

Fertility Views

Newsletter

Summer 2006

Hello everyone, and welcome to the latest Fertility Views update.

This update is to let you know about the responses we have received to the questionnaires, and how this information is helping us to make the HFEA more patient-friendly. I am sorry that this update comes some time after you filled in your surveys. We are keen to report back to you on how the findings have been used and sometimes it takes some time for the information you provide to be incorporated into our policies and activities.

Below are some of the main findings from our questionnaires, and there is a more detailed report available too, at <http://hfea.gov.uk> > For Patients > Getting started > Patients' panel



Response rate

Thank you to everyone who responded to the questionnaire - over 500 of you, out of 775 members. Of those who responded, 36% of you have stopped having treatment because you were successful, 34% are currently having fertility treatment, 15% are considering treatment and 15% have stopped treatment and have not been successful.

Who are Fertility Views members?

95% of you are female, 87% are married and the majority of you (88%) describe yourselves as White British. 42% of you are aged between 30-34, and 27% aged 35-37 years old. 10% of members are aged 25-29, and the same number aged 38-39. Only 2% of you are aged 24 or under.



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What you said about...

1. Donating eggs, sperm or embryos for research

We were keen to find out more about how much clinics tell patients, prospective patients and prospective donors about donating gametes (sperm and eggs) and embryos for research projects, as opposed to donating for treatment.

Nearly 70% of you said you had not been given any information about the kind of research that is carried out. Of those who had, most (60%) heard about it at a patient information evening or (32%) before egg collection. The doctor or nurse were the most likely people to have told you about research projects using donated gametes or embryos.

When it came to asking you if you would consider donating sperm, eggs or embryos to research, 55% of you said you had not been asked. Of those who had, most (44%) were asked at a patient information evening or (42%) before egg collection. Nurses were more likely than doctors to ask (52% compared with 32%). It was encouraging to hear that 96% of you did not feel you had been put under any pressure to donate for research.

An area where there is obvious room for improvement is in providing an opportunity for you to ask more about donating for research. Of those of you who had been asked about donating, only 40% were offered a chance to ask questions and speak with an independent person about donation. There is also scope for clinics to provide more feedback after donation - 94% of those donating had not heard if their gametes were actually used in research, and 39% of you would want to know.

This is an issue that the Authority has been looking at over the past few months, and your views were included in a paper that went to the Authority for discussion at their meeting on 10 May. At the meeting, the Authority concluded that it would be appropriate to hold a public consultation on the issues surrounding donation of eggs for research purposes.

The consultation will take place this autumn and look at issues such as the amount of information potential donors are giving about donation, including possible risks, to make sure that donors give properly informed consent.

2. How many embryos to transfer?

Understandably, the issue of how many embryos to transfer evoked many strong feelings and some of you were concerned that we were asking this question with a view to introducing a rule allowing only single embryo transfers. Research in some Nordic countries has shown very encouraging results by doing this, reducing the number of multiple births without a significant decrease in the number of singleton births.



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However, the reason for our questions on this issue was to gain a greater understanding of how patients feel about this issue and about the level of information clinics provide on possible risks to mother and babies during multiple pregnancies, and longer-term risks to the babies born.

We are also conscious that, with limited NHS funding for treatment, there is pressure for a single cycle of treatment to succeed, even if this means running the risks of multiple pregnancies. We wanted to find out the extent to which a change in the amount of NHS funding available would impact on patients' willingness to run the risks of a multiple pregnancy and birth.

Over two thirds of you were given some information about the risks involved in a multiple pregnancy before starting treatment. In most cases (86%), it was the fertility specialist who told you rather than your GP. Most of you (57%) said you would not agree to a single embryo transfer if it was recommended by medical staff as being appropriate for you. Those of you aged 40 or over were particularly likely to feel this way.

What did appear to have an impact on your views was the availability of NHS funding for treatment. 75% of you said you would be more likely to consider having one embryo transferred if there was NHS funding available for three cycles of treatment.

3. Availability of donated eggs and sperm

Since the Government introduced the law lifting donor anonymity last April, some people have been concerned that this will impact the availability of donated eggs or sperm. We wanted to find out if patients were being warned about this in advance of treatment.

81% per cent of you who have started treatment involving donor eggs or sperm have found problems with availability, a situation that the majority of you (91%) were warned about in advance. The same was true for those of you who are hoping to use sperm from a donor you have already used in order to have a brother or sister for an existing child: 76% were warned about it prior to treatment.

While it is clear that the majority of people are being warned that there may be availability problems, a minority were not. We have highlighted this with clinics and urged them to make sure all patients planning to use donated sperm or eggs are given as much information as possible, including the possibility of treatment being delayed until donor sperm or eggs are available.



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4. Satisfaction with your clinic

One of the HFEA's functions is to investigate complaints about clinics where there may have been breaches of the HFEA Code of Practice. However, we are aware that there are other issues that contribute to patient satisfaction which are not explicitly covered in the Code. We wanted to find out more about your expectations of clinics and good service.

30% of you had experienced a problem with your clinic. The main reason - mentioned by 47% of those who had a problem - was a perceived lack of empathy from clinic staff. Other concerns were around the quality and amount of information you received - not being told what would happen next, for example, feeling inadequately informed about your treatment and its implications, and a lack of information about the full costs of your treatment (see below).

Of those of you who had a problem with your clinic, 39% complained, usually to a member of the clinic staff. Almost all of you (94%) felt comfortable making a complaint in your own name, rather than anonymously. In 70% of cases, however, you did not feel that the clinic had dealt with the complaint successfully.

We have raised these issues with clinic staff, making them aware of the main causes of concern to patients and also of the lack of satisfaction with the way that complaints were handled.

Patients can also contact the HFEA via the Patient Feedback Questionnaire to let us know about their experience at a specific clinic. This feedback, both good and bad, is used by our inspectors to gain a greater understanding of patients' experience at that particular clinic, identify good practice that can be shared with other clinics, and spot where there are concerns that are common to several clinics.

5. Treatment costs

Of those of you who encountered a problem with your clinic, 43% mentioned the costs of treatment being an issue. 41% of you said you found items on your final bill that you were not expecting - usually the drug costs or a "fee to the HFEA". Of those of you who had paid for your treatment, 36% said the bill was higher than you had expected (only 2% said it was lower).

In our recent advice to Government, who are reviewing the legislation surrounding treatment, we recommended requiring clinics to provide patients with fully costed treatment plans as part of their service. These would set out exactly what the costs would be, and where additional costs might arise (for drugs and tests, for example).



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We have also drawn these findings to clinic's attention so that they can improve the information they give about costs. We continue to make it clear to patients, via our Guide to Infertility and website, that the HFEA does not charge individuals a fee for their treatment. Both NHS and private clinics pay a fee to the HFEA (based on the number of treatment cycles they carry out) towards the cost of being regulated. Many clinics treat this fee as they do the other costs of running a clinic and cover it through the fees they charge patients. Others choose to pass the full cost of the HFEA fee to their patients as a separate item in the bill. We are aware that some clinics state a higher figure as the "HFEA fee" than what we actually charge them.

6. Access to the HFEA Guide to infertility

We asked you which were the top three places you would expect to be given your free copy of the HFEA Guide to Infertility. 65% of you said you would expect your clinic to provide you with a copy (and 53% of you also mentioned counsellors providing it). 56% of you would like a copy even earlier, in your GP's waiting room. And 56% of you said it should be available at your local gym, sports or leisure centre.

We are focussing our marketing and distribution of the Guide on these three main audiences as a result of your feedback. Copies have been sent to all clinics, and they have been reminded to supply copies to their counsellors, too. We have sent copies to many UK GPs and we are currently sending copies to the main gym chains and UK leisure centres.

7. Issues of most concern to patients

In response to a question about the issues that are of most concern to you, the subject that came up most often (24% of responses) was the cost of treatment. Other concerns were access to NHS treatment (18%) and the length of waiting lists (15%).

Other issues mentioned included: the availability of funding and the postcode lottery (closely related to the cost of treatment and access to NHS treatment) and the availability of information. As with your reasons for dissatisfaction with clinics, the lack of care, understanding and support surfaced as another issue of concern, and some were worried about the implications of any new legislation or policy changes.

Thank you again for sharing your views with us. As well as the actions taken above, we circulate the findings to HFEA staff, keeping us all aware of the issues that matter to you and making sure they inform our daily work.

We have also made a donation of £500 to Cancer Research UK in the name of Fertility Views members. This was the charity most voted for by those of you who took part in the last survey.