11.1.** The Policy Manager reminded members that the decision to include patient feedback on our new website formed part of our strategy for 2014-17 and that the decisions agreed by Authority in 2015 included that:
- we will not include a system to authenticate patients, as user feedback and the stakeholder group told us this would discourage patients from taking part
 - one questionnaire will be used for both patient ratings on CaFC and to gather patient feedback for inspection reports
 - any ‘free text’ comments submitted will not be published on the website but will be available to clinics through their inspectors
 - feedback should be from recent patients and donors (within a year) and should only count towards the ratings on CaFC for 12 months
 - we will promote the tool to patients to maximise uptake.

- 11.2.** Members saw a preview of the new patient rating system on the beta version of our new website and were given an overview of the proposals to trial the feature, which will involve engaging patients, prospective patients and clinic staff in order to answer the following questions:
- Are the outputs from the rating system valuable to patients, inspectors and clinics?
 - Will patients and donors use the tool to give their feedback and will potential patients use it to help make decisions about their treatment?
 - Are HFEA procedures to manage the end to end feedback and ratings process effective?
- 11.3.** Members suggested that information on whether prospective patients are using the feature could be gathered as part of the patient feedback system by including a question about whether they used the feature as part of their own decision-making prior to treatment.
- 11.4.** Members were reassured that the trial plans to address the uncertainty around the lack of patient authentication, and agreed that this should be closely monitored and revisited in future, if necessary.
- 11.5.** Following discussion, members agreed the plans for a trial of the patient feedback survey and ratings on CaFC.

12. Strategic risk register

- 12.1.** The Head of Business Planning informed members that CMG reviewed the risk register at its meeting on 8 February. CMG reviewed all risks, controls and scores, and agreed to add a new risk relating to the forthcoming organisational change that is being planned. CMG also reviewed the two risks relating to donor conception and agreed to merge these into one single risk centred on running a good Opening the Register service. Both of these two new risks were currently at tolerance. We also updated the financial risk, since we were close to year end.
- 12.2.** As the new strategy was about to be launched, the Head of Business Planning will be working with the Chief Executive and CMG to update the risk register – and also the performance report – to align them with the new strategy. The new version of the risk register will be ready for CMG in May, AGC in June and the Authority meeting in July.
- 12.3.** The Head of Business Planning informed members that DH led an ALB Risk Network workshop recently, focused on identifying risk interdependencies between ALBs and with DH. They have put out new guidance to make sure we are all identifying and acting on any risks that we either share with another regulator, or experience as a result of another regulator's work, or potentially cause to another regulator through work we are doing. So, in the new version, each risk will have a separate section in which we can capture any risk interdependencies.
- 12.4.** Four of the 12 risks were above tolerance. Two of these risks related to IfQ and the reasons for the earlier delays were recorded. Both these risk scores had gone up and down over the past few months, reflecting what was going on at the time. Delays to beta products meant that starting on release two had been very difficult, because it was the same small team delivering it. The focus was completing the first release of the clinic portal and the website, and passing our GDS service assessment, because these first releases, especially the portal, are the groundwork for a successful release two with a new data submission system.

- 12.5.** On legal challenge, we set a high tolerance, since legal challenge will always be a risk, by virtue of the fact that we work in such an interesting policy area. It does at times, though, cause large peaks in workload for certain staff, and resource diversion. We have also had some delays in receiving judgments on some cases, which can worsen problems.
- 12.6.** The final risk above tolerance related to data. We continue to receive an unpredictable flow of complex parliamentary questions and Freedom of Information requests and, because of some turnover in the policy team, we also lost a member of staff who was particularly expert in answering complex scientific parliamentary questions.
- 12.7.** We also raised the general knowledge and capability risk at that time, because we were managing some turnover and internal churn, alongside some staff being fully occupied with IfQ. This situation was unlikely to go away during a period of organisational change.
- 12.8.** Members noted the latest edition of the strategic risk register.

13. Business plan 2017/18

- 13.1.** The Head of Business Planning reminded members of our three strategic aims for 2017-2020:
- Safe, ethical effective treatment
 - Consistent outcomes and support
 - Improving standards through intelligence.
- 13.2.** To achieve these overall aims, we need to make sure that our next three business plans are carefully planned so that we deliver these aims. We also need to make sure that our risk register is capturing the risks to delivering these things, and that our strategic performance reporting helps us to keep track of delivery. Our teams need service delivery plans in place to deliver each business plan and staff need to have personal objectives in place which link to team plans, the business plan and to the overall strategy. Finally, we need to have the right organisational structure in place, which is in progress.
- 13.3.** The Head of Business Planning gave members an overview of how we plan to meet our strategic ambitions and, following discussion, members thanked the Head of Business Planning for her excellent work and approved the near-final business plan for 2017/18. Members also noted that publication will follow, after the addition of year-end statistics and approval by DH of the budget and the business plan itself.

14. Any other business

- 14.1.** The Chair of the meeting confirmed that the next meeting will be held on Wednesday 10 May at Church House, 27 Great Smith Street, London, SW1P 3NZ. Members were asked to confirm their attendance to the Executive Assistant to the Chair and Chief Executive as soon as possible.

15. Chair's signature

I confirm this is a true and accurate record of the meeting.

Signature

Chair

Date

Performance report

Strategic delivery:

- Safe, ethical effective treatment
 Consistent outcomes and support
 Improving standards through intelligence

Details:

Meeting	Authority
Agenda item	6
Paper number	HFEA (10/05/17) 835
Meeting date	10 May 2017
Author	Paula Robinson, Head of Planning and Governance

Output:

For information or decision?	For information
Recommendation	The Authority is asked to note and comment on the latest performance report.
Resource implications	In budget
Implementation date	Ongoing
Communication(s)	<p>CMG reviews performance in advance of each Authority meeting, and their comments are incorporated into this Authority paper.</p> <p>The Department of Health reviews our performance at each DH Update meeting (based on the CMG paper).</p> <p>The Authority receives this summary paper at each meeting, enhanced by additional reporting from Directors. Authority's views are fed back to the subsequent CMG performance meeting.</p>
Organisational risk	<input type="checkbox"/> Low <input checked="" type="checkbox"/> Medium <input type="checkbox"/> High
Annexes	Annex 1: Performance report

1. Introduction

- 1.1.** The attached paper marks the beginning of a review of the existing strategic performance report. At the Corporate Management Group (CMG) performance meeting in April, we discussed the best approach to reporting on both organisational performance and progress against our new strategy.

2. Reporting on performance

- 2.1.** The previous version of the report conveyed a number of different types of information. It included various operational performance measures and volume metrics, a graphical snapshot of clinic performance in terms of success rates and ESET cycles, and a brief account of progress against our strategy on a month by month basis. In addition, Directors give verbal updates at each meeting on their areas of work, on a cyclical basis, and a set of compliance reports about the quality and safety of care was referenced in each report, and presented to the Authority annually in September.
- 2.2.** CMG reflected that the compliance model of reporting has been successful and effective, and gives the Authority a better sense of progress towards strategic aims than could be achieved through KPIs and graphs, particularly at monthly intervals. The performance report, meanwhile, has been serving multiple purposes and presents several different varieties of information.
- 2.3.** With the launch of our new strategy, the focus on a number of campaigning themes, and the end of the Information for Quality programme nearing, we felt it was time now to improve our approach to both performance reporting and progress reporting. Many of the strategic topics we will be focusing on over the next few years will lend themselves better to themed reports with some space for context and detail, narrative and impact, rather than to key performance indicators or a count of milestones met, which can be somewhat reductionist (although where there are relevant indicators, we will track them).
- 2.4.** Therefore, this paper now focuses squarely on our main operational performance indicators, to give an overall picture of how well the organisation is being run. We will report on strategy progress differently, through a series of Authority agenda items across the year.
- 2.5.** We will also consider whether a separate regular strategy report would be useful, to give the Authority an overall picture of recent progress and upcoming work.
- 2.6.** An indicative schedule is set out in the table below to illustrate the idea.

Authority meeting	Strategic update
June 2017	Add ons and treatment information Reshaping the HFEA
September 2017	Compliance items focusing on high quality, safe care
November 2017	Information strategy
January 2018	Research and innovation, including availability of embryos for research Value for money
March 2018	Using data and feedback for improvement
May 2018	Support before, during and after treatment
June/July 2018	Improving access to treatment and donation
September 2018	Success rates

2.7. In the performance report, which will continue to come to every Authority meeting, we will therefore not mirror the structure of the strategy, but arrange the report according to the main organisational management areas where meaningful KPIs and other metrics can tell us something about the overall health of the organisation, through its performance. These are:

- Our finances
- The efficiency of our licensing processes
- Information
- Our staffing.

2.8. For the time being, the summary page in the annex has been populated with the best available measures. These may change over time – for instance, under the information heading, we have included Opening the Register efficiency as our main summary indicator; once the website is live, we may wish to exchange this for the number of web hits (with a target), given the strategic importance of reaching patients.

2.9. For some time, we have included a fairly high number of volume indicators in our scorecard, as well as performance indicators. Volume indicators can be extremely useful to give a sense of the fluctuations in our workload, but our intention now is to develop, over time, more measures of quality and performance, as opposed to quantity.

2.10. The performance information presented in this report relates mainly to February data, with financial data to year end. Overall performance remains good.

3. Recommendation

- 3.1.** The Authority is asked to note the latest performance report and our proposed approach to ensuring the Authority retains good oversight of both organisational management and strategic progress.

Dashboard – February data

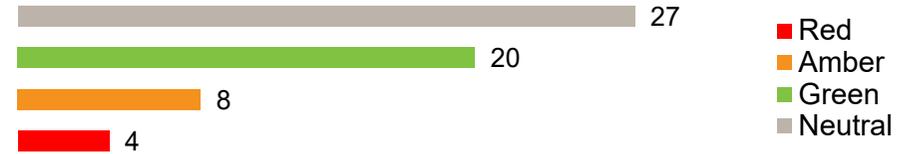
People – capacity

Establishment leavers per month
(% turnover for the year).

KPI: 5 - 15% establishment turnover

★
Leavers: 0
(12.4%)

Overall performance – RAG status (all indicators)



Information – OTR efficiency

Opening the Register requests responded to
within 20 working days

(Number on time/ number due)

KPI: 100%

★
100%
(17/17)

Licensing end-to-end

Length of the whole inspection and licensing process

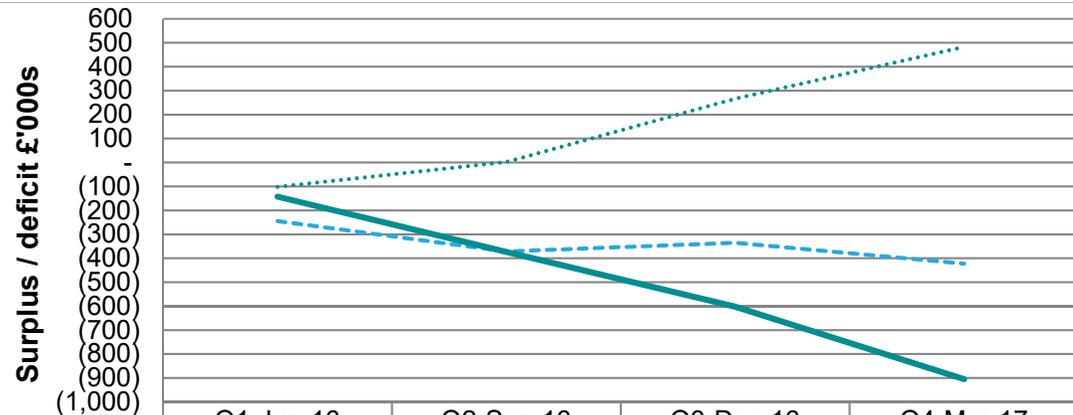
KPI: ≤ 70 working days

↓
76 days

Money – budget position (end of year)

Net position over the year - how we perform against budget.

At the end of the financial year we are showing a net surplus (surplus after removing IfQ costs) of £483k against a budgeted deficit of £422k. The budgeted deficit arose due to conservative estimates for our treatment fee income.

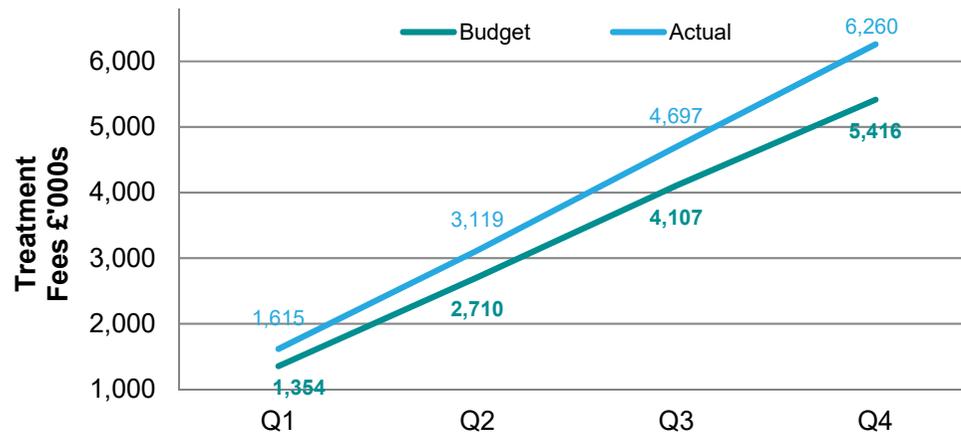


	Q1-Jun-16	Q2-Sep-16	Q3-Dec-16	Q4-Mar-17
----- Budgeted surplus/(deficit)	(244.72)	(371.68)	(335.57)	(422.31)
..... Actual surplus/(deficit)	(101.86)	2.17	266.46	482.86
———— Variance - budget to forecast	(142.87)	(373.85)	(602.03)	(905.16)

Budget status – March data

The graph above shows the overall surplus/deficit position. The graphs below show how the surplus or deficit has arisen.

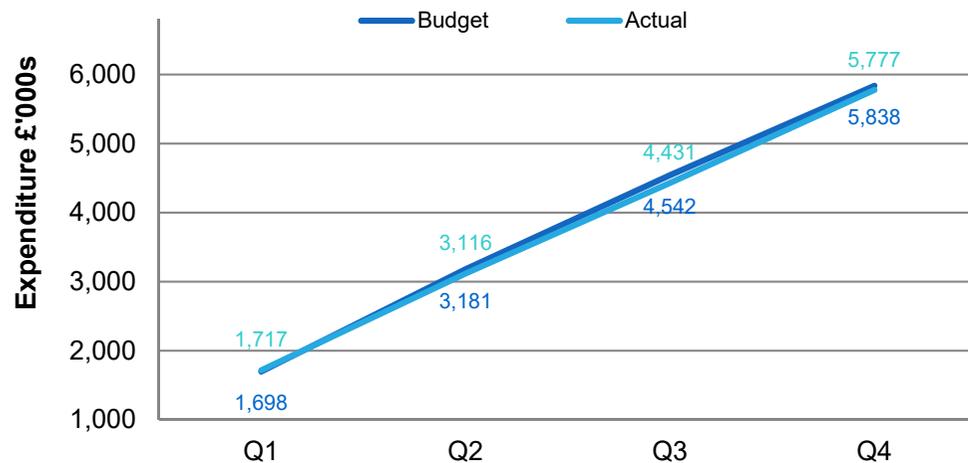
Cum. quarterly treatment income and GIA 2016-17



This graph shows our budgeted (planned) income including grant-in-aid (GIA) compared to actuals, as at the end of the financial year (31 March 2017).

As of month 12 (March 2017) we have exceeded our budgeted income by £843k.

Cum. quarterly expenditure 2016-17



This graph is the second component that makes up the surplus/deficit. This includes costs relating to IfQ, although they are being funded from reserves and it is expected that most of this cost will be transferred to the balance sheet at year end subject to audit.

The year-end position shows we are under budget by 62k (1%). This includes costs for IfQ and accruals for legal spend. Removal of IfQ costs would mean a larger underspend on expenditure of £133k which equates to 2%.

Management accounts and commentary – March 2017

Income & Expenditure Account		Mar-2017			
Accounting Period		Period 12 16-17			
Cost Centre Name		All Cost Centres			
Department Name		All Departments			
		Year to Date			
		Actual YTD	Budget YTD	Variance YTD	% Variance YTD
		£	£	£	%
Grant-in-aid		933	938	(5)	(1)
Licence Fees		5,323	4,472	851	19
Other Income		4	6	(2)	(38)
Total Income		6,260	5,416	843	16
Revenue Costs - Charged to Expenditure					
Salaries (excluding Authority)		2,623	2,679	(123)	5
Shared Services		50	81	31	(38)
Employer's NI Contributions		262	247	(14)	6
Employer's Pension Contribution		556	573	17	(3)
Authority salaries inc. NI Contributions		144	146	1	(1)
Temporary Staff costs		143	-	143	
Other Staff Costs		240	262	(22)	8
Other Authority/Committee costs		126	156	(29)	19
Other Compliance Costs		17	29	(12)	40
Other Strategy Costs		98	142	(43)	31
Facilities Costs incl non-cash		392	488	(96)	20
IT costs Costs		138	93	45	(49)
Legal Costs		374	400	(26)	7
Professional Fees		65	68	(2)	3
Total Revenue Costs		5,227	5,361	(133)	2
Total Surplus/(Deficit) before Capital & Project costs		1,032	55	977	(1,764)
IFQ & Other Project Costs - Reserves funded		549	477	72	(15)
TOTAL NET ACTIVITY		483	(422)	905	

Income

At the end of this financial year we have exceeded our planned (budgeted) income by 16%. Treatment fee income exceeded expectations by £851k (19%). Treatment fee income has been increasing since the beginning of the financial year with a slight, but expected, dip during December and January. We will be undertaking work during 2017/18 to better understand the driver for increased activity. Other income streams, which are significantly smaller, were all under budget.

Expenditure – by exception

There is a minor over-spend on total staff of 1.4%. This relates to temporary staff costs incurred to back-fill key staff working on the IfQ Programme.

Our legal spend has ended the year under budget by £26k. This underspend takes account of the interim fees awarded in a recent case .

Our spend on IT consumables has ended the year significantly over budget (£45k). A large proportion of this relates to items procured that were used within the IfQ programme in addition to those utilised in general day to day operations. The prudent approach of expensing all has been taken.

IfQ and other project costs

IfQ cost has ended the year at £549k compared to a budget of £477k – an increase of £72k (15%). The increase in spend by year end is due to delays and the desire to bring this phase of the programme to an end.

A new budget will be set for the Release 2 project which begins in Q1 of 2017/18.

Overall performance

Red/amber/green status of performance indicators – February 2017

The four red key performance indicators (KPIs) shown in the 'overall status - performance indicators' pie chart on the dashboard are as follows:

- Average number of working days between ELP/LC/SAC date and minutes being finalised (signed by the Chair). 50% of minutes were finalised within 10 working days, compared to a KPI of 100%. The average number of working days taken was 11.
- Average number of working days taken between committee meeting date at which PGD decision is made, and decision being finalised (ie, minutes signed off by SAC Chair). 0% of minutes were finalised within 10 working days, compared to a KPI of 100%. The average number of working days taken was 13.
 - These two indicators are closely related, and the scores arise from the same cause – staff turnover, resulting in a change of committee officer, requiring a period of training.
- Percentage of PGD applications processed within three months.
 - One of two items processed in February exceeded the KPI of 66 working days by one day.
- The IfQ programme has also been rated as a red risk for the past few months.

People – key performance and volume indicators

Indicator	Score	RAG	Recent trend ¹	Notes																					
Current headcount by month Headcount/ establishment	62/67	↑	<table border="1"> <caption>Headcount and Establishment Data</caption> <thead> <tr> <th>Month</th> <th>Headcount</th> <th>Establishment</th> </tr> </thead> <tbody> <tr> <td>Sep</td> <td>64</td> <td>67</td> </tr> <tr> <td>Oct</td> <td>63</td> <td>67</td> </tr> <tr> <td>Nov</td> <td>63</td> <td>67</td> </tr> <tr> <td>Dec</td> <td>62</td> <td>67</td> </tr> <tr> <td>Jan</td> <td>61</td> <td>67</td> </tr> <tr> <td>Feb</td> <td>62</td> <td>67</td> </tr> </tbody> </table>	Month	Headcount	Establishment	Sep	64	67	Oct	63	67	Nov	63	67	Dec	62	67	Jan	61	67	Feb	62	67	Overall volume (capacity) indicator. There are also three posts filled by contingent labour. During IfQ and the planning period for organisational change, we have held the two remaining posts vacant, for flexibility.
Month	Headcount	Establishment																							
Sep	64	67																							
Oct	63	67																							
Nov	63	67																							
Dec	62	67																							
Jan	61	67																							
Feb	62	67																							
Turnover: Establishment ('unplanned') leavers per month (% establishment turnover for the year).	13.9%	★	<table border="1"> <caption>Establishment Turnover Data</caption> <thead> <tr> <th>Month</th> <th>Turnover (%)</th> </tr> </thead> <tbody> <tr> <td>Sep</td> <td>9%</td> </tr> <tr> <td>Oct</td> <td>9%</td> </tr> <tr> <td>Nov</td> <td>9%</td> </tr> <tr> <td>Dec</td> <td>10%</td> </tr> <tr> <td>Jan</td> <td>12%</td> </tr> <tr> <td>Feb</td> <td>14%</td> </tr> </tbody> </table>	Month	Turnover (%)	Sep	9%	Oct	9%	Nov	9%	Dec	10%	Jan	12%	Feb	14%	KPI range: 5-15% turnover for the rolling year The public sector average is 10% (Expert HR & CIPD research 2013) which therefore forms the basis of our target. This is worked out on a rolling basis each month.							
Month	Turnover (%)																								
Sep	9%																								
Oct	9%																								
Nov	9%																								
Dec	10%																								
Jan	12%																								
Feb	14%																								
Staff sickness absence rate (%) per month.	0.4%	★	<table border="1"> <caption>Staff Sickness Absence Rate Data</caption> <thead> <tr> <th>Month</th> <th>Absence Rate (%)</th> </tr> </thead> <tbody> <tr> <td>Sep</td> <td>0.3%</td> </tr> <tr> <td>Oct</td> <td>3.5%</td> </tr> <tr> <td>Nov</td> <td>2.3%</td> </tr> <tr> <td>Dec</td> <td>1.0%</td> </tr> <tr> <td>Jan</td> <td>1.4%</td> </tr> <tr> <td>Feb</td> <td>0.4%</td> </tr> </tbody> </table>	Month	Absence Rate (%)	Sep	0.3%	Oct	3.5%	Nov	2.3%	Dec	1.0%	Jan	1.4%	Feb	0.4%	KPI: Absence rate of ≤ 2.5%. Public sector sickness absence rate average is eight days lost per person per year (3.0%).							
Month	Absence Rate (%)																								
Sep	0.3%																								
Oct	3.5%																								
Nov	2.3%																								
Dec	1.0%																								
Jan	1.4%																								
Feb	0.4%																								

¹ KPIs, where applicable, are shown as a blue dashed line in graphs. This line may be invisible when performance and target are identical (eg, 100%). Our establishment turnover KPI is a range, which is shown as a blue band in the graph.

Information – key performance and volume indicators

Indicator	Score	RAG	Recent trend	Notes																												
Number of emailed public enquiries received (cw same month last year)	200	↓	<table border="1"> <caption>Number of emailed public enquiries received</caption> <thead> <tr> <th>Month</th> <th>This year</th> <th>Last year</th> </tr> </thead> <tbody> <tr> <td>Sep</td> <td>248</td> <td>186</td> </tr> <tr> <td>Oct</td> <td>244</td> <td>168</td> </tr> <tr> <td>Nov</td> <td>238</td> <td>156</td> </tr> <tr> <td>Dec</td> <td>160</td> <td>193</td> </tr> <tr> <td>Jan</td> <td>170</td> <td>248</td> </tr> <tr> <td>Feb</td> <td>200</td> <td>259</td> </tr> </tbody> </table>	Month	This year	Last year	Sep	248	186	Oct	244	168	Nov	238	156	Dec	160	193	Jan	170	248	Feb	200	259	Volume indicator.-							
Month	This year	Last year																														
Sep	248	186																														
Oct	244	168																														
Nov	238	156																														
Dec	160	193																														
Jan	170	248																														
Feb	200	259																														
Percentage of Opening the Register requests responded to within 20 working days	100%	★	<table border="1"> <caption>Percentage of Opening the Register requests responded to within 20 working days</caption> <thead> <tr> <th>Month</th> <th>Number of requests</th> <th>% within 20 days</th> </tr> </thead> <tbody> <tr> <td>Sep</td> <td>23</td> <td>100%</td> </tr> <tr> <td>Oct</td> <td>21</td> <td>100%</td> </tr> <tr> <td>Nov</td> <td>22</td> <td>100%</td> </tr> <tr> <td>Dec</td> <td>25</td> <td>100%</td> </tr> <tr> <td>Jan</td> <td>14</td> <td>100%</td> </tr> <tr> <td>Feb</td> <td>17</td> <td>100%</td> </tr> </tbody> </table>	Month	Number of requests	% within 20 days	Sep	23	100%	Oct	21	100%	Nov	22	100%	Dec	25	100%	Jan	14	100%	Feb	17	100%	KPI: 100% of complete OTR requests to be responded to within 20 working days (excluding counselling time)							
Month	Number of requests	% within 20 days																														
Sep	23	100%																														
Oct	21	100%																														
Nov	22	100%																														
Dec	25	100%																														
Jan	14	100%																														
Feb	17	100%																														
Number of requests for contributions to Parliamentary questions	3	↓	<table border="1"> <caption>Number of requests for contributions to Parliamentary questions</caption> <thead> <tr> <th>Month</th> <th>PQs dealt with</th> <th>No. re mitochondria</th> <th>Same month last year</th> </tr> </thead> <tbody> <tr> <td>Sep</td> <td>0</td> <td>0</td> <td>0</td> </tr> <tr> <td>Oct</td> <td>6</td> <td>0</td> <td>0</td> </tr> <tr> <td>Nov</td> <td>5</td> <td>7</td> <td>0</td> </tr> <tr> <td>Dec</td> <td>2</td> <td>1</td> <td>16</td> </tr> <tr> <td>Jan</td> <td>6</td> <td>2</td> <td>16</td> </tr> <tr> <td>Feb</td> <td>3</td> <td>2</td> <td>18</td> </tr> </tbody> </table>	Month	PQs dealt with	No. re mitochondria	Same month last year	Sep	0	0	0	Oct	6	0	0	Nov	5	7	0	Dec	2	1	16	Jan	6	2	16	Feb	3	2	18	Volume indicator. Last year's numbers were notably high, for a period. Many of those PQs related to the work we were then doing on the mitochondria scientific review.
Month	PQs dealt with	No. re mitochondria	Same month last year																													
Sep	0	0	0																													
Oct	6	0	0																													
Nov	5	7	0																													
Dec	2	1	16																													
Jan	6	2	16																													
Feb	3	2	18																													
Number of Freedom of Information (FOI), Environmental Information Regulations (EIR) and Data Protection Act (DPA) requests	10	↑	<table border="1"> <caption>Number of Freedom of Information (FOI), Environmental Information Regulations (EIR) and Data Protection Act (DPA) requests</caption> <thead> <tr> <th>Month</th> <th>FOIs etc. dealt with</th> <th>Same month last year</th> </tr> </thead> <tbody> <tr> <td>Sep</td> <td>4</td> <td>9</td> </tr> <tr> <td>Oct</td> <td>1</td> <td>7</td> </tr> <tr> <td>Nov</td> <td>4</td> <td>6</td> </tr> <tr> <td>Dec</td> <td>3</td> <td>10</td> </tr> <tr> <td>Jan</td> <td>4</td> <td>8</td> </tr> <tr> <td>Feb</td> <td>10</td> <td>6</td> </tr> </tbody> </table>	Month	FOIs etc. dealt with	Same month last year	Sep	4	9	Oct	1	7	Nov	4	6	Dec	3	10	Jan	4	8	Feb	10	6	Volume indicator. There does not appear to be any trend or predictability in the volume or focus of our FOI (and other) requests.							
Month	FOIs etc. dealt with	Same month last year																														
Sep	4	9																														
Oct	1	7																														
Nov	4	6																														
Dec	3	10																														
Jan	4	8																														
Feb	10	6																														

Inspection and licensing process

Indicator	Score	RAG	Recent trend ²	Notes
Recommendations met by clinics following earlier inspections (No. met that month / No. due to be met that month)	95%	★	<p>Recommendations met (bars) and Performance (line) from Sep to Feb. KPI is 80%.</p>	KPI: 80% of recommendations due that month, completed on time by clinics.
Average number of critical/major recommendations at clinics in inspection reports that were considered by ELP/LC that month	14	↓	<p>Total critical + major (dark teal), Critical (grey), and Major (light teal) recommendations from Sep to Feb.</p>	Volume indicator
Average number of working days taken for the whole licensing process, from the day of inspection to the decision being communicated to the centre.	76	↓	<p>Average working days from Sep to Feb. KPI is 70.</p>	KPI: Less than or equal to 70 working days.

² KPIs, where applicable, are shown as a blue dashed line in graphs. This line may be invisible when performance and target are identical (eg, 100%). Our establishment turnover KPI is a range, which is shown as a blue band in the graph.

Indicator	Score	RAG	Recent trend ²	Notes														
Monthly percentage of PGD applications processed within three months (66 working days).	50%	↓	<table border="1"> <caption>Monthly percentage of PGD applications processed within three months</caption> <thead> <tr> <th>Month</th> <th>Percentage</th> </tr> </thead> <tbody> <tr> <td>Sep</td> <td>100%</td> </tr> <tr> <td>Oct</td> <td>100%</td> </tr> <tr> <td>Nov</td> <td>100%</td> </tr> <tr> <td>Dec</td> <td>60%</td> </tr> <tr> <td>Jan</td> <td>100%</td> </tr> <tr> <td>Feb</td> <td>50%</td> </tr> </tbody> </table>	Month	Percentage	Sep	100%	Oct	100%	Nov	100%	Dec	60%	Jan	100%	Feb	50%	KPI: 100% processed (i.e. considered by SAC) within three months (66 working days) of receipt of completed application.
Month	Percentage																	
Sep	100%																	
Oct	100%																	
Nov	100%																	
Dec	60%																	
Jan	100%																	
Feb	50%																	
Average number of working days taken.	57	★	<table border="1"> <caption>Average number of working days taken</caption> <thead> <tr> <th>Month</th> <th>Days</th> </tr> </thead> <tbody> <tr> <td>Sep</td> <td>59</td> </tr> <tr> <td>Oct</td> <td>56</td> </tr> <tr> <td>Nov</td> <td>59</td> </tr> <tr> <td>Dec</td> <td>62</td> </tr> <tr> <td>Jan</td> <td>52</td> </tr> <tr> <td>Feb</td> <td>57</td> </tr> </tbody> </table>	Month	Days	Sep	59	Oct	56	Nov	59	Dec	62	Jan	52	Feb	57	
Month	Days																	
Sep	59																	
Oct	56																	
Nov	59																	
Dec	62																	
Jan	52																	
Feb	57																	
Annualised (rolling year) percentage of PGD applications processed within three months (66 working days)	87%	↓	<table border="1"> <caption>Annualised (rolling year) percentage of PGD applications processed within three months</caption> <thead> <tr> <th>Month</th> <th>Percentage</th> </tr> </thead> <tbody> <tr> <td>Sep</td> <td>94%</td> </tr> <tr> <td>Oct</td> <td>94%</td> </tr> <tr> <td>Nov</td> <td>95%</td> </tr> <tr> <td>Dec</td> <td>89%</td> </tr> <tr> <td>Jan</td> <td>90%</td> </tr> <tr> <td>Feb</td> <td>87%</td> </tr> </tbody> </table>	Month	Percentage	Sep	94%	Oct	94%	Nov	95%	Dec	89%	Jan	90%	Feb	87%	KPI: As above. (Annualised score). Dips in the monthly performance will have an impact on the annualised figure.
Month	Percentage																	
Sep	94%																	
Oct	94%																	
Nov	95%																	
Dec	89%																	
Jan	90%																	
Feb	87%																	
Average number of working days taken.	56	★	<table border="1"> <caption>Average number of working days taken</caption> <thead> <tr> <th>Month</th> <th>Days</th> </tr> </thead> <tbody> <tr> <td>Sep</td> <td>54</td> </tr> <tr> <td>Oct</td> <td>54</td> </tr> <tr> <td>Nov</td> <td>54</td> </tr> <tr> <td>Dec</td> <td>56</td> </tr> <tr> <td>Jan</td> <td>54</td> </tr> <tr> <td>Feb</td> <td>56</td> </tr> </tbody> </table>	Month	Days	Sep	54	Oct	54	Nov	54	Dec	56	Jan	54	Feb	56	
Month	Days																	
Sep	54																	
Oct	54																	
Nov	54																	
Dec	56																	
Jan	54																	
Feb	56																	

Information for Quality: update on closure

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

Details:

Meeting	Authority
Agenda item	7
Paper number	HFEA (10/05/17) 836
Meeting date	10 May 2017
Author	Nick Jones, Director of Compliance and Information

Output:

For information or decision?	For information
Recommendation	<p>The Authority is asked to:</p> <ul style="list-style-type: none"> • Note the intention to launch the HFEA website and choose a fertility clinic, as live, in May 2017 • Note the activities necessary for completing the data submission project • Note the budget expectations, and the requirement to obtain capital cover
Resource implications	Set out in paper
Implementation date	During 2017–18 business year
Communication(s)	Regular, range of mechanisms
Organisational risk	<input type="checkbox"/> Low <input type="checkbox"/> Medium <input checked="" type="checkbox"/> High
Annexes:	None

1. Background

- 1.1. At the March 2017 meeting of the Authority it was agreed that the launch of the new HFEA website and the accompanying Choose a Fertility Clinic (CaFC) function, as live, should mark the formal closure of the Information for Quality (IfQ) programme.
- 1.2. This paper outlines the plans for launching our website and CaFC function, and sets out our current expectations as to completing the data submission component within the Clinic Portal, in 2017/18.

2. Work in progress

Website and Choose a Fertility Clinic

- 2.1. The primary focus of activity has been on preparing the website for launch. The judgment on the judicial review has been handed down in the HFEA's favour and there are no restrictions on the presentation of data. This means that we can make changes to CaFC to implement the Authority decisions in November 2016 around data aggregation and segregation.
- 2.2. The team has largely completed the creation of new rich content for the website including video clips and animations as well as a home page news feed, and a listings' feature.
- 2.3. In anticipation of launch, we asked clinics in December 2016 to verify their outcome data ready for publication on CaFC. This differs from previous years' exercises (due to the new focus on cumulative birth rates) but is necessary to ensure that we can start the new CaFC with a high-quality dataset (subsequent verification exercises will be more straightforward). Clinics have now completed this exercise and we are now processing this.
- 2.4. The Government Digital Service provided feedback that we must address before we can proceed to live stage. This includes the necessity of thorough security penetration testing; the completion of an exercise and report as to the accessibility of the website to all users; and confirming our arrangements for continual improvement to the website.
- 2.5. Both the CaFC data verification and the required work to satisfy GDS standards is on track, and publication is planned to take place in May 2017. A 'go live' date will be announced at the meeting.

Release 2 of the Clinic Portal – data submission project

- 2.6. This project is picking up speed following the focus on the website, and the Portal before that. Over the last 12 months, the Register has been subject to a thorough overhaul, and cleansing exercise. Critical data fields have been reviewed for error, absence or duplication and resolved, wherever possible.

- 2.7.** Data migration progress is slower given the involvement of key staff in the verification of CaFC data.
- 2.8.** Very good progress is being made on the 'front end' experienced by users and we have begun sharing the outputs of this with users. Similarly, engagement with clinics' suppliers of patient record systems is ongoing and positive.
- 2.9.** That said, there is much to do, and we continue to need the support of externally commissioned expertise (contracted in developers) to progress. We plan to release the new system to current 'EDI' users remains September 2017.
- 2.10.** Work on this final element of the Portal is taking place at the same time (and as part of) as commencing work on the Authority's strategic objectives for 2017-20. We have an organisation change programme to align our people and resources to meet these objectives, which is entering its concluding stages. Such a change programme introduces opportunities and, of course, risks, which are being managed within our usual arrangements.
- 2.11.** The change programme is impacting on some colleagues heavily involved in the project, although, we are not expecting staffing changes to take place for several months. And – as we would expect – colleagues are working hard to meet the challenging objectives of each sprint as well as being involved in establishing new teams and ways of working. We remain grateful for this commitment.
- 2.12.** As agreed at the Authority meeting in March 2017, the Authority will be presented with a report on progress with the data submission project at each of its meetings, in a similar style to this report.

3. Project budget

- 3.1.** The IfQ *programme* budget has now closed; with final expenditure (subject to final accounts) of £1.276m compared to our planned programme budget of £1.227m. That expenditure includes substantial work (to end March 2017) on the data submission project, although, as noted above, there is a considerable amount of work still to complete.
- 3.2.** However, as noted above, there is a considerable amount of work still to complete the data submission project. We estimate that the total overspend will be in the region of £350k.
- 3.3.** We propose to fund that work from our overall budget expectations for 2017/18 with some additional capital cover from the DH. As with the IfQ programme, the costs shown below relate to additional, specialist costs over and above usual revenue costs – staff employed within the establishment structure. Some of these costs are capital costs – as they are one-off costs incurred in creating an asset. As such, given the HFEAs capital expenditure is considered as part of overall Government capital expenditure we need permission, or cover, from Department of Health such that it is included within its overall capital allowance.

Resource	17/18 expenditure
Temporary staffing costs to support data migration and backfilling core staff	£90,000
Specialist external 'front-end' developer temporary staffing costs	£295,000
<i>Assurance of overall security integrity, data migration and assurance provided by consultancy firm</i>	£22,000
<i>Programme support – backfill costs for fixed term development opportunity</i>	£32,000
<i>Misc. Room bookings, user testing, engagement</i>	£11,000
	£450,000

- 3.4.** The costs shown in italics c£65,000 were always budgeted, and are carried forward from 2016/17. The data migration costs (at £90,000) are as a direct consequence of that work not completing last year, and we continue to rely on key staff to undertake that work and their core 'business as usual' responsibilities need to be covered – hence this support.
- 3.5.** The significant additional cost (£295,000) relates to specialist development expertise. Our previous estimates for the costs of this aspect of work was provided as part of the competitive tendering process undertaken in 2015. It was clear at the beginning of this year, that the contractor no longer wished to be bound to this aspect of the contract.
- 3.6.** We are continuing to discuss capital cover with Department of Health colleagues and the indications to date are positive. The risks of continuing without approval are minimal.

4. Recommendation

- 4.1.** The Authority is asked to:
- Note the intention to launch the HFEA website and choose a fertility clinic, as live, in May 2017
 - Note the activities necessary for completing the data submission project
 - Note the budget expectations, and the requirement to obtain capital cover

Pre-HFEA Voluntary Contact Register

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

Details:

Meeting	Authority
Agenda item	8
Paper number	HFEA (10/05/17) 837
Meeting date	10 May 2017
Author	Rosetta Wotton, Donor Information Manager

Output:

For information or decision?	For decision
Recommendation	Option 2 – To contract out the entire service to another suitable organisation
Resource implications	
Implementation date	January 2018
Communication(s)	
Organisational risk	<input checked="" type="checkbox"/> Low <input type="checkbox"/> Medium <input type="checkbox"/> High

1. Introduction

- 1.1. The Department of Health (DH) is no longer funding the pre-HFEA voluntary contact register (the Donor Conceived Register) service, to date managed by the National Gamete Donation Trust (NGDT), and has asked us to determine how to support the service.
- 1.2. This paper seeks the Authority's decision as to whether we bring the pre-HFEA voluntary contact register service in-house, or alternatively contract out the service further to a competitive process.

2. Background

- 2.1. The Human Fertilisation and Embryology Act has required the Authority to keep a *Register* of information about donors and treatments involving the use of donor gametes and embryos in the UK since 1 August 1991.
- 2.2. Since October 2009, the Authority has had the power to establish a voluntary contact register for people conceived following donor treatment which occurred before 1 August 1991 (pre-HFEA Act donor-conceived people):
'The Authority may set up a voluntary contact register in such a manner as it thinks fit' (section 31ZF (2)(a))
- 2.3. The Authority also has the power to disclose information from the Register, to charge applicants, and to contract out the service to another organisation.
- 2.4. Since 2004 a 'pre-HFEA' voluntary contact register has existed, and its management funded by the DH. Until 2013 this service was called UK DonorLink (UKDL) and operated as a 'pilot project' by a voluntary sector organisation; After Adoption Yorkshire.
- 2.5. In April 2013, the DH funded the NGDT to run the service – which was renamed the Donor Conceived Register (DCR).
- 2.6. Late last year the DH decided not to provide funding beyond 31 March 2017 to any organisation to run the service. The Parliamentary Under Secretary of State for Public Health and Innovation formally invited us to exercise our powers within the Act to take over the running of the service.
- 2.7. We have agreed to fund the DCR from April 2017 for a period of six months, with a three-month rolling contract and break clause, and to consult with the Authority on next steps.
- 2.8. This paper outlines the features of the current service with some options.

3. How does the Donor Conceived Register differ from the HFEA Register?

- 3.1.** Since the HFEA was set up on 1 August 1991, clinics have been legally required to submit information to us when they carry out treatment involving donor sperm, eggs or embryos. This includes information about the donor, the patient(s) and any children born as a result of treatment. All this information is stored on the secure database called the HFEA Register, which is extensively validated and verified by the clinics we license.
- 3.2.** The key features of the HFEA Register can be summarised as follows:
- The Register is mandatory; data on donor cycles is closely and continuously validated with clinics by the Authority's staff to ensure its reliability and accuracy;
 - where licensed centres close, the Authority provides, as a last resort, a means of preserving their records; all post 1991 cycles are thus stored twice – at the centre and at the Authority;
 - the licensed centre's PR and the Authority itself are accountable – and in law liable – for the maintenance of the records;
 - UK law bestows upon post-1991 donor-conceived people an entitlement to access the records held by the Authority about their genetic origins;
 - wherever a link between an individual and a donor or between siblings is established there will be a verifiable, traceable set of documentary records.
- 3.3.** The DCR service was originally set up in 2004 in response to calls from donor-conceived adults who, because there was no legislation in place before 1 August 1991, have no statutory right to access any information about their donor. Through joining the voluntary contact register and DNA analysis linking registrants, people can share information and – if they wish – have contact with other people conceived with the same donor, or with the donor themselves. The DCR also ensure support and advice is available. There are currently 323 registrants on the DCR.
- 3.4.** Though apparently similar to the HFEA Register the DCR differs in a number of significant respects. Its key features can be summarised as follows:
- information on the DCR database is provided by the registrants (rather than collected from clinics), so the only way to establish whether donors and/or donor-conceived adults are genetically related is to analyse their DNA;
 - DNA analysis is optional but most registrants do opt to carry it out. Many registrants join the DCR having already made links from other DNA sites but the DCR has an annual contract with King's College London to provide DNA analysis, which is more comprehensive than commercial DNA analysis;
 - King's College London keeps a database containing the names, DCR registration numbers and King's assigned DNA number for those who undergo DNA analysis;
 - due to the nature of DNA analysis, where links between individuals are established, they are given a *Likelihood Ratio* (LR), rather than a certainty,

that they are genetically related (a ratio of over 50 equates to a link, although the confidence factor can vary by hundreds of thousands). They are also given help and information to understand the strength of the relatedness.

- 3.5.** In February 2017, the NGDT and its DNA lab at King's College completed upgrading of the DNA database side of the register to increase the number of DNA markers used for matching. This project has resulted in the declaration of a significant number of new half-sibling matches between registrants (approx. 30 new matches).

The DCR service

- 3.6.** The key services currently offered by the DCR are:

- DNA testing undertaken by King's College London
Registrants are invoiced for this service by the DCR who will in exceptional cases subsidise the cost for those who cannot afford it, and fund additional testing where weak matches require confirmation.
- Management of the results of DNA testing, plus referral to professional counselling/intermediary support if needed/requested (currently provided by one qualified person over the telephone)
- An advice line for registrants or people considering registering
- A quarterly newsletter for registrants
- A private Facebook page for registrants

Administration of the DCR also involves:

- Initiatives to publicise/grow the DCR
- Responding to media enquiries and requests from researchers
- Supporting the Registrants' Panel which meets every 6 months on a Saturday.

- 3.7.** The volume of work is highly erratic; some weeks may require several hours while others require someone working closer to full time. It is estimated that 2.5 staff days a week are required. Regular out of hours working is also required - because of the extreme sensitivity of the issues, most registrants prefer to discuss their situation when they are not at work. Enquiries are made by email or by phone to a dedicated mobile number.

- 3.8.** Registrants very much value the DCR and our understanding is that the DH's decision to stop funding the service is driven by financial considerations rather than concerns as to the service provided.

4. Options

4.1. There are two options for the future delivery of the pre-HFEA voluntary contact register:

1. To absorb part of the service into our mainstream activities, or
2. To contract out the entire service to another suitable organisation

Absorbing into mainstream activities

4.2. The costs associated with this option include an additional member of staff at upper Band 2 level with a full-time salary circa £28,000 plus an estimated £7,000 for overheads. On current estimates the DCR takes over 100 staff days per year to maintain, though the project work set out at paragraph 3.5 above requires another circa 50 days. Those costs would reduce if staff were paid on a pro-rata basis. Additional costs would include (1) the DNA analysis and (2) counselling/intermediary support. In both cases a new contract would need to be negotiated and it is not certain that the existing arrangements and costings could be maintained.

4.3. From the perspective of users, this option would put all the various sources of information about donors and donor-conceived people in one place however; the databases themselves, and processes, vary in significant respects.

4.4. Given the significant difference between the DCR as a DNA-linking system, and the HFEA as a data system existing within a statutory regime, we would need to be very clear with users about these differences, as there is often already confusion about the post-1991 voluntary sibling contact register (DSL) we run and the DCR.

4.5. This option also presents the challenge of effectively integrating part of the service into our work. We would still need to contract out both the DNA analysis and counselling/intermediary work, as the Opening the Register team are not qualified for this purpose.

4.6. There would, in addition, be implications for other areas of the HFEA e.g. with stakeholder management, media and communications, Freedom of Information requests etc.

4.7. We have some of the expertise required to run the service but not the capacity - we are still operating within headcount controls.

Contracting out to another organisation

4.8. If we decide to continue to contract another organisation to run the voluntary contact register, we will go through a tender process to allow other organisations to bid for it, which would require some staff time. Once established, this arrangement is likely to cost around £26,000 each year, a sum which reflects the DCR's current operating costs (though project work in 2017/18 has raised the cost to just under £32,000 for the current financial year, but this is likely to decrease in subsequent years).

- 4.9.** If the current supplier were to bid for the service successfully, there would be continuity of service for its users.
- 4.10.** Contracting out the service in full offers the most straightforward solution. What would be involved would be an undertaking by the Authority to fund a third party to provide the service following a tender process and this would be put into effect by means of a standard service level agreement.
- 4.11.** There would of course be a range of performance metrics within the agreement to ensure service users' needs are met, along with a formal feedback mechanism established for registrants.
- 4.12.** We would envisage issuing an Invitation to Tender in the Summer of this year, interviewing in the Autumn and, all being well, having a contract start date in January 2018.
- 4.13.** In the meantime, the DCR continue to provide the service and maintain continuity for their service users.

Summary of options

	Option 1 – Bring in-house	Option 2 – Contract out
Cost	Salary of at least half an additional upper Band 2 staff member at £28,000 + £7,000 overheads + DNA analysis + counselling/intermediary support	Circa £26,000 (Though circa £32,000 this financial year)
Clarity	May make sense to users to have all donor-conception services under one roof May confuse users/public to have such different systems (one statutory and data-based, the other outside of the HFEA remit and DNA-based), side by side	May provide more continuity of service for users Maintains distinction of HFEA services and the DCR
Practicality	Requires an additional member of staff which is not possible due to government headcount restrictions Diverts HFEA staff from their core functions for which there is not the capacity	Dedicated staff outside of the HFEA provide the service Possibility for continuity of service for users, depending who bids for/obtains the contract

5. Recommendation

- 5.1.** Registrants very much value the pre-HFEA voluntary contact register service and the primary consideration for the Authority is to ensure that an appropriate service is maintained.
- 5.2.** We are concerned that option 1 would confuse users and the public with the HFEA's remit, and our current DSL service, which operates within a statutory regime and is data-based. The DCR operates outside of a statutory framework and is based on DNA analysis so option 2 would maintain a distinction.
- 5.3.** Aside from bringing a lack of clarity to the HFEA's remit, option 1 would also mean dispersing functions of the DCR service across a larger organisation, whereas option 2 allocates a dedicated resource to the service e.g. currently a dedicated charity.
- 5.4.** Although either option has similar costs, the impact of each option on the HFEA is markedly different. Most importantly, option 1 would require additional headcount which, in a time of tight public finances, could only be met by diverting HFEA staff from other work. This may also lead to an increased organisational risk.
- 5.5.** It is the considered view of the Executive that there is very little operational synergy between the service currently offered by DCR and by ourselves in relation to Donor Sibling Link. We would be particularly concerned that the way it links individuals is fundamentally different from the Authority's (which meets statutory entitlements enshrined in law by means of systematic validation by the primary provider, the licensed clinic).
- 5.6.** The Authority is asked to note the current arrangement in place and to discuss and agree the preferred recommendation:

Option 2: To contract out the entire service to a suitable organisation.

1. Introduction

- 1.1. We've come a long way in the last two years. This strategy builds on the achievements in the previous communications strategy and steers our communications for the next three years in line with our new corporate strategy.
- 1.2. The strategy is closely aligned to our strategic objectives of equipping patients with information to make informed choices about their care and raising the quality of care by engaging with patients to encourage them to give feedback on their treatment.
- 1.3. The main audience for this strategy is patients. We want to be the first place that patients go for impartial advice.
- 1.4. The Authority is asked to consider the new strategy.

2. What impact have we made so far

- 2.1. We have made good progress with our communications over the last two years. We have good foundations to build on and exciting new tools to use and develop. Patients have told us they like the changes we have made and how we have incorporated our new visual identity and tone of voice into our digital tools. We have:
 - A refreshed brand and visual identity which makes us clear and approachable and distinguishes between information for patients and professionals.
 - A new tone and style that makes our information easy to understand and compassionate.
 - A redesigned website based around specific patient journeys to make it easier for patients to access the information they need.
 - A redeveloped Choose a Fertility Clinic (CaFC) service and a new patient feedback feature so patients can influence the care provided by clinics and help others to make the best choices about their treatment and where to have it.
 - New rich media that provides another visual element to our communications including patient videos and a video animation to explain what to consider when choosing a fertility clinic.
 - A new Clinic Portal as our main communication channel with clinic staff.

3. Who we will focus on and how we will do it

- 3.1. The strategy has five main audiences: patients, clinics, donors, donor conceived people and their parents, the public and HFEA staff.

3.2. Patients are the main audience for this strategy. We know that we need to get to patients earlier in their treatment pathway to prepare them for treatment and we need to get more feedback from them to drive up standards in clinics. We will use the approaches in this strategy to do that. We will:

- Market the benefits of our new website and CaFC service so patients are aware of the information they provide and the benefits to them to help them make the best choices about their treatment and the support available.
- Increase our use of social media by running Twitter campaigns and putting out timely and relevant tweets so we are more connected and responsive and part of the social media conversations about fertility treatments.
- Run campaigns, on topics such as treatment add ons and patient ratings, to get clinics to step up by equipping patients with better information to challenge clinics on controversial issues and make informed choices.
- Continue to engage in qualitative face to face communication with patients by attending fertility shows to better understand their concerns to help us develop ways to address them.
- Make an impact with our partnership working with patient organisations by working together on campaigns like treatment add ons so we can make maximum impact and engage with more patients.

3.3. We will use the national media more for maintaining our public reputation as an authoritative and world class regulator, rather than to engage with patients. To do this, we will focus on:

- Significant policy issues, such as mitochondrial donation and gene editing, which demonstrate our regulatory skill.
- Working with the new intelligence team to create opportunities around data, to show that we are knowledgeable and expert in our field.
- Commenting only on other topics which tie in with our campaigns – such as treatment add ons or emotional support.

4. How we will deliver and monitor the strategy

4.1. The strategy recommends developing campaigns aimed at patients. Each campaign will be delivered based on the Government Communication Service OASIS model. This is a series of steps that can help bring order and clarity to planning campaigns, which can sometimes be a complicated and challenging process.

4.2. We have developed a new set of metrics to enable Authority members to monitor the success of the new communications strategy.

4.3. To deliver the communications strategy we will equip the communications team with the appropriate skills so they can work across all areas of communications in line with the Government Communication Service model.

- 4.4.** All the proposed communication activities will be delivered within the allocated budget. We currently spend very little on external communications so we will use the budget to focus on the things that add value as described in the strategy.

Communications strategy 2017-2020

1. Building on good foundations

We're in a better place with our communications than we've ever been before – for the first time we have the tools in place to make an impact. Our last communications strategy focussed on changing perceptions of the HFEA. We wanted to retain our regulatory stance with clinics as firm but fair, whilst changing the way that we engage with patients. We have:

- Softened our tone of voice with patients to show that we are compassionate and give clear, helpful advice
- Made more use of social media to show that we are responsive and connected to our sector and to patients
- Refreshed our visual brand to be clearer and more approachable, showing clear what is aimed at professional audiences and what is aimed at patients
- Completely redesigned our website and our Choose a Fertility Clinic (CaFC) service based on research with patients, responding to their information needs
- Introduced a new feature for patients to give feedback about their experience of care in a clinic and for that to be publicly displayed on CaFC as a clinic rating

This document gives overview of what we achieved so far and what we want to do next, how we'll do it and how we'll know if we have done it well. It includes insights on which the new strategy is based and objectives, and evaluation metrics.

2. An enabling strategy

This is an exciting time for the HFEA and the fertility sector. We have agreed a new three-year strategy that puts patients at the heart of everything we do. We want them all to receive high quality care and support, at every stage of their treatment. We want to be the first place that patients, donors and donor-conceived people go for impartial, authoritative advice. That's where our communications strategy comes in. We can't achieve our strategic objectives without effective ways of engaging with our key audience – patients. That's why this new communications strategy will support our strategic objectives by:

- Raising awareness of the HFEA - providing information for patients, donors and donor-conceived people to help them to understand what we do, what information we provide for them and how we can help them.
- Equipping patients with information - developing channels and campaigns to positively engage with patients so they have the knowledge to help them get the best treatment possible.
- Raising the quality of care - engaging patients to encourage them to give feedback on the clinic and services they have used so they and others can benefit.
- Using the media to maintain our public reputation as a robust regulator who is a trustworthy source of information.
- Engaging with our staff.

3. Our audiences and what we know about them

Understanding our audiences and how they receive information is essential to effective communications. Our audiences are:

- Patients
- Donors
- Donor conceived people and their parents
- Clinics
- The public
- HFEA staff

Patients

Patients are a priority for our corporate strategy and must be so in our communications strategy. Patients come out of primary care desperately seeking information to help them make important decisions and they don't know where to turn. They are often directed towards clinic information and clinic websites. We know from our user research that we need to get patients early in their fertility journey.

Our research gives us some valuable insight into our patients. From a demographic point of view, we know that:

- Our audience is predominately between the age of 25 and 35.
- Women are more likely to access information about fertility treatments than men.
- Most people accessing fertility treatment are heterosexual couples having treatment with their own eggs and sperm.

From our research, we also know about their needs and behaviours:

- Patients don't always find the HFEA when looking for information early in their treatment pathway but go to other sources such as NHS Choices or Mumsnet.
- Only one third (36%) of patients surveyed were aware of the CaFC service on the website.
- The website is our most commonly used resource by patients. We have an average of 110,000 visitors to the HFEA website each month.
- 49% of patients said they thought the HFEA was impartial and 61% said we are authoritative.

Donors

Donors have different information needs from patients that we will cater for with updated information and rich media on our new website.

- Donors want to learn from personal stories of people in similar situations to help them cope with the emotional challenges they face.
- Women considering being an egg donor need a lot of information before they begin the process.

Donor conceived people and their parents

These people are already well catered for with the information that is available on our website. We have information about how to access donor information and the counselling service that is available for donor conceived people. As part of the website development we will include more patient stories including some from donor conceived people. From research, we know that:

- Donor conceived people and parents of donor conceived people mainly need information on their rights and responsibilities.

- Donor conceived people want to learn from personal stories of people in similar situations to help them cope with the emotional challenges they face.

Clinic staff

Clinic staff are a captive audience for us. We don't have to fight to get their attention and we don't have to attract them via marketing. Clinic staff are an audience in themselves for the HFEA and are also an information channel to help us to get our messages out to patients.

Emerging audiences

We know there are some emerging audiences that we need to be aware of. We now provide information on our website for transgender people and have produced gender neutral consent forms.

4. Our strengths and weaknesses

We have made good progress with our communications over the last two years and have put the foundations in place to deliver the new strategy. For the first time, we have the tools to make a real impact with our communications. We have carried out a SWOT analysis has been carried out to tell us where we currently are with our communications.

<p>Strengths</p> <ul style="list-style-type: none"> Worldwide reputation as a robust regulator New website Updated Choose a Fertility Clinic service New established brand New house style guide and tone of voice New Clinic Portal Good engagement with patient and professional stakeholder groups Successful annual conference 	<p>Weaknesses</p> <ul style="list-style-type: none"> Lack of engagement with primary care No day to day contact with patients Only one third of patients accessing our current CaFC service Clinic staff not seeing the website as a good information source for patients Clinic staff not directing patients to our website
<p>Opportunities</p> <ul style="list-style-type: none"> Updated patient information on new website New Choose a Fertility Clinic service New rich media content – CaFC animation and patient videos New patient information – treatment add ons, transgender information Increased use of social media channels New patient feedback channel New campaigns More media opportunities generated from the new intelligence team and campaigns 	<p>Threats</p> <ul style="list-style-type: none"> Lack of human resources Negative fertility stories in the media Changes in Government policy

This analysis indicates there are many strengths and opportunities for the HFEA's communications.

How we will make the most of our strengths

- Publicising the new HFEA website and what it offers for patients.
- Continuing to make good use of our Twitter account and run Twitter campaigns.
- Publicising the new CaFC – every patient should know about this, it is our USP. We want to every patient to mention it, not only the one-third who do now.
- Running campaigns to share the new patient information around treatment add ons and encouraging people to contribute to the patient ratings feature on CaFC.
- Using our campaigns to generate more media opportunities.
- Continuing to develop engagement approaches with staff and patients to generate two-way communication and feedback.
- Working with the new intelligence team to generate more data to provide more media opportunities.
- Continuing our approach to media management to maintain our reputation as a world class regulator.

How we will tackle the weaknesses and threats

The SWOT analysis indicates that our engagement with primary care and GPs is weak, but we need to acknowledge that without significant new resources we are unlikely to improve this position. However, we know that many patients being referred for fertility treatment look online for information and often use NHS Choices. By developing a good information pathway from NHS Choices to our website, we can catch many more patients than we do now.

We also acknowledge that we don't have any day to day contact with patients. We will address this by working hard to publicise our website to patients, running campaigns and working with partners such as Fertility Network UK.

5. Engaging patients

We need to improve our engagement with patients to help us to drive up standards in clinics. We will use our information to help patients to prepare for treatment and support them during treatment. We want patients to share their experience of care at clinics to drive up the standards of care and help others to make informed choices. We will use the following channels to do this.

Our website

We have a new website, containing a wealth of information and need to get patients to this site. We've designed the new website to meet their needs. It contains specific information and journeys for different types of patients.

We know that the website is our best way of reaching many patients with over 110,000 visitors each month. But if we want to make an impact we need to grow that number. We also have a new and improved CaFC service – our unique selling point and something that every fertility patient should know about. Yet our research tells us the only one third of patients know about CaFC. We will increase these numbers by:

- marketing the new website and CaFC to patients

- marketing the new patient ratings tool on CaFC to patients
- improving the website on the search engine optimisation
- linking pages on the website directly from NHS Choices who are our biggest referring service and where most patients go for information after primary care.

We are introducing rich media onto our new website in the form of a video animation and patient videos. These will provide another opportunity to engage with patients and provide them with an additional information source. The CaFC animation provides a pictorial overview of the benefits of using the CaFC service and explains some of the more complicated elements of CaFC, including the reliability range.

Social media

Over the last two years we have invested much more in social media because we want to be more connected and responsive. We want to get information out there and be part of the conversation about fertility treatments.

We know our approach to social media is working. Our evaluation indicates increasing our use of Twitter has paid off, allowing us to engage with more people. In the six months to December 2016 we saw our followers rise by over 10% from 3070 to 3391. This is good news as we know that 48% of our Twitter followers are in the age range 25-35 and 70% are female which match the demographics for fertility patients. Our success with Twitter has come about through:

- timely and relevant tweeting.
- running Twitter campaigns. For Fertility awareness week and our 25th anniversary, we ran Twitter campaigns where we tweeted at least three times a day, increasing the impressions we were making on our audience.
- high profile media stories - topics such as mitochondrial donation and treatment 'add-ons' generated public and media interest in the HFEA via our Twitter account.

We will continue to take this approach to increase our following on Twitter and engagement with stakeholders. We will also consider developing other social media tools such as Facebook.

Partnerships

We have strong relationships with fertility patient and donor organisations, especially with Fertility Network UK (FNUK), the main consumer group. We meet regularly with them and the smaller patient groups to share information, collaborate on projects such as patient ratings and run joint campaigns such as treatment add ons. This gives us more kudos with patients that we don't always have on our own. And it gives us access to patients and legitimacy which helps to engender trust in the HFEA amongst patients.

Fertility shows and events

We've been doing these for the last two years and whilst it doesn't give us access to a high number of patients it is great for qualitative engagement. It helps us to understand patients' worries and concerns to help us develop our information. It also improves our reputation with patients as being helpful and available to them. We know that people prefer face to face engagement wherever possible. We use different ways for face to face engagement including:

- Fertility shows – we now attend fertility shows in London and Manchester, reaching 1000 people in one weekend. This is an ideal opportunity to direct people to our website and CaFC service and hand out our flagship publication the Getting started guide.
- Speaking at patient events – we have speaking slots at patient shows and partner events to promote our role and the services we offer to patients. We must continue to optimise these.

Campaigns

As part of the communications strategy we will be introducing campaigns to help to get specific messages across to patients. These will include campaigns on:

- Treatment add ons – letting patients know that we have honest and balanced information put together with the help of our expert scientific panel and letting clinics know that we expect them to up their game in this area
- Patient ratings – letting patients know they can influence others by rating their clinic via our website.
- Website and CaFC – raising the profile of these channels as valuable sources of information for patients.

6. Clinics

Clinic staff are an important audience for us for two reasons. First to improve practice. We have a duty to publish best practice guidance and to promote compliance with the law and that guidance. Clinics need to know what we expect of them, including what information they should give their patients. Second, to reach patients. Clinics are a communications channel to patients; we can guide clinics to give our information to their patients.

Research with clinics tells us that clinic staff use the current website for information such as consent forms and the Code of Practice and that they consider it primarily for clinics rather than patients. Very few clinic staff said they would direct patients towards the HFEA website as a source of information. This is concerning as it means patients are missing out on our accessible, impartial information and being directed towards clinic websites and leaflets that we know aren't always reliable. We have designed the new Clinic Portal as a dedicated channel for clinics, whilst pitching the website as being primarily for patients. With the portal, we now have a good platform, not just for communicating to clinics, but also as an opportunity to lead the sector and provide learning.

We have a good relationship with clinic staff, particularly with professional bodies, which we have worked hard on over the past few years. This has come from good stakeholder work, but also an investment in face-to-face meetings like the annual conference.

Communication with clinic staff

We will continue to communicate to clinics in a timely manner via several channels to tell them what we expect from them to deliver the best quality care for patients. We will do this using:

- Clinic Focus – we will be redesigning Clinic Focus to become a signposting tool for clinics to the new Clinic Portal where the information will be housed.
- Clinic Portal - we will develop this further over the coming months to make it the main communication channel for clinics and to introduce an editorial element and learning tools.
- Annual conference – this is a great opportunity to interact with over 200 members of clinic staff face to face. Feedback from the 2017 conference tells us for half of the respondents it was their first face to face interaction with us and the most popular reason for attending was to learn more about the HFEA and how we work.
- HFEA workshops – we run workshops for clinic staff on a range of topics and know these are well received. They provide a face to face opportunity to talk about specific issues.

- Stakeholder meetings – we hold regular meetings with the professional stakeholder groups and staff working in clinics. They provide opportunities to seek opportunities for collaboration, gather views on new guidance and service and to give early warning of what's coming up.

Communication with patients via clinics

Clinics can help us to reach patients and get our messages across. To do this we will:

- Encourage clinics to promote the new website and its features to their patients, so that they are well prepared for treatment and the choices they will need to make.
- Produce marketing materials that clinics can use to help promote some of our new initiatives such as the patient ratings tool on CaFC.
- Communicate to clinics about the new patient ratings system and the importance of engaging with patients to encourage them to support the initiative.
- Produce marketing materials for clinics to use at inspection time to inform patients that the clinic is being inspected and encourage them to give their feedback to help the inspectors and other patients.
- Coach/brief the HFEA inspectors on the work the HFEA is doing so they know what to say to clinics and are ambassadors for the HFEA.
- Develop new ways of communicating some of our key data that is relevant to the clinics.

7. Our public reputation

We are an internationally renowned regulator who is well respected. We are known for consulting widely with the public and stakeholders on important issues and regulating carefully. Parliament has confidence in us. This reputation comes out in the media coverage of us.

Our approach to media management

Our experience with the national media shows that it helps us in two ways: to maintain our reputation as a robust regulator, on issues such as mitochondrial donation; and to show that we are knowledgeable and insightful about the sector we regulate through our data reports. It is less successful at getting to patients, other than through issues, such as treatment add ons, which connect with our campaigns.

We know that the big stories will always generate media coverage without us having to do very much. Our statements are usually included in the stories and reflect our tone well. We have been praised for our media handling on stories about mitochondrial donation. We will continue with this approach to media management.

How we will generate media interest

Our focus for proactive media stories will be around:

- Campaigns - we will be running a major campaign around treatment add ons. We will use this to generate media opportunities including broadcast interviews and magazine features.
- New data – we hold a wealth of data that is interesting and useful to patients and the media. We will make better use of this data to generate media opportunities. We will look at new ways of releasing our data and using new data to create maximum coverage to reach as many people as possible. We can release data contained in the trends report at different times rather than in one go to provide more media opportunities.

8. HFEA staff

Since the last communications strategy we have improved our engagement with our staff by introducing a monthly bulletin as a new communications channel and continuing to engage via staff meetings, the intranet and the monthly staff newsletter. A priority is to develop a new intranet that is modern and can give staff a lot of information about working at the HFEA all in one place. We will continue to communicate effectively with staff and will monitor how well we are doing via the annual staff survey.

9. How we'll know how we've done

To be an effective part of the business, communications needs to demonstrate how it contributes to its effectiveness, that's where evaluation comes in. A range of measures will be introduced to evaluate the different areas of the communications strategy. By introducing measurement, the Authority will be able to evaluate the contribution that communications make towards the achievements of the HFEA.

Objective	Target
Patients using the new digital channels to access the information they need	<p>More people visiting the website each month</p> <p>Increasing the number of patients who know about CaFC to at least 60% by May 2017</p> <p>Analysing the in-page patient feedback</p> <p>Qualitative feedback from user testers/focus groups to monitor what works well/not so well with the website</p> <p>A reduction of 5% per month for email enquires</p>
Improving our engagement via social media	<p>Increase our Twitter followers by 10% per year</p> <p>Issue at least 20 tweets per month</p> <p>Run at least three Twitter campaigns per year</p>
Increasing patient feedback	<p>At least 10 patients per month</p> <p>Evaluating the usefulness of the patient ratings tool via the survey</p> <p>Increase the volume by 10% of patients giving feedback compared to the old paper system</p>
Media management	<p>At least one article from the HFEA in each stakeholder publication</p> <p>Responding to all media enquiries within requested deadlines</p> <p>Maintaining and increasing our coverage of reports on our data e.g. fertility trends statistics.</p>