

Authority Paper



Committee:	Authority Meeting
Meeting Date:	28th March 2006
Agenda Item:	2
Paper Number:	HFEA (15/02/06) 299
Paper Title:	Draft Minutes of the Authority Meeting of 15 February 2006
Author:	Committee Secretary
For Information or Decision?	Decision
Resource Implications:	None
Recommendation to the Committee:	The Authority is asked to confirm the minutes as a true and accurate record of the 15 February 2006 meeting

HUMAN FERTILISATION & EMBRYOLOGY AUTHORITY MINUTES OF THE 153rd AUTHORITY COMMITTEE MEETING (PART 2 – Non-Confidential)

Royal College of Obstetricians and Gynaecologists
27 Sussex Place, London, NW1 4RG

The Authority meeting was quorate with 18 Members attending, 12 lay members and 6 professional members.

PRESENT

Suzi Leather
Sam Abdalla
David Archard
David Barlow
Ivor Brecker
Iain Cameron
Walter Merricks
Chris Barratt
Neva Haites
Simon Jenkins

Ruth Fasht
Helene Hayman
Richard Harries
Emily Jackson
Maybeth Jamieson
Chris Barratt
Susan Price
Clare Brown
Jennifer Hunt

IN ATTENDANCE

Tim Whitaker
Barry MacDonald
Sarah Marsh
Ramen Chaterjee
Chris O'Toole

Trish Davies
Frances Clift
David Tellis
Helena Hird
John-Paul Maytum

OBSERVERS

Ted Webb (Department of Health)

- | | | Action |
|----------------|---|---------------|
| Item 1. | Apologies, Welcome & Conflicts of Interest | |
| 1.0 | Apologies were received from:

Sharmila Nebhrajani
David Barlow | |
| 1.1 | The Chair welcomed the new Authority member, Dr Susan Price to the Authority. Dr Price is a Consultant in Clinical Genetics for Northamptonshire with an interest in ethics. | |
| 1.2 | The Chair also welcomed the new observer from the Human Genetics Commission (HGC) to the meeting, Dr Christine Patch. Dr Patch is a Clinical Genetics Counsellor. | |
| 1.3 | In addition the Chair thanked Martin Richards of the HGC for all his hard work as an Authority observer. | |
| Item 2. | Minutes of the meeting held on 11 January 2006
[Paper HFEA (11/01/06) 299] | |
| 2.0 | The Authority were content with the minutes from 11 October 2006. | |
| Item 3. | Matters Arising & Previous Actions
[Paper HFEA (11/01/06) 300] | |
| 3.0 | 11/01/06 5:9.5

The SANT group met on the 14th February 2006. | |
| 3.1 | 11/01/06 5:9.5

Angela McNab has met with Professor Toft and findings will be reported to the SANT group (14.02.06). | |
| Item 4. | Chair's Report
(Verbal Report) | |
| 4.0 | The Authority heard that the Chair had met with Phil Willis, Chair of the House of Commons Science and Technology Committee. A meeting has also been had with Kevin Barron, Chair of the House of Commons Select Commission to build close working relationships with parliamentarians in light of the 'Review of the Act'. | |
| Item 5. | Chief Executives Report
(Verbal Report) | |
| 5.0 | The CE informed that Authority that she has met with the | |

Commissioning Board of Northern Ireland and the Commissioning Consortium in London to see what can be learnt about different working practices.

- 5.1 Both were aware of the Code of Practice and the Guide to Infertility but much less aware of the HFEA's analysis of feedback or adverse incident reports and are keen to use such information on their commissioning and monitoring.
- 5.2 The European Assisted Conception Committee have met again and coding and traceability was discussed. A survey has been sent to all member states to find out current working practices and a workshop will be held in March to update all members as progress with the Directive and to support implementation plans.
- 5.3 An interactive website has been developed so all aspects of the EU Tissue Directive (in relation to ART) can be discussed between member states as the implementation process is progressing.

**Item 6. Regulatory, Finance & HR Report
[Paper HFEA (11/01/05)]**

6.0 Regulation

It was reported that all inspections to the end of year have been planned and a new incident report is being designed.

6.1 Finance

The Finance Director informed the Authority that the forecast now stands that the HFEA break even at the end of the year due to cost reductions and the £159K additional funding to cover the staff pension increase.

- 6.2 The seasonal dip in fee income for December has not shown as normal but is still expected.

The HAP and EDI projects are both on budget.

6.3 HR

The Authority heard that there has been a slight rise in turnover this month because HAP project staff coming to the end of their contracts are leaving early having found new jobs.

- 6.4 The HR department have been very busy organising CV

workshops and interview training for the HAP team as their contracts are ending shortly. The head count will fall from 190 to 84 at the end of March.

6.5 Sickness & absence is very low and currently under 2%.

Item 7. Procurement of Gametes and Embryos for Research [Paper HFEA (15/02/06) 294]

7.0 The paper was introduced by Angela McNab.

7.1 It was noted that Walter Merricks declared a 'conflict of interest' with the 'donation for treatment' issue. The Chair did not deem it necessary for him to leave the meeting during the discussion.

7.2 The Authority discussed the issue of egg sharing for treatment and for research. A number of points were raised:

7.3

- donors may feel more comfortable donating eggs for research rather than treatment and this may affect the supply of eggs?

7.4

- there may be a greater emotional risk to be considered when donating eggs for treatment should the recipient become pregnant but not the donor

7.5

- the quality of freshly donated eggs for research would be welcomed by clinics who have at present to use almost exclusively failed fertilized eggs

7.6

- the number of clinics offering an egg donation programme for research is likely to be quite small because it is such an expensive process

7.7

- older women (over 35) can donate for research but cannot donate for treatment and this may increase the number of eggs available overall

7.8

- however, if a potential egg sharer has the choice between donating eggs for research or treatment it was thought they would most likely choose research which may reduce the number of eggs available for treatment

7.9

- there are different types of research and donors should be informed what type of research they are donating to and the likelihood and timescale of medical success

due to the research

- 7.10 The Chair summarised that it is difficult to distinguish the difference between donating for research or treatment (in terms of public benefit) and there is considerable uncertainty about supply.

Consent

- 7.11 The Authority discussed the issue of consent and a number of points were raised by the Authority
- 7.12
- Is the act of making an offer coercive?
- 7.13
- Would an employee consent to a research project purely because they feel under obligation to the employer?
- 7.14
- How do you ensure that coercion does not happen within families with a family member being pressured to donate or agreeing to donation without knowing the full facts?
- 7.15 The Chair stated that the Authority must look at existing good practice for these special cases and adopt the same policy.
- 7.16 The Authority thought that independent counselling would allow freely informed consent in these cases.
- 7.17 The Authority needs to think further about the information given to patients in these circumstances to prevent inducement or coercion.
- 7.18 At this point the Chair of the Ethics and Law Committee read out their recommendations on this issue:
- 7.19 **1 Import of embryos for research**
- ELC recommends that the criteria relating to the import of embryos for research should be extended to cover the import of eggs and sperm. However, we recommend that the final guideline (at Annex A) be amended to read ‘the importing centre must be able to provide reasonable assurances that the donor has not been paid’.

7.20 **2 Use of fetal and cadavaric tissue to produce eggs for research**

ELC recommend that the HFEA maintain its existing policy that the donation of fetal or cadavaric material to produce eggs for research is permitted (in line with Polkinghorne Guidelines), provided that fully informed consent is given.

7.21 **3 Egg donors**

ELC recommends that women who wish to donate eggs to research programmes, whether they are undergoing IVF for their own treatment (egg sharers) or only undergoing IVF in order to donate (egg donors), should be subject to the same criteria as those women wishing to donate for treatment purposes (as per conclusions of the SEED review).

7.22 In cases where the egg or sperm donor is an employee either at a fertility centre or a research centre, ELC recommends that their gametes be used in a research programme at a different centre.

7.23 The Chair summarised that more work needs to be done on the issues raised and the paper should come back to the Authority in May. The Chair thanked staff and the Ethics and Law Committee for their work on this paper. It was noted that it should be made clear that it should be the woman herself who played the key role in deciding whether she will donate for treatment or research.

(Ivor Brecker left at 3.30pm)

**Item 8. Budget & Business Plan 06/07
[Paper HFEA (15/02/06) 295]**

8.0 Angela McNab introduced the paper.

8.1 The Authority heard that a draft of the paper has been submitted to the Arms Length Body Team (ALB Team) and key areas have been agreed. However, it has not been signed off, or final budget agreed and so the plan is subject to change. The Executive will be looking at possible contingency plans should changes take place and these will be reported to OFC.

BM

The Authority requested the following changes:

- 8.2 Page 3 - paragraph 3:- 'European Assisted Conceptions Consortium' should have the acronym (EACC) after it name
- 8.3 Page 8 - 'Code of Practice Review' need to be added to key objectives. Exact wording to be discussed at a later date
- 8.4 Page 8 - paragraph 6 - needs to be reworded to include the strengthening of regulation overall
- 8.5 Page 8 - paragraph 3 - 'and parents of donors' should be added to the end of the sentence
- 8.6 Page 9 - the acronyms need to be explained
- 8.7 Page 10 - Key Objective 5
 'to work with the Department of Health and COREC to review our regulatory interface' needs to be added as an objective
- 8.8 The Authority were informed that the budget now balances for this year and costs remain unchanged apart from £94,000 to finish the EDI project.
- 8.9 The Finance Department have been putting together an approximation of how much implementing the EUTD may cost in the 4th quarter. This will be incorporated into the plan submitted to the Department of Health.
- 8.10 The Chair requested the revised Business Plan to be sent to the Authority before the Department of Health or at the very least, at the same time. **MW**

Item 9. Policy on Dealing with Complaints about the HFEA [Paper HFEA (15/02/06) 296]

- 9.0 There was an amendment on page 4 - Stage 3 - paragraph 2
- 9.1 The final sentence should read 'The other two panel members **will** be identified and selected by the Chair of the panel for their knowledge and expertise in specific areas'
- 9.2 Page 3 - 'Complaints which cannot be covered by this Procedure' the following should be added:
- 9.3
- Complaints against particular clinics - reference to be made to the HFEA's other

complaints procedure

- 9.4
 - Matters that are the responsibility of other regulatory bodies
- 9.5
 - Add the last paragraph from page 4 - 'If the complaint concerns a decision by a Licence Committee it will be referred through the HFEA Appeals process under the Human Fertilisation & Embryology Act 1990 the Human Fertilisation & Embryology (Licence Committee and Appeals) Regulations 1991

9.6 The Authority requested that each point under this category include an example of where to go should you have a complaint.

MW

Item 10. Analysis of Patient Feedback

[Paper HFEA (15/02/06) 297] and presentation

- 10.0 Ramen Chaterjee gave a presentation on the data collected from the Patient Questionnaire.
- 10.1 The Authority raised the point that clarification needs to be made on the size of the centre when analysing the number of responses. The Authority heard that this will be taken into account for further analysis.
- 10.2 The Authority asked if the Regulation Department had ideas to increase the response as it is currently quite low (11.9%). The Authority were told that a new poster for centres has increased the profile of the Patient Questionnaire and a new 'Centres Web Portal' for patient feedback.
- 10.3 The Authority thought it sensible to have the feedback forms available throughout the year rather than sending them out just before an inspection.

Item 11. Communications Activities Update

[Paper HFEA (15/02/06) 298]

- 11.0 The Authority heard that marketing the guide to GP's and patients is proving successful. The HFEA are also redesigning the website to make it clearer to use. The new site will go live in May at the May Authority meeting.
- 11.1 The Authority congratulated the Communications Department on their handling of publicity overall.
- 11.2 The Chair asked for a Communications Update to come to the Authority quarterly.

TW

**Item 12. RATE update
(Verbal Report)**

12.0 The HFEA executive will be attending a meeting with the ALB Steering Group this week.

12.1 A Steering Group has been set up by the Department of Health to look at the transition to RATE. This group will have its first meeting shortly.

Item 13. Any Other Business

13.0 There was no other business to discuss.

Item 14. Date of the next meeting

The next Authority meeting will be held on 28th March 2006 at 2pm.

I confirm this to be a true and accurate record of the meeting

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Chair

Date