

Minutes of Authority meeting

10 May 2017

Strategic delivery: Setting standards Increasing and informing choice Demonstrating efficiency economy and value

Details:

Meeting	Authority
Agenda item	2
Paper number	HFEA (28/06/17) 839
Meeting date	28 June 2017
Author	Erin Barton - Inspections, Logistics and Projects Officer

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	<input type="checkbox"/> Low <input type="checkbox"/> Medium <input type="checkbox"/> High

Annexes

Minutes of the Authority meeting on 10 May 2017 held at Church House, 27 Great Smith Street, London SW1P 3NZ

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

Members

There were 9 members at the meeting, 6 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 third 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 Dr Andy Greenfield and 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 15 March 2017

- 2.1.** Members agreed the minutes of the meeting held on 15 March, for signature by the Chair of the meeting.

3. Chair's report

- 3.1.** The Chair provided members with a summary of events that she attended since the Authority meeting on 15 March 2017.
- On 16 March, we held our Annual Conference where we launched our new strategy for 2017-20. The day was a huge success with over 300 attendees. The Chair thanked staff who volunteered on the day and those who attended.
 - On 29 March, she chaired our Remuneration Committee with Margaret Gilmore and Anita Bharucha. In the evening, the Chair was invited to take part in the Progress Educational Trust debate held at the Royal College of Obstetricians and Gynaecologists about fertility treatment add-ons.
 - On 19 April, the Chair, along with the Chief Executive, visited the Frances Crick Institute and met Kathy Niakan and Robin Lovell-Badge to talk about Kathy's HFEA licensed research using gene editing techniques.
 - On 2 May, she chaired the Appointments Committee with Margaret Gilmore and Anita Bharucha where they agreed to renew the appointments of Elizabeth Haxby and Samuel Stein to our independent Appeals Committee.
 - On 4 May, the Chair, along with the Chief Executive visited Hull IVF Clinic and met Stephen Maguiness and Christine Leary.
- 3.2.** Finally, the Chair thanked members for their contributions over the past business year.

4. Chief Executive's report

- 4.1.** The Chief Executive advised members that on 21 March he attended the Audit and Governance Committee, and on 29 March he attended the Remuneration Committee to discuss our restructure proposals. We received Cabinet Office approval for a small voluntary redundancy scheme and are now looking to recruit to a number of new roles to ensure that we are organised to meet our strategic ambitions over the next three years.
- 4.2.** On 13 April, the Chief Executive attended the Health and Care Leaders Senior Talent board meeting, and on 18 April he was interviewed by South Korean TV about gene editing research.
- 4.3.** On 3 May, the Chief Executive spoke at the NHS BT Senior Leadership Development programme event in Leamington Spa.

Press coverage

- 4.4.** The Chief Executive informed members that it had been a busy few weeks in terms of media interest in the fertility sector.
- 4.5.** Daily Mail investigation into IVF clinics: The Daily Mail published several articles last week as part of an investigation into practices at a number of licensed fertility clinics. The paper made allegations about egg donation, egg freezing and OHSS. We issued a statement in response which was quoted in the Mail saying that we would investigate any allegations and will take regulatory action where we judge that it is merited. The Chief Executive advised that it would be inappropriate to comment further on the substance of the allegations until we have investigated and reported our findings to a Licence Committee.

- 4.6.** In addition, we will be assessing the extent to which there are wider lessons for the regulatory regime and the sector as a whole. The Chief Executive informed members that he had written to all PRs and would report back to the Authority.
- 4.7.** Treatment add ons: The Chair participated in a recent PET debate on treatment add ons which led to a number of stories in the media. This is a key part of our new strategy and was discussed at our recent annual conference.
- 4.8.** Woman's Hour: The Director of Strategy and Corporate Affairs appeared on Woman's Hour to discuss how patients make decisions about what to do with their embryos after treatment. She raised the issue of promoting embryo research to patients, which is a key element of our new strategy.

5. Committee Chairs' updates

- 5.1.** The Chair of the Statutory Approvals Committee (SAC) reported that the committee met on 30 March and 27 April. It considered five preimplantation genetic diagnosis (PGD) applications in March and one request for Special Directions, all of which were approved. At the April meeting, five PGD applications and one request for Special Directions were considered. The minutes have not yet been published. The Chair noted that the volume and complexity of their workload had increased, and thanked members for their contribution.
- 5.2.** The Deputy Chair of the Licence Committee advised members that the committee met on 4 May to consider one research licence renewal, one interim inspection report, two executive updates and one additional report. 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 four times since the Authority last met; on 24 March, 6 and 21 April, and 5 May. The panel considered four renewal applications, six interim inspection reports, seven licence variations, and one application for HLA tissue typing, all of which were approved. The Licensing Officer approved four licence variations. She advised members that the new Head of Planning and Governance was no longer a member of the Executive Licensing Panel, and that the Head of Regulatory Policy had taken over as Deputy Chair.
- 5.4.** The Chair of Audit and Governance Committee (AGC) advised members that the committee met on 21 March and, aside from the usual standing items and updates from internal and external audit, the committee received reports on:
- Finance and resources, from the Director of Finance and Resources
 - Strategic risks, from the Head of Business Planning (now Planning and Governance)
 - Contracts and procurement, and the whistle blowing policy, from the Head of Finance
 - Information standards
 - Cyber security, Information Governance Group activities, resilience and business continuity management, and an update on the IfQ programme, from the Director of Compliance and Information
 - A final report on board effectiveness which the Chief Executive will circulate to members, to get their views on the two recommendations relating to internal communication and training for new members.

- 5.5.** On IfQ, the Chair of AGC advised members that the committee will continue to monitor progress and expenditure on the data submission project and will be looking at benefits realisation for the IfQ programme once it has been concluded.
- 5.6.** The Chair informed members that, as previously mentioned, the Remuneration Committee met on 29 March and the Appointments Committee met on 2 May.

6. Performance report

- 6.1.** The Chief Executive introduced this item, advising members of the proposed changes to the existing strategic performance report, which reported on both organisational performance and progress against our strategy.
- 6.2.** Members will retain oversight of the overall health of the organisation and its performance through the performance report, which will continue to come to every Authority meeting and will include meaningful KPIs and other metrics relating to key management areas including:
- Our finances
 - The efficiency of our licensing processes
 - Information
 - Our staffing.
- 6.3.** These main performance indicators may change over time as new measures become available or become more important.
- 6.4.** We will report on strategy progress differently, through a series of Authority agenda items across the year. These themed reports will provide greater context, detail, narrative and impact.
- 6.5.** The Director of Compliance and Information summarised activity and performance within his directorate. Since the last Authority meeting, the 2016/17 inspection year had concluded and all planned inspections had been completed, alongside various additional inspections and new licence applications.
- 6.6.** The Director of Compliance and Information reassured members that we investigate all allegations made by whistleblowers and patients, and that the recent reports in the Daily Mail will be investigated thoroughly following our usual process. All material evidence will be formally reviewed and discussed with the clinic concerned, who will be provided with a draft report which they may comment on. This report will be presented to a licensing committee and appropriate regulatory action may be taken.
- 6.7.** Members heard that the problems with videoconferencing and the telephone system which were affecting committees had been resolved. Meetings will be brought back onsite cautiously and the IT team will be working with members individually to overcome any barriers to holding an effective meeting.
- 6.8.** One of the red performance indicators in the report related to the percentage of PGD applications processed within three months. There were only two applications, one of which was processed one day outside of the KPI which made the overall percentage drop dramatically. This was not a concern and was partly due to staff changes within the organisation.

- 6.9.** The Director of Compliance and Information informed members that the Statutory Approvals Committee had been issued with Office 365 with the aim of making the process of agreeing minutes more straightforward. Whilst this functionality is not available as predicted, paper circulation is more effective.
- 6.10.** The Director of Strategy and Corporate Affairs informed members that the Annual Conference was attended by 300 members of the sector, including both senior staff and people who had not previously attended one of our conferences. The feedback was very positive, with 70% of respondents reporting that their expectations had been met or exceeded. Attendees particularly enjoyed the Chair's speech on showing leadership within clinics and the speech was published on the Clinic Portal for everyone who could not attend. Attendees also responded well to the workshops which were run and attended by members. The two most popular focussed on support for transgender patients and providing good emotional support for patients. Feedback also provided some ideas for next year's conference including live streaming of talks, using different types of technology and other improvements with regards to the venue.
- 6.11.** We made the greatest impact on Twitter in one day than ever before, on the day of the conference. This was affected by the Chair's announcement that we had issued the first licence to perform mitochondrial donation in the UK. Our tweets on the day received over 9000 views which grew our social media following.
- 6.12.** The Director of Finance and Resources informed members that we ended the financial year with a surplus of just over £1m, which is primarily due to treatment activity being higher than forecasted.
- 6.13.** Members were interested in using the findings of our planned study into the various factors affecting the demand for treatment to predict our future income more accurately and, if appropriate, adjust our treatment fee. Any adjustments would need to take into consideration the views of our fees stakeholder group which in the past has preferred a stable fee for a reasonable period of time over fluctuation, and would need to be approved by the Treasury.
- 6.14.** Our year-end accounts have been produced in draft and will be audited by the National Audit Office over a period of two weeks, before being presented to the AGC on 13 June for sign off. Restrictions on government bodies while in purdah will delay parliamentary sign off until July, but this will hopefully take place before parliamentary recess.
- 6.15.** Following discussion, members noted the latest performance report and endorsed our proposed approach to ensuring the Authority retains good oversight of both organisational management and strategic progress.

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 main focus was preparing the site for launch following the successful resistance of a legal challenge. 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.
- 7.3.** Clinics have now completed the verification of their outcome data ready for publication on CaFC. The Government Digital Service (GDS) provided feedback that we must address before we can proceed to live stage. This included the necessity of thorough security penetration testing which has now been completed, and the completion of an exercise and report as to the accessibility of the website to all users. The recommendations in this report are being addressed and publication is planned to take place following the final GDS assessment in May 2017.
- 7.4.** The majority of remaining work relates to the data submission component of the programme. Progress has been made with regards to data migration and external reports have shown our processes to be working well. Further work on the clinic front-end experience requires the support of contracted developers to progress. We plan to release the new system to current 'EDI' users, which is around half of all licensed clinics, in September 2017. It will take longer to roll the system out to clinics using third party suppliers to submit data.
- 7.5.** IfQ will formally close when the website is launched although the Authority and AGC will continue to receive progress reports on the remaining data submission project work. There will be an IfQ closure report to reflect on lessons learned and benefits realised as part of the programme.
- 7.6.** The original programme of £1.227m has all been accounted for with a slight overspend. The remaining work will be delivered as a project within our 2017-18 Business Plan commitments and an additional expenditure of £350,000 will be required. This additional expenditure is consistent with our new strategy and organisational restructure which includes a small two person development team who will procure a programme of development and continuous improvement of our systems.
- 7.7.** The Director of Strategy and Corporate Affairs informed members that changes have been made to CaFC based on the decisions made by the Authority in November 2016, following the successful resistance of a legal challenge referred to earlier. These changes are not visible to the public yet but they will be ready to publish shortly. We are presenting top level performance based on births per embryo transferred for patients having fresh IVF under the age of 38. We have produced an animation for the home page of CaFC which is designed to help patients to view success rates in context and consider other measures of performance, such as patient ratings and inspection reports, as equally important.
- 7.8.** Work has been done to improve accessibility of the website following recommendations from our GDS assessment. We have passed the plain language assessment and will be publishing a kitemark on that. Internal audit has approved our process for producing corporate information, and we are going through the process of acquiring the Information Standard which is a government standard for patient facing information. We have been working with NHS Choices

which is the main referrer into our website, to create a smooth transition from their website to our own.

7.9. Members were interested in how we will continue to monitor performance and demonstrate effectiveness particularly in relation to CaFC. The Director of Strategy and Corporate Affairs advised members that this would be covered later in the meeting as part of our Communication Strategy for 2017-2020.

7.10. Members noted:

- the intention to launch the HFEA website and CaFC, as live, in the next few weeks
- the activities necessary for completing the data submission project
- the budget expectations, and the capital cover consequences.

8. Pre-HFEA voluntary contact register

8.1. The Donor Information Manager informed members that the Department of Health (DH) is no longer funding the pre-HFEA voluntary contact register, the Donor Conceived Register (DCR) service, which to date has been managed by the National Gamete Donation Trust (NGDT), and has asked us to determine how to support the service.

8.2. 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

8.3. The costs associated with bringing the service in-house would include additional salary costs of circa £28,000 plus an estimated £7,000 for overheads. Further costs would include the DNA analysis, and counselling and 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.

8.4. It makes sense to users to have all donor conception services under one roof, although the databases and processes vary in significant respects and this may confuse users to have such different systems side by side.

8.5. 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 and intermediary work, as the Opening the Register team are not qualified for this purpose. It would be difficult to acquire an additional member of staff whilst still operating within our headcount controls and whilst we have some of the expertise required to run the service, we do not have the capacity. The only way to create capacity would be to divert HFEA staff away from their core duties. There are also implications for other areas of the HFEA for example with stakeholder management, media and communications, and Freedom of Information requests.

Contracting out to another organisation

8.6. 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. Based on the DCR's current operating costs, this arrangement is likely to cost around £26,000 each year.

- 8.7.** Contracting out the service would maintain the distinction between the HFEA register and the DCR and if the current supplier were to bid for the service successfully, there would be continuity of service for its users. The HFEA would retain oversight of the service to ensure service users' needs are met.
- 8.8.** Members were concerned about the implications of diverting staff and resources away from other core functions, especially during a period of organisational change.
- 8.9.** Members were also interested in the continuity of service and contacts for users, if the current supplier were to bid for the service successfully. They were assured that there would be a range of performance metrics and a formal feedback mechanism within any agreement to ensure that the quality of service is maintained.

Decision

- 8.10.** Members stressed that the priority is to maintain a high quality service for donors and donor-conceived people, and felt that this could be best achieved by contracting out the entire service to another suitable organisation.
- 8.11.** Members asked the Executive to do some further work to estimate the likely increase in the number of registrants and ongoing costs, to decide on the most suitable type of contract.

9. Communications strategy 2017-2020

- 9.1.** The Head of Engagement gave an overview of our new communications strategy for 2017-2020, which is closely aligned to our strategic objectives of providing patients with information to make informed choices and raising the quality of care by encouraging patients to give feedback on their treatment.
- 9.2.** The strategy has six main audiences: patients, clinics, donors, donor-conceived people and their parents, the public and HFEA staff. The main audience for this strategy is patients.

Patients

- 9.3.** From our research, we know that:
- 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.
- 9.4.** As part of our new strategy, we will:
- Get to patients earlier in their fertility journey by working alongside NHS Choices
 - Market the benefits of our new website and CaFC service
 - Increase our use of social media including Twitter

- Make better use of rich media including animations and videos
- Run campaigns to improve care by providing 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
- Make an impact with our partnership working with patient organisations on campaigns like treatment add ons so we can make maximum impact.

9.5. We know our approach to social media is working and we will continue to take this approach to increase our following on Twitter and engage with stakeholders. We will also consider developing other social media tools such as Facebook.

Clinics

9.6. The strategy also focuses on our communications with clinics to improve practice by setting out what we expect of clinics and what information they should give to their patients. We also aim to reach patients by encouraging clinics to give our information to their patients and to direct patients to our website. We will produce marketing materials for clinics and brief our inspectors who are in regular contact with clinics.

Media management

9.7. We know that the media helps us by maintaining our reputation and showing that we are knowledgeable about the sector. We will generate media interest by:

- Running campaigns, starting with a major campaign around treatment add ons which we will use to generate media opportunities including broadcast interviews and magazine features
- Making better use of data, and looking at ways of releasing data to create maximum coverage and 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.

How we will know how we've done

9.8. We have developed a new set of metrics, and will continue to add more, to enable Authority members to monitor the success of the new communications strategy.

9.9. Members were asked to consider the new strategy, in particular:

- Do you agree to making patients our main focus for this strategy?
- Do you agree with our suggested approach to media management?
- Is social media important to the HFEA?

9.10. Members were assured that, although not a main focus in our communications strategy, work was being done to direct geneticists and researchers to specific areas of our website which may be less visible now due to the website's new focus on patients.

9.11. Some members asked whether more could be done to reach patients earlier through their GPs but heard that online digital marketing is a far more efficient and cost-effective way to reach our demographic. We know that many patients being referred for fertility treatment look online for information and often use NHS Choices. We aim to reach more patients by developing a good information pathway from NHS Choices to our website.

- 9.12.** Members were keen to ensure that the HFEA can be easily found through search engines, and to market the benefits of our new website and CaFC service where appropriate, for example during interviews or other media appearances.
- 9.13.** Members advised a cautious approach to the use of Facebook and wanted clarity around what we expect to achieve. Facebook creates a new platform for patients and the public to ask questions, and this must be monitored carefully. Members heard that Facebook would be beneficial in running campaigns alongside other patient organisations, such as Fertility Network UK who currently use Facebook successfully to reach patients. We will use Facebook in a selective way and develop our approach over time.
- 9.14.** Some members requested guidance on how they could help to support the social media strategy, for example by retweeting posts from our account.

Decision

- 9.15.** Following discussion, members agreed with the focus of the new communications strategy and the suggested approach. The Executive agreed to continue to work to deliver the strategy with the help of a subgroup of members.

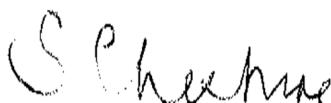
10. Any other business

- 10.1.** The Chair of the meeting confirmed that the next meeting will be held on Wednesday 28 June at 10 Spring Gardens, London, SW1A 2BU. Members were asked to confirm their attendance to the Executive Assistant to the Chair and Chief Executive as soon as possible.

11. Chair's signature

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

Signature



Chair: Sally Cheshire