

April 2007

Fertility Views

Newsletter

Your views make
a **difference**



Welcome

Many thanks to all of you who took the time to respond to our December 2006 survey. We were delighted to have over 500 responses on a wide range of issues, from the types of information you value to your experience of counselling.

During our most recent open meeting, the Authority went through the findings in detail and discussed emerging issues, particularly around counselling.

Over the coming weeks, we will be sharing some of these findings with clinics as well as looking at ways in which we can develop the way we regulate.

Who are Fertility Views members?

- 97% of you are women. This is unsurprising although we're always looking to balance the numbers – male partners are very welcome to join too!
- 88% of you are married. Of those who are unmarried, 9% live with a partner of the opposite sex, 2% of you are single, separated or divorced, and 1% of you live with a partner of the same sex.
- The majority of Fertility Views members (56%) have stopped having treatment, with 37% of you having a successful outcome.

30% of you are having treatment at the moment, and 14% were considering treatment when you completed the survey in December.

- Most of you (36%) are aged between 30 and 34. 28% of you are aged between 35 and 37, 14% of you are aged 38-39 and 14% of you are over 40. Those under 30 make up 8% of Fertility Views membership.
- 94% of you are white British, Irish or other. Other ethnic groups are represented by less than 1% of Fertility Views members. 55% said you are Christian.
- 40% of you live in South East England or London. Representation from Scotland, Wales and Northern Ireland is 6%, 4% and 2% of the membership respectively.

Success rates when choosing a clinic

We wanted to know whether your doctor gave you a figure for how likely you were to have a baby, such as a percentage chance of success.

You said..

65% of you said yes
35% said no.

Interestingly, more people over 40 (79%) were given a figure compared to younger age groups.

We asked you what, if you were paying for your own treatment, was the lowest chance of success that you would consider acceptable.



You said..

94% of you said you would pay for treatment if there was a 25% chance of success, and just over half of you would pay when the chance of success dropped to 10%.

There were 23% of you who would also consider paying for treatment if there was a less than 5% chance of success.

Approaches to choosing a clinic

We like to keep up to date with patients' approaches when choosing a clinic, so that we can assist them in the best way we can. We questioned you on which approach you took in your search for a clinic.

You said..

27% of you said that you had no choice of which clinic to go to and went to the one that you were referred to. 23% of you said that you would choose a clinic near to your home/work.

“Success rates are key to me as I need to have something to rationalise what we are doing.”

What also was quite important to you was choosing the clinic with the best success rates for the type of treatment you were considering.

What we're doing..

We will be using what you told us to review the way we present information, particularly in our 'Find a clinic' search, used on the website.

Your response also gives us useful information about the lowest chance of success that you consider acceptable when undergoing treatment.

Important issues you are facing

We like to hear about the important issues you have faced when going through infertility treatment and we wanted to know why they were so meaningful to you.

You said..

Top 5 issues facing you:

- Success rates 66%
- Cost of treatment 64%
- Emotional impact of treatment 42%
- Waiting times 33%
- Access to treatment 31%

The majority of you found that success rates and cost were your main concerns. Interestingly, 72% of those currently going through treatment said that success rates were more important. Whereas 75% of those considering treatment, said that cost was the most important issue. The emotional impact of the treatment also served as a significant issue for 42% of you.

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For success rates, you explained that it was important that you had the greatest chance of success from each treatment due to the emotional and financial impacts of each treatment.

In terms of cost, you mentioned treatment being too expensive and the number of previous failed treatments making it very expensive to carry on with further treatment as factors that made cost important. Your concerns over the NHS postcode lottery and wanting more free cycles from NHS were also raised.

“It’s a lot of money we are paying out time after time, and there is also a strain on our marriage with the costs.”

What we’re doing..

Success rates continue to be an important area of concern for you. We are continually looking at ways to encourage the sharing of best practice between the most successful clinics and the rest of the sector.

The HFEA does not regulate the cost of private treatment and therefore has no power in this area. You have told us in the past that knowing how much you will pay up front is important so we are looking at ways of improving payment plans in clinics.

We are aware of the emotional impact that going through treatment can have. It is often useful to talk about your feelings with

someone who doesn’t know you or your partner (if you have one).

Counselling can help you explore your feelings, become clearer about your situation and find new ways of coping. Many of you told us that you did not have counselling during your treatment so we will be looking at ways to improve access within centres over the coming months.

Information you value

We were keen to find out what information about clinics you found most valuable when deciding where to go for treatment. We also wanted to know which websites you visited for information and support.

Along with this we asked if you had visited our redesigned website and what you thought about the content.

You said..

Live birth rates are by far the most important information for you when deciding where to go for treatment, but some of you primarily go to a clinic close to where you live or work. Other information you value is cost of treatment, information from the HFEA and implantation rates.

The most popular sites you visit for information and support are Fertility Friends, Infertility Network UK and Babycentre.co.uk.

Almost half of you had visited the new HFEA website. You said the site was well designed



and it was easy to find the information you wanted. Along with this 73% of you said the complexity of information was at the right level.

“Treatment is very expensive, some clinics have long waiting times and it’s good to know statistics of clinics to check your your chances of success.”

What we’re doing..

We are continuing to look at the way we present information, especially clinic success rates. With the launch of the new clinic statistics in the ‘Find a clinic’ section of our website this summer, we will be providing Implantation rates for the first time.

We are also looking at better ways of marketing our public website, and continuing to improve the information we are providing to patients.

Counselling services

We wanted to find out more about the counselling services you were offered when you went for treatment and how helpful you found it.

You said..

61% of you said you did not have counselling before or during your treatment.

For those that did have counselling the majority of you were offered this service free of charge with only 10% of you paying.

55% of you also said you would strongly recommend it to others or it was quite helpful to your treatment.

For those of you that did not have counselling:

- 45% of you felt it did not add much to your treatment.

Other reasons were:

- it was not suggested by the clinic, or
- you did not think to have counselling.

59% also said from not having counselling, you did not feel it had any adverse effects on you and would not consider it in future. Whereas, 41% think it would have been helpful and would have liked the chance to talk to a counsellor.

What we’re doing..

Your response to counselling was a particular area of concern for the HFEA at our recent open meeting and one that prompted a long debate.

Your responses mirror findings from our driving improvement report published late last year. This issue will be examined over the coming months and will be a key area of discussion at our Annual Conference in June.



Access to treatment

In the past we have looked at the barriers people have to receiving treatment. We wanted to find out more about some of your concerns with regards to race or status when accessing services.

You said..

A small percentage of you said you had encountered problems with fertility treatment due to status or race.

Your sexuality

- 40% of people who are living with a partner of the same sex said they had encountered problems (5 panel members were represented in this category)

Your religion

- 2% of people who say they have a faith or religion said they had encountered problems. 6 out of the 7 people who encountered problems were of Christian faith.

Your race

- 7% of black, minority or ethnic respondents said they had encountered problems. (29 panel members were represented in this category)

Your disability

- 19% of people with a disability said they had encountered problems (21 panel members were represented in this category)

People who did have problems with race or status said they wanted more flexibility, sensitivity and acceptance by clinics. You also felt that clinics should cater to your religious beliefs and sexual preferences.

“Monitor clinic’s policies for who they will agree to treat. Help patients to register complaints if they are discriminated against.”

What we’re doing..

It is important that we know the variety of barriers that people face when undergoing fertility treatment. We will continue to monitor this closely.

If you do experience any problems in regards to discrimination you can submit a complaint by following our complaints about licensed centres policy on our website at www.hfea.gov.uk/en/1001.html

Thank you again for sharing your views with us. We will be contacting you again with another questionnaire in summer.