

January 2008

Fertility Views

Newsletter

Your views make
a **difference**



Welcome

Many thanks to all of you who took the time to respond to our September 2007 survey. The HFEA are grateful for your continued support in sharing your views about fertility treatment.

Over the coming weeks, we will be sharing the findings from this survey with clinics and others in the sector.

Who are Fertility Views members?

- 96% of you are women
- 1% of you are under 25, 34% of you are aged between 25-34, 62% are 35-44, and 4% are over 44
- 91% of those who responded are white (British, Irish or other), while 9% are from other ethnic groups.

What is your current status of treatment?

- 48% stopped having treatment and it was successful
- 26% are currently having treatment
- 16% stopped having treatment and it was unsuccessful
- 10% are considering treatment.

Costed treatment plans

We wanted to find out if you had unexpected charges when paying for treatment as well as how transparent clinics are with their costs. We also wanted to know how you felt about clinics providing you with a personal costed treatment plan.

You said..

Out of the 85% of you that were paying for your treatment:

- 79% received a price list
- 31% were given a verbal list of costs
- 20% were given a personal costed treatment plan.

49% received this information at the first consultation, while 43% of you received it before your treatment started.

“Must emphasise the need to get costs up front, I feel I was totally taken advantage of at [my centre] where the costs were never clear.”

27% of those given information about the cost of their treatment were subsequently charged additional costs they weren't expecting.



Drug costs were cited as the most common type of unexpected additional cost (61%). You also said there were a range of additional costs including supplementary treatments, blood tests, scans and embryo freezing.

4 in 5 of you who didn't receive a costed treatment plan said you would have liked one (88%).

What we're doing..

The information you told us will feed directly into a review that is taking place at the HFEA.

The review is looking at placing a requirement that clinics provide an individual costed treatment plan to all patients prior to treatment commencing.

Our intention is to implement this in 2009 with the help of patient groups and professional bodies.

Information from the HFEA

We are in the process of reviewing the HFEA Guide to Infertility, our main printed form of communication with patients. As part of our review, we wanted to know if it's still relevant as a magazine and how it might be improved in future editions.

You said..

Over half of you believe that it is important to have printed information from the HFEA as well as the information being provided on the HFEA website.

"I found everything I wanted in the Guide, although I used clinic websites for previous years' success rates and more up to date success rates..."

88% of you had read the Guide and most of you had either ordered or downloaded it from the HFEA website.

Areas of the guide you were most positive about were:

- General information about infertility (69%)
- The different treatments available (64%)
- The list of HFEA Licensed clinics (63%)
- Information on finding the right clinic for you (50%)

Some of the improvements you suggested were:

- Including the most recent clinic success rates as well as historic information to compare with
- Giving more detail to success rates, e.g. a breakdown of success rates dependent on region/cause of infertility or method of treatment.
- Detailed breakdown of costs including the variation between treatments and different clinics
- More information on the reason for certain costs within certain treatments
- Detail on the NICE guidelines and policies of local Primary Care Trusts on funding



What we're doing..

The information you provided will be fed directly into the project for reviewing our Guide. We are also holding patient focus groups to gather more detailed feedback. The next edition of the Guide is expected to be launched in late 2008.

Access to your treatment information

With a revised Human Fertilisation and Embryology Bill on the horizon, one of the proposed changes is allowing researchers access to a patient's treatment information with their consent. We wanted to find out how you felt about this.

You said..

Most of you (80%) said you would be happy for researchers/health experts to have access to your individual treatment data for a follow up study with your child.

The majority of you said that you would be happy to allow researchers for medical purposes, access to your data (89%), GPs (60%), or clinical experts (51%).

What we're doing..

We will be feeding this information back to the Department of Health as well as parliamentarians as they review the Bill.

HFEA Regulation

The HFEA Licence Committee regularly makes a range of decisions about licensing activities for all fertility and research clinics within the UK. From these activities, we wanted to know what you felt was important for us to communicate to patients.

You said..

You told us that you would like to see more information about your clinics regulatory activities published on the HFEA website. Your priority was for information about when a clinic's licence was taken away (96%) and if the HFEA was taking regulatory action (94%).

Almost two thirds of you believe that if the HFEA found a problem at your clinic (that was not an immediate risk to patients) they should be given no longer than 3 months to show improvements.

What we're doing..

This will be looked at in terms of improving information to patients and help them be more informed about their clinic choice as well as those undergoing treatment.

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'Find a clinic' success rates

Along with our Guide to Infertility, we are also reviewing the way we present success rate data and clinic information. We wanted to know what you thought of our current 'Find a clinic' search and look at where improvements could be made.

You said..

80% of you had used the 'Find a clinic' search and 70% of you thought it was a useful tool.

In terms of the most useful information or information you would like to see included:

- Information on clinic live birth rates (87%)
- Comparing different success rates side by side (77%)
- Comparing a clinic's success rates with national success rates (75%)

"I would like to see success rates dependent upon the cause of infertility."

Other information you would like to see in 'Find a clinic':

- Access to detailed clinic ratings
- Success rates by age of patient
- Satisfaction ratings from patients
- Number of cycles that patients undertake for success

- Up to date information and statistics
- A clinic's specialist area of expertise
- Personal comments from patients (especially those who were unsuccessful)
- The cost of treatment and ways of paying

Although nearly all of you considered any live birth to be a desirable outcome, when asked about specific outcomes, only 14% say triplets are desirable and 54% say twins are desirable.

What we're doing..

Your feedback will go into a thorough review that the HFEA will be undertaking in the new year. We will also be doing some more research with individuals to continue to improve the usability of the online search tool.

Blastocyst transfer

We wanted to know how many of you had blastocyst transfer in your treatment and how successful you were. We also wanted to know that if there were a higher chance of success with blastocysts than a regular 2-3 day embryo, would you be more likely to have less transferred in your treatment.

You said..

19% of you said you had blastocyst transfer with your treatment, and from that group:

- 79% had 2 blastocysts transferred
- 11% had 3 blastocysts transferred and
- 10% had 1 blastocyst transferred.



50% of you were unsuccessful with your treatment. Of those of you that were successful:

- 38% had a singleton birth
- 11% had twins
- 1% had triplets

We wanted to know who you think should make the decision about how many blastocysts you should have transferred in your treatment.

- 81% said it should be the patient in consultation with their clinician and
- 13% believe it should be the patient who decides.

What we're doing..

The information you gave fed into the report on Multiple births that went to the HFEA Authority for consideration in November 2007. A report of this decision can be found on our website at www.hfea.gov.uk/multiplebirths

We are working towards implementing a policy together with patient groups and clinics.

Important issues you are facing

You said..

The biggest issues currently facing you are:

- Cost of treatment (39%)
- Emotional impact (18%)
- Success rates (13%)

What we're doing..

As the HFEA does not regulate the cost of fertility treatment, we are unable to enforce any changes to do with how much clinics are charging you, or how the NHS funds treatments.

However we will be making our information available to health providers and commissioners who make decisions on these matters.

“More information about the NICE guidelines for NHS funding for treatments and why such funding still differs according to the area you live in.”

We are looking at bringing in a requirement for clinics to issue costed treatment plans, so you don't receive hidden costs during treatment.

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