

Authority Paper

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| Committee: | Authority Meeting |
| Meeting Date: | 21/02/07 |
| Agenda Item: | 11 |
| Paper Number: | HFEA (21/02/07) 360 |
| Paper Title: | HFEA Communication Activities Update |
| Author: | Tim Whitaker |
| For Information or Decision? | Information |
| Resource Implications: | Within Business Plan Budget |
| Implementation: | Within 2006/07 Business Plans |
| Communication: | The Authority is asked to note the report. |
| Organisational Risk: | Low |
| Recommendation to the Committee: | To note the report |
| Evaluation: | <ul style="list-style-type: none"> • Monitoring of media coverage • Website evaluation • Feedback from audiences |

INTRODUCTION

This report outlines communication activities and performance since October 2006 set against the 2006/07 Business Plan.

1. Key activities

1.1 Annual Review Meeting

The third HFEA Annual Review Meeting was held on 7 December at 1 Great George Street. 45 stakeholders attended, with a high drop-out rate largely due to difficulties on the transport network that evening. This meeting has previously been used as an opportunity to launch the Annual Report, however this year Angela McNab presented an overview of the performance of the UK fertility sector based on an analysis of last year's clinic inspections, patient complaints, and reported incidents between 1 April 2005 and 31 March 2006, entitled 'Driving Improvement: Lessons from the UK's fertility sector'. The report was well-received by guests and resulted in press coverage Evening Standard, Daily Telegraph and Daily Mail.

1.2 Public Authority Meeting

A Public Authority Meeting was held at the BMA on 18 October 2006. 34 stakeholders attended on this occasion. This was high because of interest in the Multiple Births and SET presentation. We knew that this was a guaranteed agenda item well in advance and so were in a position to invite stakeholders with a specific interest in this matter. Much positive feedback was received; attendees appreciated the opportunity to attend, emphasised the quality of the discussions which took place and valued the chance to speak to members after the meeting

2. Patient Communication activities

2.1 Fertility Views Survey

The latest survey of the HFEA's online patients' panel, Fertility Views, has provided some valuable insights into what information patients find helpful. The survey addressed issues about success rates and counselling.

Most of the 515 respondents said they had no choice in the clinic they went to, 27% having been referred. 23% said they chose the clinic nearest their home or workplace. Clinic success rates were the basis of choice for 18%.

With the interest in success rates, it was encouraging that two thirds of respondents said their clinic gave them a statistical estimate of their chance of having a baby. This was more likely to be true for patients over 40. The

responses suggest that more patients would prefer being told about their chance of success in percentage terms.

We asked members what, if they were paying for their own treatment, was the lowest chance of success that they would consider acceptable. Almost all (94%) said they would pay for treatment if they knew it had a 25% chance of success. This fell to 54% if there was only a 10% chance of success. 23% said they would still consider going ahead with treatment at their own expense if the chance of success was lower than 5%.

Members also shared their views on how valuable they found counselling. Only 39% of respondents had had counselling, the majority using the free service provided by their clinic. Of those who had counselling, 34% said it was very helpful and they'd strongly recommend it to others, while more than half said it was quite helpful or had been worth doing.

Of those who did not have counselling, 21% said that their clinic had not suggested it and 10% found the additional cost off-putting. 42% of those who did not have counselling said they wish they had, or that with hindsight they might have found it helpful - especially those whose treatment had been unsuccessful. Copies of the slides for this survey can be found at Appendix A.

2.2 Patient information on website

Visits to the website have continued to increase over the past four months with a total of:

- 109,575 visits and
- 614,865 page views (not including 'find a clinic').

The patient information is by far the most visited section which backs up our initial research on who visits our website.

Most visited sections of the site

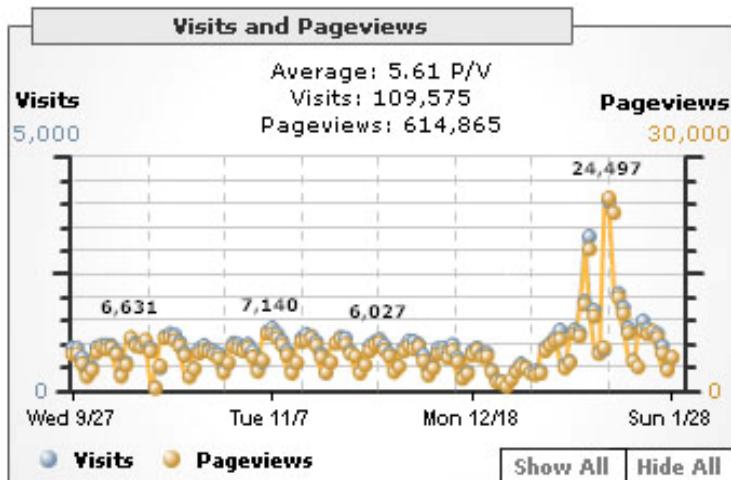
| | Section | Page views |
|---|------------------|-------------------|
| 1 | Find a clinic | 416,307 |
| 2 | For Patients | 40,054 |
| 3 | About the HFEA | 18,223 |
| 4 | How we Regulate | 15,825 |
| 5 | For Clinic staff | 13,034 |
| 6 | For Press | 10,104 |
| 7 | For Donors | 11,286 |

Most visited pages on the site

| | Page Titles | Page views |
|----|-------------------------------------------|-------------------|
| 1 | HFEA Guide to infertility (download page) | 20,979 |
| 2 | FAQs about treatment | 10,503 |
| 3 | Facts and figures | 13,295 |
| 4 | Publications | 8,928 |
| 5 | Choosing a Clinic | 8,617 |
| 6 | Clinics (patient area) | 8,150 |
| 7 | Inspection Report clinics A-B | 8,798 |
| 8 | Funding | 5,706 |
| 9 | FAQs about choosing a clinic | 5,980 |
| 10 | Treatments explained | 6,032 |
| 11 | Understanding clinic success rates | 5,165 |
| 12 | Inspection Reports | 6,083 |
| 13 | The Code of Practice | 4,784 |
| 14 | Patient stories | 7,669 |
| 15 | FAQ's about the HFEA | 3,949 |
| 16 | Inspection reports clinics E-L | 6,073 |
| 17 | IVF treatment lifecycle | 3,722 |
| 18 | Treatments | 4,003 |
| 19 | About infertility | 3,608 |
| 20 | January – FOI Disclosure log | 4,536 |

2.3 Trends in website visits

27 September 06 – 27 January 07



This graph shows a marked increase in visits to the website in January during the Authority decision around Human-Animal Hybrid Research and the following week after the BBC Panorama programme.

Peaks in website usage - January

Page views

Average Mon/Tues 12,441
 15/16 Jan Mon/Tues **47,109**

On 15 January 2007, the website had the busiest day of traffic since the site was launched with 4 times the traffic of an average day.

After BBC's Panorama episode was aired, the website received as much traffic in the hours of 9pm-10pm as it would receive in one day with 5,479 pages viewed.

Most visited pages 15th – 28th January 2006

The table below shows the most visited pages on the website for a two week period from 15 January

Most notable increases in visits were to:

- the Inspection reports page for ARGC
- Press statement on regulatory action
- Helpline FAQs
- FOI disclosure log (Driving improvement scores)

| | Pages | Page views | Average |
|----|---------------------------------------------------------------------------------------------------------------------------------|-------------------|----------------|
| 1 | For Patients | 8638 | 4396 |
| 2 | HFEA Guide to infertility | 4758 | 1491 |
| 3 | Facts and figures | 3333 | 1346 |
| 4 | How we Regulate | 2748 | 1953 |
| 5 | Inspection reports - clinics A/B | 2608 | 713 |
| 6 | Press Statement regarding regulatory action at Assisted Reproduction and Gynaecology Centre and Reproductive Genetics Institute | 2147 | New |
| 7 | About the HFEA | 2386 | 3277 |
| 8 | For Press | 2370 | 1089 |
| 9 | Choosing a Clinic | 2241 | 769 |
| 10 | FAQs about treatment | 2207 | 1010 |
| 14 | Helpline FAQs | 1950 | New |
| 20 | FOI disclosure log - January 07 | 1385 | 10 |

2.4 Trends in website usage October -January

Find a clinic section – most accessed clinic pages

| Page Titles | Pageviews |
|----------------------------------------------------------------------|------------------|
| 1 Assisted Reproduction and Gynaecology Centre | 17,371 |
| 2 The Lister Fertility Clinic | 8,529 |
| 3 The Woking Nuffield Hospital | 6,310 |
| 4 IVF Hammersmith | 6,010 |
| 5 UCH London | 5,978 |
| 6 The Bridge Centre The Centre for Reproductive Medicine - Barts, | 5,387 |
| 7 London | 5,371 |
| 8 London Fertility Centre | 5,276 |
| 9 Assisted Conception Unit, Kings College | 2,795 |
| 10 Chelsea & Westminster Hospital | 4,727 |
| 11 CRM London | 4,476 |
| 12 CARE Manchester | 4,461 |
| 13 Guys Hospital | 4,173 |
| 14 London Women's Clinic | 4,136 |
| 15 Essex Fertility Centre | 4,124 |
| 16 Cromwell IVF and Fertility Centre | 2,175 |
| 17 Manchester Fertility Services LTD | 3,775 |
| 18 The Harley Street Fertility Centre | 3,758 |
| 19 Centre for Reproductive Medicine - Bristol | 1,782 |
| 20 Oxford Fertility Unit | 3,231 |

2.5 Patient factsheets

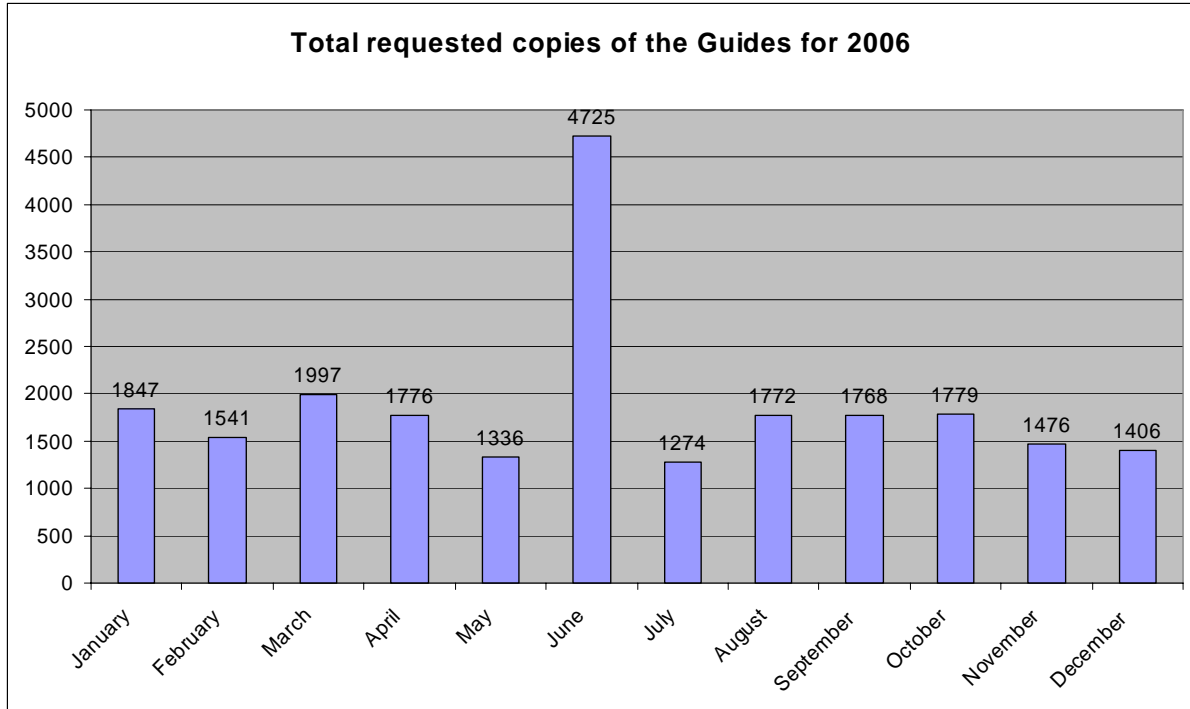
The new printer-friendly and practical patient factsheets have proved to be a useful tool for patients visiting the website. The statistics below show how many of the most recently published patient factsheets have been downloaded since November 2006:

| Patient factsheet | Number of downloads |
|---------------------------------------------------------------------------------------------|----------------------------|
| What is ICSI? | 580 |
| Multiple pregnancies and births: considering the risks | 361 |
| Importing donor sperm | 328 |
| Freezing and storing embryos | 269 |
| Freezing and storing your eggs | 206 |
| Assessing the welfare of the child: information for people having fertility treatment | 164 |

2.6 Guide to Infertility

During the reporting period, Guides have been requested by surgeries, GPs, libraries and schools, as well as individual patients. In October 2006 we mailed out copies of the Guide to health clubs and in December Guides were sent to licensed treatment centres to replenish stocks.

The graphs below illustrate the numbers of requested copies over 2006 and 2007 to date.



In the first month of 2007 there were 1619 copies requested.

2.7 Patient and public enquiries

From 1st October 2006 to 31st January 2007, the HFEA received 7710 public enquiries. 3744 were emails received through admin@hfea.gov.uk and 3966 were phone calls. (N.B. This excludes enquiries received by the HFEA Helpline which was set up following the BBC *Panorama* programme.) Many of the enquiries were requests for the Guide, while others involved referring to the website and publications. 397 enquiries asked for more detailed information and were forwarded to Communications and Policy and 22 to Regulation (for enquiries on import licences or complaints). 43 enquiries were for “Others” which included press enquiries and FOI requests.

The top 10 type of calls dealt with by Reception were:

| No | Type of Question | Number of calls received |
|----|-------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------|
| 1 | Can you help me find a clinic? | 249 |
| 2 | Can you recommend a clinic near to us for treatment/how to proceed? | 184 |
| 3 | Members of the public who were looking for a clinic offering specific treatment type and who were guided to the “At a glance” file on the website | 176 |
| 4 | Sperm Donors who want to get more information | 157 |
| 5 | How can we find a clinic that carries out PGD/sperm washing | 137 |
| 6 | Where are the league tables you produce? | 131 |
| 7 | Looking for a clinic that does egg storage/freezing | 127 |
| 8 | Public referred to INUK | 119 |
| 9 | I am over 45 and the clinic statistics on your website only go up to 40 – 42. Where can I get data for my age group and/or where can I get treatment? | 112 |
| 10 | I am in my late 40s. I want to find a clinic that will treat me | 70 |

Other topics that still feature high compared with the previous three months were:

- Importing donor sperm and the shortage of donors
- Where can we get up-to-date statistics and when will more recent statistics be published?
- After the publication of the “Driving Improvement” report, there was an increased number of callers asking for details about it and for our up-to-date

“league tables” and recent statistics. Some callers were concerned that their clinic was not mentioned at all – and so were some of the clinics.

- An increasing number of same sex couples and single women seeking treatment and looking for a clinic that would treat them has been noted.
- More women ask for clinics that do “Natural cycle IVF or IUI”
- Egg freezing became a topic after press attention
- IVM – what it involves and which clinic offers this treatment. This has now been added to the FAQs on our website.
- Hybrids became another hot topic following press attention around the time of the last authority meeting. Members of the public to voice their opinion on the hybrid decision. Callers who required more detailed answers were forwarded to Charles Lister.

2.8 Awareness of HFEA and Top Ten

In order to target our public relations activity, facilities staff are asking people calling for information how they have heard about the HFEA. Sources were as follows:

1. BBC Website incl. Panorama programme (1361 mentions)
2. HFEA Website (1308 mentions)
3. Clinic/Nurse/GP recommendation (525 mentions)
4. Recommendation by friends/family (365 mentions)
5. Search engine (269 mentions)
6. Other website (216 mentions)
7. Fertility Friends website (204 mentions)
8. Didn't say (117 mentions)
9. Seen a copy of the Guide (66 mentions)
10. Other Newspaper/Unspecified Publication (63 mentions)

3. Links with PCTs

We have continued to market the Guide to Infertility to PCTs. The NHS Alliance has sent a briefing on HFEA's activities to all its members. The Multiple Births and Embryo Transfer Advisory Group has included representation from PCTs in its work. Finally, the Chief Executive has been visiting a number of PCTs to brief senior staff.

4. Parliamentary Relations

4.1 Select Committee on Science and Technology

The Chair, Chief Executive and Authority Member Neva Haites appeared before the House of Commons Select Committee on Science and Technology on 31st January 2007, to give evidence to its inquiry into hybrids.

4.2 Links with MPs

Evan Harris MP visited the Authority and met with the Chair and Chief Executive to discuss the need for research using hybrids.

5. Relations with Clinics

5.1 HFEA website

The clinic staff section of the website is proving to be popular, since the launch of the new consent forms in September, that page has received over 5,000 visits.

5.2 HFEA Update

The next HFEA Update is due be mailed out to clinics by mid-February of this year, and some of the featuring articles will be on the new Chair of HTA and HFEA, the new Code of Practice, the latest Fertility Views survey results and on the consultation on hybrids and chimera.

6. Policy Launches and Public Consultations

6.1 Donating Eggs for Research: Safeguarding Donors

The consultation period ran from September to December 2006. There were 90 responses to the consultation as well as 26 letters and emails expressing views on the issues raised in the consultation. Views were received from many organisations, including the British Fertility Society, the Medical Research Council, Hands off our Ovaries, the British Medical Association and the Association of Clinical Embryologists amongst others.

The consultation responses were analysed and a summary of the responses was presented to the Ethics and Law Committee (ELC) along with other information gathered as part of the review. The recommendations and discussion of ELC are presented in Authority paper 357 this month. Following the Authority decision, any changes to the guidance required following the Authority decision will be carried out later in the year. This will take place later than originally planned due

to resource constraints as a result of the additional work around hybrids and chimeras.

6.2 Multiple Births Stakeholder Meeting

The consultation period for the Multiple Births after IVF policy review will run from the end of March 2007 until the end of June 2007. During this period, two public meetings will be held. The first will take place in Manchester, aimed primarily at patients (but also inviting clinicians, NHS commissioners, public health experts and parents of multiple births), and one in London, primarily aimed at clinical practitioners (but still including all of the above). The first meeting aims to explore patients' views, their motivations and concerns, and what they consider to be the role of the HFEA in addressing the problems of multiple births. The second will offer clinicians - particularly those who might not feel represented by the professional bodies' views - an opportunity to feed into the consultation process as well. This meeting will also consider questions regarding embryology, patient and embryo selection and cryo-preservation in more detail.

7. Media Relations Activities

7.1 Press Releases

Summary Press Releases October 06 – January 07

09-10-2006 – Communities urged to speak out to ensure they get the fertility services they need

People from minority ethnic communities across Great Britain are being urged to make their voice heard on the fertility services they receive by the Human Fertilisation and Embryology Authority – the UK's Fertility regulator – as new figures showing that hundreds of thousands of people from these communities are having difficulty starting a family.

13-10-2006 – Single women and lesbian couples urged to speak out on the fertility services that they receive

Single women and lesbian couples across the UK are being urged to make their voice heard on the fertility services they receive by the Human Fertilisation and Embryology Authority – the UK's Fertility regulator – as new figures showing that a growing number of these women are coming forward for fertility treatment.

06-11-2006 – HFEA announces new Authority members

Four new Authority members have been selected to the sit on the Human Fertilisation and Embryology Authority for three years from 7 November 2006 by the NHS Appointments Commission.

20-12-2006 – New Chair of Human Tissue Authority and Human Fertilisation and Embryology Authority appointed

It was announced today (20 December 2006) that Shirley Harrison will be appointed as Chair of both the Human Tissue Authority (HTA) and Human Fertilisation and Embryology Authority (HFEA). This appointment will take effect from 1 January 2007.

08-12-2006 – Inspections show that patients need more information on fertility treatment (*Driving Improvement Report*)

The Human Fertilisation and Embryology Authority (HFEA) – the fertility regulator – have analysed the performance of all the clinics offering IVF and donor insemination to provide an overall picture of standards in the UK.

11-01-2007 – Press Statement Regarding Human-Animal Hybrid Research
Members of the Human Fertilisation and Embryology Authority discussed yesterday (Wednesday) the broad principles for handling any research proposals into hybrid and chimera research.

15-01-2007 – Press Statement regarding regulatory action at Assisted Reproduction and Gynaecology Centre and Reproductive Genetics Institute, London

There have been a number of concerns expressed in the media today about two London IVF clinics run by Mr Mohamed Taranissi - The Assisted Reproduction and Gynaecology Centre, Upper Wimpole Street, and the Reproductive Genetics Institute, Weymouth Street

7.2 Review of Media Issues October 06 – Jan 07

October 06

Natural cycle IVF – a number of articles around the time of the conference arranged by Geeta Nargund.

Hybrids – reports that two teams had submitted applications to the HFEA

Single women – reports based on HFEA figures showing a growing number of single women having treatment

Older mothers – articles following Richard Harries' interview with the Times which quoted him as saying older women should not be barred from having IVF. Separat articles on American research showing that being an older mother is no greater risk to health

Multiple births – articles saying that HFEA is looking to cut the number of multiple births. Report crediting IVF multiple births for putting a strain on neonatal services.

Various research stories from ASRM conference – studies on vitamin pills, antidepressants and mobile phone use and their effect on fertility. Paper suggesting more US women considering social egg freezing.

November 06

Sperm donors – stories about sperm shortages (as a result of publicity from fertility4life, formerly known as ManNotIncluded) and a Progress Educational Trust survey which said the public supported anonymity for donors

Hybrids – a significant amount of coverage looking at the issues and the ethical dilemmas of hybrid research

PGD – a number of stories about PGD babies as part of pre-publicity for the BBC One series 'A Child Against All Odds' which transmitted in November and December

December 06

Driving Improvement report – coverage led on the range of incidents occurring in IVF labs

Review of the Act/ White paper – a range of stories, most about the removal of the 'need for a father' but also saying hybrid research would be banned and others saying all social sex selection would be banned

IVF Drugs – research shows that women are wasting money and harming their health on unnecessarily strong ovarian stimulation

Eggs for research – coverage of the HFEA's decision to allow altruistic donation to the research projects at Newcastle

IVM – reports saying In Vitro Maturation may provide a good source of eggs for IVF

January 07

Hybrids – Scientists fears if HFEA follows the white paper proposals to ban this research plus reports on the HFEA's decision to consult on this matter

Driving Improvement – reports focused on individual clinic scores following Freedom of Information request

Oldest IVF mum – 67-year-old gives birth to twins after treatment in the US

Louise Brown – First IVF baby gives birth after natural conception

Mohamed Taranissi – BBC Panorama do undercover investigation into treatment at Mr Taranissi's London clinics. Coverage of HFEA's regulatory action including visit to clinics on 15 January. Some stories featuring patients unhappy with treatment received. Series of articles critical of HFEA's behaviour from patients and commentators in The Sun and The Times. Patient protest against HFEA outside one of the clinics. (N.B. The Press Team are undertaking a more detailed evaluation of this coverage.)

7.3 Key media issues for February 2007 onwards

The supply of donors for IVF treatment

February 07

Eggs for research policy announcement

March 07

Launch of new HFEA code of practice (of interest to professional press)

Launch of Multiple Births consultation

April 07

Launch of Hybrids consultation

Late Spring/Early Summer

Implementation of EU Tissues and Cells directive (including regulation for Internet Sperm Services and sperm-sorting sex selection clinics)

Draft Bill reforming fertility legislation and early parliamentary scrutiny

8. Internal communications

A review of current internal communications activities within both the HFEA and HTA is drawing to a close. On completion, outcomes of the review will be used to form the foundations of a robust Internal Communications Strategy capable of supporting business needs now and in the future. This work has been carried out in tandem with the HTA.

Strategy proposals at a glance:

- The development of a systematic cascade structure, for which a draft paper is currently under review, entitled 'Core Briefing and Feedback Structure',
- A review of the HFEA Intranet's navigation, content, management and access.

- Implementation of a weekly e-bulletin, an e-mail that brings together time-bound information relevant to all staff. The focus will be on reducing the volume of e-mail traffic and better coordinating HFEA 'messaging'.
- Production of a RATE calendar that incorporates all scheduled meetings, proposed announcements and key milestones.
- Creation of a duplicate RATE TRIM section, where all information relating to RATE may be stored and made available to all in accordance with confidentiality clauses.
- Development of a set of internal communications best practice guidance that is easy to use and adaptable to the given situation.
- Undertake a yearly internal communications audit which considers the methods of delivery and content.

9. Chair and Chief Executive's speaking schedule

The following future speaking engagements are planned for the Chair Shirley Harrison in 2007:

March 15th Stem Cells Workshop, British Council/Moscow,

Since October 2006, Angela McNab, Chief Executive, has carried out a range of speaking engagements, including:

23rd October Public Policy Panel, Stem Cell Research: The Way Forward, Stem Cell Foundation (NYSCF) Research Conference, New York

24th October Panel discussion with representatives from countries outside the US and 'Strengthening science through regulation – the UK experience', Baker Institute Stem Cell Conference: Avenues of Advancement (Stem Cells: Saving Lives or Crossing Lines), Washington

28th November Getting the Green Light: Applications for Stem Cell Research, C5's International Symposium on Stem Cell Regulation and Commercial Enterprise 2006 (Getting the Green Light: Licensing Applications for Stem cell research), Kensington

16th December Patient's Choice and the Informed Patient - Patient's Perspective, First World Congress on Natural cycle/Minimal Stimulation IVF

The following future speaking engagements are planned for the Chief Executive in 2007:

28th February Keynote presentation: Addressing the regulatory issues surrounding stem cells and the way forward, London Technology Network Stem Cells and Regenerative Medicine event

9th March Bertorelli Foundation, Switzerland (Presentation, tbc)

13th March Keynote presentation: Building International Approaches for Stem Cell Regulation, Stem Cell Conference, San Francisco

29th April IFFS 19th World Congress on Fertility and Sterility, International Convention Centre, Durban, South Africa (Presentation, tbc)

6th July Series of possible presentations, Australia

10. Forthcoming HFEA Activities

10.1 Launch of Multiple Births Consultation document

The launch of the Multiple Births Consultation document is scheduled for the end of March 2007. Further details on this will follow shortly.

10.2 Launch of Hybrids Consultation document

The launch of the Hybrids Consultation document is scheduled for the end of April 2007. Further details on this will follow shortly.

10.3 Annual Conference

The HFEA Annual Conference is planned for 5 June 2007 and will be held at the Royal College of Surgeons, as in previous years. We expect to confirm the Conference agenda shortly.

Annex A - Fertility Views Survey