

## 1.0 Introduction

1.1 Fertility Views, HFEA’s patients’ panel, was set up in May this year to consult with patients to get regular feedback on the quality of information and services they experience before, during and after fertility treatment.

1.2 The results of this research will help inform improvements to fertility treatment services in the UK and the provision of information for patients.

1.3 Opinion Leader Research (OLR), an independent research company manages the panel and analyses responses.

1.4 A recruitment questionnaire and two attitudinal questionnaires have been carried out. This paper introduces findings.

## 2.0 How the panel works

2.1 To date approximately 750 people have joined the panel. The majority of panel members were recruited after sending a flyer out with every request for our *Guide to infertility* and via articles on BBC News online and HFEA website. In addition we advertised on Fertility Friends and Infertility Network UK websites. The composition of the panel is in Appendix 1.

2.2 It is intended to run up to three surveys a year with a sample of at least 100 panellists per survey. Members will be contacted and asked to fill in an online questionnaire about their experiences of fertility treatment and different issues within the industry. Over time the surveys can be used as a form of tracking research to test whether experiences and perceptions have changed. Below are the findings from the first wave survey of the panel. This focused on information people use seeking treatment and choosing clinics; attitudes to regulation; what they see as important issues in fertility treatment and what they want the HFEA to do.

2.3 After each survey panel members will be sent an online newsletter summarising the main findings and outlining how we are responding to their views.

2.4 Panel members have indicated that they are willing to become involved in further research, such as HFEA consultations and focus groups, to provide more detailed feedback on specific issues as required.

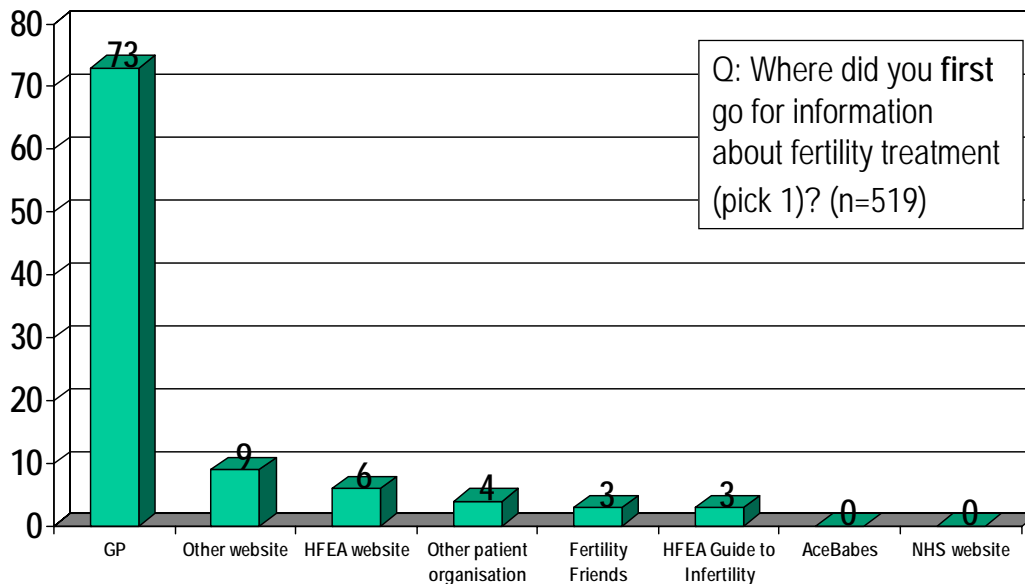
## Key findings

### 3.0 Information for patients

#### 3.1 *Sourcing information about fertility treatments*

3.1.1 The graph below clearly demonstrates the importance of GPs as the first port of call for people wanting more information about infertility.

### Sources of information on fertility treatment



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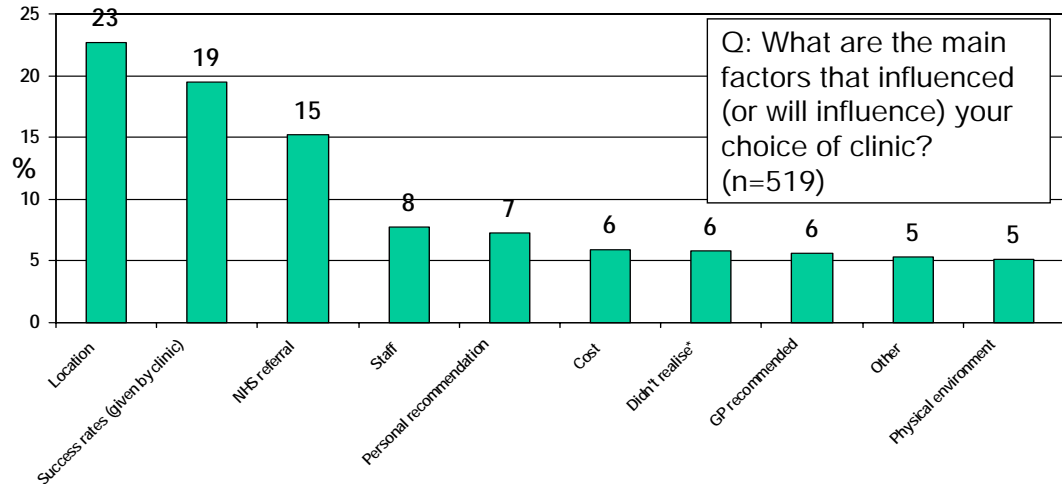
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### 3.2 Access to fertility treatment and choosing a clinic

3.2.1 Just over two thirds of our panel found it quite or very easy to access the treatment they wanted. The remaining found treatment quite or very difficult to access.

3.2.2 The graph below shows the main factors that influence patients when they choose a clinic. Clearly location is the most significant factor.

## Influence on choice of clinic



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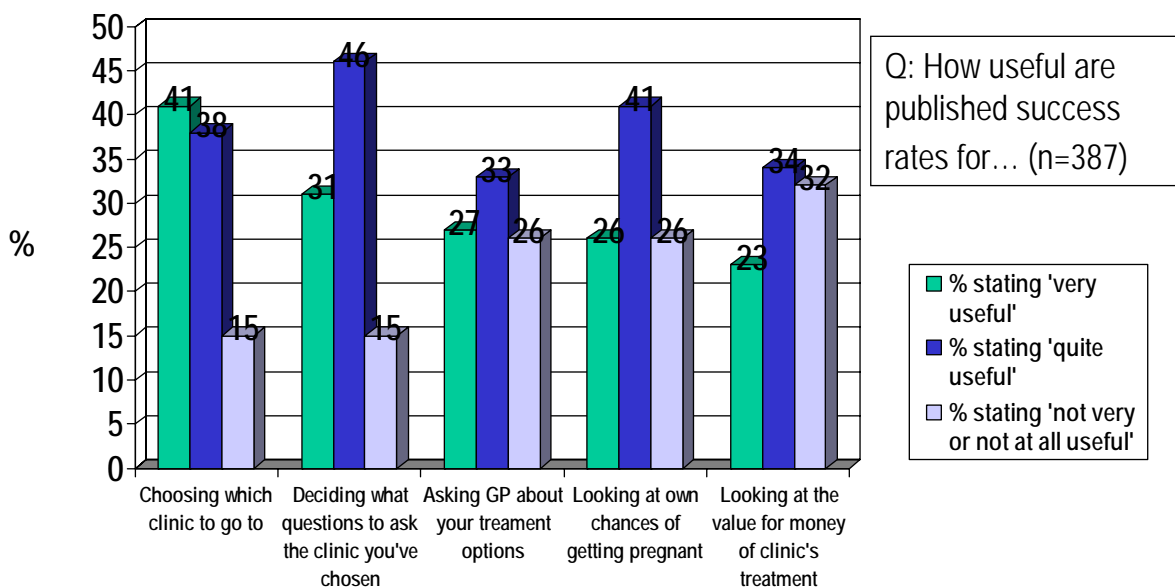
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### 3.3 How people currently use published success rates of clinics

3.3.1 As seen in the graph below panel members consider success rates very or quite useful for:

- choosing which clinic to go to (79%)
- deciding what questions to ask the clinic (77%)
- looking at chances of getting pregnant (67%)
- asking a GP about treatment options (60%) and
- looking at the value for money of a clinic's treatment (57%).

## Usefulness of published success rates for...

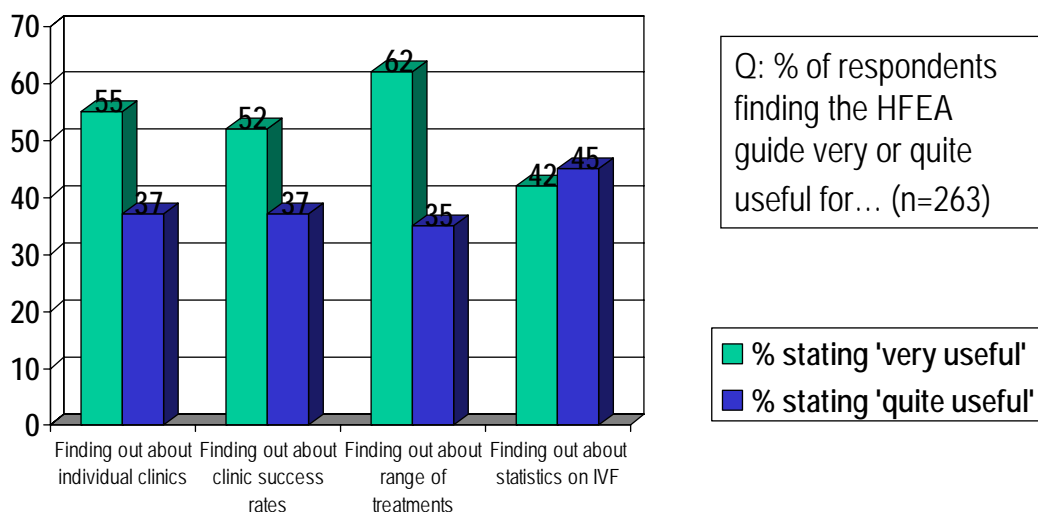


### 3.4 Views on the HFEA guide to infertility 2005/06

3.4.1 Of the panel 68% had read the new *Guide to infertility*

3.4.2 The key topic that the guide was most useful for was the range of treatments, followed by individual clinic information, clinic success rates and statistics on IVF.

## Usefulness of the HFEA guide to infertility



### 3.4.3 Panellists made a number of suggestions to improve the guide:

- 26% emphasised the need to make the statistics/ data and success rates easier to understand (eg a quick reference table of clinic statistics for the treatments they provide)
- 11% wanted more up-to-date statistics
- 11% wanted more in-depth information on success rates (eg split by age, treatment)
- 11% wanted more information on individual clinics (eg individual approach/ specialisations, locations).
- Additional comments requested clearer guidance on how to read the guide and information on acceptance criteria and prices.

### 3.4.4 Quotes:

***“I really wanted to know the comparison between various centres and national statistics at a glance.”***

***“Limitations of the stats provided in the guide. For example, the success rates are based on the sample for a particular clinic, but there is no information on the nature of those particular patients.”***

### 3.5 **Views on the interactive clinic search**

3.5.1 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.

3.5.2 Suggestions to improve the service included a comparison of clinics, more up-to-date and more detailed information.

3.5.3 Quote:

***“I would like to see a deeper level of data stratification. We are investing huge sums of money and need to know our realistic chances with each clinic. For any other investment of this size you would expect much more data!”***

### 3.6 **Attitudes to HFEA patient information**

3.6.1 Of the 49% of the panel who had read an HFEA patient leaflet, 87% found the information very or quite useful. Currently leaflets are distributed mainly via clinics. 63% wanted to access the information both on the internet and in print.

3.6.2 Panel members stated that they would like to see more HFEA patient information about:

- different types of treatments/ options available/ routes to treatment
- fertility treatment prices/ costs/ financial information/ where to get funding/ eligibility criteria for funding
- support groups, questions to ask the clinic/ GP, details of emotional support/ counselling
- other information eg websites, side effects of drugs, alternative treatments and timescales.

3.6.3 Quotes:

***“Information on the rough price the treatment may be. I know this will differ from clinic to clinic and from treatment to treatment, but a guide may be useful.”***

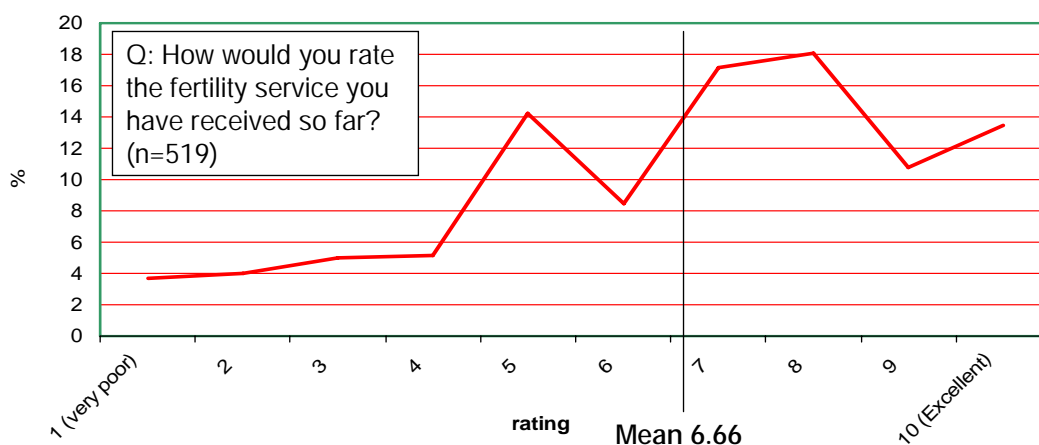
***“Comparisons between IVF and ICSI, including success rates and factors relating to age.”***

## 4.0 **Patient satisfaction**

### 4.1 **Rating of service and support, and improvements they would like to see**

4.1.1 Sixty per cent of panellists 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.

## Ratings of fertility service



60% of participants rated the service 7 or above and 18% of participants rated the service 4 or below



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4.1.2 In terms of support, around half (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.

4.1.3 Where people are getting support 61% are getting that from their partner, family and friends, 8% from medical staff, 7% from counsellors and 2% from patient groups.

4.1.4 Of the services that panel members received, they considered the 'human' aspects of the service, such as emotional support and customer service, were of the greatest value. Of those who made comments:

- 14% mentioned friendly/ caring/ kind/ helpful staff
- 8% mentioned that the consultant was approachable/ understanding/ positive/ explained everything well
- 7% mentioned the GP was supportive/ caring/ understanding
- 7% mentioned the counselling service.

4.1.5 In terms of improving overall services, 14 % who responded to this question said waiting times could be improved and 14% wanted better or more information and advice.

Other improvements mentioned were GPs being more aware of infertility and making the service more personal so you don't just feel like a number.

4.1.6 Quotes:

***“I have received excellent support throughout my treatment from the nursing staff at both clinics I have had treatment at. Fertility treatment is extremely difficult to cope with emotionally and understanding staff are imperative.”***

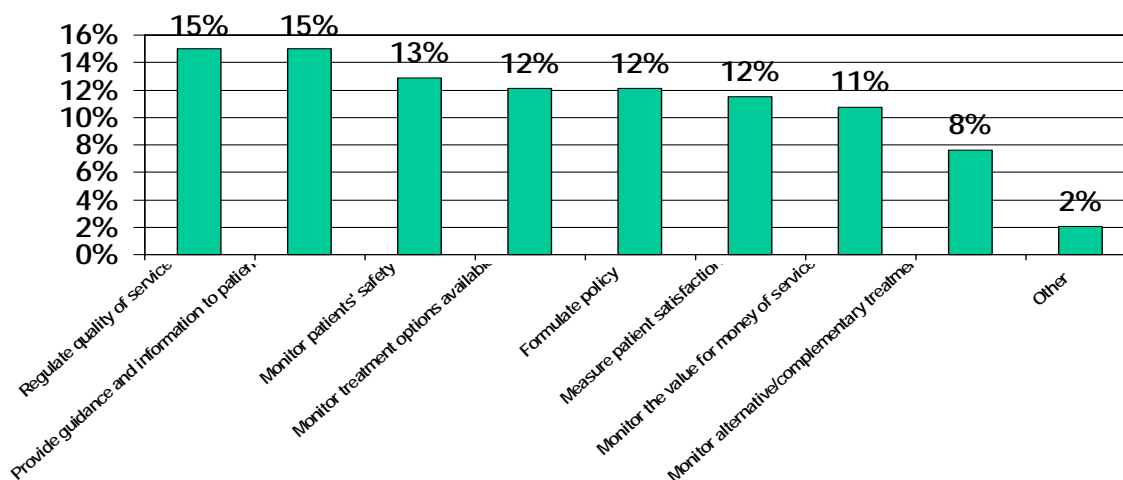
***“At most clinics the service is very impersonal – it feels very much like a sausage factory – go round the IVF conveyor belt and if you’re lucky it will work and you’ll fall off, otherwise go to the back of queue and we’ll see you on your way round again (oh and give us £5000 each time you go round).”***

## 5.0 HFEA and regulation

### 5.1 Purpose of a regulator in the fertility sector

5.1.1 The panel were asked for their opinions on what they believed a fertility regulator should do. You can see from the table below there were a range of responses. The only specific activity mentioned that is not in our remit is to monitor the value for money of services (11%).

### What do you think a body that governs fertility treatment should do? (n=519)



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### 5.2 Attitudes to HFEA

5.2.1 The survey showed most people (69%) knew a little about the HFEA, but only 15% knew a lot about the organisation.

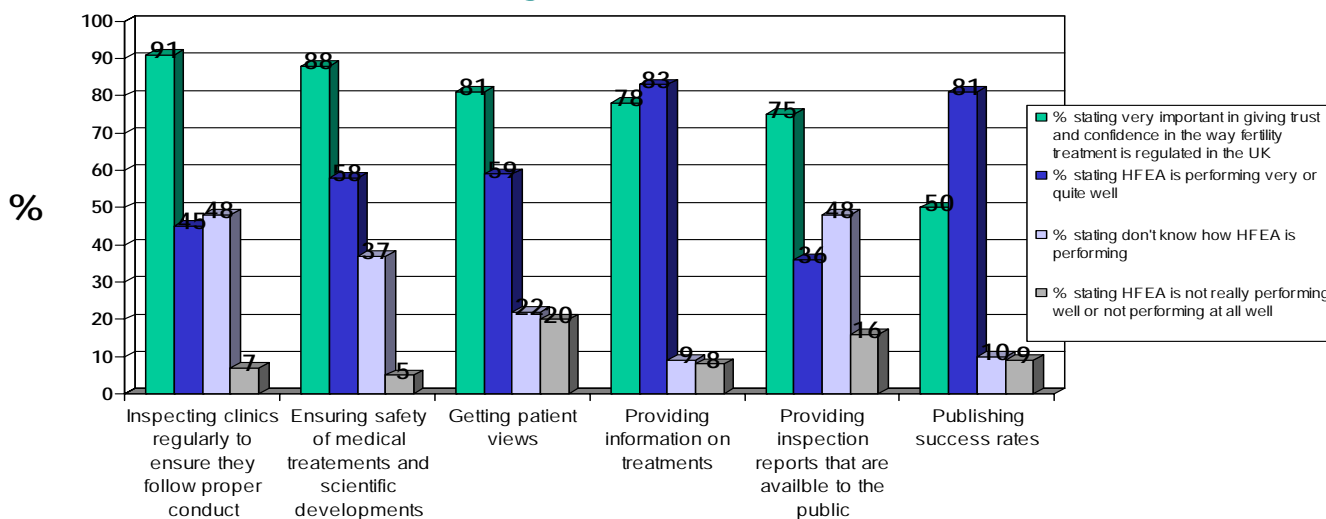
5.2.2 The panel were asked whether HFEA is protecting the interests of patients: nearly 50% believe it is, 12% it is not and 39% don't know.

5.2.3 The panel were asked whether HFEA is up-to-date with scientific advances: more than 50% of believe it is, 6% it is not and 39% don't know.

5.2.4 The panel were asked whether there is adequate ethical scrutiny of fertility treatment: more than 70% believe there is, 7% there is not and 22% don't know.

5.2.5 The panel were asked what they considered to be the factors that would be very important in giving trust and confidence in the way fertility treatment is regulated in the UK. The graph below charts them and how they think the HFEA is performing against them.

### Importance and performance of HFEA against fertility factors (n=387)



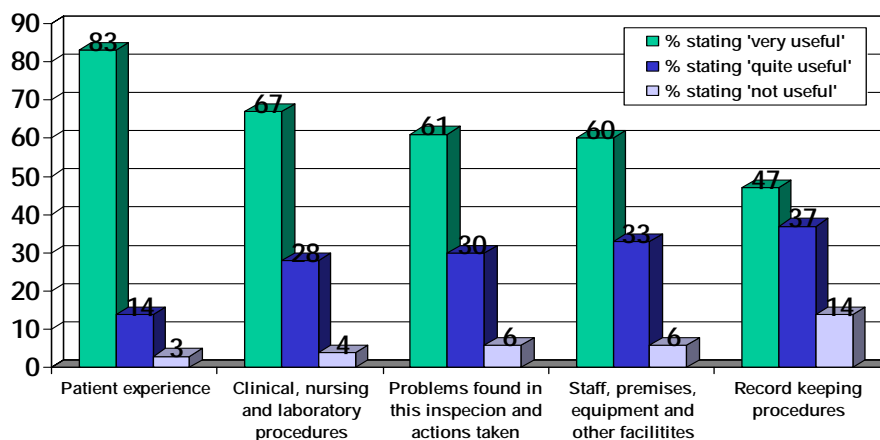
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### 5.3 Inspection reports

5.3.1 Given the importance of patients' panel views about inspections, the panel was then asked about inspection reports and what they should contain.

## How useful would you find the following in clinic inspection reports? (n=387)



### 5.3.2 Other information panel members would like to see in a clinic inspection report include:

- patients' experiences
- success rates
- waiting lists/ times
- expertise of staff
- how procedures compare/ differ to other clinics.

#### Smaller issues mentioned were:

- types of patients dealt with
- complaints procedure
- aftercare
- cleanliness
- costs
- support/ counselling services
- open hours/ days
- staff turnover
- staff training/ qualifications
- facilities.

## 6.0 Important issues facing patients

### 6.1 *Issues facing patients regarding fertility treatments*

6.1.1 Panel members were asked what the most important issues currently facing them with regards their treatment.

- 25% of responses mentioned cost of treatment (financial pressures, fears of amount they will have to spend and how to pay for it, value for money, saving up for treatment, cost discrepancies 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, low success rates compared with abroad, low success rates in Wales and Scotland, not wasting 'gos' at clinics with poor success rates).
- 18% mentioned waiting lists and times
- 17% mentioned availability of/ difficulty of getting NHS funding
- People also mentioned the emotional effects of fertility treatment (9%), the postcode lottery/ inequality in treatment access (7%), limiting embryo replacement (9%) and quality of care by staff (8%), personal support/ counselling (7%).
- There were also a range of other more specific issues mentioned. A few mentioned donor shortages, the removal of donor anonymity and the need to recruit more donors. Equally a few mentioned the restrictive nature of welfare of the child forms. A small number mentioned the need for more information about reproductive immunology. Issues such as fertility tourism did not figure. A few criticised the HFEA's move to single embryo transfer as being overly restrictive.

6.1.2 Quote:

***“Clinics which are under-performing should not be allowed to continue to drain people of their finances and emotions without delivering!!!”***

## 7.0 What the HFEA should be doing

### 7.1 *What the HFEA should be focusing on*

7.1.1 The panel were asked what they thought the issues were that 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 (prior to treatment eg what to expect during treatment, information on clinics to help make informed choices)
- 13% said monitoring success rates (eg improving success rates, looking at why there are such differences between clinics, transparency, ensure badly performing clinics take action)

- Other key issues mentioned were: lowering costs (as treatment is seen as very expensive); listening to patients' views (patients want to feel listened to, their views taken into account in legislation, complaints procedures) and inspecting clinics and services (making sure clinics meet standards, are properly run and ethically sound and that staff are qualified). Another issue was "ending the postcode lottery" although access issues do not fall within the HFEA's remit.

7.1.2 These were the most important issues highlighted. The range of other issues mentioned were very similar to the issues identified as being important to individuals. Overall the demand was for a regulator which ensured safety in clinics, monitored standards in clinics and supported patients in terms of information.

7.1.3 Quotes:

***"Inspecting the clinics so they are consistently good – they should all offer the same opportunities and standards."***

***"Why are some clinics so much better than others?"***

***"Getting adequate information to patients prior to treatment. I was kept completely in the dark as to what the treatment would involve until it was about to happen."***

***"Monitor and publish success rates to ensure badly performing clinics take action."***

***"My personal feeling is that HFEA should be focusing on providing information on risks with procedures (eg transferring more than one embryo) rather than trying to 'legislate' for those risks, taking choice away from the patient."***

## Appendix 1: The composition of the panel

- 94% are female
- 13% are under 30 years
  - 41% are between 30-34
  - 26% are between 35-37
  - 10% are 38-39
  - 10% are over 40
- 85% of the sample are married
- 73% currently do not have children under 18
  - 27% do. 70% of those that do used fertility treatment
- 94% are White (British, Irish or other)
  - 1% are Indian
  - All other ethnic groups are under 1%
- 67% are working full time (30+ hours a week)
  - 17% are in part time work (8-30 hours a week)
- 48% are currently having treatment
  - 25% are considering treatment
  - 19% have had successful treatment
  - 8% have had unsuccessful treatment
- 33.9% have been having treatment for less than a year
  - 25.4% for 1-2 years
  - 15.65% for 2-3 years
  - 10.07% for 3-4 years
  - 14.75% for more than 4 years
- 85% have never used donated sperm or eggs
  - 3% using donated eggs now, 3% used donated eggs in the past
  - 5% using donated sperm now, 4% used donated sperm in the past
- 66% are paying for treatment themselves