Minutes of the Authority meeting on 20 May 2026 held at 2 Redman Place, London

Members present	Julia Chain (Chair) Tim Child Frances Flinter Tom Fowler Zeynep Gurtin Graham James Alex Kafetz	Alison McTavish Geeta Nargund (online for items 1-5) Catharine Seddon Anya Sizer Christine Watson
Apologies	Rosamund Scott Stephen Troup	
Observers	Emma Heslington, Department of Health and Social Care (DHSC) (on-line)	
Staff in attendance	Peter Thompson (Chief Executive) Rachel Cutting (Director of Compliance and Information) Clare Ettinghausen (Director of Strategy and Corporate Affairs) Tom Skrinar (Director of Finance, Planning and Technology) Dina Halai (Head of Policy, Scientific) Rachel Cooper (Head of Legal) Sophie Tuhey (Head of Planning and Governance) Shabbir Qureshi (Risk and Business Planning Manager) Alison Margrave (Board Governance Manager)	

Members

There were 12 members at the meeting – 8 lay and 4 professional members.

1. Welcome, apologies and declarations of interest

1.1. The Chair opened the meeting by welcoming Authority members and HFEA staff to the meeting.

1.2. The Chair also welcomed observers and stated that the meeting was being recorded in line with previous meetings and for reasons of transparency. The recording would be made available on the HFEA website to allow members of the public to view it.

1.3. Declarations of interest were made by:

- Tim Child (consultancy work within the fertility sector overseas)
- Anya Sizer (freelance advisory work within the fertility sector)
- Alex Kafetz (member of The Advisory Board to the Patient Safety Commissioner)

2. Previous minutes and matters arising

2.1. The Chair introduced the minutes from the meeting held on 11 March 2026 and thanked those members who had contributed to the minutes.

2.2. The minutes of the meeting held on 11 March 2026 were agreed as a true record of the meetings and could be signed by the Chair.

Matters arising

2.3. The Chair informed members that the matters arising from the previous meeting had been actioned as detailed in the report.

2.4. Members noted the matters arising report.

Standing Orders

2.5. The Chair reminded the Authority that at its last meeting they had agreed to implement changes regarding straightforward special directions applications being heard by the Executive Licensing Panel (ELP) and tasked the Head of Licensing to implement these proposals.

2.6. The paper before the Authority presents the required amendments to the standing orders.

2.7. The Board Governance Manager introduced the paper and explained in detail the proposed amendments to the standing orders for straightforward special directions applications to be heard by the ELP.

2.8. The Board Governance Manager stated that the Authority had received notification via a written motion regarding the intention to amend the standing orders at this meeting.

Decision

2.9. Members unanimously voted in favour of the changes to the standing orders.

Action

2.10. The Board Governance Manager to publish the revised standing orders.

3. Chair and Chief Executive's report

3.1. The Chair gave an overview of her engagement with key stakeholders and her attendance at decision-making committees of the Authority.

3.2. The Chair informed members that she and the Chief Executive had attended a meeting with the Permanent Secretary and Chief Scientific Officer to discuss life sciences and law reform; this was a positive meeting. The Chair stated that it was disappointing that The King's Speech did not include any reference to the HFEA's proposed law reform.

3.3. Again, with the Chief Executive the Chair had attended the DHSC ALB Chairs and Chief Executives meeting.

3.4. The Chair informed members that unfortunately the annual accountability meeting with DHSC had to be postponed to June due to a scheduling conflict with DHSC sponsors.

3.5. The Chief Executive commented that there were two bills of interest in The King's Speech, the first being the NHS Modernisation Bill notably the provision of information and a single patient record.

3.6. The second bill being the Regulating for Growth Bill and he explained how certain elements of this bill could assist regulators.

3.7. He informed members that he had attended an event regarding the 14-day rule project hosted by Nuffield Council on Bioethics. It is anticipated that their report will be published in the Autumn and he would keep members appraised of this report.

3.8. The Chief Executive informed members that the HFEA had given oral evidence to Woman and Equalities Committee inquiry on egg donation and egg freezing on 18 March 2026.

Decision

3.9. Members noted the Chair and Chief Executive's report.

4. Committee Chairs' report

4.1. The Chair introduced the report and invited Committee Chairs to add any other comments to the presented report.

4.2. The Statutory Approvals Committee (SAC) Chair (Frances Flinter) stated that the committee continues to meet monthly and the recent set of minutes have just been approved.

4.3. The SAC Chair reminded members of the process for considering Pre-Implantation Genetic Testing for Monogenic Disorders (PGT-M) applications and the benefit of having an independent peer reviewer and reports from the Genetic Alliance. The committee considers all this information, including evidence submitted by the clinic, when considering a PGT-M application.

4.4. The SAC Chair informed the Authority of the progress in reviewing the PGT-M list. As medical treatment has advanced it is prudent to review the conditions authorised for testing to see whether they still meet the legal threshold for being licenced. Several expert reviewers are working with the HFEA to complete this work and review the over 2,000 licensed conditions; thanks were expressed to all working on this project. It is anticipated that this work will be presented to the Authority in the Autumn.

4.5. The Chair commented that this is a large project but it is essential to see whether the previously licensed conditions still meet the legal threshold for being licensed.

4.6. The Licence Committee (LC) Chair (Graham James) informed the Authority that the committee had met on the 7 May and the minutes are not yet approved.

4.7. The LC Chair informed members that the May meeting was unusual in that all items before the committee related to research applications. Two items were executive updates when the committee had adjourned decision making previously and requested further information and clarification.

4.8. The LC Chair spoke of the detailed review of papers which committee members undertake on all applications. He spoke about the number of eggs and embryos which are required for some research applications.

4.9. The LC Chair remarked that five observers had attended this meeting.

4.10. The Audit and Governance Committee (AGC) Chair (Catharine Seddon) informed members that the whilst the AGC has not formally met since the last Authority meeting, they had reviewed and commented on the draft Governance Statement for the 2025 Annual Report and Accounts. The AGC will consider the full draft Annual Report and Accounts at its next meeting and this document will then be brought to the July Authority for approval.

4.11. The AGC Chair reminded members that she had informed them at a previous meeting of the very significant fee increases which had been set by the National Audit Office (NAO). Following discussions with NAO regarding HFEA's concerns, this increase had been reduced by 50%.

4.12. Members were informed that NAO had also undertaken to have early and more transparent discussions with HFEA regarding future audits and a meeting had been set up for early June.

4.13. The Chair thanked the AGC Chair for her work in leading the discussions with NAO and for securing a fee reduction.

4.14. The Scientific and Clinical Advances Advisory Committee (SCAAC) Chair (Tim Child) informed members that the HFEA will host its annual horizon scanning meeting at ESHRE 2026. As the event is being held in London the HFEA had been able to expand the attendee list.

4.15. The SCAAC Chair spoke about the format of the horizon scanning meeting with experts presenting key topics which are then discussed by the attendees. A report from this meeting will be presented to the Authority later in the year.

4.16. The Chair thanked the Committee Chairs for the reports and expressed thanks to the committee members and the staff who service the various committees for their hard work. The Chair stated that committee papers and minutes are published on the HFEA website.

4.17. The Chair referred to the PR event which the HFEA had hosted in April. This was an extremely good event with an engaging agenda and good organisation.

4.18. The event had achieved a 97% satisfaction rate from attendees which demonstrates the strong and trusted relationship between the HFEA and the sector.

4.19. Members noted the Committee Chairs' reports.

5. Performance Report

5.1. The Chief Executive introduced the performance report and reminded members of the Key Performance Indicators (KPIs) which are used to measure performance. The report before the Authority measures the performance for the period April 2025 to March 2026.

5.2. The HFEA's performance across all 19 KPIs has remained consistently strong throughout the year. The compliance KPIs had moved up and down throughout the year but this did not indicate any structural problems just that some reports were more complex than the others and required more engagement with centres. The Chief Executive stressed that all licenses were issued on time throughout the year.

5.3. Throughout the year applications for embryo testing increased from 45 in the previous year to 84 this year. All PGT-M applications were processed with minimal delay and the Chief Executive thanked the members of SAC and relevant staff members.

5.4. The Chief Executive informed members that the OTR waiting list had reduced significantly during the year. Decreasing from 768 requests in April 2025 to 226 in March 2026. Members were informed that between 120 to 200 requests are being dealt with each month

5.5. The Chief Executive explained that the average waiting time for closing applications in the last quarter of the year was 61 days. Although some applications are more complex and take longer due to the increased communications with clinics and checking of data that is required.

5.6. Regarding the HR KPIs an average sickness absence of 2.5% was recorded and staff turnover was within the 5-15% tolerance, with the upper limit being breached just once. Staff morale and satisfaction continue to be high and the HFEA measures these through a variety of different activities.

5.7. The Chief Executive informed members that the time which the HFEA takes to fill vacancies is very swift compared to other public bodies and this played an important role in managing

workload and maintaining morale. The AGC will receive a detailed report on HR issues in June 2026.

5.8. The Chief Executive concluded by stating that performance for March 2026 continued to be strong with 10 indicators rated Green, seven Amber, two Neutral and none Red.

Strategy and Corporate Affairs

5.9. The Director of Strategy and Corporate Affairs informed members of the Patient Organisation Stakeholder Group (POSG) and Professional Stakeholder Group (PSG) meetings which took place in April and May. Both groups continue to feedback that they find these meetings valuable.

5.10. The Director of Strategy and Corporate Affairs informed members that organisational updates were circulated to both meetings a week beforehand and this meant that the meetings could focus on the substantive agenda items. The Director of Strategy and Corporate Affairs provided further information on agenda items for both groups.

5.11. Members were informed that work is progressing on the Fertility Trends report and it is anticipated that this will published toward the end of June.

5.12. The Director of Strategy and Corporate Affairs informed members that the FAQs relating to unregulated sperm donation had been updated on the HFEA's website. This work had also been supported by posting across the HFEA's social media channels.

5.13. Members were informed that the Director of Strategy and Corporate Affairs had spoken at the recent BICA annual conference and spoke about the latest trends shaping the fertility sector.

5.14. The Director of Strategy and Corporate Affairs highlighted the event which the HFEA will host at ESHRE 2026.

5.15. In response to a question regarding declining number of enquiries via phone and email the Director of Strategy and Corporate Affairs stated that this is consistent with other organisations and can be attributed to the increased use of AI Google summaries and use of other AI models. Changes have been made to the HFEA website which should make information easier to find so we would expect the number of enquiries to continue to fall.

Compliance and Information

5.16. The Director of Compliance and Information referred to the inspection schedule for the year and highlighted the 11 additional inspections which were carried out due to whistleblowing, complaints or regulatory concerns. She commented that this highlighted the HFEA's agile response to regulatory concerns.

5.17. Members expressed their appreciation to the OTR team for their efforts in reducing the waiting list during the year.

5.18. A member questioned whether the level of OTR applications is expected to stay steady or could there be a surge in applications? The Director of Compliance and Information responded that the team continues to carefully monitor demand, but there could be additional surges in demand which would require strategic decisions on resources.

5.19. The Director of Compliance and Information reminded members of the technology improvements which had been made during the year and the positive impact these improvements had in responding to OTR requests.

5.20. The Chief Executive commented on the increase in donation treatments and that if the percentage of people requesting information increased too then the HFEA would need additional resources to meet this demand.

5.21. A member spoke of the assurance provided by the Chief Executive and Director of Compliance and Information in monitoring OTR demand and the reassurance this provided to the Authority.

5.22. A member spoke of the important role of the OTR service in providing sensitive information. They noted that the average waiting time from application is 61 days but less complex applications can be processed in under 30 days and this reflected the efficient handling of applications. They also complimented the Authority's ability to manage such a delicate area of information.

5.23. The Director of Compliance and Information thanked members for their positive comments which will be fed back to the OTR team. The Director of Compliance and Information reminded members of the OTR process and the time constraints in which clinics are meant to respond to the HFEA's communications. Unfortunately, some clinics do not adhere to these deadlines and the HFEA will continue to raise awareness of this requirement through publications such as clinic focus.

Finance, Planning and Technology

5.24. The Director of Finance, Planning and Technology stated that the Framework Agreement with DHSC has been finalised and is awaiting final Departmental sign off. The final agreement will be published on GOV.UK, the HFEA website and in the libraries of both Houses.

5.25. In addition, the formal Business Plan 2026-2027 had been finalised and approved by the Department and published on the HFEA's website.

5.26. The Director of Finance, Planning and Technology informed members that the HFEA is recruiting additional IT resource, based on an IT plan which had been developed earlier in the year. This will provide further capability and resilience for the team.

5.27. Members were informed that the Phoenix programme is moving at full tilt with a huge effort from the IT team and staff across the organisation in designing and testing the new systems. It is anticipated that the HFEA will migrate from its current document management system to SharePoint at the end of June. The switch over for Epicentre is planned for the end of July.

5.28. The Director of Finance, Planning and Technology informed members that he meets weekly with the internal team managing the Phoenix programme and monthly with the suppliers. The SMT have also held a few discussions about possible contingencies which might be required for the programme.

5.29. Members were informed that an interim DSPT audit was conducted in April and the HFEA is currently awaiting detailed feedback which will help the team firm up the evidence for the final submission in June. The Director of Finance, Planning and Technology stated that the SIRO report, which will be presented to the June AGC, will also provide an overview of information governance work throughout the year.

5.30. The Director of Finance, Planning and Technology reminded members that the HFEA had been forecasting a deficit for 2025/26 since the summer and this had been driven largely by lower then expected income and a particularly busy 12 months which meant that it was harder to reduce costs in-year. The HFEA had undertaken a range of actions to reduce this deficit and the

starting pre-audit year end position is a deficit of £299k, which is net of an under-recovery of income against budget of £343k and expenditure being below budget by £44k. This deficit will be covered either by the HFEA's reserves or through additional Grant-in-Aid.

5.31. Members were informed that the audit is progressing well and thanks were given to the Finance Team for their work in compiling all the information for the auditors. The Director of Finance, Planning and Technology gave an overview of the audit process and highlighted a few areas which may need additional reporting to satisfy the auditors.

5.32. The Director of Finance, Planning and Technology commented that whilst Departmental and HMT clearance for this year's fee change was received later than hoped for, the HFEA had been able to ensure clinics were aware of the changes in time. He informed members that an update was provided on the fee review at the recent PR event.

5.33. A member questioned the underspend in training and commented on the importance of training and staff being able to access this. The Director of Finance, Planning and Technology responded that the HR budget had been increased last year and a few projects, such as targeted leadership training had been delayed but will commence later this year.

5.34. The Chair requested delegation from the Authority under article 6.1 of the standing orders to approve amendments to General Direction 0005. This General Direction sets out the specific mechanism by which PRs must submit and verify data for Choose a Fertility Clinic (CaFC) and updates are required to reflect PRISM.

Decision

5.35. The Authority agreed delegation to the Chair to approve amendments to General Direction 0005.

5.36. Members noted the performance report.

Action

5.37. Executive to liaise with the Chair regarding General Direction 0005.

6. Embryo Testing

6.1. The Chair introduced this agenda item and reminded members that they last considered the current practice and emerging issues relating to embryo testing at their September 2025 meeting and agreed that guidance for the sector is needed and should be brought back to the Authority for review.

6.2. The paper at this meeting sets out the work that has been undertaken since September 2025 and identifies the areas on which decisions are required by the Authority. The Chair thanked the staff and Authority members who had worked on this.

6.3. The Head of Policy introduced the paper and stated that that the Human Fertilisation and Embryology (HFE) Act 1990 (as amended) (the "1990 Act") prohibits embryo testing except for one of the purposes permitted in the Act (the "Permitted Purposes").

6.4. The Head of Policy explained that testing embryos is a licensable activity and clinics need to have a licence that includes testing embryos to be able to carry out this function. In addition, testing embryos under 1(b) can only take place for conditions approved by the HFEA's Statutory Approvals Committee (SAC), and testing embryos under 1(d) can only take place on a patient-by-patient basis following approval by SAC.

6.5. Members were informed that the methodologies for carrying out genetic testing have advanced significantly since the law was passed. Sophisticated testing now routinely generates data which go beyond simple binary results for which the testing was originally sought. These developments raise the question of what, if any, additional information may lawfully be obtained from permitted testing. Continuing, the Head of Policy stated that there is also the possibility of coming across genuinely accidental and unavoidable incidental findings, which, unlike additional findings, are not sought.

6.6. The Head of Policy referred to the Authority discussion regarding current practice and emerging issues relating to embryo testing which took place at the September 2025 meeting and their request that guidance for the sector is needed and should be brought back to the Authority for review.

6.7. The Head of Policy also referred to the draft guidance which had been developed with the assistance of several Authority members.

6.8. The Chair thanked the Head of Policy for the introduction of the paper and asked that the Authority now consider the paper section by section.

6.9. The Head of Policy summarised the proposal to require clinics to record the reason for testing in each case under 1(a) and 1(e). Members were informed that clinics would not be required to submit this information to the HFEA, but it may be the subject of inspection in the usual way.

6.10. In response to a question the Head of Policy explained that testing under 1(b), 1(c) and 1(d) requires approval from the SAC, so there was no need to apply this proposal to testing for those purposes as the reason for testing was already recorded. Members noted the framework in which the SAC operates and the decision tree it follows to ensure that conditions meet the legal threshold for being licenced.

6.11. The Head of Policy referred to section four of the paper regarding what positions the Authority could take regarding obtaining information on additional SAC-approved conditions with the intention of using that information in clinical decisions making when testing under 1(b). The potential benefits and considerations in relation to each option were explained in detail.

6.12. There was a discussion about whether the principles of the 100,000 Genomes Project / Genomics England were relevant to embryo testing. A member highlighted that it is important to differentiate between population screening in research settings and in clinical settings. Population screening of people in the UK as part of this project was carried out in a research setting.

6.13. Members noted that whole genome sequencing is reducing in cost and the time that it takes and therefore that it is becoming easier to find out about many if not all SAC approved conditions in one go. However, the Head of Policy pointed out that it would not be possible to obtain fully informed consent for testing of all SAC approved conditions in one test. The significance of each condition would need to be explained, and the patient would need to be offered implications counselling about each one and clearly, this is not possible for over 2,000 conditions.

6.14. Overall, members were supportive of option ‘b’ in paragraph 4.7 of the paper, ie information on some other HFEA-approved conditions can be obtained and used in clinical decision-making when testing under 1(b), since it is consistent with the wording of the act but were concerned about how the parameters on which other conditions could be tested for would be drawn. A member expressed a view that unless there is a known predisposition due to parents carrying a

faulty gene, clinics should not go looking for conditions where there is no particular risk. Members requested that the Authority have the opportunity to see the guidance before it is issued to clinics so that they have the opportunity to review what option 'b' would look like in practice.

6.15. Members suggested that the Executive reach out to the National Screening Committee to help determine which additional conditions could be tested for.

6.16. Option 'a' in paragraph 4.7, ie information on other HFEA-approved conditions cannot be obtained and used in clinical decision-making when testing under 1(b), was thought to be too restrictive and not in the patients' interest.

6.17. Members discussed the inequity in the law between allowing additional testing when there is no particular risk under 1b but not 1a.

6.18. The Head of Policy referred to section five of the paper regarding the proposed approach to incidental findings being used in clinical decision making. The Head of Policy explained the difference between additional findings and incidental findings.

6.19. Members agreed that receipt of incidental findings should be rare but that there is a small chance that clinics may receive information on incidental findings therefore it is important to provide clinics with guidance on how to act in such an event.

6.20. Members noted that if an unavoidable incidental finding identified is one which has not been approved for testing by the HFEA under 1(b), but is one which the Person Responsible deems to be associated with a serious condition, then an application should be made to the SAC to have the condition approved.

6.21. A member highlighted that data collection cannot be avoided by the laboratories that undertake testing, therefore the guidance should place the onus on clinics avoiding unnecessary data analysis.

6.22. A member referred to the information provided by The British Society for Genetic Medicine (BSGM) regarding incidental findings and the clear pathway identified between the laboratory and clinic. The member commented that this may be a useful source of information and that the HFEA could consider including flowcharts as part of the guidance.

6.23. The Head of Policy reminded the Authority that at the September 2025 meeting it had agreed to review where a previous broad 'group' approval has been given for what was termed, "chromosomal rearrangements (various)". The Head of Policy explained the reason for the recommendation to remove this 'umbrella' authorisation from the approved list of conditions that can be tested for under 1(b). Members agreed to this proposal and noted the proposed next steps in section eight of the paper, including having a transitional period.

6.24. The Authority discussed that the use of preimplantation genetic testing involving polygenic scores (PGT-P) is not lawful and noted that the HFEA had published earlier in the year a blog on PGT-P and an article in BioNews (publication by the Progress Educational Trust (PET)) to explain that PGT-P is unlawful in the UK as it does not identify a particular gene, chromosome or mitochondrial abnormality.

6.25. The Authority noted that these public statements also explain that embryos can only be selected for transfer based on information from testing that meets a specified purpose in law, and that the prohibition on performing PGT-P in the UK cannot therefore be circumnavigated by having the

analysis carried out in another jurisdiction, and then using the results from that analysis to select embryos for treatment in the UK.

6.26. The Head of Legal informed members that data about an embryo that cannot lawfully be used to make treatment decisions in the UK is not regarded as the patient's personal data. Therefore, patients do not automatically have a right to the embryo's full sequence of raw genetic data under UK's data protection laws.

6.27. The Authority felt that a clear statement setting out the HFEA's position regarding data about an embryo that cannot lawfully be used to make treatment decisions in the UK not being part of the patient's personal data would be beneficial for clinics.

6.28. The Chair drew the discussion to a close and thanked all for their in-depth discussion.

Decision

6.29. The Authority agreed:

- the recommended approach of requiring clinics to record the reason for testing under 1(a) and 1(e)
- that in principle information on some other HFEA-approved conditions can be obtained with the intention of using that information in clinical decision making when testing under 1(b), with the caveat that they need to see what the guidance looks like
- the recommended approach of requiring clinics to record the reason for testing additional conditions under 1(b)
- the recommended approach with regard to unavoidable incidental findings
- the removal of the umbrella "chromosomal rearrangements (various)" authorisation from the approved list of conditions that can be tested for under 1(b)
- the final draft guidance to be circulated to the full Authority for any last minute comments (substance not style) and then sign-off of the final draft guidance to be delegated to Frances Flinter, Tim Child and Rosamund Scott.
- to delegate sign off on consequential changes to General Directions and Standard Licence Conditions, to the Chair
- that the HFEA should publish a clear statement setting out the HFEA's position on PGT-P and that data about an embryo that cannot lawfully be used to make treatment decisions in the UK is not regarded as the patient's personal data.

Action

6.30. Executive to implement the Authority's decisions.

7. Any other business

7.1. The Chair thanked everyone for their active participation in the meeting and for the high quality of papers before the Authority. There being no further items of any other business, the Chair closed the meeting and reminded members that the next full Authority meeting is being held on 1 July 2026. Details of this meeting, including how to request to observe, is posted on the HFEA website.

Chair's signature

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

Signature

Chair: Julia Chain

Date: 1 July 2026