



Minutes of Authority meeting 16 November 2016

Strategic delivery:

Setting standards

Increasing and
informing choice

Demonstrating efficiency
economy and value

Details:

Meeting Authority

Agenda item 2

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Meeting date 15 December 2016

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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 16 November 2016 held at ETC Venues, Victoria, 1 Drummond Gate, London SW1V 2QW

Members present	Sally Cheshire (Chair) Rebekah Dundas Dr Andy Greenfield Yacoub Khalaf Margaret Gilmore	Ruth Wilde Dr Anne Lampe Anthony Rutherford Kate Brian Anita Bharucha
Apologies	Bishop Lee Rayfield	
Observers/Presenters	(Department of Health)	
Staff in attendance	Peter Thompson Nick Jones Juliet Tizzard Catherine Drennan Paula Robinson	Charlotte Keen

Members

There were 10 members at the meeting, 6 lay members and 4 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 sixth meeting of 2016. As with previous meetings, it was being audio recorded and the recording would be made available on the HFEA website to enable interested members of the public who were not able to attend the meeting to listen to the HFEA's deliberations.
- 1.2. Apologies were received from Bishop Lee Rayfield.
- 1.3. Declarations of interest were made by:
 - Kate Brian (Regional organiser for London and the South East for Infertility Network UK)
 - Yacoub Khalaf (Person Responsible at a licensed centre)
 - Anthony Rutherford (Consultant in Reproductive Medicine and Gynaecological Surgery at a licensed centre)
 - Ruth Wilde (Senior Fertility Counsellor at a licensed centre).

2. Minutes of Authority meeting held on 14 September 2016

- 2.1. Members agreed the minutes of the meeting held on 14 September, subject to a minor amendment, for signature by the Chair.

3. Chair's report

- 3.1.** The Chair welcomed Richard Sydee to his first Authority meeting as Director of Finance and Resources. Richard joined the HFEA on 1 November and is the shared Director between the HFEA and the Human Tissue Authority (HTA), replacing Sue Gallone.
- 3.2.** The Chair provided members with a summary of events that she had attended with organisations in the IVF sector and the wider health and care system since the last Authority meeting.
- 3.3.** On 15 September, the HFEA marked its 25th anniversary. The HFEA was the first regulator of IVF and human embryo research and it was testimony to all those involved that it had stood the test of time so well and was considered to be the standard against which regulation in the field was judged. The event provided a chance to celebrate those achievements in more detail with past colleagues and some of the HFEA's most important stakeholders. The Chair thanked all those who attended and a particular thanks to HFEA staff who helped put the event together.
- 3.4.** On 28 September, the Chair attended the Department of Health's arm's length bodies (ALBs) chairs and non-executive directors (NEDs) policy context seminar on accelerated access, and on 10 October she attended the ALB chairs and NEDs Ministerial round table meeting at the Department of Health with the Parliamentary Under Secretary of State for Health, Lord Prior of Brampton.
- 3.5.** On 18 October, the Chair, together with the Chief Executive, had an introductory meeting with the new Parliamentary Under Secretary of State for Public Health and Innovation, Nicola Blackwood.
- 3.6.** On 11 November, the Chair, together with the Chief Executive attended a meeting on the cost of publically funded IVF, involving NHS England, representatives from the sector and the Department of Health.
- 3.7.** Finally, the Chair advised members that she had been working with the Department of Health on the appointment of two new Authority members. Shortlisting took place in late September, with interviews in October. As ever, the recruitment attracted a number of high quality candidates and Cabinet Office approval of the appointment of the successful candidates should follow shortly.

4. Chief Executive's report

- 4.1.** The Chief Executive advised members that, on 21 September, he, together with the Chair of the Authority's Audit and Governance Committee, appeared before the Department of Health's Risk and Audit Committee meeting, one of a number of meetings involving all ALBs to look at system wide risks and how they could best be managed.
- 4.2.** On 27 September, the Chief Executive spoke at Health and Social Care Leadership Scheme seminar, and on 27 October he participated in a peer review workshop on managing talent. The Health and Social Care Leadership Scheme brings together the Department of Health and all of the Chief Executives of the health sector's ALBs to identify senior talent within the system.
- 4.3.** On 1 November, the Chief Executive attended a meeting at the Academy of Medical Science (AMS), held to assess the regulation and governance of health research five years on since the AMS report which had led to the establishment of the Health Research Authority (HRA).

- 4.4.** On 3 November, the Chief Executive, together with the Interim Head of Regulatory Policy, spoke to a Norwegian delegation about the HFEA's work on mitochondrial donation, embryo research, donation and other issues.

Press coverage

- 4.5.** The Chief Executive advised members that there had been a busy period for press coverage since the last Authority meeting. The National Fertility Awareness week had generated a lot of coverage and the Director of Strategy and Corporate Affairs would go into more details in item six. There were two other issues which were of particular importance.
- 4.6.** Samantha Jeffries case: the Chief Executive reminded members that Samantha Jeffries was seeking permission to continue to store embryos made with her and her dead husband's gametes. Mrs Jeffries believed that she and her husband had consented to storage for ten years but that this had been changed by the clinic to two years to match the period of time for which there was NHS funding and she sought to restore the ten-year consent through the courts. The HFEA had agreed with her position, as did the clinic. Judgement had been handed down about six weeks ago and the Judge accepted that it was the true intention of the husband to consent to storage for ten years. The Judge had therefore ruled that Mrs Jeffries had effective consent for ten years.
- 4.7.** The Chief Executive emphasised that there was a clear lesson for clinics to follow the HFEA's long-standing advice that the statutory storage period to which patients were entitled must not be overwritten by any separate agreement about the funding of storage, whether paid for by the NHS or the patients themselves.
- 4.8.** Baby born using mitochondrial donation in Mexico: there had been considerable media interest in this story. The baby was now five months old and healthy. The American doctors had made it clear they had gone to Mexico precisely because there were no rules governing mitochondrial donation there. The Chief Executive commented that it was for individuals to judge the ethics of such an approach.

5. Committee chairs' updates

- 5.1.** The Chair of the Statutory Approvals Committee reported that the committee had met on 29 September and 27 October. There had been four preimplantation genetic diagnosis (PGD) applications on 29 September, three of which were approved and one adjourned pending further information. At the meeting on 27 October, there had been one PGD application, which was approved, and two Special Directions applications, one of which was approved and one refused.
- 5.2.** The Chair of the Licence Committee reported that the committee had met on 10 November, when the committee received two executive updates. The minutes of the meeting had not yet been published.
- 5.3.** The Director of Strategy and Corporate Affairs advised members that the Executive Licensing Panel (ELP) had met four times since the last Authority meeting; on 23 September, 7 and 19 October and 4 November. For the first three meetings, the panel had considered 17 items in total, all of which were approved and noted. There was one renewal licence application; nine interim inspection reports; five licence variations, one application for HLA tissue typing and one progress report. At the meeting on 4 November, the minutes of which had not yet been published, the

panel had considered 4 items. There was one interim inspection report; two licence variations and one progress report.

5.4. The Chair of the Audit and Governance Committee (AGC) advised members that the committee had met on 21 September, and had received reports on:

- A Directorate update and contribution to the HFEA strategy, from the Director of Strategy and Corporate Affairs
- Risks, including staffing and patient/stakeholder engagement, from the Director of Strategy and Corporate Affairs
- An IFQ update on managing risks, from the Director of Compliance and Information
- Strategic risks, from the Head of Business Planning
- Updates from the Internal and External Audit teams
- A progress report on the implementation of audit recommendations
- Cyber security, from the Head of IT
- Updated reserves policy from the Head of Finance

5.5. The Chair of the Scientific and Clinical Advances Advisory Committee (SCAAC) reported that the committee had met on 17 October and had considered the following items:

- The multiple births strategy
- A paper and presentation on in-vitro derived gametes from Professor Azim Surani from Gurdon Institute in Cambridge
- HFEA website content review – treatment ‘add-ons’
- The NICE IUI guideline review.

6. Strategic performance report

6.1. The Director of Strategy and Corporate Affairs reminded members that National Fertility Awareness week had taken place between 31 October and 6 November. Fertility Network UK ran a campaign called ‘Hidden Faces’ which was a series of short films with people who were going through, or had had, fertility treatment and their experiences or having treatment and their journey, regardless of the outcome. The Director of Strategy and Corporate Affairs presented one of the films to members which could be found on YouTube at <https://www.youtube.com/watch?v=6OK5mqXGPek>.

6.2. The Director of Strategy and Corporate Affairs advised members that there had been a lot of public discussion about fertility during National Fertility Awareness week, which had culminated in the Fertility Show on 5 and 6 November in London, which attracted 3,000 visitors. We met many of those visitors at our stand, distributing 500 ‘Getting Started’ guides and showing them Choose a Fertility Clinic (CaFC). The Director of Strategy and Corporate Affairs also gave a talk on how to understand IVF statistics. The Fertility Show was a good opportunity for the HFEA to engage with people at all stages of the IVF process and for them to have access to all the information the organisation could provide to assist them in making informed choices.

- 6.3.** The Director of Compliance and Information highlighted key points within his Directorate from the Strategic Performance Report. Firstly, the time taken for the licensing process to be complete was the lowest it had been, with the average time being 50 days from start to finish. Secondly, in terms of PGD applications received from clinics who were seeking to test for a new condition which had not already been approved, the time taken to process those applications was also down to around 50 days, which demonstrated very good progress at this time.
- 6.4.** The Director of Finance and Resources gave a brief overview of financial performance. Over the last six months there had been a slight increase in the treatment fee income against that which had been forecast. There was no obvious reason or pattern but the Director of Finance and Resources emphasised that the Executive were very sighted on the increase.
- 6.5.** Following a discussion, members noted the latest strategic performance report.

7. Information for Quality: update

- 7.1.** The Director of Compliance and Information explained that the IfQ programme was a comprehensive review of the information that the HFEA held, the systems that governed the submission of data, the uses to which it was put and the ways in which the information was published. It included:
- The redesign of the HFEA's 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 would be accredited
 - A revised Register of treatments, which would include the migration of historical data contained within the existing Register
 - The redesign of the HFEA's main internal systems that comprised the Authority's Register and supporting IT processes.
- 7.2.** The Director of Compliance and Information explained that this presentation was to update members on:
- Progression to a fully live HFEA website and Clinic Portal
 - 'Release two' progress – data submission system development
 - Information policy
 - IfQ programme conclusion
 - Programme timelines and budget.
- 7.3.** HFEA website and CafC: the Director of Compliance and Information advised members that these two products were released to public beta in July 2016 and feedback had been positive. However, as reported at the September Authority meeting, it was felt that both the website and CaFC should not proceed to live until February 2017. This was in recognition of the Judicial Review, which was scheduled to take place on 19 and 20 December, and the need to secure final GDS approval, currently planned for late January 2017.

- 7.4.** For the purposes of the programme, the Director of Compliance and Information advised members that the website and CaFC was largely concluded, and the additional design and development work that needed to take place was already included within the existing contract. Subject to assessment, the product would be live in February 2017, and the current HFEA website decommissioned.
- 7.5.** Clinic Portal (release one): the Director of Compliance and Information reminded members that this element of the portal would allow clinics to conduct all transactions with the HFEA other than treatment data submission. Members noted that the report to the September Authority meeting confirmed that the portal was released in beta form on 12 July, and anticipated that the GDS assessment was scheduled to take place on 28 October.
- 7.6.** A consequence of the beta testing was the identification of issues and bugs and the Director of Compliance and Information informed members that the resolution of these had required more time and effort than anticipated. As a consequence, the Executive had decided to reschedule the GDS assessment for 21 November so that further and final user testing could be undertaken on 3 November.
- 7.7.** For the purposes of the programme, the Director of Compliance and Information advised members that the Clinic Portal, subject to GDS assessment, was largely concluded. It was anticipated that the Clinic Portal would be released as live in December and current portal decommissioned.
- 7.8.** Clinic Portal (release two): the Director of Compliance and Information reminded members that this was the component that replaced the current clinic data submission application. This was a substantial undertaking requiring both extensive foundational work and a new 'front end' service that would be experience by clinic users. Much of the foundational work was well advanced, as had previously been reported to members. A new Register database had been designed with a new data structure, with each item defined in a data dictionary, which was in the process of being accredited by NHS Digital. Cleansing of vital data prior to the migration of the current Register database was in the process of being finalised, with a Register migration strategy in place. A set of new expectations as regards clinics' information management arrangements was also being developed.
- 7.9.** The Director of Compliance and Information informed members that challenges remained with this aspect of the programme. Whilst much of the foundational work had progressed well, it was likely that the remaining work would absorb the majority of the remaining time and resource attached to the programme.
- 7.10.** Release two (data submission development): the Director of Compliance and Information advised members, as outlined above, that there had been much progress, with more to do, on the necessary foundational work in transforming the data submission system. This included the data dictionary and accreditation, Register data migration and the information policy.
- 7.11.** Information policy: the Director of Compliance and Information advised members that, since there had been a substantial investment by the HFEA in developing a new information architecture, the Executive wanted to develop a set of principles to underpin the HFEA's approach to information and how those principles supported the delivery of the organisations' strategic objectives. Members noted that a draft information policy would be presented to them at the January 2017 meeting and would encapsulate the following reasoning:

- A new information architecture was being created
- There would be an easier process for clinics to submit data and check or verify the accuracy of their data
- This was an opportunity to establish much clearer accountabilities with a new information bargain with clinics
- The emerging policy would make that bargain transparent – substantial proposals would be presented in January
- An extant policy was in place until the new policy was adopted.

7.12. Timelines and budget implications: the Director of Compliance and Information reminded members that a revised programme plan had been finalised and signed off by the IfQ Programme Board in January 2016, in line with the overall £1.134m agreed by the Authority. The Executive did not anticipate the programme exceeding this figure at 31 March 2017, although the consequences of the revised timeline, and the financial implications of this, were being worked through.

7.13. The variance in September was explained by an underspend originally forecasted for the security consultant and this underspend should balance in the coming months once the work was completed and invoiced.

7.14. Following a discussion, Authority members noted:

- Progress since the last Authority meeting, noting the launch of the HFEA website and clinic portal
- The delays to 'Release Two' – the new data submission system
- The conclusion of the programme in March 2017
- The HFEA's emerging information policy
- Programme timelines and budget implications.

8. Choose a fertility clinic

8.1. The Director of Strategy and Corporate Affairs presented this item and reminded members that a major strand of work within the IfQ programme was the redesign of the HFEA website, incorporating the Choose a Fertility Clinic (CaFC) service. The current CaFC service is used by 15,000 patients each month to research and select a licensed clinic for their fertility treatment. However, the current CaFC was last redesigned in 2009 and is dated, overly complex and built on old technology. The new service, currently in its beta phase, had a fresh new design with new features and a much simpler presentation of birth statistics.

8.2. The Director of Strategy and Corporate Affairs reminded members that they had made a number of policy decisions in January 2015 about how birth statistics would be calculated. Whilst developing CaFC for the past year, a number of presentational decisions had also been made about the birth statistics and members would now be asked to make final decisions about how births statistics would be calculated and presented. Following those decisions, the Executive would then redesign CaFC, ready for the launch of the live service early next year.

- 8.3.** The Director of Strategy and Corporate Affairs reminded members that the new CaFC was built on the following principles:
- Birth rates are not the only measure of quality in a clinic
 - Information about each clinic should be clear and helpful
 - CaFC should be the go-to place for birth statistics.
- 8.4.** The Director of Strategy and Corporate Affairs advised members that the point of the beta feedback period was to receive public feedback and to test with individual users so that improvements could be made before the live version was launched. In order to inform decisions during the meeting, members had been presented with reports from the beta feedback period and members noted they should give consideration to this feedback in order to inform their decisions.
- 8.5.** The Director of Strategy and Corporate Affairs emphasised that it is important to bear in mind some peculiarities in the fertility sector in the UK:
- With 60% of patients self-funding, clinics compete to attract patients
 - Patient case mix variation – most of which is not captured in the HFEA's data – affects outcomes
 - The size of the clinics across the UK varies enormously
 - Therefore, presenting meaningful data is complex and difficult.
- 8.6.** The Director of Strategy and Corporate Affairs informed members that the most reliable statistics are calculated from national data, which is based on nearly 70,000 treatments each year. Once data is presented clinic by clinic, however, statistical reliability became a real issue. For the larger clinics, chance variation does not have a significant effect on outcomes, but this is an issue for small clinics and even medium sized ones.
- 8.7.** For this reason, confidence intervals in the CaFC data had been included since it was first launched in 2009. Without them, the data would be misleading. In the beta CaFC, the term 'reliability range' is used, which shows how confident the HFEA is that a clinic will repeat its success rate in the future. Although, patients found this difficult to understand, the advisory group had discussed this issues and agreed that such an important health warning should not be abandoned. Instead, the HFEA should seek to increase clarity and understanding through the design and wording on the page, using feedback from user testing.
- 8.8.** The Authority considered the options and recommendations in the paper. The Chair advised members that decisions would be taken by exception (ie, only if someone did not agree with the recommendation would they let the Chair know). The Authority was asked to consider the IfQ advisory group's recommendations and alternative options.

Births per embryo transferred

- 8.9.** The Director of Strategy and Corporate Affairs reminded members that, in January 2015, based on advice from the IfQ advisory group, Authority members decided that the primary headline birth rate for IVF should be births per embryo transferred. Adopting this rate would mean a greater emphasis on the clinical and embryological practices of the clinic and would promote the HFEA policy on single embryo transfer, as a double embryo transfer would reduce a clinic's birth rate in this calculation. The beta CaFC service uses this birth rate measure.

- 8.10.** However, some respondents during the beta feedback survey argued against births per embryo transferred, claiming it acts as a disincentive to replace the number of embryos that are clinically indicated and is difficult for patients to understand as it does not give them a picture of their overall chance of success.
- 8.11.** Looking at the views expressed during the beta feedback period in the round, the HFEA was of the view that there was no case for changing the policy of having births per embryo transferred as the headline measure for the following reasons:
- It promotes good practice around embryo transfer
 - It reinforces the HFEA's policy to reduce multiple births
 - It is understandable to patients if explained well
 - It is supported by the majority of professionals, the advisory group and the BFS.
- 8.12.** Members were asked to consider the IfQ Advisory Group recommendation to retain births (ie, birth events) per embryo transferred as the headline IVF birth rate on CaFC or to consider using a different birth rate.
- 8.13. Decision:** All members agreed to retain births (birth events) per embryo transferred as the headline IVF birth rate on CaFC.

Presenting the headline statistic at the top of the page

- 8.14.** The Director of Strategy and Corporate Affairs advised members that, in the beta feedback period, users were asked for their views about whether CaFC should have a headline statistic at the top of the page. Thoughts about this were:
- Most people supported a headline measure, so long as it was aggregated
 - It should be something which enables a comparison between clinics
 - A few suggested showing more than one age group at this point
 - The advisory group thought that a simple 'consistent with the national average' tick would be more meaningful.
- 8.15.** The Director of Strategy and Corporate Affairs therefore asked members to consider how the HFEA should present the headline IVF birth rate at the top of the page and in search results from the following three options:
- Remove birth rate information altogether
 - Present only where or not the rate is consistent
 - Present the clinic rate as a percentage, alongside the national rate (as it is now in beta).
- 8.16.** Members were asked to choose between the three options for how the IVF birth rate should be presented at the top of the clinic profile page and in search results.
- 8.17. Decision:** All members agreed to accept the recommendation of the Advisory Group, that the HFEA presents only whether or not the rate is consistent with the national average. This needs to be appropriately labelled to show what the underlying calculation is.

What should be included in the headline birth rate calculation?

- 8.18.** The Director of Strategy and Corporate Affairs advised members that users were asked for their views about what types of IVF and what ages should be included here. The key points were:
- Age aggregation and treatment aggregation as done in beta CaFC are very unpopular
 - Because of the impact of age on success, grouping all ages may disadvantage some clinics treating older patients
 - Some treatments are used for different reasons to standard IVF
 - Both may make the birth rate less meaningful to patients.
- 8.19.** The Director of Strategy and Corporate Affairs asked members to consider the following recommendation and options about what types of IVF treatment should be included in the calculation:
- **Recommendation:** only fresh IVF and ICSI cycles with the patient's own eggs
 - **Option 1:** exclude natural (unstimulated) IVF
 - **Options 2:** include natural IVF.
- 8.20.** Members were also asked to consider the following recommendation and alternatives about age banding:
- **Recommendation:** present the statistics for just under 38s
 - **Alternative one:** present it for the 'gold standard' patient
 - **Alternative two:** present it for both under 38 and 38 and over
 - **Alternative three:** present it for more age categories.
- 8.21.** Members were asked to consider the IfQ Advisory Group recommendation that the IVF birth rate calculation should use only fresh IVF and ICSI cycles with the patient's own eggs. Members were also asked whether or not unstimulated (natural) IVF should be included.
- 8.22. Decision:** All members agreed that the IVF birth rate calculation should use only fresh IVF and ICSI cycles with the patient's own eggs. All members agreed that unstimulated (natural) IVF should not be included in this calculation. Natural IVF is treatment with no drug stimulation at all. Mild stimulation falls into the stimulated IVF statistic. It was decided that it is important to make it clear that any reference to IVF excludes natural IVF – this being consistent with the decision to exclude egg donor IVF and PGS/PGD.
- 8.23.** Members were asked whether they agreed with the recommendation from the IfQ Advisory Group to present, at the top of the page and in search results, the statistic for just under 38s or to consider one of the alternative approaches.
- 8.24. Decision:** All members agreed that with the recommendation from the IfQ Advisory Group to present, at the top of the page and in search results, the statistic for just under 38s. There should be an explanation that this is a quality measure of clinics and not an indicator of a patient's own chances of success. All members agreed that, further down the page, the IVF birth rate should continue to be shown as 'all ages', 'under 38' and '38 and over'.

Births per egg collection time period

- 8.25.** The Director of Strategy and Corporate Affairs advised members that a few respondents had suggested the HFEA review the time period for the births per egg collection calculation, so that it can be aligned with the time period for births per embryo transferred. The advisory group discussed the issue and recommended that the HFEA should retain the current time period of two years from the time of egg collection. They felt that their original recommendation had been made after lengthy deliberation and they could not see a compelling reason for departing from this decision.
- 8.26.** The Director of Strategy and Corporate Affairs asked members to consider the following recommended and alternative option in relation to the time period for births per egg collection:
- **Recommended option:** advisory group recommendation: retain the two-year time period
 - **Alternative option:** reduce the time period to one year to align with births per embryo transferred.
- 8.27.** Members were asked whether they agreed with the IfQ Advisory Group recommendation to retain the two-year time period for births per egg collection.
- 8.28. Decision:** All members agreed to retain the two-year time period for births per egg collection.

9. Annual review of SCAAC work

- 9.1.** The Scientific Policy Manager gave an update of the work of the Scientific and Clinical Advances Advisory Committee (SCAAC) in 2016. The work of the committee is integral to the HFEA; we rely on the group of the experts to provide highly technical and specialist advice on advancements in the field in order to ensure the HFEA makes robust and sensible decisions.
- 9.2.** The Scientific Policy Manager advised members that SCAAC met three times each year to consider advances in science and clinical practice, which were relevant to the Authority's work. The committee kept the HFEA up to date with a fast moving area and consisted of Authority members and external advisors.
- 9.3.** The committee continued to include a broad range of clinical and scientific expertise in its membership, including:
- Obstetrics
 - Gynaecology
 - Embryology
 - Andrology
 - Clinical genetics
 - Preimplantation genetics
 - Stem cell biology
 - Epigenetics.
- 9.4.** SCAAC has a number of key functions which included:

- Horizon scanning functions
- Updates on key areas of research
- Patient information
- Policy development
- Novel processes.

- 9.5.** The Scientific Policy Manager advised members that SCAAC carried out its horizon scanning function annually, with the aim of identifying issues that could have an impact on the field of assisted reproduction or embryo research. Issues were identified by thoroughly reviewing all journal articles from the previous year and issues were prioritised according to criteria including the HFEA's remit, potential patient demand, technical feasibility and ethical or public interest issues.
- 9.6.** Issues identified as high priority were incorporated into the HFEA's business plan and work plan for the Executive, SCAAC and the Authority.
- 9.7.** The Scientific Policy Manager advised members that the annual horizon scanning international panel meeting was held, as is usual, at the annual meeting of the European Society of Human Reproduction and Embryology (ESHRE) which this year was in Helsinki, Finland. The panel discussed the HFEA's egg freezing data, noting that this was a unique data set. The panel also discussed the planned treatment add-ons work of the HFEA and provided an update on recent issues from their respective countries. This enabled the Executive to pick up on pioneering and quickly progressing areas of research to bring to SCAAC. One area that was noted as progressing significantly this year was that of in-vitro derived gametes.
- 9.8.** Researchers were investigating whether it was possible to develop eggs and sperm in the laboratory using early germ cells, embryonic stem cells or other human cells. Eggs and sperm derived from such cells in the laboratory were called in vitro derived gametes or artificial gametes. It was not legal to use these types of gametes in treatment in the UK but they could be used for research purposes. The research was thought to be valuable in a research in terms of understanding embryo development and developmental biology.
- 9.9.** The Head of Regulatory Policy advised members that SCAAC considered three standing items on an annual basis:
- Alternative methods to derive embryonic stem (ES) cells or embryonic-like stem (ES-like) cells
 - Health outcomes in children conceived using assisted reproductive technologies
 - Embryo culture media.
- 9.10.** For some time, the committee had focussed on the first two items and, more recently the third item. However, there had also been an increasing focus on SCAAC providing significant input into patient advice, in line with the HFEA's commitment, as an organisation, to ensure that patients had access to high quality, meaningful information. An example of this was the HFEA's work on drafting new information on treatment add-ons.
- 9.11.** The Scientific Policy Manager reminded members that one of the HFEA's key strategic aims was to improve the information about treatments that was available to patients. Media coverage in this

area highlighted that there was much controversy around which add-ons clinics provided and the extra cost to the patient.

9.12. The HFEA's aim in this area was to:

- Provide clear, impartial information about certain treatment add-ons on the new website
- Introduce a 'traffic-light' system for communicating the level of evidence for each add-on.

9.13. The Executive planned to provide easy to understand information on the following topics:

- Endometrial scratching
- Time lapse imaging
- Elective freeze-all
- Embryo glue
- Assisted hatching
- Reproductive immunology
- Egg activation
- Intrauterine culture
- PGS.

9.14. This information would be regularly monitored through the HFEA's horizon scanning function and would therefore be an evolving and constantly changing area of the website.

9.15. The Scientific Policy Manager reminded members of the HFEA's plans to reinvigorate the multiple births policy. In order to do this, advice had been sought from SCAAC. In 2008, multiples births from ART was one in four. It was now about one in seven live births, with the current target being one in ten. In 2008, the vast majority of patients received double embryo transfers. However, elective single embryo transfer (eSET) was now more common, and, since 2009, multiple births had gradually decreased whilst pregnancy rates were maintained.

9.16. Following discussion, SCAAC members:

- Highlighted the potential risks of double blastocyst transfer
- Suggested further analysis could further explore cumulative data sets (taking more than one year)
- Emphasised more work on highlighting the negative impact of multiple births.

9.17. The advice from SCAAC would be fed back to the multiple births stakeholder group.

9.18. In conclusion, the Scientific Policy Manager advised members that SCAAC played a key role in ensuring that the HFEA was up-to-date with scientific advances and would also play a key role in the HFEA's focus on improving patient information. The Executive would use the committee to ensure that patients understood the evidence base for given treatments.

9.19. In 2017, in addition to the committee's standing items, SCAAC would focus on:

- New technologies in genetic testing
- Gene editing

- ICSI – best practice.

9.20. Members noted and welcomed the presentation and agreed that it would be helpful to circulate it more widely.

10. Draft business plan 2017/18 and strategic risk register

10.1. Members noted the two items and the Chair invited members to send any comments to the Head of Business Planning.

11. Any other business

11.1. The Chair confirmed that the next regular meeting would be held on 18 January at Church House Westminster, Dean's Yard, Westminster, London SW1P 3NZ. Members were asked to confirm their attendance to the Executive Assistant to the Chair and Chief Executive as soon as possible.

12. Chair's signature

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

Signature 

Chair

Date 15/12/16

