

Authority Paper

Committee:	Authority Meeting
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Paper Number:	Paper HFEA 298
Paper Title:	HFEA Communication Activities Update
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For Information or Decision?	Information
Resource Implications:	Within Business Plan Budget
Implementation:	Within 2005/6 and 2006/07 Business Plan
Communication:	None
Organisational Risk:	High
Recommendation to the Committee:	To note the report
Evaluation:	<ul style="list-style-type: none"> • Monitoring of media coverage • Feedback from audiences

INTRODUCTION

This report outlines communication activities and performance since September 2005 set against the 2005/06 Business Plan.

1. Key activities

1.1 Annual Report

1500 copies of the Annual Report were produced and laid before Parliament on November 14th. The change in style this year incorporated a useful timeline on key changes in fertility treatment and regulation and a more journalistic, less corporate, focus on key achievements. The report was distributed in a targeted mailing to key stakeholders.

1.2 Annual Meeting

The Annual Meeting was attended by approximately 60 stakeholders in the evening following the HFEA Research Conference on 1st December. The Annual Report was launched at this event. The Chair and Chief Executive highlighted key achievements and future developments. The meeting was regarded as a good networking opportunity and stakeholders consisted mainly of clinic staff, representatives from professional organisations, Human Tissue Authority staff, media and an MP

1.3 Review of the Act

The HFEA response to the Government's consultation on the Review of the HFEA Act was published on 24th November and appears on the HFEA website. Copies of the response have also been sent to key stakeholders and selected MPs.

1.4 HFEA Research Conference

The Research Conference was held on the 1st December. Approximately 80 people attended this year, about half of whom had attended in the past. Their aims were to learn about the latest developments in the field of embryo research, and current work in this field. Again, formal feedback was very positive, with delegates very appreciative of the frankness of discussion and opportunity to meet peers. Almost all said their aims in attending had been met fully or in general.

1.5 Public Authority Meeting

One public meeting was held on October 11th. The meeting was announced in advance to stakeholders via centre mailings and web sites (HFEA, patient groups and science sites such as Bionews). Around 40 observers were present, mostly consisting of clinic staff, but also students and representatives from pro-life and patient groups. Feedback showed that people appreciated the opportunity to observe a meeting and see how the HFEA makes decisions.

2. **Patient Communication activities**

2.1 Fertility Views (HFEA online Patients' Panel) progress

Fertility Views, the HFEA's virtual patients' panel, has provided invaluable feedback over the past six months. Fertility Views is run by Opinion Leader Research, a specialist company with experience of running on-line patient panels for public sector organisations. The panel is composed of around 750 prospective, current and former patients, the majority of which were recruited after sending a Flyer out with every request for our *Guide to infertility* and via articles on BBC news online and the HFEA website. A report went to the October Authority meeting covering the first wave surveys of the panel. Issues covered were view on: how people source information about infertility, success rates, the role of a regulator in the fertility sector, how they access and choose treatment, and how they rate that service. Also their thoughts on the *Guide to infertility*, the interactive clinic search, clinic inspection reports and patient information and identifying their current issues. The next panel survey is scheduled for February

2.2 Patient Organisations Meeting

As part of the Patients Strategy the first meeting with all patient organisations was held with the support of IN UK. The intention is to meet them twice yearly and give feedback on issues and hear their concerns. The following organisations attended:

- I N UK
- Multiple Births Foundation
- The Daisy Network
- Verity
- Tamba
- Chana

- Multiple Birth Foundation
- NGDT
- Donor Conception Network
- National Endometriosis Society
- Adoption UK
- Cancer BACUP
- ACeBabes

The first meeting was very constructive, with suggestions of the HFEA providing editorial copy for groups' magazines, and with groups volunteering to provide feedback on issues such as patients' views on egg sharing and egg donation.

2.3 Patient Leaflets

Two patient briefings have been added to the website since the summer: 'Information for people considering gamete donation' and 'Information for people using donated gametes in their treatment'.

We are currently reviewing all the patient information leaflet content, and topics on which feedback shows more information would be appreciated, with a view to developing a new series of HFEA Patient Information which would be primarily web-based. The volume of traffic on our website shows us that this is a medium that patients value (not least for its anonymity), accessing information according to their needs. Providing information from the website, which can be printed out, also means that we will be able to update, and add to, information speedily, without incurring design and printing costs.

2.4 Marketing of the Guide to Infertility

The HFEA Guide to Infertility and Directory of Clinics continues to be by far the most popular publication requested by members of the public, with around 100 requests for it each week.

A marketing programme was undertaken from September to December to raise awareness of the Guide among PCTs, SHAs, PALs and GPs, with a range of activity, including mailings to over 4,000 individuals as well as advertising on websites and message boards, and flyers in delegates' packs at conferences for health professionals. We have also targeted alternative health centres, public libraries, pharmacies, relationship counsellors, women's groups (including those supporting ethnic minorities),

During the last quarter of 2005, we received more requests for the Guide (4,400 copies were requested) than at any other time of the year. Editorial coverage in the Chief Medical Officer's newsletter has led to a strong demand for the Guide from GPs in January. We are on track to have distributed all 30,000 copies printed by the time the next edition comes out at the end of April.

2.5 Patient and Public Enquiries

The HFEA received around 3,893 regular emails and requests for information from members of the public, primarily patients since September. The volume throughout the year fluctuates, with the period May and June following the publication of the Guide to Infertility being the busiest months.

Information requests are primarily for details not provided (or found) on our website. The most popular are:

- clarification of the outcome data published in the Guide to Infertility,
- questions about funding for treatment
- questions about specific treatments in clinics

We are working to address the latter points in the FAQs section on the new website.

2.6 Website

Use of the website continues to grow, with 246,202 visits to the site over six months, compared with 195,494 for the same period last year.

The most popular areas of the site are the interactive Guide to Infertility, with over 50,000 visits during this period, compared with 17,500 for the 'find a clinic' feature in the same period last year. The Guide to Infertility and the Code of Practice were the other most used areas, with about 30,000 visits and 25,000 visits each.

Interestingly, the number of hits on the 'contact the HFEA' area of the site was slightly lower than last year (around 8,000 emails during six months) which suggests that the information provided on the site is meeting users' information needs. It also supports the strategy to develop the website this year, making it even easier to navigate, and to move to more web-based information for patients and potential patients, rather than printed copies.

2.7 Awareness of HFEA and Top Ten

In order to target our public relations activity, facilities staff are asking people calling for information how they heard about the HFEA. The HFEA website was the main source by a long way (mentioned by 1,700 people), with other sources as follows:

1. Clinic/nurse/GP recommendation (780 mentions)
2. ITV's "Precious Babies" programme information line (700)
3. Internet search engine (480)
4. HFEA's Fertility Views website (300)
5. Family or friend recommendation (185)
6. Fertility Friends website (155)
7. Daily Telegraph coverage of "Guide to Infertility" launch (125)
8. Two stories in The Times' "Body and Soul" section on infertility issues (105)
9. HFEA leaflet or flyer (85)

3. **Links with PCTs**

Apart from more targeting the Guide to Infertility at PCTs there has been a meeting with the NHS Alliance to explore a partnership with HFEA. This will include establishing website links, an HFEA briefing for their members (PCTs, GPs and Practice Managers) and possible participation in the NHS Alliance Conference. The proposed briefing will also include ways of trying to get feedback on information needs of PCTs and GPs.

4. **Parliamentary Relations**

4.1 Links with MPs

A copy of the latest HFEA Parliamentary Briefing was sent to every MP and members of the Scottish and Welsh assemblies, as well as to selected peers: about 1,000 in all. The Briefing focused on infertility as a public concern, explaining the HFEA's regulatory role, including to promote public confidence in both ART and embryo research. We also highlighted the number of people in every constituency who could be affected, and the information we could provide to help their constituents.

We continue to invite a selected group of Parliamentarians to our events, including the Annual Review meeting, open authority meetings, and the forthcoming Annual Conference (at which Minister Caroline Flint is speaking), raising awareness of the HFEA and providing opportunities for them to engage with us. We have advertised the Annual Conference in a

special 'men's health' supplement to the Parliamentary magazine, The House, alongside an article about male infertility to which we contributed information. We are currently working on a programme of possible activity for the year ahead, including briefing opportunities for Parliamentarians and their researchers around the Review of the Act, and an HFEA presence at Party Conferences.

Meetings have been held with the following MPs: Andrew Lansley MP (3rd November); Steve Webb MP (9th November); and Phil Willis MP, Chair of the House of Commons Science and Technology Select Committee (1st February) and Kevin Barron MP, the Chair of the House of Commons Health Select Committee (8th February).

Work is starting on forming links with MEPs on selected issues.

5. Relations with Clinics

5.1 New HFEA Update

Every quarter, we produce the HFEA Update, a magazine for clinic staff, reporting on activities that affect clinics and their staff, and providing named contacts at the HFEA if they have questions on our activities. It also provides an opportunity for us to raise forthcoming issues, and notify clinics about events. We have recently redesigned the Update to give it a more professional and modern look and tone.

5.2 Centre Mailings

We have for some time started a monthly mailing of HFEA information to centres so that they receive most information from us at a single time, rather than a steady stream of communication. This includes Chief Executive's and Chair's letters, and information on our events, consultations, policy changes, and other business. We are consulting with the Licensed Centres Panel on how to improve communication with clinics in terms of the provision and targeting of information.

6. Policy Launches and Public Consultations

6.1 Seed Launch

The SEED Review was launched on 7th October 2005 at a press conference (see Section 7 for an analysis of feedback)

The final report was edited and produced in pdf for the HFEA website and also targeted at key stakeholders and those who respond to the consultation.

6.2 Welfare of the Child Launch

The Welfare of the Child Review was launched on 3rd November 2005 (see Section 7 for an analysis of feedback)

The final report was published on the HFEA website, and key stakeholders and those who responded to the consultation were sent a letter about the report.

6.3 PGD Consultation event 'Choices and Boundaries'

The public meeting on 12 December to look at the issue of PGD attracted 115 delegates. They represented universities, hospitals and clinics, special interest groups, lawyers, social workers and counsellors, among others. HFEA edited and produced a discussion paper and questionnaire in both print and web-based versions.

Feedback was generally positive and appreciative of the opportunity to discuss this issue in public and hear from those involved. Some individuals felt that the event had not allowed enough time to hear from those strongly opposed to PGD. However, only 21 delegates filled in evaluation forms, so it is hard to quantify if this was a widespread view. Of those who did fill in evaluation forms, most were attending an HFEA event for the first time, and considered that their aims in attending had been fulfilled.

The total downloads from the HFEA website of the Choices and boundaries PDF for the consultation period was 2,973.

7. Media Relations Activities

7.1 Press Releases

Summary of Press Releases Issued July 05 - Dec 05

24-11-2005: New laws for fertility treatment and embryo research - Regulator adds its experience to Government blue print

The HFEA's submission to the Review of the Act.

15-11-2005: Scientists must be engaged with the public if the UK is to stay a leader in stem cell science, regulator warns

Suzi's speech to the Progress Educational trust saying that researchers must continue to be engaged with public opinion to provide confidence about the work that they are doing and reassuring people that their research is beneficial and appropriate.

10-11-2005: Should we be allowed to test at conception for conditions such as Alzheimer's?

The launch of the 'Choices and Boundaries' discussion paper.

08-11-2005: Public say IVF benefits outweigh the risks but are concerned about the long-term consequences of treatment

The research on public attitudes to IVF treatment

03-11-2005: HFEA announces new Authority members

The appointment of David Archard and Ruth Fasht, and the reappointment of Sharmila Nebhrajani.

02-11-2005: Improved welfare checks system will be better, fairer and clearer for fertility patients, GPs and clinics

Launch of revised Welfare of the Child guidance.

07-10-2005: Who are the UK's sperm donors? - Fertility regulator presents national picture of the people who donate

Launch of the SEED report with an analysis of the demographics of donors.

08-09-2005: HFEA grants licence to Newcastle Centre at LIFE for Mitochondrial Research

11-08-2005: Should embryo screening help parents prevent passing on a wider range of inheritable diseases?

Announcing that the HFEA will look at the issues around using PGD for lower penetrance conditions.

28-07-2005: Fertility regulator looks to reduce the risks of IVF treatment

Announcing the group looking into the issues around multiple births and embryo transfer.

7.2 Review of Media Issues since September 2005

Review of media issues September - December 2005

August / September 2005

- The Government announced the start of its Review of the Human Fertilisation and Embryology Act. This would be subject to a three-month public consultation until November 2005.
- The Government highlighted the need to crackdown on web-based sperm providers and this would be looked at in the course of the Review of legislation.
- Ahead of the Government's consultation, a discussion on the appropriateness of using PGD to test embryos for inherited genetic disorders was announced by the HFEA.
- The HFEA issued a licence to Newcastle to carry out research into mitochondrial diseases. This decision was made on appeal following a previous judgement that had refused permission for the work to be licensed.
- The Scottish Executive launched a consultation on fertility provision on the NHS in Scotland.
- Lord Winston advised caution over the use of stem cells in treatment saying that many of the successes associated with the research had been "over-hyped".
- A survey into male infertility revealed that 2.5 million men in the UK had fertility problems and this was proving to be a growing problem. Smoking and alcohol consumption were cited as major contributory factors to the increase in infertility.
- The Roslin Institute reported a successful outcome in its research using parthenogenesis. The results meant raised the possibility of deriving embryonic stem cells as a more ethically sound alternative to using fertilised human eggs.

October 2005

- The conclusions of the SEED Review were published by the HFEA including the new HFEA guidance. Careful preparation of material for the media launch – in particular a comparative analysis of the demographics of donors over the last 10 years – allowed the media to look forward positively to the changes in the donor system, rather than continue to reiterate stories about donor anonymity (which was not the subject of the review).
- A woman gave birth to the first set of twins born from frozen eggs. The eggs had been frozen at Midland Fertility Services for two years. It is the second time in the UK that there has been a successful pregnancy following egg freezing.

November 2005

- The HFEA announced the findings of the review on Welfare of the Child policy. This received widespread coverage. Again, careful and thorough preparation of material for the media allowed them to focus on the key improvements in the system (clarity, focus, reduction in bureaucracy) rather than focus on the merits, or otherwise, of the Welfare of the Child provision (which, as law, was not within the scope of the review).
- New Authority members, Ruth Fasht and David Archard, were appointed by the Secretary of State and in addition Sharmila Nebhrajani became the Deputy Chair of the Authority.
- The document, Choices and Boundaries, was published as part of the discussion process
- The HFEA completed its response to the Government's Review of the Act and this was submitted prior to the closing of the consultation process at the end of the month.

December 2005

- Following speculation in November over questionable aspects of his research, cloning pioneer Professor Hwang Woo-Suk, resigned from his position at Seoul National University. Throughout the month, there was global media coverage of Hwang's demise and investigations by the university found him guilty of fabricating results of his research.
- Prof Ian Wilmut suggests that stem cell trials could be carried out on terminally ill patients
- Government announces £12 million of funding for stem cell research in Scotland and NE England

7.3 Key Media Issues for 2006

There are a number of issues which are likely to be covered by the media in the first half of 2006.

Hwang scandal

- The media interest arising from the scandal surrounding Hwang Woo-suk in South Korea is likely to continue as the issue of regulating and verifying stem cell research continues to raise questions regarding the integrity of the research and the expectation of its possible outcomes.
- *Nature's* pledge to look at how they verify results from research papers submitted to them is a clear example of this.
- The focus of media attention is beginning to shift to the two UK research teams in Edinburgh and Newcastle who are now 'world leaders' in carrying out CNR research projects with scrutiny of their integrity and ongoing outcomes.
- Comparisons between South Korea and the UK are likely to continue, looking in particular at the regulation of stem cell research and how fraudulent practice can be prevented.

Multiple births / single embryo transfer

- The work of the MBSET panel is set to continue throughout 2006 and media interest is likely to remain throughout the year.
- The clear conflict between the need to reduce the risk of multiple births and the view of patients who are concerned that SET might reduce their chances of conceiving is a strong basis for continuing coverage.
- The debate over NHS provision for fertility treatment adds another element to ongoing media interest as papers such as Prof. Ledger's (BJOG, on multiple births) are published.

Altruistic donation for research

- The issues surrounding ethical sourcing of human eggs for research is likely to receive high media interest over the coming months.
- This will be largely due to the debate over whether the Authority will allow women to donate altruistically for research, but fall-out from the

Hwang scandal will raise issues of how to ensure there is no conflict of interest for those donating and that patients donating via 'spare' or unfertilised eggs from IVF cycles are fully aware of the implications of donating and of the research.

- This is likely to link in to debates surrounding the difficulties of sourcing donor eggs of high quality and how some researchers have proposed to avoid this problem by using hybrid embryos created using animal eggs

Use of chimeras / hybrids

- As previously mentioned, the debate over the use of chimeras and hybrids in embryo research is likely to continue as proposals for their use are made.
- This may also prompt debate over the revised definition of these entities when the HFE Act is reviewed.

PGD Report

- The report from the *Choices and Boundaries* public discussion paper and the public debate is likely to prompt media interest when it is published in Spring 2006.
- The nature of the coverage will depend on the findings of the report, but it is likely to focus on public views of seriousness / onset / penetrance of diseases that PGD can be used to test for, within the context of the HFEA's decision-making process for PGD.
- This issue is also likely to link to debate on the Review of the HFE Act with regard to PGD decision-making

'The Day Job' - Regulation in action

- How the HFEA go about their business of regulation on a daily basis is likely to become a subject of media interest as we move towards more transparency about how we make decisions and interact with centres to ensure regulation is being followed.
- This could link closely to coverage about public confidence in the HFEA, which the MORI poll showed was based on confidence in our system of inspections and guidance to clinics. Fertility Views 'Online Patients Panel' also confirmed the importance of inspections

Patient feedback / Fertility Views

- Following on from the previous issue, there is likely to be media interest in the feedback that patients have given back to the HFEA and how the Authority respond to this.
- Interest is likely to peak at the times when the outcomes of the Fertility Views patient panels are published throughout the year.

Guide to Infertility and Directory of Clinics

- Following from the huge media interest that was shown at the launch of last year's Guide to Infertility & Directory of Clinics, high levels of media interest can be expected in April 2006 with the launch of the 2006 – 2007 Guide.
- The new format of this year's Guide is also likely to feature with a split between the Guide and the Directory to make information easier to access and less overwhelming for patients. The issue of implantation rates is likely to generate interest although there is a danger this will be confusing to patients.

Review of the Act

- Media interest will be constant on this issue in 2006 as it impacts on almost every other issue that appears in coverage of the HFEA. The decision on whether there will be a Bill launched in 2006 will attract interest.
- The appearance of the Minister at the Annual Conference in March is also likely to prompt questions from the media regarding Parliamentary time for the Review.

Starting Life

- The BBC's major 6-part documentary *Starting Life* is due to air in late 2006, though some reports suggest it may slip to early 2007.
- The programme aims to cover all aspects of assisted reproduction and is planned for BBC1 midweek primetime and will be presented by Robert Winston.
- The trailing of the programme through to its appearance is likely to prompt high levels of media interest for the issues each 'episode' covers, including:

- IVF
- PGD
- Multiple births
- Causes of infertility
- Gamete donation & storage
- Fertility tourism

8. Internal communications

The HFEA intranet site is being improved and a revised look will be launched in early March. Use of the intranet is growing with staff using it, rather than 'all staff' emails, to communicate news, policy changes, events, etc to colleagues. Further improvements are planned for later this year, along with more training for departmental intranet representatives.

The Staff Forum was set up in September 2005 with the agreed overall purpose of improving the quality of the organisation and the working lives of staff. The Forum provides a strong network in which Forum members communicate directly and regularly with their constituent groups to gain feedback on the issues that arise whilst all staff are aware of clear methods to bring items to the Forum, anonymously if they wish. To date, the Forum has focussed on the feedback from the Staff Survey, specifically looking at issues that affect staff morale.

Several staff events have been held, including a very successful Christmas party, organised by a sub-group of the Staff Forum, a debate on the pros and cons of PGD and a screening of the BBC's "Real Lives" programme on three sisters who had a child together, with one donating an egg and one acting as a surrogate for the third, infertile, sister. Further events are being planned, including presentations on the new HFEA website and Guide to Infertility, screenings of relevant television programmes, and a Communications team presentation to demystify our role within the HFEA.

9. Chair and Chief Executive's speaking schedule

Since September 2005, Suzi Leather, Chair, has carried out a range of speaking engagements, including:

- 31st October** Looking to the Future: Implementing the Human Tissue Act and the Coroners Amendment Rules
- 15th November** Progress Educational Trust – Putting Stem Cells into Practice: Ethical, Legal and Social Issues
- 1st December** HFEA Research Conference

The following future speaking events are diaried:

- 14th March** World Forum on Science and Civilisation 2006
- 19th - 20th April** Stem Cells, Tissue Engineering and Regenerative Medicine
- 24th April** The Royal Society of Medicine Symposia
- 11th May** National Bereavement Day
- 10th June** National Infertility Day
- 12th June** Frontiers of Gynaecological Practice – Annual Scientific Meeting, Manchester

Since September 2005, Angela McNab, Chief Executive, has carried out a range of speaking engagements, including:

- 12th October 2005** Presentation on SEED findings, National Gamete Donation Trust
- 5th December 2005** Balancing the requirements of FOI with the day job, FOI Conference, London
- 6TH January 2006** Review of the Act, Persons Responsible Meeting

The following future speaking events are diaried:

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| 9th March 2006 | Title to be confirmed, Italian Register, Rome |
| 14th March 2006 | Stem Cell Policy: Global Strategies for Supporting Research" panel discussion, The Stem Cell Meeting, San Francisco |
| 24th March 2006 | Title to be confirmed, University of Portsmouth |
| 29th March 2006 | HFEA Annual Conference |
| 15th Sept 2006 | Informing the patient and the public 3rd Symposium on Data Collection and Art Monitoring, Belgrade |

10. Selected Future Events and Activities

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|---|---|
| 25th Feb 2006 | RCN Fertility Nurses Conference |
| 6th March-
10th March 2006 | Endometriosis Awareness Week |
| 10th March -
19th March 2006 | National Science Week |
| 29th March 2006 | HFEA Annual Conference |
| Late April
2006 | Launch new Guide to Infertility |
| April/May 2006 | Launch new HFEA website |
| April 2006 | Launch of new web-based patient information |
| 4th May-
5th May 2006 | Primary Care Conference, Birmingham NEC |
| 12th June 2006 | National Infertility Day |
| 4-8 Sept 2006 | BFS Summer College |
| 7 Sept 2006 | BICA Annual General Meeting |
| 2-9 Sept 2006 | BA Science Week |