

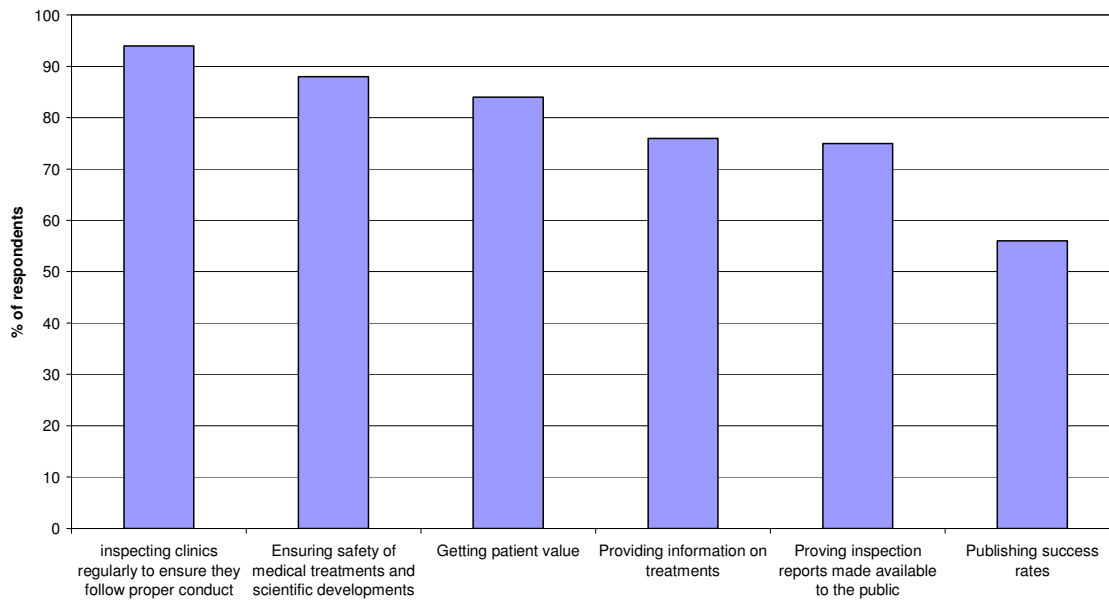
HOW PATIENTS FEEL ABOUT FERTILITY TREATMENT AND ITS REGULATION

- Information from the HFEA Fertility Views patient panel and from wider public attitude research**

Patient views about fertility treatment

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.

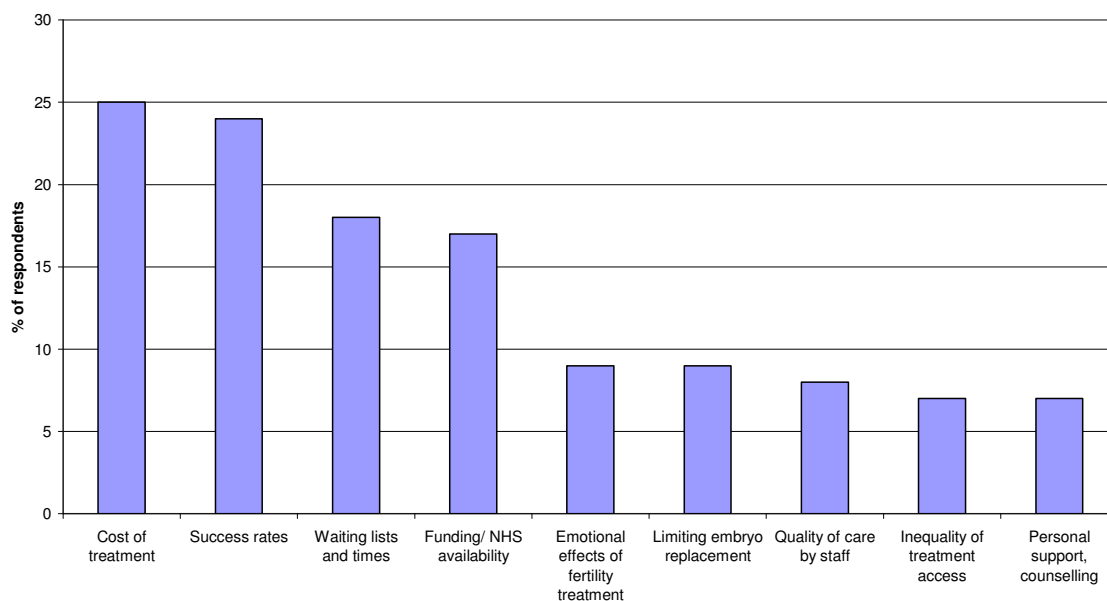
Issues that are important to confidence in the UK fertility sector



Issues facing patients regarding fertility treatments

Members of the Fertility Views panel were asked what the most important issues currently facing them with regards their treatment.

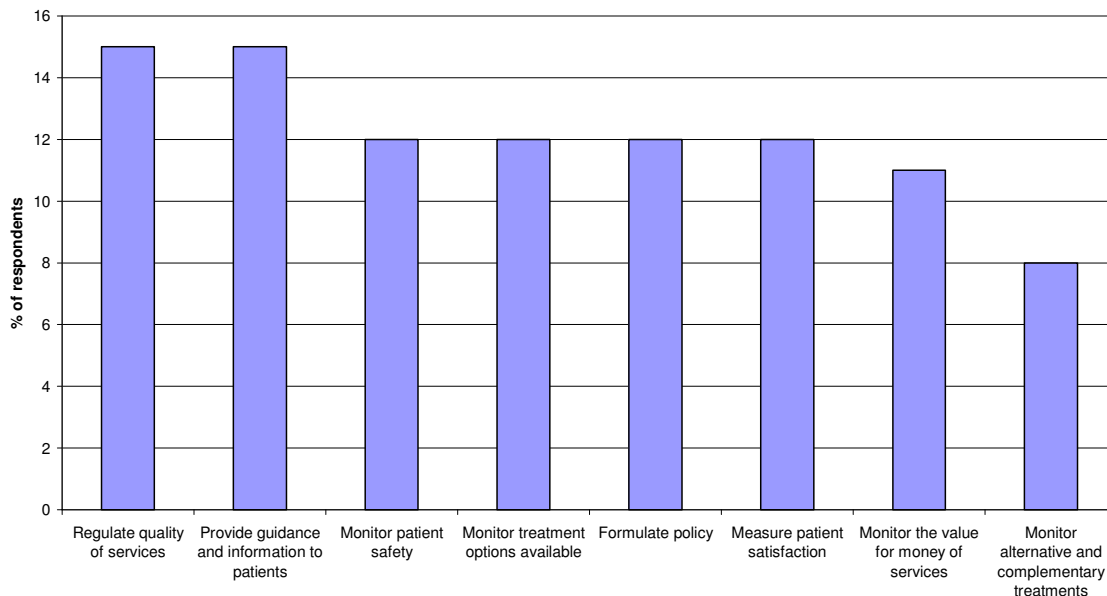
Important issues for patients regarding fertility treatment



- 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.

“Clinics which are under-performing should not be allowed to continue to drain people of their finances and emotions without delivering!!!” (Female, 35-37, London)

What do you think a body that governs fertility treatment should do?



What the HFEA should be focusing on

Members of the Fertility Views panel were asked what they thought the issues were that the UK Fertility regulator 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)
 - 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.

A 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.

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

“Inspecting the clinics so they are consistently good – they should all offer the same opportunities and standards.” Female, 38-39, Cheshire.

“Why are some clinics so much better than others?” Female, 30-34, Devon.

“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.” Female, 35-37, Bournemouth.

“Monitor and publish success rates to ensure badly performing clinics take action.” Female, 30-34, Liverpool.

“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.” Female, 30-34, Leicestershire.

WIDER PUBLIC ATTITUDES TO FERTILITY TREATMENT

The HFEA commissioned polling experts MORI to carry out a research study, interviewing a representative sample of 1,929 adults across the UK in March 2005 to find out their opinions. This report gives some of the preliminary findings of this research.

The HFEA felt it was important not to attempt to lead public opinion in the research questions, but to look at the underlying factors and opinions of people. So in a number of questions – particularly when asking people to suggest who they felt should be involved and who should be making the final decisions about issues – the options of ‘independent regulator’ or ‘the HFEA’ were not included. However, in those areas where the public would be expected to have some knowledge of the HFEA, then it was included as part of the questions.

Overview

There is widespread agreement that fertility treatment represents a major advance in science. Nearly half of adults regard fertility treatment as something with unknown consequences, and a large majority calls for regulation of the prices charged by clinics for fertility treatment.

Knowledge about Treatment

Spontaneous association with the phrase ‘fertility treatment’ is high, with over eight in ten adults citing something related to the field.

- Over half (58%) associate fertility treatment with couples who need help with fertility or conception, with help getting pregnant or with fertilisation.
- Nine in ten (91%) correctly identify at least one type of fertility treatment when prompted - women aged 35 to 44 being most likely to do so (98%).
- Nine in ten adults (90%) also agree that fertility treatment allows couples who may not have been able to, to have children, with half the public agreeing strongly.
- In-vitro fertilisation (IVF) is the best known type of fertility treatment, mentioned by almost three-quarters after prompting (72%). Women in general are more likely than men to name specific treatments such as IVF or drug therapy.
- Over two in three adults (69%) have had, or know someone who has had, fertility treatment.

Attitudes towards Fertility Treatment

Are the benefits worth the risks?

Overall attitudes towards fertility treatment are largely positive. Far more say the benefits of fertility treatment outweigh the risks, than the risks outweigh the benefits (50% compared with 13%).

Those who know of someone who has had fertility treatment are even more likely to view the benefits as exceeding the risks, with almost two-thirds (64%) doing so, compared to 44% among those not knowing such a person.

However, young people are more concerned: those in the 15-24 age group are more likely than all other age groups to believe the risks of fertility treatment to outweigh the benefits (22%).

Despite most people feeling the benefits outweigh the risks of fertility treatment, just under half (48%) say fertility treatment has unknown consequences, with far fewer - one in five - disagreeing. Women aged 45-54 are much more likely to agree than others, with 63% doing so. Those who believe regulations to be too relaxed are also more likely to agree (65%) that the consequences of fertility treatment are unknown.

However, three in five (59%) disagree with the proposition that fertility treatment is tampering with nature and therefore unethical. Women aged 25-44 are most likely to disagree with the statement. Conversely, those with no formal qualifications are more likely to view fertility treatment negatively in this regard.

A good thing and part of modern medicine?

There is widespread agreement that fertility treatment represents a major scientific advance. 85% believe this (and 31% agree strongly), with just 3% disagreeing. The only group with agreement significantly below average (at 69%) is those with no formal qualifications, but even among this group a mere 6% disagree, and the remainder are neutral or express no opinion.

There is less consensus on fertility treatment being a routine medical treatment. While over half agree that it is (55%), around a quarter (23%) disagree. Women (27%) are more likely to disagree than men (18%), with women aged 25 to 34 and 45 to 54 being particularly sceptical (34% disagree in each case).

Attitudes towards Regulation of Fertility Treatment

Is regulation keeping up?

There is a marked split in opinion on whether regulation **is** keeping up with developments. Approaching half of adults (45%) have a fair amount of confidence that rules and regulations are keeping pace with science. However a significant minority of people (35%) say they have not very much or no confidence at all. One in five don't know how they feel.

When asked about **trust** in the system, approaching two in three (63%) trust the regulatory system for fertility treatment specifically to keep pace with scientific advances, while 10% do not trust the system to do so.

When asked specifically about whether they trust the regulatory system for fertility treatment more people are neutral or express no opinion (42%) than give any other response. While over one in three (37%) disagree that they have a lack of trust in the system for regulating fertility treatment, over one in five agree (20%).

Are the rules tough enough?

Half (51%) agree that Britain probably has tough rules compared with other countries (8% disagree), and over half (59%) expect that the rules governing fertility treatment are well enforced (11% disagree). Inspectors are trusted to highlight any misconduct occurring in fertility treatment facilities by 59%, with 14% disagreeing. A similar proportion trusts the regulatory system to fully consider patients' interests (61%), with one in ten disagreeing.

When asked specifically about the severity of regulations governing fertility treatment half (49%) believe regulation to be about right, with 12% saying they are too strict and 15% saying regulations are too relaxed.

The costs of treatment?

Support for regulating prices which clinics charge for fertility treatment is high, with over three-quarters (76%) agreeing prices should be controlled. Those who strongly agree make up over a third of the public (37%). Disagreement with the regulation of such prices is registered by only 3%.

Who should be involved in making decisions?

The groups the public trust most to be involved in discussions about fertility treatment are doctors working in NHS hospitals (51%) and GPs (50%).

The UK regulator is trusted to be involved in discussions on fertility treatment by more than a third (39%). This rises to 49% in the higher socio-economic groups [the ABC1s], and even further to 58% among graduates.

Politicians are much less trusted by the public – with only 5% trusting MPs to be involved in decisions. Scientists working for Government are trusted by 15%.

Those who know someone who has had fertility treatment are almost twice as likely as those who have not to place their trust in the HFEA (57%, compared with 31%).

Who should be involved in regulation?

Doctors working in NHS Hospitals (52%) and GPs (48%) are most often selected (in this survey) to be involved in discussions about how to regulate fertility treatment. The UK Regulator again performs relatively well, being chosen by 42% to be involved. The higher socio-economic groups are considerably more likely to name the HFEA than the lower ones (though this is often the case when the UK public are asked of their knowledge of institutions). MPs are mentioned by 12%.

Reflecting the results of the earlier question (about who should be involved in discussions about how to regulate fertility treatment), doctors working in NHS hospitals (31%) are most often chosen to have the greatest involvement in discussions about how to regulate fertility treatment. The HFEA comes a close second with 28%, followed by GPs at 25%.

It is notable that the UK regulator's relative position increases on the third question in this sequence, when people are asked about who should have most involvement on regulation.

Who should provide information?

In terms of provision of honest and balanced information about fertility treatment and its regulation, doctors working in NHS hospitals (43%), GPs (42%), BPAS (35%) and HFEA

(33%) are the most trusted institutions. The media are least trusted to provide honest and balanced information, 42% saying they would not trust them. Religious leaders are not trusted by 38%.

Who should make the rules?

Joint responsibility between doctors and Parliament for formulating regulations regarding fertility treatment is the public's preferred option. Almost two-thirds (63%) of the public state this.

A quarter (26%) believe doctors should have sole responsibility for formulating regulations, but only 5% feel this responsibility should lie solely with Parliament. This reinforces the findings that the public places far less trust in MPs and Government than doctors to be involved in discussions about how to regulate fertility treatment.

What makes people trust the system?

Honesty and openness are the keys to instilling trust in the regulatory system for fertility treatment, with 13% saying spontaneously that these factors would give them trust in the system. This rises to 47% when respondents are prompted. It is followed (at the prompted question) by a system that monitors developments after they have become available to the public, and is prepared to withdraw them if there are concerns (41%).

CONCLUSIONS

Attitudes to Treatment

Views on fertility treatment are largely positive – particularly in relation to it representing a major advance in science. Although a majority of people believe it is a routine medical treatment, around half of the public still feel that fertility treatment has unknown consequences.

We believe that these public views show the importance of building and maintaining a consensus between wider society and the doctors and scientists involved in delivering treatment. Although people accept that fertility treatment is something that doctors routinely offer, the public acceptance of this activity is not unconditional and the public are not unreflective about the consequences and risks.

Many people still have concerns about the long-term consequences of providing fertility treatment and views suggest that a sufficiently trusted and balanced system of regulation is important in underpinning public confidence to permit ongoing use of these techniques. This shows that consensus should not be taken for granted and continued trusted regulation is needed to maintain consensus and confidence in these activities.

APPENDIX: **The wider context**

Previous research has found that, in general, the UK public are mistrusting of genetic science as a whole¹.

- Only a quarter of people trust those 'in charge of new developments' to act in society's interests – while a third do not.
- While just under a quarter of people think that government legislation will protect the public from risk, nearly twice as many people disagree.
- Six in ten people believe that genetic scientists only tell the public what their employers want the public to hear.

¹ Park A et al (2004), British Social Attitudes – the 21st Report, London: Sage Chapter 6 'Genomic Science: Emerging public opinion'