

# Minutes of Authority meeting held on 25 January 2023

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## Details:

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Area(s) of strategy this paper relates to:	The best care – effective and ethical care for everyone The right information – to ensure that people can access the right information at the right time Shaping the future – to embrace and engage with changes in the law, science and society
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Agenda item	2
Meeting date	22 March 2023
Author	Debbie Okutubo, Governance Manager

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## Output:

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For information or decision?	For decision
Recommendation	Members are asked to confirm the minutes of the Authority meeting held on 25 January 2023 as a true record of the meeting.

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Resource implications

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Implementation date

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Communication(s)

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Organisational risk	<input type="checkbox"/> Low	<input checked="" type="checkbox"/> Medium	<input type="checkbox"/> High
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## Minutes of the Authority meeting on 25 January 2023

Members present	Julia Chain Jason Kasraie Frances Flinter Zeynep Gurtin Alison Marsden Tim Child	Guhrun Moore Alex Kafetz Graham James Jonathan Herring Geeta Nargund
Apologies	Catharine Seddon Alison McTavish	Frances Ashcroft
Observer	Amy Parsons (Department of Health and Social Care – DHSC)	
Staff in attendance	<b>In person</b> Peter Thompson Richard Sydee Clare Ettinghausen Rachel Cutting Debbie Okutubo Shabbir Qureshi Amanda Evans	<b>Online</b> Paula Robinson

### Members

There were 11 members at the meeting – seven lay and four professional members.

## 1. Welcome and declarations of interest

- 1.1. The Chair opened the meeting by welcoming Authority members and the DHSC colleague present. The Chair also welcomed staff and observers who were present and those online and stated that the meeting was audio recorded in line with previous meetings and for reasons of transparency the recording would be made available on our website to allow members of the public hear it.
- 1.2. Declarations of interest were made by:
  - Jason Kasraie (PR at a licensed clinic)
  - Tim Child (PR at a licensed clinic) and
  - Geeta Nargund (Clinician at a licensed clinic).

## 2. Minutes of the last meeting and matters arising

- 2.1. Members agreed that the minutes of the meeting held on 16 November 2022 were a true record and could be signed by the Chair subject to the following change:

8.6 to read:

“...The Head of Information responded that the Donor Conception Network (DCN) currently provide information and peer support...”

- 2.2.** Members agreed that action 8.20 on the matters arising report could be removed as the Executive had signed the contract with the Hewitt Centre and that there will not be any disruption to the existing service during the transition period.
- 2.3.** The status of all other matters arising were noted.

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### **3. Chair and Chief Executive's report**

- 3.1.** The Chair gave an overview of her engagement with key stakeholders, her attendance at sector related conferences and the decision-making committees of the Authority.
- 3.2.** The Chair gave a summary of her attendance at the Fertility 2023 conference held in Belfast. She further commented that the legislative reform consultation will begin in February and that part of the plan was to visit clinics to ensure a wide range of views are gathered.
- 3.3.** The Chief Executive (CE) provided an update on the key external activities that he had been involved in since the last Authority meeting.
- 3.4.** Members were advised that the new Secretary of State for Health was keen that Arms-Length Bodies (ALBs) work together and share intelligence where relevant.
- 3.5.** The Chief Executive continued that he had a meeting with the National Aids Trust to discuss their concern at the current restrictions on people living with HIV becoming donors. This issue has also been raised by some clinics who the Chair has visited. The DHSC is awaiting recommendations from the Advisory Committee on the Safety of Blood, Tissues and Organs (SaBTO) before considering any next steps with this issue.

#### Decision

- 3.6.** Members noted the Chair and Chief Executive's report.

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### **4. Committee Chairs' reports**

- 4.1.** The Chair invited committee Chairs to add any other comments to the presented report.
- 4.2.** The Licence Committee Chair (Alison Marsden) noted that a number of recent cases were very complex. Notably, they were having to meet out of their normal meeting cycle to review a particular complex case.
- 4.3.** The Statutory Approvals Committee (SAC) Chair, (Jonathan Herring) stated that there had been three committee meetings since the last Authority meeting. At the December meeting, SAC conducted their annual committee effectiveness review.
- 4.4.** The Audit and Governance Committee (AGC) deputy Chair (Alex Kafetz) gave a summary of the meeting in the absence of the Chair, Catharine Seddon. He commented that the committee agreed the approach to our risk appetite, tightened up the wording on the risk strategy and carried out the effectiveness review. Members were advised that at the end of the meeting there was a training on understanding financial statements which was facilitated by KPMG, our external audit partner firm.
- 4.5.** The Chair thanked all Authority members for their hard work and time commitment on the various committees.

## Decision

- 4.6.** Members noted the committee Chairs' reports.
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## 5. Performance report

- 5.1.** The Chief Executive commented on staff sickness absence which had increased significantly mainly due to two staff members on long term sick leave.
- 5.2.** On PRISM, the Chief Executive commented that the system was working well. Three clinics had experienced delay in uploading information due to them switching to a third-party provider.
- 5.3.** It was noted that back-dated validation errors had recently been released to clinics as part of the Choose a Fertility Clinic (CaFC) refresh plans. The Chief Executive thanked all clinics that were correcting the errors and further commented that this put us in good stead to predict when CaFC would be updated.
- 5.4.** It was noted that we were aiming to have CaFC timelines confirmed between April and June 2023. However, the current prediction was that the best-case scenario for CaFC being ready to be updated was September 2023 whilst the worst case was June 2024 depending on validation errors being fixed and the verification period required.

## Strategy and Corporate Affairs

- 5.5.** The Director of Strategy and Corporate Affairs presented this item.
- 5.6.** It was noted that there was huge media coverage of the donation report published at the end of 2022 with significant interest in the number of children born from donor conception since 1991, the level of overseas donors at present and the upcoming changes to anonymity.
- 5.7.** Members were advised that the consultation on changes to the Human Fertilisation and Embryology Act would open at the end of February for six weeks.
- 5.8.** The next Scientific and Clinical Advances Advisory Committee (SCAAC) meeting will be held on 6 February and would be the first time that add-ons would be rated according to the new ratings system. Publicity on the new system and ratings would take place later in the Spring.
- 5.9.** There had been some recent parliamentary interest in areas around fertility including two current private members bill in the House of Commons.

## Compliance and Information

- 5.10.** The Director of Compliance and Information commented on the OTR service. It was noted that it continued to be a busy service. There were 57 applications in December and 43 applications in January 2023. The vacant post has been recruited to, and the team was now at its full staffing complement. The new improved team structure will assist in reducing the time to sign off applications.
- 5.11.** In terms of licensing performance, it was noted that there were clinics who demonstrate good compliance but some clinics have more complex inspections due to several areas of non-compliance being identified. This may lead to post inspection activity such as management review meetings, requisitions for further information and accountability meetings. These activities can lead to an increase in the time it takes for reports for a licensing committee to be finalised. This will therefore mean our KPIs will not always be met.

**5.12.** The inspection schedule is very busy over the coming months with inspections currently booked to August 2023.

### Finance and Resources

**5.13.** The Director of Finance and Resources commented on the financial indicators in the performance report. As at November the forecast was showing a surplus against budget of £599k which was largely due to our income and the underspends within our expenditure. There are less than 10 clinics that have not caught up with their submissions, but the remaining 92 have been reconciled and were billed on actual submissions.

**5.14.** Members asked that if we were showing a surplus of £599k and it was returned to the DHSC, that was a large part of our grant in aid. The Director of Finance and Resources responded that we would not be sending it back to the DHSC and that we were in discussion on its usage as the Treasury rules of not spending our surplus still applied.

### Decision

**5.15.** Members noted the performance report.

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## 6. Draft Business Plan 2023/24

**6.1.** The Chair advised members that we were required to set a business plan each year and that it would need to be approved by the DHSC. Members were reminded that there was an initial discussion at the November Authority meeting where priorities were noted and the Head of Planning and Governance subsequently circulated a report to members on priorities and trade-offs.

**6.2.** The Head of Planning and Governance thanked members for their responses and commented that in addition to our statutory work, in the first half of the coming business year, the major priorities would be:

- development work on the Opening the Register (OTR) service
- servicing our public body review, and
- completing our current work on the Act reform.

**6.3.** We would then assess the resource available to progress actions relating to regulatory transparency and the Government's Women's Health Strategy.

**6.4.** Members were advised that the full business plan might be brought back to the March meeting, or circulated for comment between Authority meetings, depending on the timing of the DHSC review and approval process.

**6.5.** Members asked how vacancies and staff sickness might impact the delivery of the work in the business plan. The Head of Planning and Governance responded that it had been taken into consideration, to the extent possible, when the Corporate Management Group (CMG) met to discuss priorities. The Chief Executive also commented that the business plan assumed that we had sufficient human resources to do the work and that if staff turnover and/or sickness affected delivery, we would do the maximum possible with the available resources.

**6.6.** Members were given the assurance that delivery would always be based on what could be achieved with the resources at any given time.

- 6.7.** The Chair commented that we do not yet know the timetable for the public body review, but that if that was delayed, whether staff should consider if deprioritised work could be moved up the priority list. The Chief Executive responded that the public body review would impact mainly on the senior team but that available resources would still be taken into consideration.

#### Decision

- 6.8.** Members approved the draft business plan activities for 2023/24 and noted that the further development of the business plan would now take place. Members would be kept informed of progress.

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## 7. The Register research panel (RRP) and data research

- 7.1.** The Head of Research and Intelligence presented this item. Members were reminded that the HFE regulations allowed disclosure of information for research purposes. As part of our work in reviewing the Act, staff met with some researchers in June 2022 who had used HFEA register data in their research to discuss where legislative changes would be of benefit to improve data research.
- 7.2.** In their responses, four areas were highlighted:
- Cost recovery
  - Research following egg, sperm or embryo donation
  - Consent to non-contact research, and
  - Child consent.
- 7.3.** Members were advised that since the introduction of the 2010 regulations, the RRP had approved 20 projects: nine projects were currently active and 11 had been completed.
- 7.4.** Members commented that limited number of researchers were using this data. The Head of Research and Intelligence confirmed this but commented that the plan was on raising awareness and we had the processes in place to handle requests.
- 7.5.** In response to a question, members were advised that researchers are required to provide reasoning for why each data field is required in their research. Research projects require research ethics committee approval and researchers typically only use identifiers to link HFEA register data to other health databases. Identifiers are stripped from the linked data prior to being provided to the research establishment.
- 7.6.** Members commented that the panel seemed to be entirely reactive, but the proposal looked like it was designed to promote research. The Chief Executive responded that we were not suggesting that the panel should limit research but we have an unused asset and we would like it to be better utilised.
- 7.7.** Members discussed the proposal to approach DHSC with suggested changes to the 2010 regulations and the following points were discussed:
- 7.8.** Members were concerned that raising the price from the current capped £5,000 could discourage research applications. The Director of Strategy and Corporate Affairs responded that we could not unilaterally do this as costs are set in regulation and we would be seeking a cost recovery model

rather than a single cost. She further commented that informal discussions and feedback received was that other organisations charged far greater amounts for access to their data.

- 7.9.** It was noted that regulations restricted research to UK based or UK related organisations that could utilise the research.
- 7.10.** Members commented that any change to an opt out system of consent to research was only useful if people knew to opt out and asked how users would be made aware. The Head of Research and Intelligence responded that we would have to respect the consent given previously and we would need to find ways of making the public aware of how to opt out of their data being used in research.
- 7.11.** The Director of Compliance and Information responded that at the Fertility 2023 conference, feedback was that when consent shifted to electronic consent it decreased.
- 7.12.** Professional members commented that clinic staff were very good at discussing the issues involved and getting consent from patients to data research.
- 7.13.** Members asked if there could be a UK hub to encourage international collaboration as it was important to encourage international use of the data.
- 7.14.** In response to a question, the Head of Research and Intelligence commented that according to legal advice, [section 251](#) was not applicable to our regulations.
- 7.15.** Also, that enabling data sets following linkage to be available to other researchers following the completion of the original project was one of the directions of travel we were pursuing. Members were advised that should they be convinced of the case for reform, the DHSC will be approached and members will be kept updated.
- 7.16.** The Director of Strategy and Corporate Affairs commented that we have always had limited capacity to handle a high volume of requests and that 2023 would be a test year to see how things developed. It was also noted that through higher coverage of our data reports and use of data in the media and social media, anonymised register information is featured publicly on a daily basis.
- 7.17.** The Chair commented that it was good to see that we were getting good use of our data.

#### Decision

- 7.18.** Members supported an approach to the DHSC to make the case for changes to the 2021 regulations.

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## 8. Presentation on Opening the Register (OTR)

- 8.1.** The Directors of Compliance and Information and Strategy and Corporate Affairs presented this item.
- 8.2.** Members were reminded that the change in the law in 2005 meant that donor conceived children could access identifying information about their donor once they turned 18 in 2023.
- 8.3.** The Director of Compliance outlined key challenges for donor conceived individuals, donors, clinics and the HFEA.

- 8.4.** The Director of Strategy and Corporate Affairs outlined three workstreams planned for this year, as well as the key risks and what we could do to mitigate them.
- 8.5.** Members noted the risks identified including the reputational risks and that the use of postal address to communicate was very limiting.
- 8.6.** A member asked if patients could be contacted using NHS numbers and see if the HFEA could find out if donors were still alive. The Director of Strategy and Corporate Affairs responded that this was something that we were currently seeking advice on and we would need to consider what information, and basis for contact, the donor had been given initially.
- 8.7.** Members were given the assurance that we would bring updates back to them and engage with external stakeholders and clinics.
- 8.8.** Members commented that we need to find positives in these stories and that a number of donors were open to contact following the change in legislation.
- 8.9.** Members suggested that a cautious approach in relation to cyber security should be taken and should also be added to the risk register.
- 8.10.** The Chair commented that there was a great deal of interest in this area and as the information provider, we would need to proceed with care.
- 8.11.** Members would be provided with short talking points on the key facts in this area.

#### Action

- 8.12.** Include cyber security in the risk register and provide members with talking points and regular updates to future Authority meetings.

#### Decision

- 8.13.** Members noted the ongoing activities relating to Opening the Register.

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## 9. Any other business

- 9.1.** There was no other business.
- 9.2.** The next meeting will be on 22 March 2023.

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## Chair's signature

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

#### Signature



Chair: Julia Chain

Date: 25 January 2023