

Fertility Views update **October 2005**

Hello everyone and welcome to the first *Fertility Views* update.

The update gives an overview of the results of the surveys you completed and outlines what we are going to do with the information. A more detailed report is available at <http://www.hfea.gov.uk/ForPatients/PatientsPanel>

How Fertility Views, the patients' panel, is made up

- 94% are female, 85 % are married
- 13% are under 30 years, 41% are between 30-34, 26% are between 35-37, 10% are 38-39 and 10% are over 40
- 73% currently do not have children under 18, 27% do. 70% of those that do used fertility treatment
- 48% are currently having treatment, 25% are considering treatment, 19% have had successful treatment and 8% have had unsuccessful treatment
- 66% are paying for treatment yourselves
- 67% are working full time (30+ hours a week), 17% are in part time work (8-30 hours a week)

What you said about:

Sourcing information about fertility treatment

- Three quarters of you went to your GP first to get information about fertility treatment, the rest mostly used the internet

Access to treatment and choosing treatment

- Just over two thirds of you found it quite or very easy to access the treatment you wanted, although the rest of you found treatment quite or very difficult to access
- The top five factors you consider when choosing a clinic are: location, success rates, NHS referral, clinic staff and personal recommendation

Success rates

- Published success rates were most useful for choosing which clinic to go with 40% finding them very useful for this purpose. 30% found them very useful for deciding which questions to ask the clinic they had chosen and 27% for asking their GP questions about their treatment options

HFEA guide to infertility

- 68% of you had read this year's guide
- You found the guide most useful for information about the range of treatments, followed by individual clinic information, clinic success rates and statistics on IVF

Interactive clinic search

- Of the 34% who had seen the interactive clinic search on the HFEA website, 91% found it very easy or quite easy to use and 87% found the information gained very or quite useful

Patient information

- Of the 49% of the panel who had read an HFEA patient leaflet, 87% found the information very or quite useful. 63% wanted to access the information both on the internet and in print

Service and support

- Sixty per cent of panel members rated their experience of fertility services 7 or above where 1 = very poor and 10 = excellent. Nearly 1 in 5 rated the service 4 or below. The average rating for a clinic was 6.66
- 52% of participants felt they were getting a little or a lot of emotional support from their clinic against 22% who felt they were getting no support at all

The role of a regulator in the fertility sector

- Panel members thought the key activities a regulator should do are: regulate the quality of service, provide guidance and information to patients, monitor patients' safety, monitor treatment options available, formulate policy and measure patient satisfaction. Monitoring the value for money of services was mentioned, although this is not currently with the HFEA's remit

Clinic inspection reports

- Panel members thought they should include: patients' experiences, success rates, waiting lists/ times, expertise of staff and how procedures compare to different clinics

Issues facing patients

- 25% of responses mentioned cost of treatment (how to pay for it, value for money, cost differences between clinics, whether to carry on with treatment due to cost)
- 24% mentioned success rates (likelihood of treatment being successful, success rates of clinics and why they differ, regional variations)
- 18% mentioned waiting lists and times
- 17% mentioned availability of/ difficulty of getting NHS funding

What the HFEA should be focusing on

- 16% said equality or consistent standards between clinics
- 16% said giving more information and more up-to-date information to patients
- 13% said monitoring success rates
- Other key issues mentioned were: lowering costs, listening to patients' views and inspecting clinics and services

How we are using your feedback

The Authority held a meeting on 11 October which considered the panel's findings. There was a lot of discussion about how the results can feedback into the Authority's work.

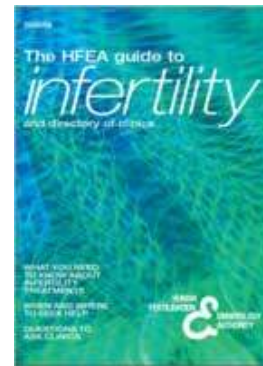
Already we are:

- increasing the promotion of the HFEA guide to infertility to GPs and doctors' surgeries and also to patients
- improving the Guide, clinic success rates, the interactive clinic search and the web site to make them clearer for patients
- looking at whether we can produce information about the costs of treatments as part of our Guide
- reviewing all our patient leaflets to take into account what the panel has told us
- reviewing the support and information provided to patients as part of our inspections

- working to increase the number of patients filling in our patient inspection questionnaires so we can include the patient experience in the inspection report
- carrying out a review of why success rates vary. We will then work with clinics to reduce the disparities and share best practice between clinics
- setting up meetings with all the patient organisations to discuss the panel's findings
- sharing the panel's findings with clinics
- publicising inspection reports as a source of information for patients to help when they are choosing clinics

Have you read the HFEA guide to infertility? Do you know a friend who would like a copy? Has your GP got a copy?

Don't forget you can get free copies of the HFEA guide to infertility by emailing admin@hfea.gov.uk or calling 020 7291 8200.



Thank you for your help in completing the survey, we value the feedback. The next *Fertility Views* survey will be early next year.

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