

Pilot national fertility patient survey

2018



Introduction

About us

We are the independent regulator of fertility treatment in the UK, responsible for licensing and monitoring fertility clinics and setting the standards they must meet. Our vision is for everyone who steps foot in a fertility clinic to have high quality care.

We also provide clear, impartial, reliable information on fertility treatments and clinics and collect data on treatments, which we use to monitor trends in the sector and make improvements.

Background to this report

We believe that the key to providing high quality care is ensuring that patients' and partners' voices are heard and feedback is acted upon. It's only through listening to those who have been through fertility treatment that real, impactful improvements can be made.

That's why we've commissioned what is, to the best of our knowledge, the largest and most representative survey of fertility patients in the UK, certainly in recent years.

We chose YouGov to conduct this survey on our behalf after a tender process. You can find details about the methodology used in the main YouGov report.

How we will use the results of the survey

This survey provides an opportunity to understand the experiences of patients and their partners in fertility clinics, to understand what matters most, and to understand what changes could have the greatest impact on their experiences at a difficult point in their lives.

We will use the results of the survey to:

- identify areas where there could be more, or improved quality of, communication
- support our work with the NHS and clinical commission groups (CCGs) to ensure patients receive coordinated care that is tailored to their needs
- identify practical steps that clinics can take to reduce negative patient experiences
- ensure clinics and we are providing high quality information for patients to support their decision making and involvement in their treatment.

Due to the wide scope of the research, there is a large amount to digest and we believe the results will form a fundamental evidence base for our future work, including shaping our future strategic plans.

We will develop ways to share lessons from the survey with all stakeholders through a variety of formats which may include presentations, workshops, articles and thematic briefings. We will also be considering how the survey could run in the future should we wish to replicate it to monitor progress over time on specific areas we target. provides on location and success rates.

Summary of the results

- Overall, most patients (75%) are satisfied with their treatment experience. There are no significant differences in satisfaction levels among private or NHS clinic users, between patients and partners, nor between those that had undergone more or less cycles.
 - Just over three quarters (78%) of those who have visited a fertility clinic in the past two years spoke to a GP about their options when they first started thinking about fertility treatment. Just over half (54%) of patients are satisfied with the advice their GP provided, a sizable minority (26%) were not.
 - The majority (73%) are satisfied with the coordination and administration of treatment and this is significantly higher for those whose most recent treatment was in a private clinic (78%), than for those who most recently used an NHS clinic (65%). This difference may reflect the resources available to the private sector. Private clinics in general are perceived to be more flexible, with their users more likely to be satisfied than NHS clinic users. An element of service provision comes through quite strongly – when people are paying, they expect better standards.
 - Patients are more likely than partners to say that they felt involved and treated with respect and dignity in certain aspects of the fertility treatment process; those participating in the focus groups suggested that female partners are likely to feel more involved than male partners.
 - Although three quarters (75%) remember receiving information about how to access counselling, one in five (20%) report not receiving any information. Patients welcome friendly and personable staff making an effort to learn their (and their partners') names.
- Seemingly small changes, such as where staff talk to patients and their partners while they're waiting for their appointments, has a positive impact.
- On the topic of feedback, 63% of respondents said that they felt able to provide feedback at any time. Very few can recall being told about formal feedback channels upfront and, perhaps as a result of this, few see this as an official part of the treatment process.
 - Just over three fifths (62%) of those whose most recent treatment was at a private clinic said they paid more than they expected to, compared to less than a quarter (23%) of those who visited an NHS clinic. Just over three quarters (77%) of fertility clinic users who had additional treatments used a treatment add on were satisfied with how open and transparent the costs of these were.
 - Private clinic users are more likely to say they are aware of the HFEA than those who most recently used an NHS clinic (76% vs. 64%). A fifth (20%) of those that had treatment in the past two years considered the '[Choose a Fertility Clinic](#)' function on our website as an important tool in choosing a particular clinic, particularly the information it provides on location and success rates.

Full report





The National Fertility Patient Survey



Human
Fertilisation &
Embryology
Authority



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1 Management summary

1.1 Introduction

- 1.1.1 The Human Fertilisation and Embryology Authority (HFEA) is the UK's independent regulator of fertility treatment and embryo research that sets standards for and issues licences to fertility clinics and centres, and collects data about fertility treatments and their outcomes.
- 1.1.2 The HFEA identified a need to conduct research with both patients and their partners who have used fertility clinics to understand the experience of care across the fertility sector, using a systematic approach to allow comparisons over time and across patient groups.
- 1.1.3 The results of this research will allow the HFEA to build up a picture of the patient experience, and identify any areas where the quality of patient care could be improved.

1.2 Summary of findings

Route to treatment

- 1.2.1 When seeking out initial information about fertility treatment, the most popular sources are search engines (60%), clinic websites (51%), the HFEA website (45%) or their GP (41%).
- 1.2.2 The medical professionals that patients are most familiar with - GPs - are often seen as a key access point to treatment. However, whilst just over half (54%) are satisfied with the advice their GP provided, a sizable minority (26%) were not. This has not significantly changed over time. A good start to the treatment process is crucial; the qualitative phase suggests that negative experiences at this stage can have a negative impact on patients, and can make them question whether the rest of the fertility experience will be difficult / challenging.
- 1.2.3 The most popular reasons for choosing a particular clinic were the location (51%), information about success rates (44%) and having a good first impression of the clinic and staff (36%). There is a need to fit treatment around patients' busy lives, and choosing the right clinic for them is key.



Organisation and coordination

- 1.2.4 The majority (73%) are satisfied with the coordination and administration of treatment and this is significantly higher for those whose most recent treatment was in a private clinic (78%), than for those who most recently used an NHS clinic (65%). Private clinics in general are perceived to be more flexible, with their users more likely to be satisfied than NHS clinic users. An element of service provision comes through quite strongly – when people are paying, they expect better standards.
- 1.2.5 Perhaps in line with increased pressures on the NHS over the past few years, those who used an NHS fertility clinic within the last two years are less likely to say they are satisfied than those who used one between two to five years ago (52% vs. 72%). However, this shift is not mirrored in the private healthcare system with 81% of those that had treatment in the past two years saying they are satisfied, compared to 83% of fertility clinic users two to five years ago.

Communicating and interacting with healthcare professionals

- 1.2.6 The vast majority (82%) of fertility clinic users say they are comfortable asking questions and many feel that they are listened to when they do ask questions. However, sometimes the amount of information received in the consultation can be overwhelming, and it would be helpful to have hard-to-access information recorded to take away, either in note form or as a voice recording.
- 1.2.7 For around three in four (74%) the success rates were felt to be clear. However, one in four (26%), felt the chances of success were not made clear and some said it made the process harder to comprehend.
- 1.2.8 For most (76%), the detail provided about their treatment (often formalised as a 'treatment plan') was 'just about right', while for one in five (19%) there is too little detail. From this it can be inferred that it is about giving patients enough detail, but without overwhelming them.



Emotional support

- 1.2.9 Although three quarters (75%) remember receiving information about how to access counselling, one in five (20%) report not receiving any information. Mandatory pre-treatment counselling for sperm donors is seen as useful, but there is quite a mix of comments on counselling overall, dependent on the counsellor themselves and format (e.g. group, partner). There are calls for counselling at points further along the fertility journey.
- 1.2.10 The most helpful forms of support tend to be people they already know, with 48% saying their partner was helpful and 41% friends and family. For 31% it was an online support group. During treatment, nurses are perceived to be the most approachable (78%), whilst consultants are slightly less so (63%).

Respect and dignity

- 1.2.11 Patients were more likely than partners to say that they felt involved and treated with respect and dignity in certain aspects of the fertility treatment process; those participating in the focus groups suggested that female partners are likely to feel more involved than male partners.

Cost and treatment add-ons

- 1.2.12 The most commonly used treatment add-ons were clinical techniques, such as an endometrial scratch (27%), embryo glue (23%) or embryoscope (22%). Holistic add-ons are less often mentioned, although around one in four (26%) had had acupuncture in the last two years.
- 1.2.13 The majority (77%) of those that had treatment add-ons were satisfied that the costs were open and transparent, however, some paid slightly more than expected.



Overall satisfaction

- 1.2.14 Three quarters (75%) of those that used a fertility clinic in the past two years say they were satisfied with the fertility treatment overall. There are no significant differences in satisfaction levels among private / NHS clinic users, between patients and partners, nor between those that had undergone more or less cycles. The outcome is a key determinant in overall satisfaction; around nine in ten (89%) of those that were successful say they are satisfied overall, with no one saying that they were dissatisfied. For those that were unsuccessful, three in ten (30%) say that they were dissatisfied. Yet even for those who were ultimately unsuccessful, for over half (52%), their view of the overall process was predominantly positive.
- 1.2.15 The key driver model shows that the main drivers of satisfaction are the “interest shown in you as a person”, the quality of counselling (for those that received it) and the coordination and administration of treatment. Relative to other high impact aspects of patient satisfaction, the “interest shown in you as a person” is not as well rated. Improving patient satisfaction for this measure is likely to have the greatest impact on overall satisfaction with the fertility treatment process as a whole.
- 1.2.16 The advice provided by GPs and the ease of access to fertility treatment are the lowest performing measures for patient satisfaction, however they are not significant drivers of overall satisfaction, perhaps because of that applies only to one early stage in the journey.

HFEA

- 1.2.17 Over seven in ten (71%) are aware of the HFEA. This is highest amongst those who have undergone five or more cycles which rises to over eight in ten (84%), which is significantly higher than those who have had three to four (77%) or one to two cycles (68%).



2 Methodology

- 2.1.1 To help inform questionnaire design, involve patients in that process and generate insights for this report we held four focus groups – in London and Manchester, and four online focus groups to allow patients and partners based across the UK to participate. These were formed of patients with male partners and there were an additional eight one to one in-depth interviews conducted with patients with same-sex partners, or no partner, again spread across the UK.
- 2.1.2 All respondents in the qualitative phase were either in the process of receiving fertility treatment, or had been through the process in the last two years (with either a successful or an unsuccessful outcome). Within the sample, there was a skew towards IVF (male partners) that is in line with the statistics on the number of treatments each year. The approach also included IUI or IVF (female partners, no partner), and a mix of those using NHS / private treatment. There was a mix of social grade and location (mix of urban / rural, and spread of locations across the UK) whilst their age fell out naturally in recruitment.
- 2.1.3 The quantitative phase was based on the findings from the qualitative phase. The questionnaire was tested through a set of cognitive interviews with patients and amended after their feedback. The survey was conducted online and disseminated through a number of different channels, including the YouGov research panel and an open survey link, which was posted on various media channels.
- 2.1.4 The survey was carried out between 3rd September and 2nd October 2018. The total number of responses was 1,017 patients or partners and the data was weighted to be representative by treatment type, age, region and partner status according to statistics provided by HFEA.
- 2.1.5 The main focus of this report is on those who used a fertility clinic in the last two years, of which 637 responses were achieved. Comparisons are made with those who used a clinic between two and five years ago, a total of 295 responses. Summary figures are given for those that had treatment in the last five years, totalling 932 respondents.



- 2.1.6 Throughout the report, we highlight interesting differences between sub-groups (often marked with a circle on the charts) where these are significantly different than could be expected by chance ($p < 0.05$). The data is analysed by patient / partner status, most recent clinic type, location, funding and number of cycles, and success of treatment.
- 2.1.7 Further details of the respondent breakdown within the data can be found in Appendix A.



3 The route to fertility treatment

3.1 Accessing information

Summary of key findings

- When seeking out initial information about fertility treatment, the most popular sources for those that used a fertility clinic in the past two years were search engines (60%), clinic websites (51%), the HFEA website (45%) or their GP (41%).
- Similarly, those that used a fertility clinic in the past five years were most likely to use search engines (57%), clinic websites (49%) and their GP (43%) to find out information.
- Of those that used a fertility clinic in the last two years and spoke to a GP about their options, around half (54%) were satisfied with the advice provided.
- This is similar to the overall group that had treatment in the past five years, of which 56% say they were satisfied with their GP's advice.

3.1.1 When those who used a UK fertility clinic within the past two years first thought about fertility treatment, three in five (60%) turned to search engines to find out more information. An increasingly popular information source, only half (50%) of those who used a fertility clinic between two and five years ago said they used them to find out more. When using search engines to seek out information on fertility treatment, most use key search terms – such as ‘not conceived after a year’ or ‘IVF’ – to help refine their search.

3.1.2 Following this, the most popular sources of information were clinic websites (51%), the HFEA website (45%) or their GP (41%).

3.1.3 Clinic websites allow patients to assess the range of treatment options available and review treatment prices. Most also seek out additional information on clinic websites – including information on the consultants (e.g. credentials) and success rates. These factors are felt to give them a steer on treatment quality. Those using the HFEA website are positive about the treatment descriptions contained on the site.



3.1.4 Additional information sources include fertility blogs and forums – where they are looking for information about the patient / clinic experience – and open evenings and fertility fairs. Clinic open evenings allow them to review facilities, speak to staff and seek out additional information. Individuals speak positively about fertility fairs, which allow them to see a number of clinics in one place, though these can be overwhelming.

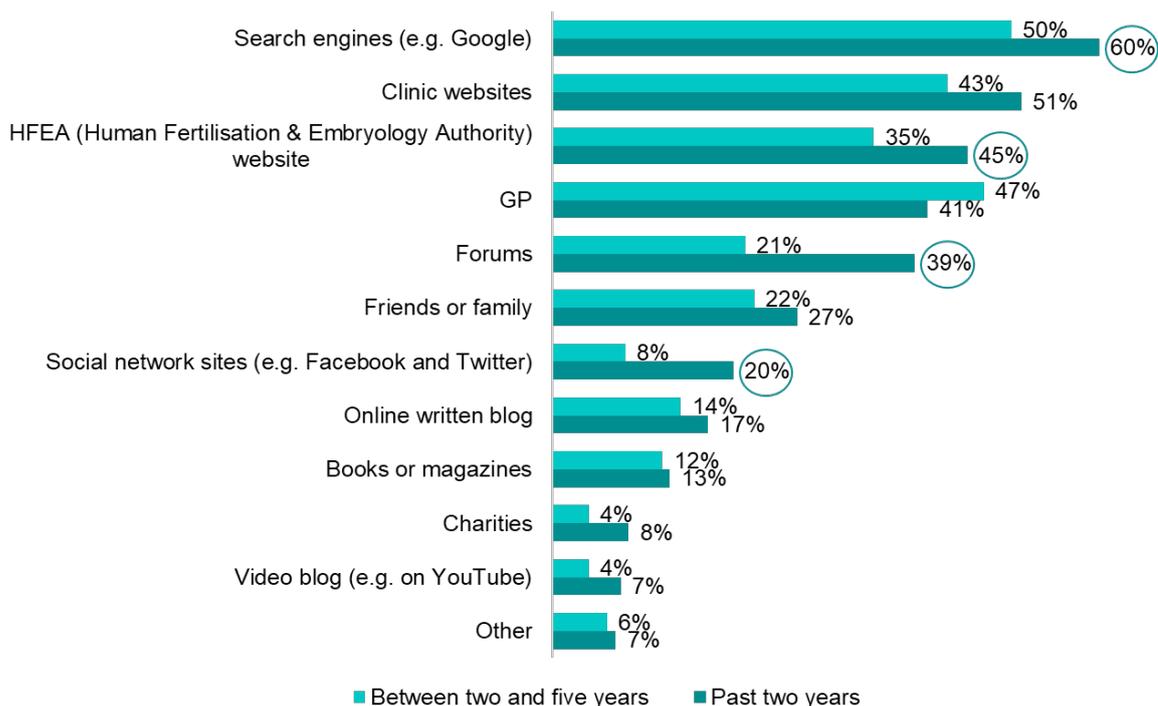
“[The] GP was the first point of call and then a bit of research. My sister-in-law had had IVF, and I went to the clinic she recommended – if she hadn’t recommended it I’d still be looking into it now” (focus group participant)

“I initially looked into clinics advertised on the tube, then I started researching clinics via Google and online forums” (focus group participant)

“I went to the fertility show – lots of different clinics [all in one place], and people from the association of acupuncturists. There were workshops and shows” (focus group participant)



Figure 1: When you first thought about fertility treatment, which, if any, of the following did you use to find out more?



Base: All who used a UK fertility clinic within last two years (N=637); between two and five years ago (N=295)

- 3.1.5 In an interconnected world, forums are an increasingly common information source when looking for information about fertility treatment. Around two in five (39%) fertility clinic users in the last two years cited them, slightly higher than around one in five (21%) of those that had treatment between two and five years ago.
- 3.1.6 In line with these findings, social network sites have also increased in popularity over the course of the past few years, with one-fifth (20%) of clinic users in the past two years saying they use them, compared to 8% of those that used a clinic between two and five years ago.



- 3.1.7 The use of search engines amongst recent fertility clinic users is consistent regardless of where they most recently received treatment. However, those who most recently visited a private clinic (with or without NHS funding) were more likely to use clinic websites than those who most recently used an NHS clinic (56% vs. 44%).
- 3.1.8 Similarly, those whose most recent treatment was at a private clinic were also much more likely to use the HFEA website for initial information, compared to those who visited NHS clinics (50% vs. 37%).
- 3.1.9 The use of the HFEA as an initial source of information about fertility treatment has risen significantly – those who used a clinic within the last two years are significantly more likely to have turned to the HFEA than those who visited a clinic between two to five years ago (45% vs. 35%).
- 3.1.10 Just over three quarters (78%) of those who have visited a fertility clinic in the past two years spoke to a GP about their options when they first started thinking about fertility treatment. This has not significantly changed over time.
- 3.1.11 GPs – the medical professionals patients are most familiar with – are often seen as a key access point to treatment. Indeed, as the first step towards NHS funding or advice and guidance, they play an important role in the referral process. While patients recognise that GPs are not fertility specialists and won't have 'all the answers', they do expect to them to provide information and guidance at this stage. They do not, however, always get the practical information / guidance that they require, and some see GPs as a barrier to treatment. Many patients said that they were simply told to 'carry on trying' to conceive naturally, or to 'give it more time' when they first visited their GP, adding more time to the process and drawing out the experience.

“GP was dismissive, blasé, said that most wouldn't fall pregnant in first year and a half... I was referred after a third appointment” (focus group participant)



“The GPs had very little subject specific info so referred us straight to a fertility clinic... We were expecting a lack of knowledge but still found it unacceptable” (focus group participant)

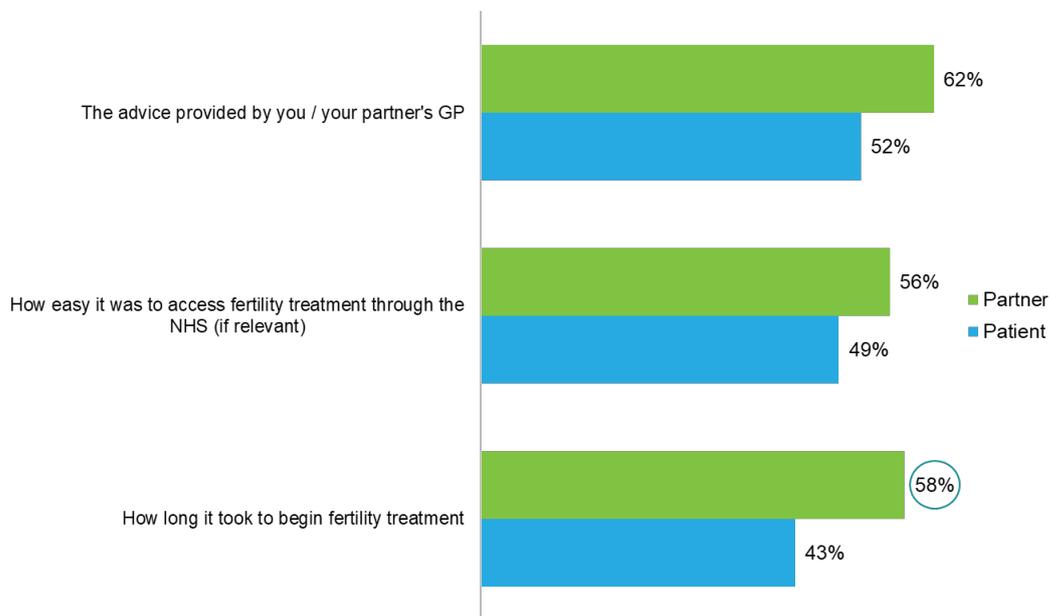
- 3.1.12 The result of this, those that were not satisfied with the advice provided by their GP were significantly more likely to be private clinic users (79% vs. 52%), whilst those satisfied were more likely to have used an NHS clinic most recently (46% vs. 21%). This suggests that experiences with GPs, whether positive or negative, play a key role in the decision regarding clinic type.
- 3.1.13 Those in London and the South East were much less likely to speak to a GP than those from other areas in the UK – 72% and 83% respectively.
- 3.1.14 Those who used a private clinic in the last two years were less likely than NHS clinic users to say they spoke to a GP about their options (76% vs. 84%).
- 3.1.15 Information from friends and family plays a role for just over a quarter (27%). In the earliest stages of the journey, recommendations from friends, family and work colleagues help to shape treatment choices. Their honest, impartial information is trusted, and helps them to get a real sense of the fertility treatment experience.

3.2 Initial satisfaction

- 3.2.1 Of those who spoke to a GP when they first considered fertility treatment, just over half (54%) were satisfied with the advice provided. However, a quarter (26%) say they were dissatisfied by the advice provided, significantly higher for patients (29%) than partners (14%).
- 3.2.2 There were not significant differences in initial satisfaction with regards to age or treatment type.
- 3.2.3 Of those that used a fertility clinic in the past two years, partners were more likely than patients to say that they were satisfied with how long it took to begin fertility treatment (58% vs. 43%). There were not significant differences in satisfaction levels between patients and partners with regards to the advice provided by a GP and the ease of accessing fertility treatment through the NHS.



Figure 2: When you first thought about fertility treatment, how satisfied or dissatisfied were you with...?



Base: All patients / partners who used a UK fertility clinic within last two years (N=522 / 115)



- 3.2.4 Many dissatisfied patients did not receive the advice / support they expected from their GP. Being told to 'wait one to two years' for treatment, or to 'continue trying to conceive naturally' is seen as very 'dismissive' – especially if they're not given any advice on what they can do to increase their chances of conceiving in this time. Others also comment on GPs being insensitive – for example, telling them they're too old for fertility treatment or too overweight to conceive – which can be upsetting and hurtful. Negative experiences at this stage can colour respondents' expectations of the future fertility journey. In contrast – positive experiences with GPs at this stage can have a positive impact on the overall experience. For example, GPs that are proactive around the referral process (e.g. referring patients to a clinic / specialist quickly), or GPs that have a good working understanding of the treatment process and can offer information / advice (e.g. about the different options available / most suitable options), are positively received as they can help patients to access the right type of treatment for them, and move through the system at speed.
- 3.2.5 Half of those who have accessed fertility treatment via the NHS were satisfied with how easy it was to do so; the referral process from GP to NHS clinic is generally said to be quick and easy. However, once they are in the system, accessing treatment can be more challenging. Many comment on poor internal comms (e.g. doctors not reading notes, doctors not knowing what other doctors are doing), and some also comment on logistical challenges (e.g. being sent to different NHS units for different tests / treatments). This can draw out the process.
- 3.2.6 Those living outside London and the South East were significantly more likely to be satisfied with the ease of getting fertility treatment via the NHS than those in London and the South East (57% vs. 43%).
- 3.2.7 Just under half (46%) said they were satisfied with how long it took to begin fertility treatment. Those whose most recent treatment was in a private clinic were significantly more likely to say they were satisfied (53%) than those who visited an NHS clinic (36%). However, those using their own funding and those who sought NHS funding had comparable satisfaction on the time it took to begin fertility treatment (both 47%).



3.3 Accessing treatment

Summary of key findings

- For those that had treatment in the last two years, the location (51%), information about success rates (44%) and having a good first impression of the clinic and staff (36%) were the most important reasons for choosing a clinic.
- Overall for those that had treatment in the last five years, the most important reason for choosing a particular clinic is also location, with half (51%) citing this reason. Information about success rates (41%), GP referral (35%) and a good impression of the clinic and clinic staff (34%) are the next most important reasons.

3.3.1 The most popular reasons for choosing a particular clinic, for those that had treatment in the last two years, were the location (51%), information about success rates (44%) and having a good first impression of the clinic and staff (36%).

3.3.2 It is unsurprising that location is key. Ultimately, a clinic must be convenient so that they can fit their treatment into their lives, and many look for clinics close to work or home. Success rates are an important consideration in the shortlisting process. While success rates are based on generalisable (versus specific) data, it does serve as a guide; a high success rate can be enough to tip the balance if they are deciding between two clinics. Finally, the impression of the clinic. In terms of the opening hours, flexible appointment times, facilities and atmosphere also plays a role. Patients want to receive treatment in a comfortable, supportive environment.

“Success rates were quite influential – the main thing over locality. They break it down from successful pregnancies and successful live births so it was easy to understand” (focus group participant)

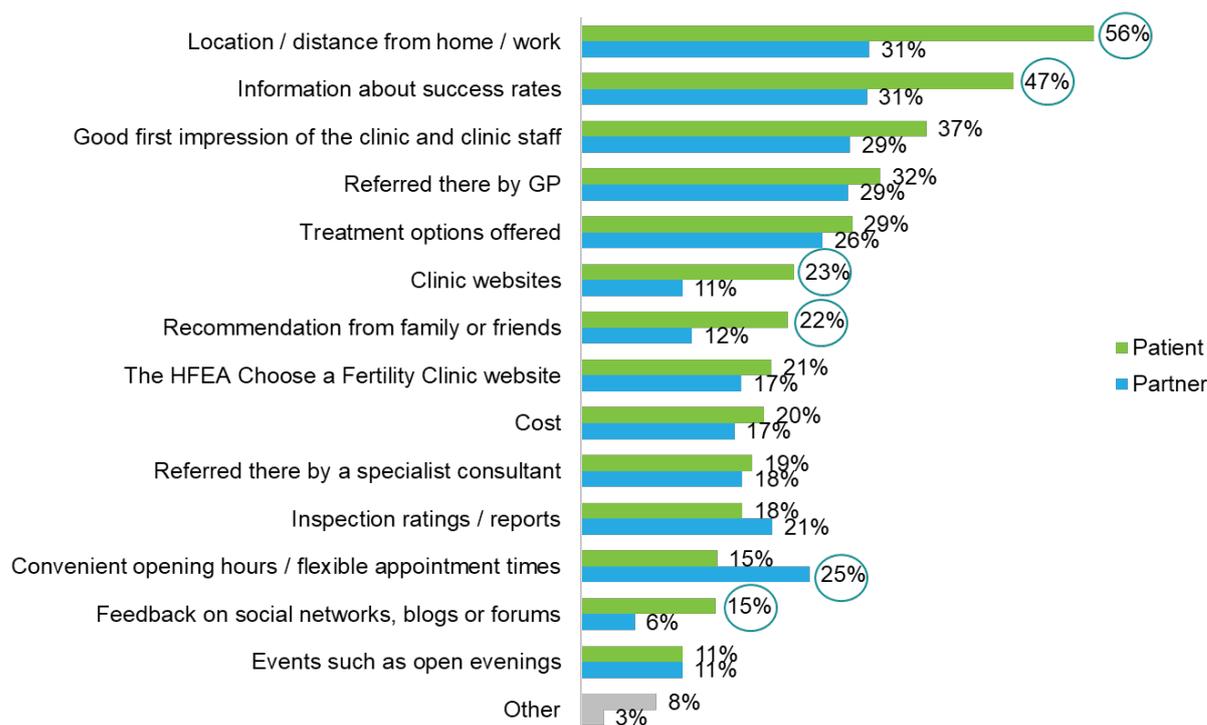
*“Success rates are a big thing, if they don't have great success rates it makes you not want to use them – there is obviously a reason...”
(focus group participant)*



“We looked on the internet to find the right clinic – focusing on reviews and success rates, and picked a clinic based on these factors – plus being nearby” (Interview participant)

“We preferred the consultant at one clinic, the one we ended up using, because he was more forthcoming with information and broke things down better. He seemed competent and knowledgeable, even if he was a little bit blunt” (Interview participant)

Figure 3: Which of the following were the most important reasons you used a particular clinic or clinics? Please tick the 6 most important reasons.



Base: All patients / partners who used a UK fertility clinic within last two years (N=522 / 115)



- 3.3.3 A fifth (20%) of those that had treatment in the past two years considered the HFEA 'Choose a Fertility Clinic' website an important tool in choosing a particular clinic, particularly the information it provides on location and success rates. Seeing the HFEA website as an important source of information has significantly risen - only one in nine people (12%) who had treatment between two and five years ago remembered it as an important reason to choose a clinic.
- 3.3.4 Partners of those undergoing fertility treatments are more likely than patients to consider convenient opening times a key reason to choose a clinic, while patients are more likely to prioritise location, success rates, recommendations, and social network feedback.



4 The patient experience

4.1 Organisation and coordination of care

Summary of key findings

- Of those that used a fertility clinic in the last two years, the majority (73%) are satisfied with the coordination and administration of treatment.
- This is similar to the total figure for those that had treatment in the last five years, of which around three in four (74%) were satisfied.
- Over two thirds (70%) of those who used a fertility clinic in the last 2 years were satisfied with the length of time between appointments and over half (55%) were satisfied they could contact a named person at the clinic.
- In total, those that had treatment in the past five years were more likely to say they were satisfied between the length of time between appointments (72%) and that they could contact a named person at the clinic (58%).

4.1.1 Satisfaction surrounding the organisation and coordination of care is high, with the majority (73%) of those who have visited a fertility clinic in the past two years saying they are satisfied with the coordination and administration of the treatment. This is significantly higher for those whose most recent treatment was in a private clinic (78%) than for those who most recently used an NHS clinic (65%). This reflects the findings of the qualitative phase which indicates that while access to treatment is relatively consistent across NHS / private clinics, private clinics are said to be more flexible in terms of access to appointments, and in ensuring a dedicated contact across the fertility treatment journey (especially for those that have had experience of both NHS and private treatment).

4.1.2 For each of the measures of satisfaction surrounding the organisation and coordination of care, those who most recently used a private clinic are more likely to be satisfied than those whose most recent treatment was in an NHS clinic. This could be a result of increasing pressures on the NHS, which have not impacted private healthcare services in the same way.



Figure 4: Coordination NHS / Private

Those using **NHS clinics** report some challenges with accessing appointments and waiting times, and in having a consistent designated contact; however, most are relatively happy with the experience.

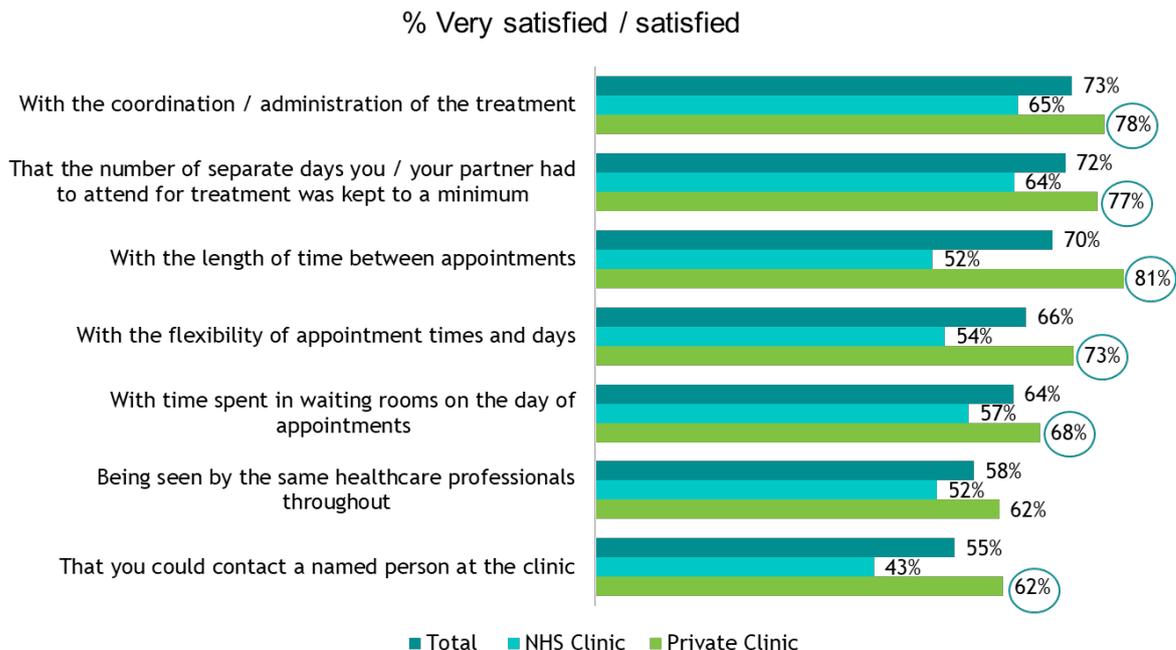
- **Access to appointments** can, for many, seem limited and inflexible (especially by those that have experienced both private and NHS treatment). With few appointments early in the day or late afternoon / early evening, fitting appointments around work / other commitments, can be challenging
- **Waiting times** are only problematic when delays aren't effectively communicated; patients understand that delays can occur, but when it's up to 30 minutes and they've not been updated, it can be very frustrating.
- **Continuity of care** is generally good, especially if they've completed several rounds of treatment and have a 'treatment team'; continuity of care is especially important with regards to consultants, as it means they understand their patients' history and know about their key needs.
- **Designated contacts** may be available to patients (phone numbers / emails of nurses / consultants), but accessing their support is not always easy (e.g. unanswered emails).

Those receiving treatment in **private clinics**, are broadly more positive about the experience. However, as they're paying for treatment, they have higher expectations for the treatment they receive.

- **Access to appointments** is considered to be excellent, as clinics offer flexibility (e.g. early / late time slots), and a range of facilities (e.g. parking), so that patients can fit appointments into their lives
- **Waiting times** are rarely an issue, with only minor delays reported. When there are delays, these are clearly communicated, and staff are very apologetic.
- **Continuity of care** is generally excellent, with most saying that they have the same 'team' each time; continuity of consultant / embryologist etc., is considered to be crucial.
- **Designated contacts** are a key part of the private clinic experience; respondents report having designated contact numbers (for nurses and consultants), plus emergency numbers too (minority).



Figure 5: How satisfied or dissatisfied were you with these aspects of organisation and coordination?



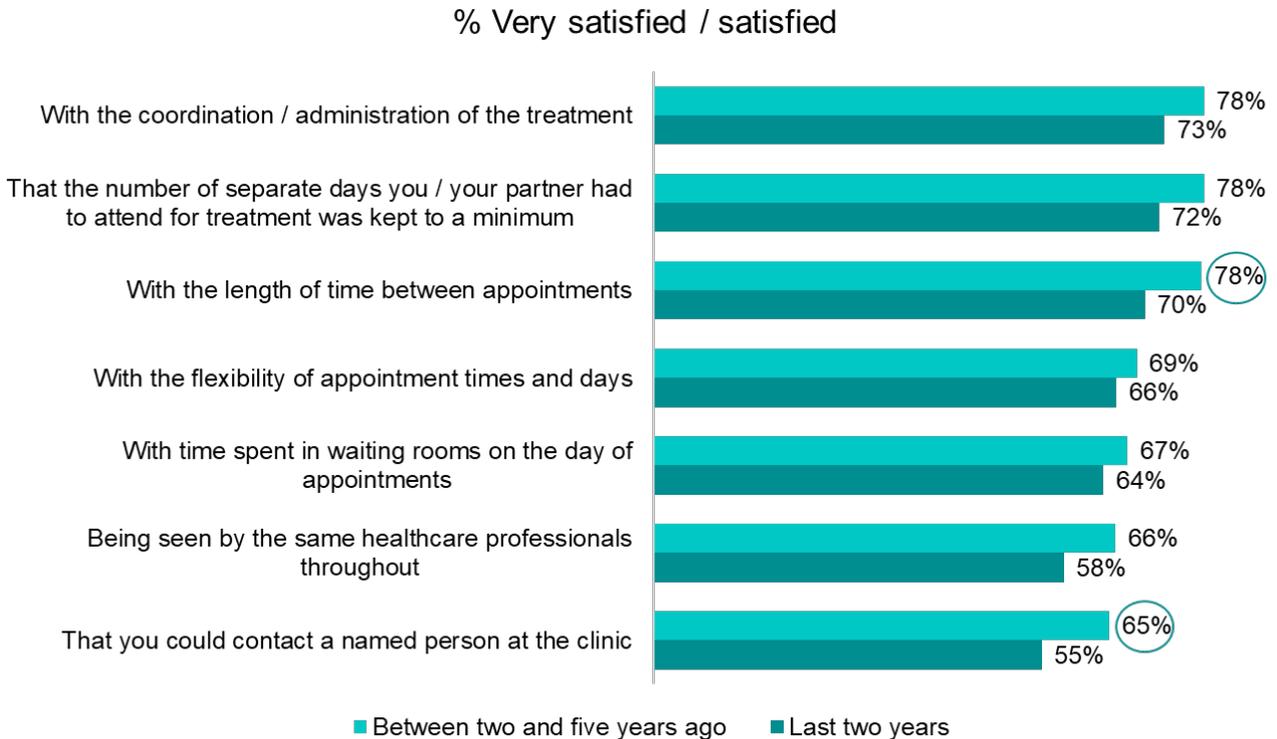
Base: All who used a UK fertility clinic within last two years (N=637); Private Clinic (N=386); NHS Clinic (N=244).

- 4.1.3 The biggest disparity between satisfaction levels of those who most recently used a private clinic, as opposed to NHS clinic users, is with the length of the time between appointments (81% vs. 52%). However, there is not such a significant difference in satisfaction about being seen by the same healthcare professionals throughout (62% vs. 52%).
- 4.1.4 Those that had undergone five or more cycles were more likely than those who were in their first or second cycle to say that they were satisfied with the length of time between appointments (85% vs. 65%).
- 4.1.5 Additionally, those who used a fertility clinic between two to five years ago are more likely to say they were satisfied with the length of time between appointments than those in the past two years (78% vs. 70%).



- 4.1.6 The difference in satisfaction levels with the length of time between appointments is particularly pronounced when considering those whose most recent treatment was in an NHS clinic. For those that had treatment between two to five years ago, over three in five (72%) say they were satisfied. This has fallen significantly, and for those that had treatment on the NHS in the past two years, 52% were satisfied – a decrease of 20 percentage points.
- 4.1.7 Whilst there has been a significant decline in satisfaction with waiting times for NHS clinic users, this shift is not mirrored in the private healthcare system. Satisfaction has remained fairly stable for those who most recently used a private clinic with 83% of those who have treatment between two and five years ago saying they were satisfied, compared to 81% of those who had treatment in the past two years.

Figure 6: How satisfied or dissatisfied were you with these aspects of organisation and coordination?

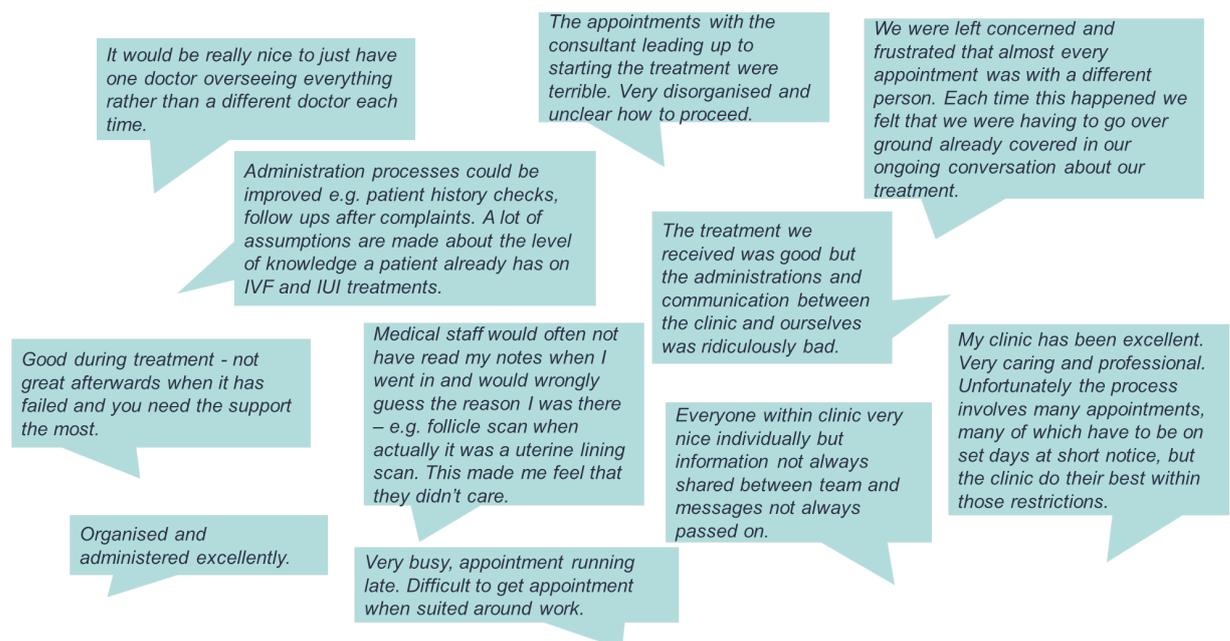


Base: All who used a UK fertility clinic within last two years (N=637); between two and five years ago (N=295)



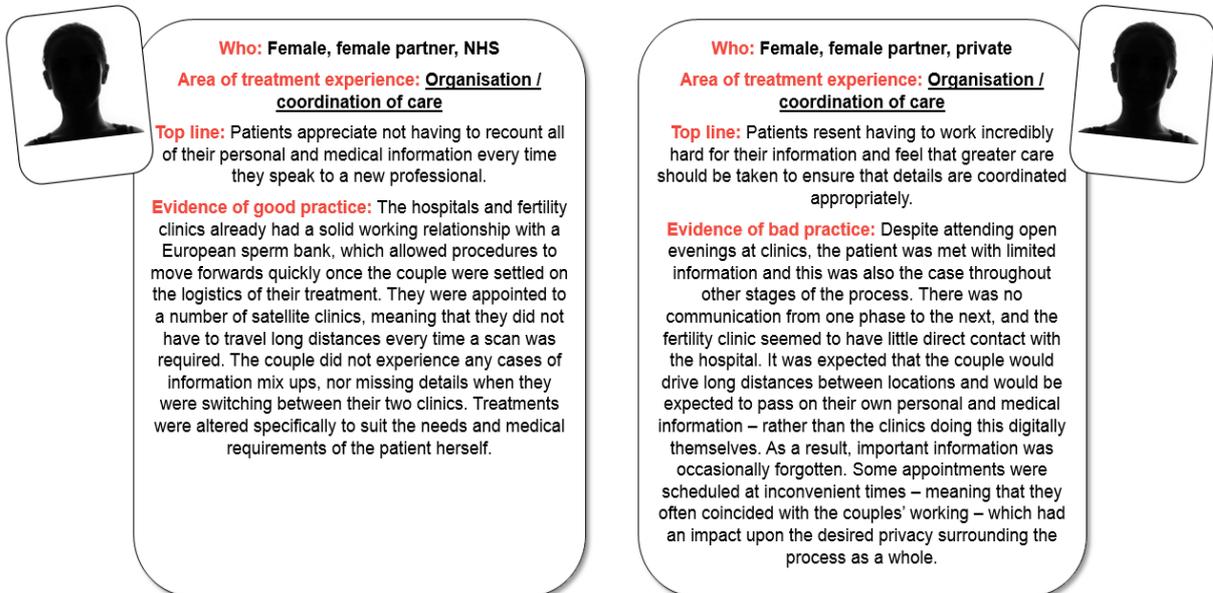
- 4.1.8 Additionally, those that had treatment in the past two years were more likely to say that they were dissatisfied with being able to contact a named person at the clinic than those that had it between two and five years ago – 27% and 18% respectively.
- 4.1.9 Whether or not the treatment was successful did not affect satisfaction levels regarding organisation of care, with no significant differences between the two groups.
- 4.1.10 Although the majority were satisfied with various aspects of the organisation and coordination of care, when asked to expand on their experiences, it became evident that a large number felt frustrated with the administrative process. For some, this was a result of a lack of communication, a sense of confusion and errors being made.

Figure 7: If you have any comments or experiences you would like to share about the coordination of treatment.



- 4.1.11 Case studies illustrating both positive and negative patient experiences of organisation / coordination of care are shown below.

Figure 8: Case studies of organisation and coordination



4.2 Communication and interaction with healthcare staff

Summary of key findings

- The majority (82%) of those that used a fertility clinic in the past two years said they felt comfortable asking questions, similar to the overall figure for those that used a clinic in the last five years (83%).
- Two thirds (69%) of those that had treatment in the last 2 years said they had enough time with the healthcare professionals. This is slightly lower than the overall figure for those that had treatment in the past five years (72%).
- For those that had a treatment plan in the last two years, the detail was mostly just about right (76%). For one in five (19%) there is too little detail.
- Similarly, for those that had a treatment plan in the last five years, the detail was mostly just about right (77%). For over a quarter (17%) there was too little detail, and for a small minority (3%) there was too much detail.



- 4.2.1 With regards to communication and interaction with healthcare staff, over four-fifths (82%) felt comfortable asking questions; around seven in ten (72%) felt involved in treatment decisions and felt that they were listened to. They were least likely to say that they felt able to provide feedback at any time, however this was still a sizable number (63%).
- 4.2.2 In the focus groups, few reported concerns about raising questions during appointments / consultations. However, having the option to ask questions after consultations is also key. The amount of information shared in consultations can be overwhelming, and many said that it was only after they had left the room that they would think of questions to ask, this is especially the case during the first round of treatment when there is a lot of new information to digest.
- 4.2.3 Most agree that they feel that they are listened to when they ask questions. However, some medical professionals are seen as more open and approachable than others; a sizeable minority say that consultants can be rushed and dismissive in comparison to nurses, but they recognise that this is partly due to the complex information they are imparting.

“There was no judgement... they told us there is no such thing as a stupid question” (focus group participant)

“[With] our main doctor, it felt like you were always in and out – she was way too busy to be there, she had too much other stuff to do – it felt like you were a science experiment...” (focus group participant)

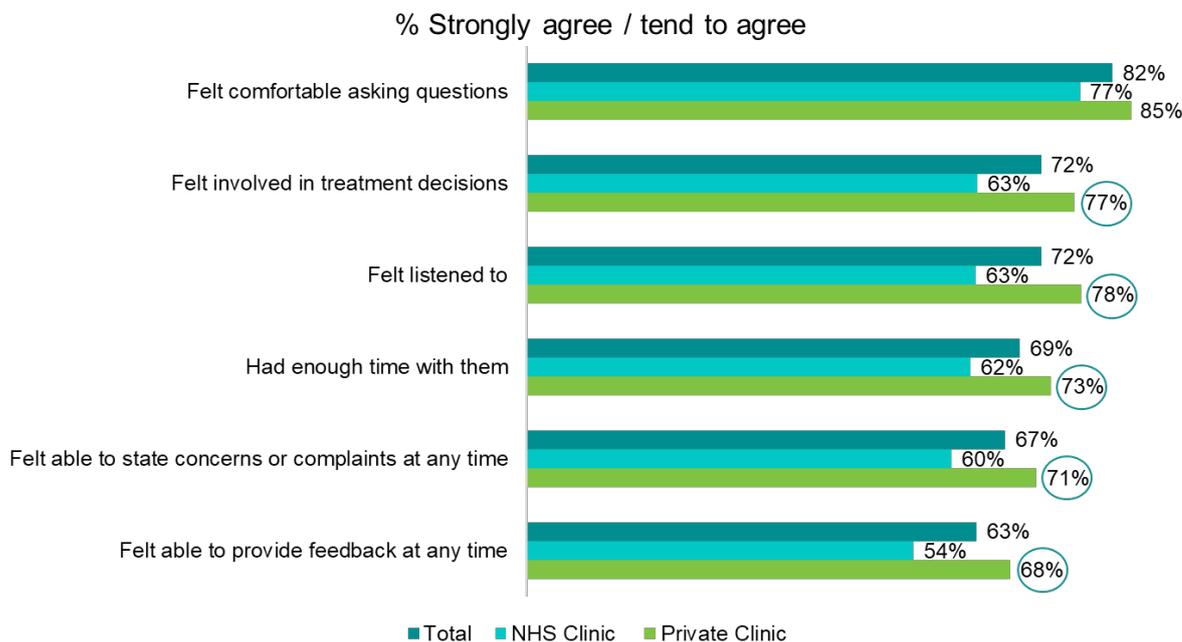
“There were times when we felt we weren't given enough time to take in all the information” (focus group participant)



4.2.4 When it comes to best practice, it’s clear from the qualitative phase that patients are looking for medical professionals that give them time to digest information and give them the opportunity to ask questions wherever required – be it in the consultation room, or later on (via email or phone). Patients also welcome the opportunity to ask the less serious or ‘silly’ questions they may have, without judgement. Bad practice in here relates to medical professionals being – or appearing – too busy for patients to ask questions, or dismissing any questions that patients raise.

4.2.5 For each of the statements, and in line with earlier findings, those whose most recent treatment was in a private clinic were more likely than those who used an NHS clinic most recently to say they agreed with the statements.

Figure 9: To what extent would you agree or disagree with the following aspects of communication and interaction...



Base: All who used a UK fertility clinic within last two years in a Private clinic (N=386); NHS clinic (N=244).

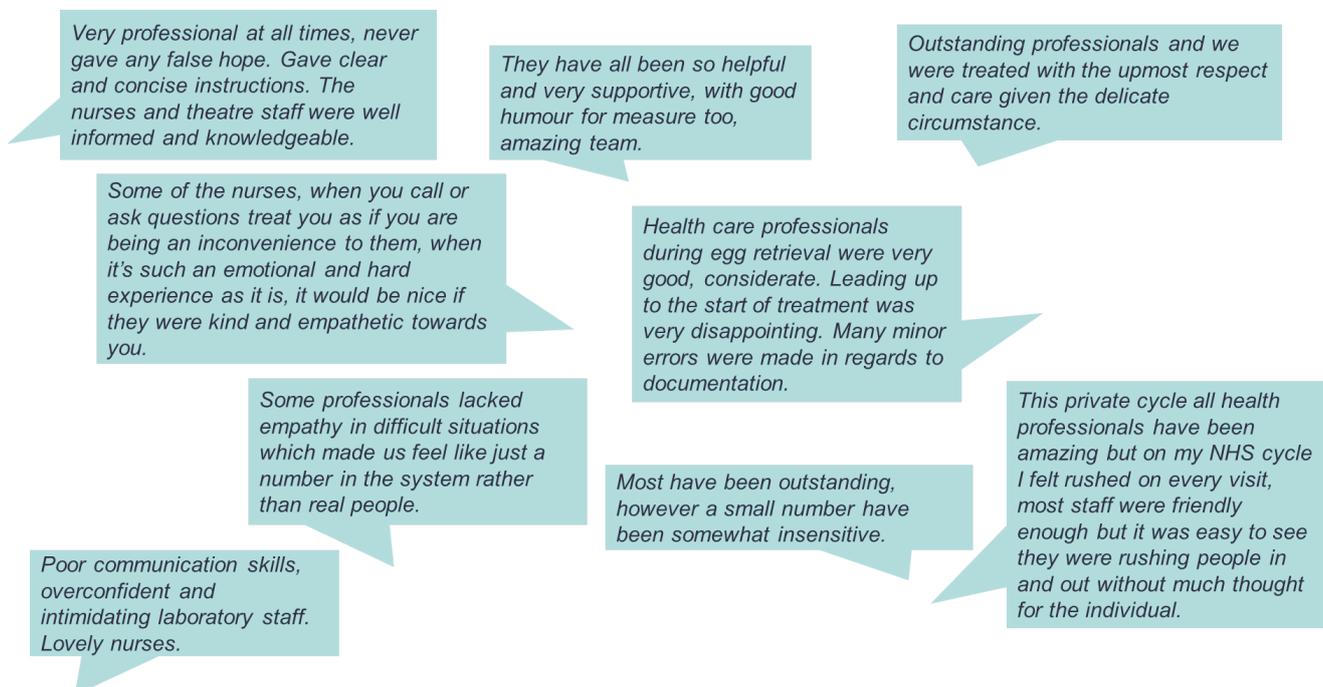


- 4.2.6 Over a quarter (27%) of NHS clinic users disagreed that they had enough time with the healthcare professionals, dropping to one-sixth (16%) of those who most recently used a private clinic. NHS clinic users were also more likely to disagree that they felt comfortable to provide feedback at any time (30% vs. 17%) and that they felt comfortable asking questions (15% vs. 6%).
- 4.2.7 Those who used a fertility clinic in the past two years were more likely than those who did between two and five years ago to say they were dissatisfied that they had enough time with the healthcare professionals (21% vs. 12%).
- 4.2.8 They are also more likely to disagree they felt able to state concerns or complaints at any time (20% vs. 13%) and that they felt able to provide feedback at any time (22% vs. 14%).
- 4.2.9 Those who received treatment in London and the South East were less likely than those elsewhere in the UK to say they felt comfortable asking questions – 77% and 86% respectively.
- 4.2.10 Patients that had undergone five or more cycles were more likely to say that they felt involved in the treatment decisions than those that had just completed one cycle (80% vs. 65%). With more cycles we might expect higher levels of knowledge and, possibly, involvement as a result of experience.
- 4.2.11 Many spoke very highly of the healthcare professionals they encountered, praising their support and professionalism. Yet, perhaps a result of the amount of people requiring treatment, some felt that the healthcare professionals lacked empathy and that the process felt rushed.
- 4.2.12 When it comes to providing feedback, some are actively doing this during treatment (feeding back negative experiences about, for example, counselling), or at the end of their treatment via feedback forms. However, not all felt comfortable providing feedback during the treatment process; the qualitative phase suggest that some individuals were concerned about the potential repercussions on their future treatment if they provide negative feedback during treatment itself.



4.2.13 Very few can recall being told about formal feedback channels upfront and, perhaps as a result of this, few see this as an official part of the treatment process. When feedback is sought from patients it is at the end of the process. However, some would prefer this to come one to two months later, when they have processed the outcome (especially where this has been a negative outcome), and can provide more focused feedback.

Figure 10: If you have any comments about your experiences with health professionals please type in here.



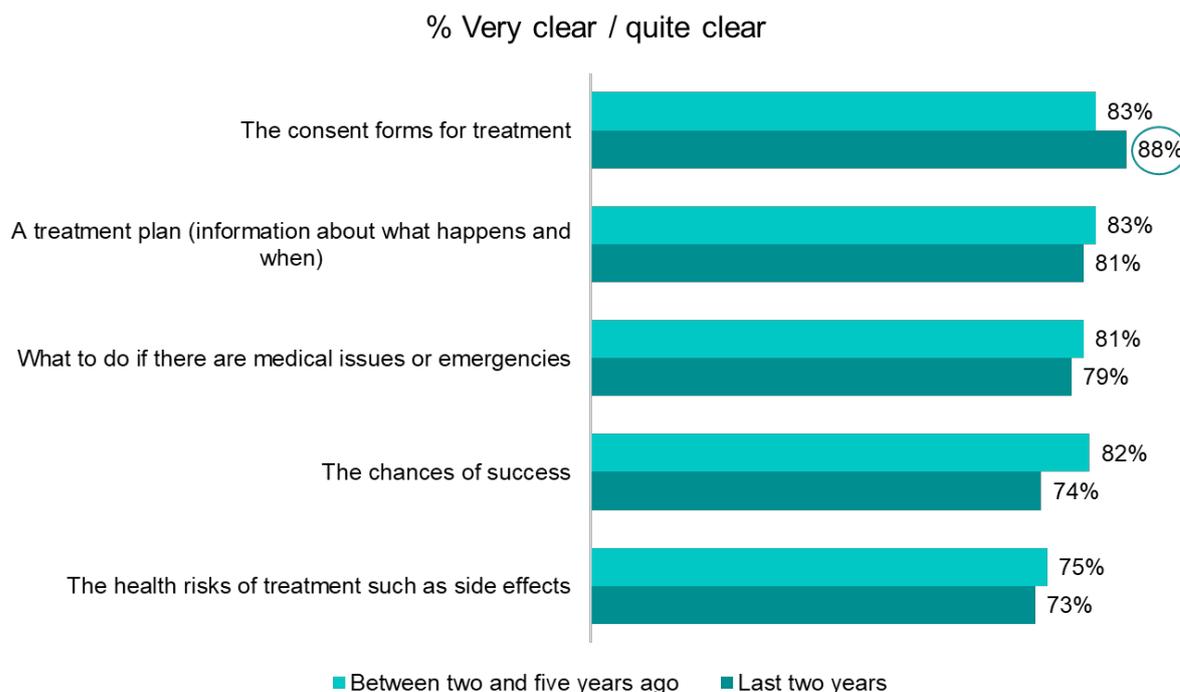
4.2.14 For the most part, the details of the treatment – consent forms, plan, and chance of success – were communicated clearly. The vast majority (86%) of those who have visited a fertility clinic in the past two years said that the consent forms for treatment were clear. Patients were more likely than partners to feel the consent forms were clear (89% vs. 72%), contributing to a narrative that partners did not always feel included and informed about all aspects of the process.



- 4.2.15 A similar proportion (81%) felt that the treatment plan (information about what happens and when) was clear. This is significantly higher for those whose most recent treatment was in a private clinic (84%) than for those who used an NHS clinic (75%).
- 4.2.16 A quarter (26%) of those who used a fertility clinic in the past two years felt the chances of success were not made clear to them. This is significantly higher than for those that had treatment between two and five years ago, of which 17% said they were not clear. Qualitative insight indicates that chances of success are often explained in percentage terms – for example, ‘if do X you are Y% likely to conceive’, or ‘women aged X are Y% likely to conceive – which many find difficult to contextualise. This generalised information can be misleading as it does not take other factors, such as patients’ health status or lifestyle, into account.
- 4.2.17 This could feed into overall satisfaction, with three in five (62%) of those that were dissatisfied saying that the chances of success were not clear, compared to just 15% of those who were satisfied.



Figure 11: To what extent, if at all, were each of the following aspects clearly communicated to you by the clinic?



Base: All who used a UK fertility clinic within last two years (N=637); between two and five years ago (N=295)

4.2.18 For all of the statements, those who were given information on counselling were more likely than those who were not to agree with them, suggesting that some clinics have more comprehensive communication than others.



Figure 12: To what extent, if at all, were each of the following aspects clearly communicated to you by the clinic?

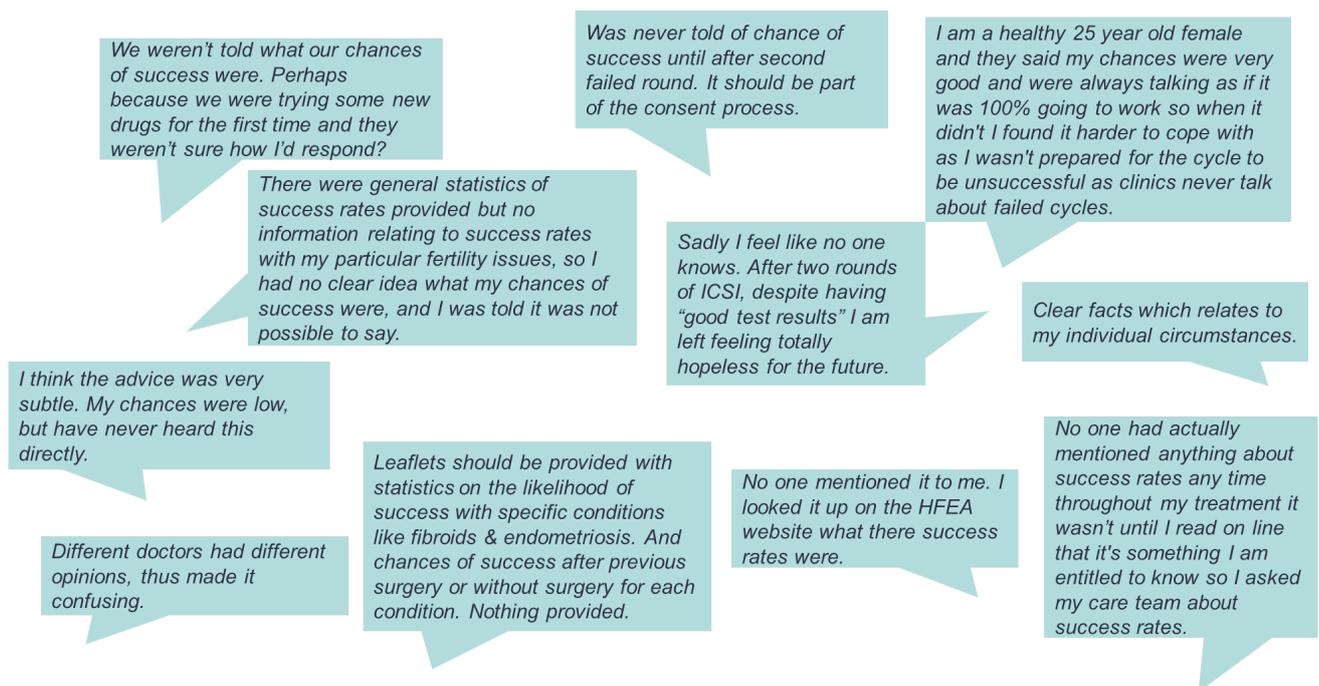
	Information on counselling	No information
The chances of success	81%	47%
A treatment plan	83%	73%
The consent forms for treatment	92%	68%
The health risks of treatment such as side effects	78%	55%
What to do if there are medical issues or emergencies	83%	61%

Base: All who used a UK fertility clinic within last two years that were given information on counselling (N=498); those that were not (N=113)

4.2.19 Not being informed of success rates left respondents confused, with some saying it made the process harder to comprehend. Information tailored to the individual would be useful (e.g. linked to their age and health status), especially if it were communicated at the start of the treatment process.



Figure 13: If you feel the chances of success were not clearly communicated, please add why you think that and what might make it clearer.

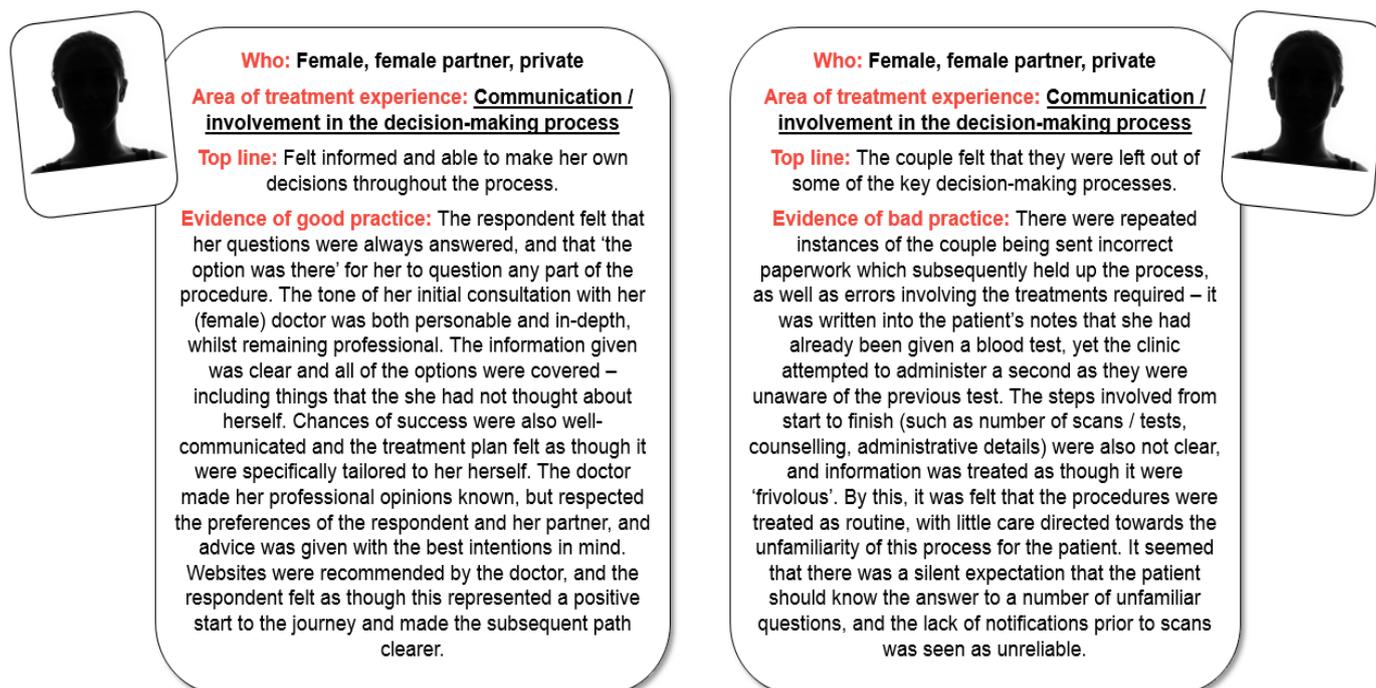


4.2.20 Three quarters (76%) of those who used a fertility clinic in the past two years felt the detail of the treatment plan was 'just about right'; nineteen percent said there was too little detail; and only two percent too much detail. This was the same for those whose most recent treatment was in a private clinic and an NHS clinic (76%), and for patients as opposed to partners (76%). Respondents that took part in the qualitative phase said that 'good' treatment plans were clear, well set out (e.g. with bullet point format and tables), with all of the important information clearly shown (e.g. timelines outlining when treatment would take place, when drugs should be taken etc.). There was a preference for succinct documents (e.g. in PPT format), rather than long Word documents. 'Poor' treatment plans tended to be either very long or very short, and therefore too detailed (to hold their attention), or not detailed enough (leaving them with questions). Ultimately, they're looking for a succinct treatment plan that gives them all the information they need (visually / graphically where possible), in a simple and succinct format.



- 4.2.21 Those who used a fertility clinic in the last two years were more likely than those who had it between two and five years ago to say that the treatment plan contained too little detail (19% vs. 12%).
- 4.2.22 Four out of five (81%) felt they would have known who to contact if there was a medical issue or emergency away from the clinic. This was significantly higher for those who have had five or more cycles (89%) than for those who had one (75%), which could be a result of the link between the length of time they have been trying for and increasing involvement.
- 4.2.23 Case studies illustrating both positive and negative patient experiences of communication are shown below.

Figure 14: Case studies of communication and interaction





4.3 Emotional Support

Summary of key findings

- For those that had treatment in the last two years, the forms of support most respondents considered helpful tend to be people they already know, with 48% saying their partner was helpful and 41% friends and family.
- This is similar for those that had treatment in the past five years; helpful forms of support cited were partners (45%), friend or family members (39%) and online support forums (28%). When thinking about which one of these was the most important, fertility clinic users were most likely to say their partner (35%).
- For those that had treatment in the last two years, nurses are perceived to be the most approachable (78%) during treatment, whilst consultants are slightly less so (63%).
- This is in line with those that had treatment in the last five years, where nurses were seen as the most approachable (76%) followed by doctors/consultants (65%) and reception staff (63%).

- 4.3.1 Fertility treatment is highly emotional and support – whether informal (such as friends and family) - or formal (such as counselling), is important.
- 4.3.2 Not everyone can recall being offered counselling. Three quarters (75%) of those in the past two years say they were given information about the clinic's counselling service and how to arrange an appointment with a counsellor. One in five (20%) reported that they were not given information about counselling services, and a further four percent were not sure if they had been.
- 4.3.3 This was similar for those whose most recent treatment was in a private clinic (76%), and NHS clinic (75%), and did not differ from patient (76%) to partner (72%). Those receiving treatment in London and the South East were less likely than those elsewhere in the UK to say they were offered counselling (83% vs. 67%).



4.3.4 While many are being offered counselling at some point during the process, the availability, frequency and quality of this is mixed. Quality of counselling is dependent on the individual counsellor in question, with factors including a counsellors' availability (for example, when the patient needed support following a miscarriage), their individual counselling style (e.g. using 'floury' language versus offering practical advice / support), and the amount information discussed (e.g. level of detail on the ethical considerations related to using donor sperm) all strongly influencing the experience.

"It was really good, it helped me realise I did want to carry on – it was focused on what I wanted" (focus group participant)

"It did make us think about stuff... potentially beneficial, definitely not detrimental" (focus group participant)

"The private [counsellor] was wishy washy – the NHS counsellor was more practical" (focus group participant)

"She [the counsellor] explained to me that... It would be more about talking about what had happened and how to deal with it... I decided to have another one after first round didn't work [and the counselling was] really good, it helped me realise I did want to carry on – it was very much focussed on what I wanted and what I wanted to do..." (interview participant)

4.3.5 The mandatory pre-treatment counselling for those using sperm donors is considered to be useful / informative. However, other pre-treatment counselling (e.g. group counselling 'forums'), where couples are brought together to hear about the options available, is less well received. It is said to be too generalised to be helpful, and too impersonal to resonate. Counselling at the end of treatment often focuses on the next round of treatment, rather than their emotional experience of the previous round. Some call for counselling one to two months after treatment when they are less emotional and can discuss their experience with greater clarity of mind.



“You have to have counselling when you have sperm donation, because of the non-anonymous thing ... and also again when we decided to do egg sharing. But it was not offered at other points” (focus group participant)

“They talked about the impact of using donor sperm... it will be different for the babies” (focus group participant)

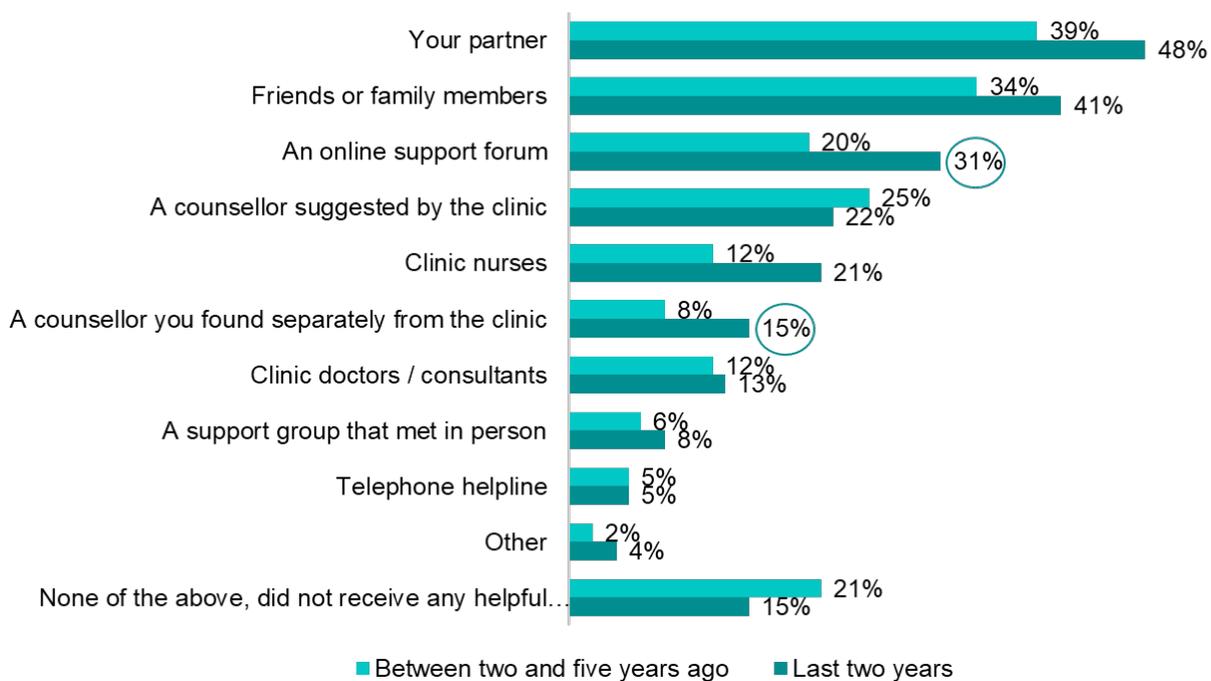
“Unfortunately afterwards, there’s not a lot of help... that’s where the hospital doesn’t come through” (focus group participant)

“At the time when you’re going through it you’re mourning... you’re not ready to pour everything out” (focus group participant)

- 4.3.6 The most helpful forms of support tend to be people that respondents already know, with 48% saying their partner was helpful, 41% friends and family and 31% an online support group.
- 4.3.7 Online support forums have become a more popular form of support over recent years, with 31% of those that have used a clinic in the past two years citing them in comparison to 20% of those who used a clinic between two and five years ago. This is in keeping with earlier findings that forums have becoming an increasing popular source of information about fertility treatment.



Figure 15: From which, if any, of the following did you or your partner receive emotional support that was helpful? Please tick all that apply.



Base: All who used a UK fertility clinic within last two years (N=637); between two and five years ago (N=295)

- 4.3.8 Those living in London and the South East were less likely than those elsewhere in the UK to say they found an online support forum helpful (25% vs. 36%) or a counsellor suggested by the clinic (15% vs. 28%).
- 4.3.9 By contrast, those living in London and the South East were more likely than those elsewhere in the UK to say they thought a counsellor they found separately from the clinic was a useful form of support (18% vs. 12%).
- 4.3.10 Patients were more likely than partners to cite friends or family members as a helpful form of support, with 47% of patients saying so in comparison with 17% of partners. They were also more likely to say that an online support forum was helpful (35% vs. 16%) with the majority of fertility forums are for those going through treatment. In contrast, partners were more likely than patients to say a telephone helpline gave them helpful support (11% vs. 4%).



- 4.3.11 Of those that said one or more of these was a helpful source of emotional support, the most helpful form of support was their partner (35%) followed by an online support forum such as a fertility Facebook group (18%) and a counsellor found independently of the clinic (11%). Individuals also experience 'informal' counselling, through clinic support staff who offer a listening ear when required.
- 4.3.12 Partners are more likely than patients to say they thought a counsellor suggested by the clinic was the most helpful source of support (15% vs. 4%).
- 4.3.13 Those who used an NHS clinic most recently were more likely than those who used a private clinic to say that clinic nurses were the most helpful support (11% vs. 2%), echoing the high praise for nurses earlier in the report.
- 4.3.14 Those that received counselling were generally satisfied. The vast majority were content with the continuity of care, with 84% saying they were satisfied about being seen by the same counsellors throughout.
- 4.3.15 A similar proportion were satisfied with how contactable the counsellors were (80%), the quality of the counselling they received (80%), how helpful they found it (77%) and the flexibility of appointments (75%).
- 4.3.16 Those who visited a clinic in the past two years were more likely than those who used one between two and five years ago to say they were satisfied with how helpful they found counselling (77% vs. 60%). However, for the other measures of satisfaction, there were not significant differences over time.



Figure 16: Thinking about the counselling you received during your most recent experience, how satisfied or dissatisfied were you with...?



Base: All those who received counselling in the past two years (N=218); between two and five years ago (N=88)

4.3.17 For each of these measures of satisfaction, there were no significant differences between those whose most recent treatment was in a private clinic, in comparison to an NHS clinic.

4.3.18 With regards to support, nurses were perceived to be the most approachable, with over three in four (78%) saying that they felt they could somewhat / to a great extent. Nurses are more naturally linked to emotional support (versus consultants – the ‘information givers’) and they are currently delivering this well. Most are able to talk to nurses about the emotional side of the experience, who provide a listening, sympathetic ear. Nurses are considered to be kind, friendly, and gentler than consultants, however, this approach can inspire false confidence at times, for example, if they have had a series of negative outcomes.



- 4.3.19 The approachability of nurses was significantly higher for those who most recently used a private clinic (83%) than an NHS clinic (69%), and for outside London and the South East (82%) as opposed to London and the South East (73%).
- 4.3.20 There is an upward trend for finding nurses approachable across the number of cycles. Those who had undergone three cycles (89%) were more likely to say so in comparison to those that had two cycles (75%) or one cycle (81%).
- 4.3.21 Doctors and consultants were seen by most to be approachable (63%). Whilst both patients and partners found nurses equally approachable, partners were more likely than patients to say they found doctors / consultants approachable (79% vs. 60%). Consultants are seen to play a very specific role in the process – as specialists they're there to provide information, context and to deliver news – they are delivering factual information first and foremost, rather than emotional support; while some individuals say that their consultants are sensitive and display emotional intelligence, the qualitative phase suggests that many find their consultants blunt or brusque in interactions (especially when delivering negative news) and often difficult to contact.
- 4.3.22 Approachability was again higher for those whose most recent treatment was in a private clinic than an NHS clinic – 68% vs. 57% respectively.
- 4.3.23 Over three in five (62%) said that reception / administrative staff were somewhat / to a great extent approachable for support, rising to 68% of private clinic users in comparison to 53% of NHS clinic users. Receptionists and other staff (e.g. nurses outside a patient's core care team) come into contact with patients during the course of their treatment, and play a key role. Patients welcome friendly and personable receptionists; receptionists making an effort to learn their (and their partners') names and talking to them while they're waiting for their appointments has a positive impact.

“The more senior the consultant, the less personable they are”

(focus group participant)



“Yes – the consultant was lovely, very supportive... considerate and compassionate in the situation. We’re still seeing consultant and nurses in treatment” (interview participant)

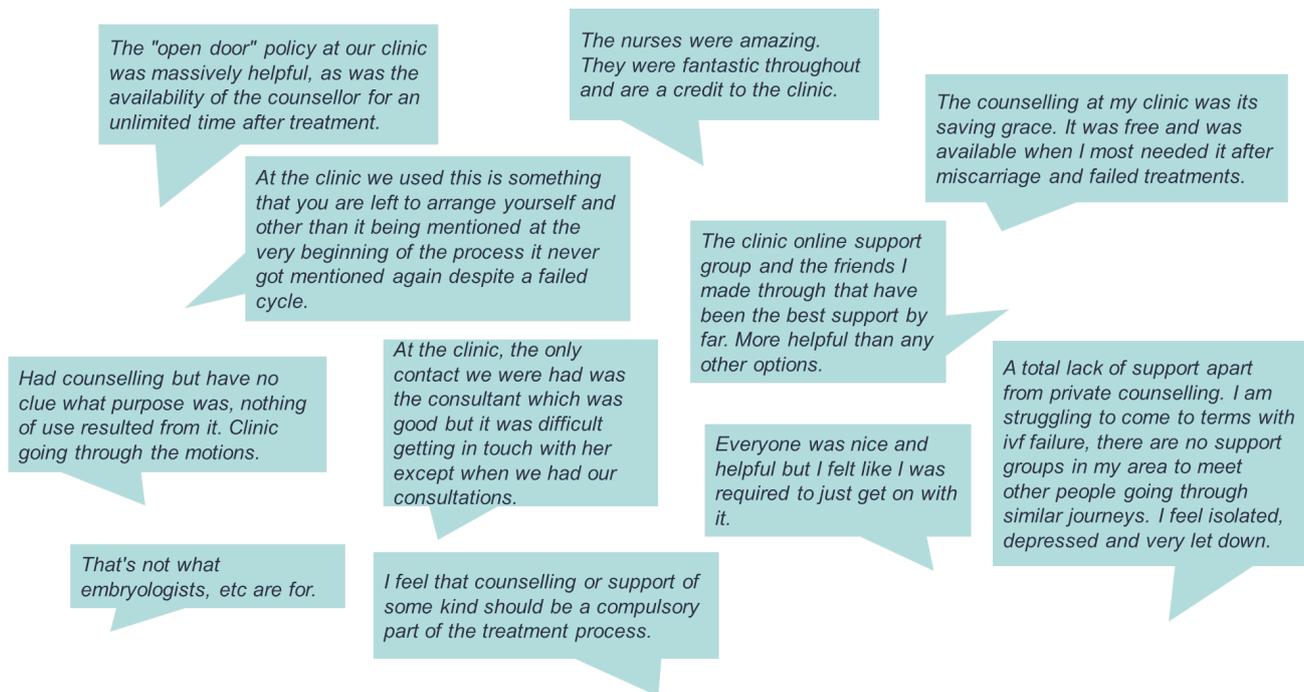
“Nurses are kind and friendly, gentle and honest” (focus group participant)

“They [receptionists] remembered me and my name. You’d see the same people each time” (focus group participant)

- 4.3.24 Embryologists were considered the least approachable (55%), with no significant differences between clinic type or partner / patient status.
- 4.3.25 The comments around counselling and support illustrate just how different experiences of counselling can be. Many praised the nurses and their experience of counselling as a whole, recognising its role in getting them through such an emotional time.
- 4.3.26 Compulsory counselling was mentioned in the qualitative phase as a necessary improvement to the fertility treatment journey. Although the current counselling experience – and desire for counselling – is mixed, there is a clear role for compulsory counselling at key points in the process. By making counselling compulsory, and offering a choice of counsellors, patients will have access to a sounding board during the most challenging times.
- 4.3.27 Others did not recognise the need for counselling, or found that it was unhelpful or difficult to organise which was off putting.

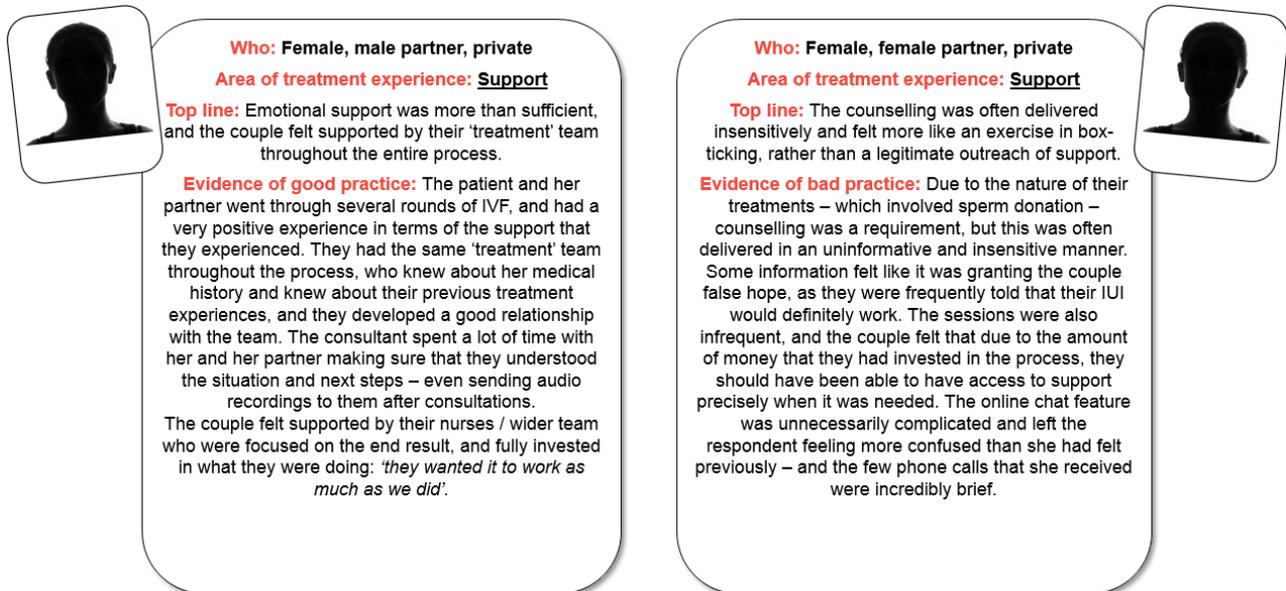


Figure 17: If you have any comments or experiences you would like to share about counselling or support please type in here.



4.3.28 Case studies illustrating both positive and negative patient experiences of support are shown below.

Figure 18: Case studies about counselling



4.4 Respect and dignity

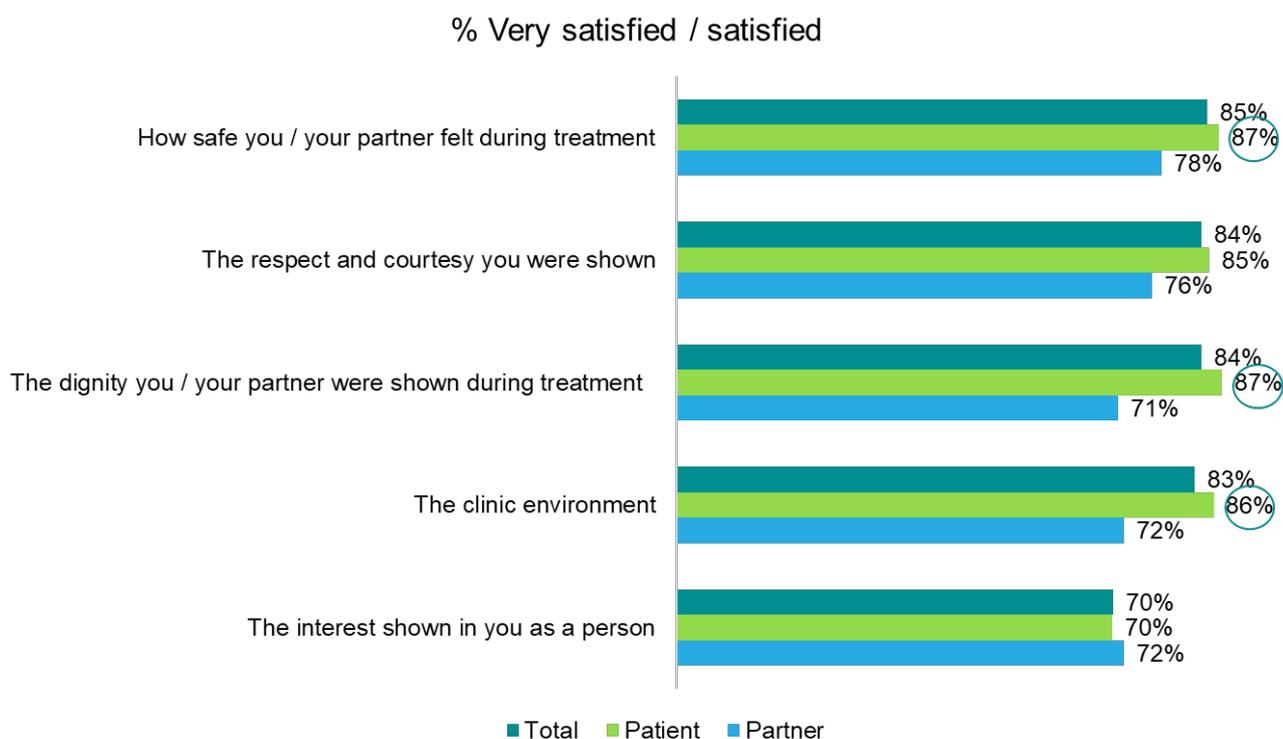
Summary of key findings

- Patients were more likely than partners to say that they felt involved and treated with respect and dignity in certain aspects of the fertility treatment process; those participating in the focus groups suggested that female partners are likely to feel more involved than male partners.
- For each of the measures of satisfaction surrounding respect and dignity, those that used a fertility clinic in the past five years have similar views to those that had it in the past two years, with no significant differences.



4.4.1 Patients were more likely than partners to say that they felt involved and treated with respect and dignity in certain aspects of the fertility treatment process. Partners tended to slightly underreport patients' satisfaction with how safe they felt during treatment; whilst 87% of patients were satisfied with how safe they felt, only 78% of partners said they were satisfied with how safe they thought their partner felt. It is positive that these figures are so high, but suggests there is still progress to be made with reassuring the partner about the process. This finding is echoed with 87% of patients saying they felt satisfied with the dignity they were shown during treatment, compared to 71% of partners when thinking about their partner.

Figure 19: How satisfied or dissatisfied were you with aspects of respect and dignity?

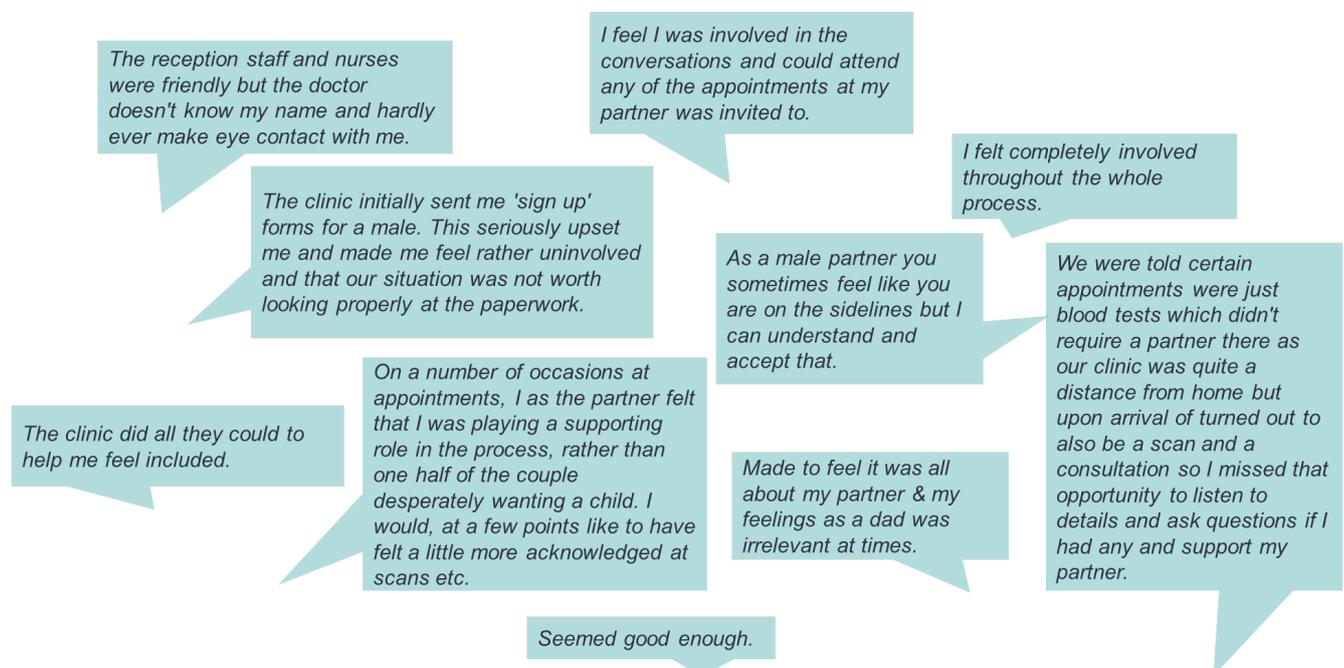


Base: All who used a UK fertility clinic within last two years (N=637).



- 4.4.2 Around eight in ten (78%) patients with partners said that they were satisfied with the extent their partner was treated as a person. This was significantly higher for those whose most recent treatment was in a private clinic (84%), in comparison to those who used an NHS clinic most recently (70%), in keeping with earlier findings.
- 4.4.3 Whilst the majority of partners were satisfied with the respect they were shown (76%) and the interest shown in them as a person (72%), some partners felt excluded and side-lined. Male partners are rarely included in conversations – few say that their partner is referred to by name or spoken to directly during consultations or addressed in letters, which shows a lack of respect; just a minority say that their partners are included. Interestingly, female partners are generally more engaged with – they often attend consultations, are called by name, and are involved at all the key points in (e.g. during egg removal / implant); however, they are more likely to be seeking out treatment in private clinics, where engagement is often higher.

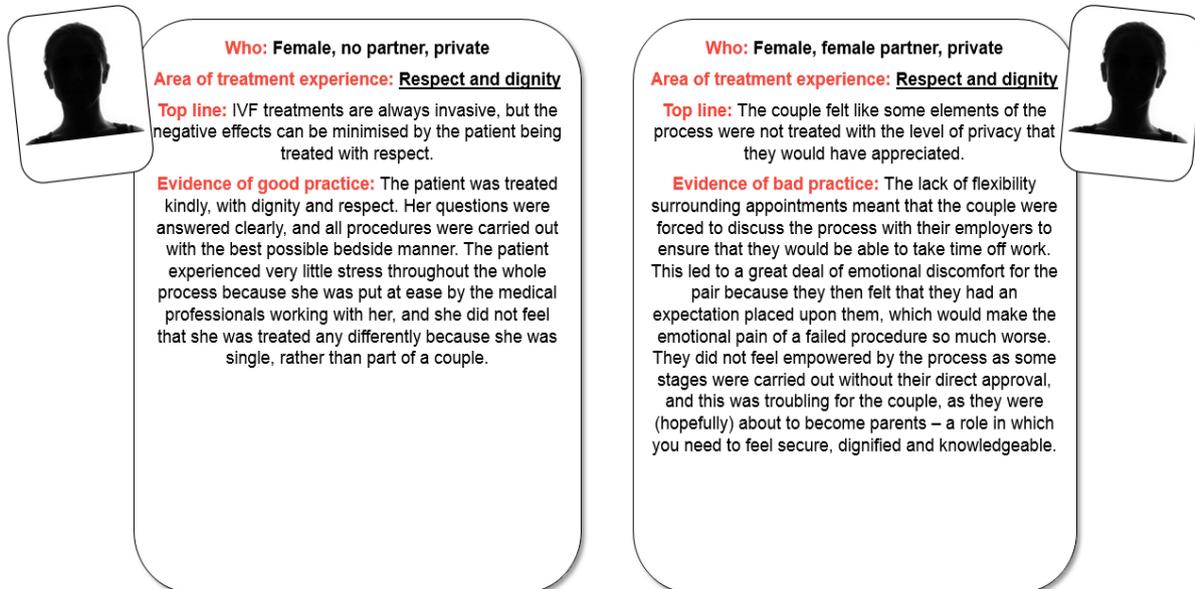
Figure 20: Thinking as a partner, how else (if at all) would you have liked to be included by the clinic?





- 4.4.4 It was clear that there are a number of points in the fertility treatment process where patients can experience indignity and a lack of respect – namely during medical procedures, and in waiting rooms.
- 4.4.5 Some feel undignified during medical procedures. They are not always acknowledged by medical staff during treatment – either ignored and overlooked, or treated like a ‘piece of meat’ – which can lead to an undignified experience. In addition, there are occasions where staff do not set expectations for medical procedures upfront, such as the need for a scan. This needs to be better communicated, so that they’re prepared for their procedure and have a chaperone if required.
- 4.4.6 Shared waiting rooms are often unpleasant and unsettling for patients. Mixing maternity and fertility patients in waiting rooms is insensitive and distasteful, particularly for those that are in hospital for important checks, or following miscarriage. Waiting room information materials such as posters of babies and mums can be seen as insensitive, and a stark reminder for those struggling to conceive.
- 4.4.7 Case studies illustrating both positive and negative patient experiences of respect and dignity are shown below.

Figure 21: Case studies on respect and dignity



4.5 Treatment add-ons

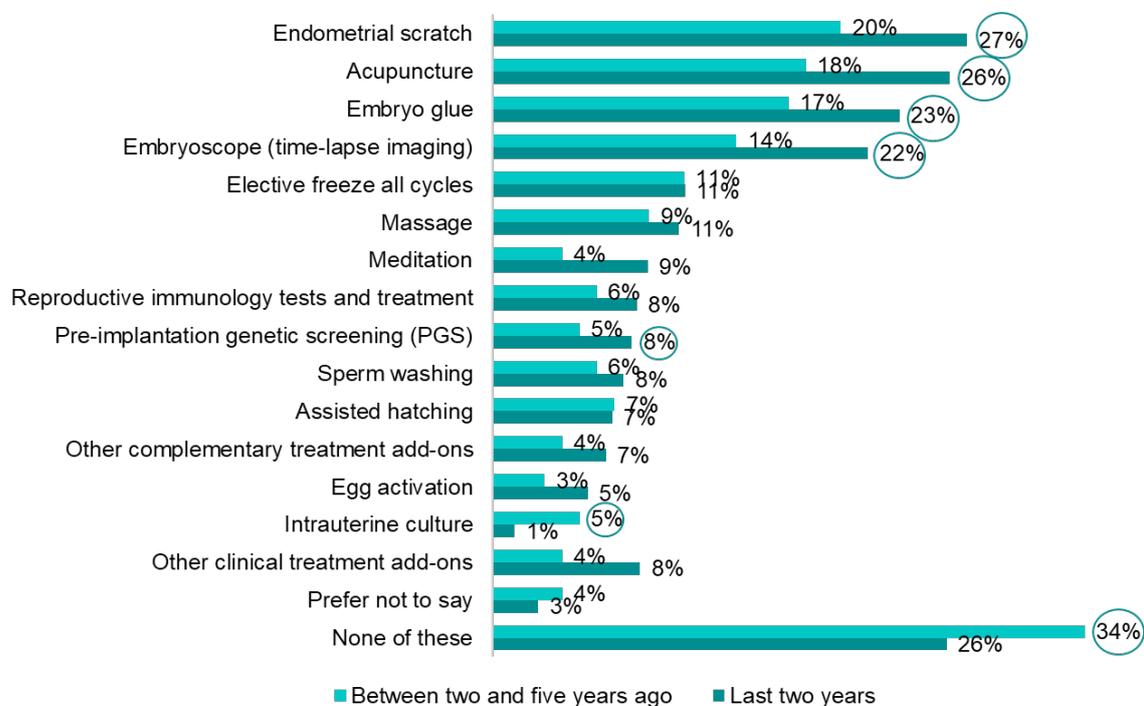
Summary of key findings

- For those that had treatment in the last two years, three quarters (74%) had at least one type of treatment add-on, similar to 71% of those in the past five years.
- The most commonly used treatment add-ons for those that used a fertility clinic in the past two years were clinical techniques, such as an endometrial scratch (27%), embryo glue (23%) or embryoscope (22%).
- For those that used a fertility clinic in the past five years, the most popular add-ons were endometrial scratch (25%), acupuncture (24%) and embryo glue (21%).



- 4.5.1 Treatment add-ons such as embryoscope and scratch and glue, are the most frequently mentioned and used. Just over a quarter of those who visited a fertility clinic within the past two years said they have ever had an endometrial scratch (27%) while just under a quarter have had embryo glue (23%) or embryoscope (22%). Holistic additional treatments are less often mentioned; over a quarter (26%) of those receiving fertility treatment in the last two year reporting having received acupuncture.
- 4.5.2 Those receiving treatment more recently reported higher levels of additional treatment use than those between two to five years ago – endometrial scratches (27% vs. 20%), acupuncture (26% vs. 18%), embryo glue (23% vs. 17%) and embryoscopes (22% vs. 14%).
- 4.5.3 In general, it is increasing common to have a treatment add-on. Three quarters (74%) of those that visited a fertility clinic in the past two years cited any of the treatment add-ons, compared to two thirds (66%) of those that had treatment between two and five years ago.

Figure 22: In relation to fertility treatment, have you / your partner had any of the following additional treatments (often known as treatment add-ons)?





Base: All who used a UK fertility clinic within last two years (N=637); between two and five years ago (N=295)

- 4.5.4 Recent fertility clinic users in London and the South East were more likely to have had Pre-implantation Genetic Screening (PGS) than those elsewhere in the UK (11% vs. 5%). Those outside London and the South East were more likely than Londoners to have used embryo glue treatment (32% vs. 13%).
- 4.5.5 Those whose most recent treatment was in an NHS clinic were more likely than private clinic users not to have used any treatment add-ons (37% vs. 19%).
- 4.5.6 Just over three quarters (77%) of fertility clinic users who used a treatment add-on were satisfied with how open and transparent the costs of these were. Those whose most recent treatment was in a private clinic were significantly more likely to be satisfied with this than those who visited an NHS clinic (81% vs. 65%). Similarly, those who used their own funding for their most recent treatment were more likely to be satisfied with cost transparency than those who used NHS funding (79% vs. 71%).

4.6 Costs of add-ons

Summary of key findings

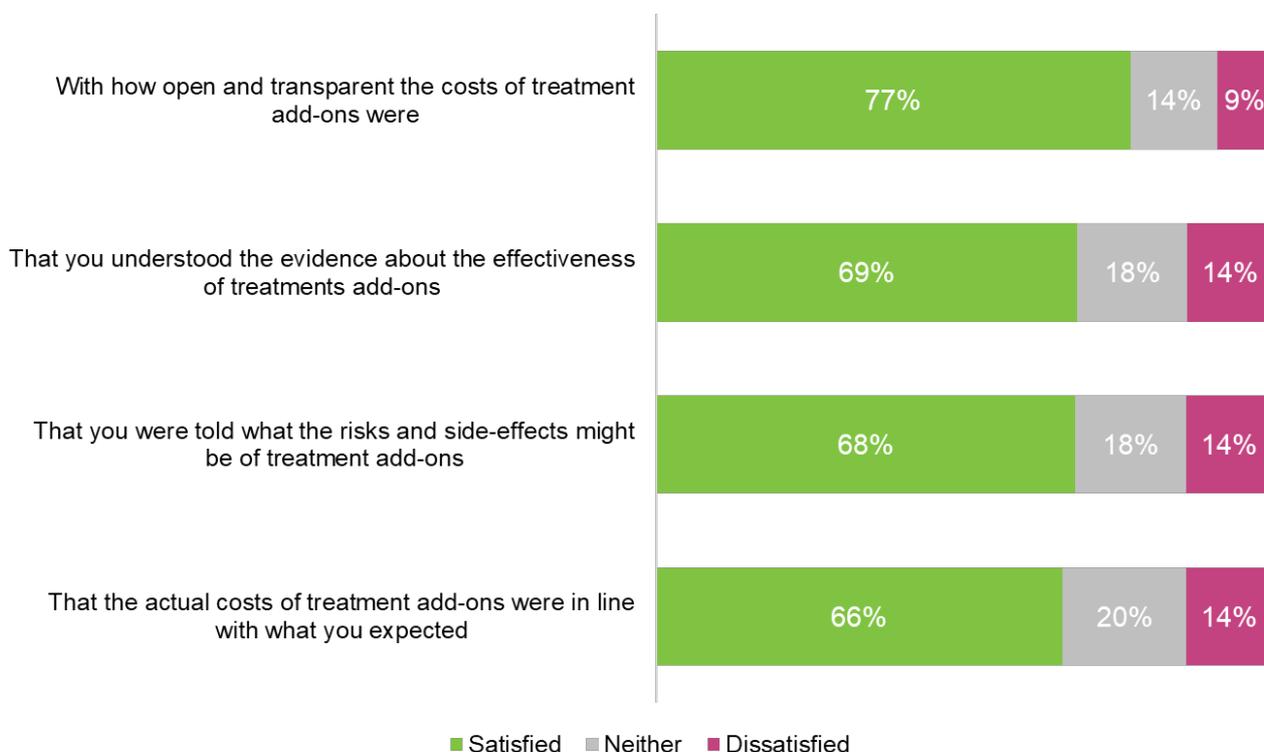
- Around four-fifths (77%) of those that had treatment in the past two years were satisfied with how open and transparent the costs of treatment add-ons were, similar to those that had treatment in the past five years (79%).

- 4.6.1 During their initial research, price information is said to be visible: most are able to locate set costs on clinic websites, allowing them to take an informed view of the options. While they recognise that advertised costs are generic, they do act as a useful starting point and help to set expectations.



4.6.2 There is an upward trend for satisfaction across the number of cycles a fertility clinic user has undergone, implying that more cycles leads to better knowledge about the costs, greater acceptance of them or ability to pay. Those who had undergone five or more treatment cycles (86%), were more likely to be satisfied with how open and transparent the costs of treatment add-ons were than those who had only been through one to two cycles (69%) or three to four cycles (83%).

Figure 23: How satisfied or dissatisfied were you with aspects of cost?



Base: All those who had additional treatments within the last two years (N=432).

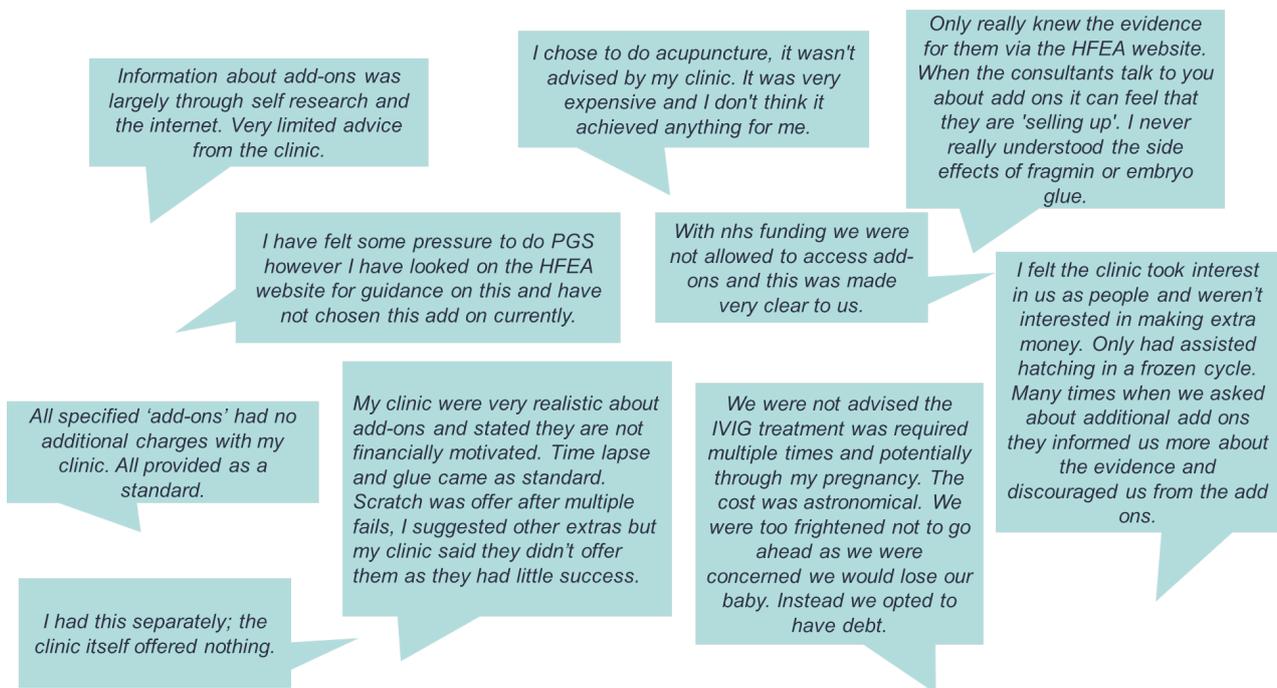
4.6.3 Over two thirds (69%) of fertility clinic users who used treatment add-ons were satisfied that they understood the evidence about the effectiveness of them. A similar proportion (68%) of fertility clinic users who had additional treatments were satisfied they were told the risks and side-effects.



- 4.6.4 Fertility clinic users in London and the South East were more likely to be dissatisfied that they understood the evidence about effectiveness than those from elsewhere in the UK (19% vs. 9%).
- 4.6.5 Two thirds (66%) of fertility clinic users were satisfied that the actual costs of treatment add-ons were in line with what they expected. While different clinics offer different costs / inclusions, they do inform patients about the core costs upfront. Some elements (e.g. extra drugs, scratch and glue) fall outside of core costs, but they are not felt to be prohibitive for most. At the end of treatment patients receive itemised bills, with a breakdown of key elements, which aids transparency.
- 4.6.6 Those whose most recent treatment was in a private clinic were significantly more likely than NHS clinic users to be satisfied that costs were in line with their expectations (69% vs. 55%).
- 4.6.7 Consistent with the satisfaction around cost transparency, those who had been through five or more treatment cycles were significantly more likely to be satisfied that the costs were as they expected (81%) than those who had only been through one or two cycles of treatment (57%).
- 4.6.8 While many were satisfied with their use of treatment add-ons, when asked for further comments, many explained that their choices were informed by independent research rather than clinical advice. Where clinics did offer advice, many found it realistic and helpful about offering evidence and success rates. Respondents in the qualitative phase said that although they were informed of treatment add-ons over the course of their treatment, it was often in later rounds of treatment (or in their final round) that they'd that look engage with these fully – in a final bid to get pregnant.
- 4.6.9 Some felt pressure or that they were being 'upsold' additional treatments, with negative financial and emotional implications, but these comments were rarer.



Figure 24: If you have any comments or experiences you would like to share about treatment add-ons please type in here.

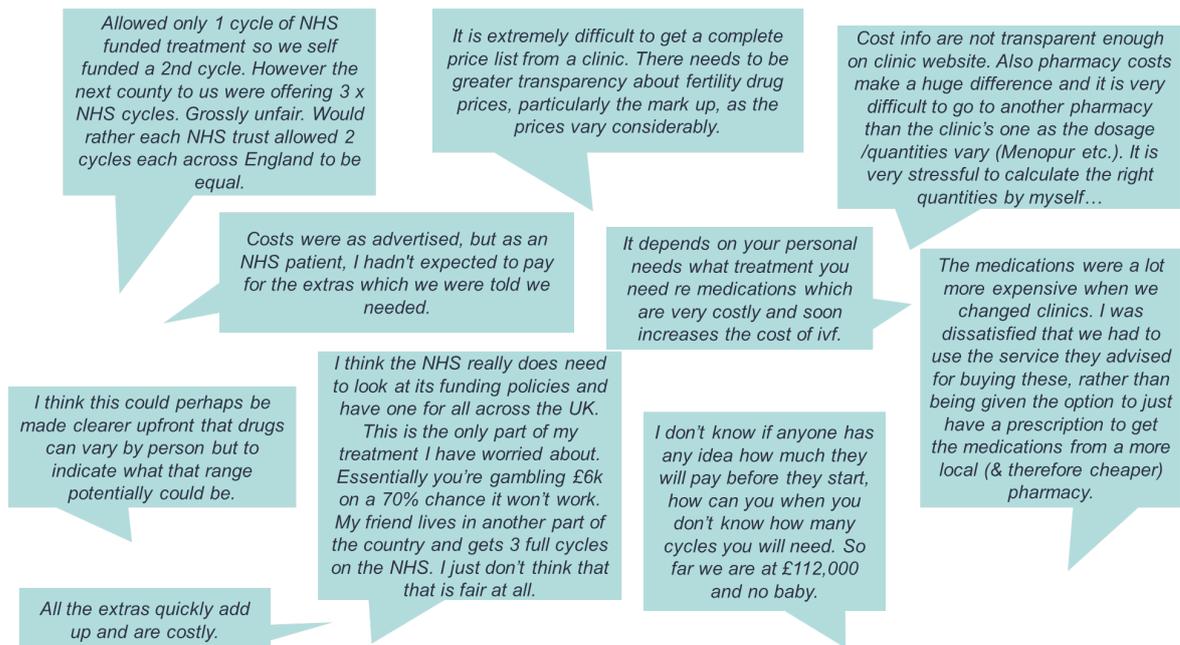


4.6.10 Of those who self-funded their fertility treatments or used treatment add-ons, half (50%) said they ended up paying more than they originally expected. Around a third (32%) said the cost was about the same as their first expectations. From the qualitative phase, just a small number said that they paid more than expected. For these respondents, it was mostly due to the costs of fertility drugs (to stimulate egg growth). While doctors could give an estimate of the cost of drugs involved prior to treatment, it was only when treatment was underway that they could provide a more accurate costs. Those that needed to use more fertility drugs than expected had to pay more as a result.



- 4.6.11 Just over three fifths (62%) of those whose most recent treatment was at a private clinic said they paid more than they expected to, compared to less than a quarter (23%) of those who visited an NHS clinic. A similar proportion (60%) of those who used their own or private funding for the most recent treatment ended up paying more than expected, while only a quarter (24%) of those whose treatment was entirely or partly NHS funded said the same.
- 4.6.12 Over three in five (63%) fertility clinic users who had undergone five or more cycles of treatment said they ended up paying more than they expected when they started, with almost a quarter (23%) saying the cost was a lot more than expected.
- 4.6.13 Many of those who self-funded their fertility treatments or used treatment add-ons spoke about the unpredictability of costs – from not knowing how many cycles of fertility treatments are required in order to be successful, what additional treatments are needed, or how medications vary from person to person.
- 4.6.14 In terms of medication, respondents expressed frustration with having to use clinics' associated services rather than having a standard prescription that could be fulfilled at any pharmacy. Additionally, the variation in personal medication needs makes an impact on cost which respondents found hard to predict beforehand.
- 4.6.15 At an overall level, respondents expressed frustration with the varying levels of costs covered by the NHS. With Clinical Commissioning Groups (CCGs) having individual eligibility criteria to fulfil, respondents who paid for their own treatment / who had additional treatments felt the system is unfair.

Figure 25: If you have any comments of experiences you would like to share about costs in general, which may or may not include how they compared to those advertised on clinic websites, please type in here?



4.7 Overall satisfaction with fertility treatment

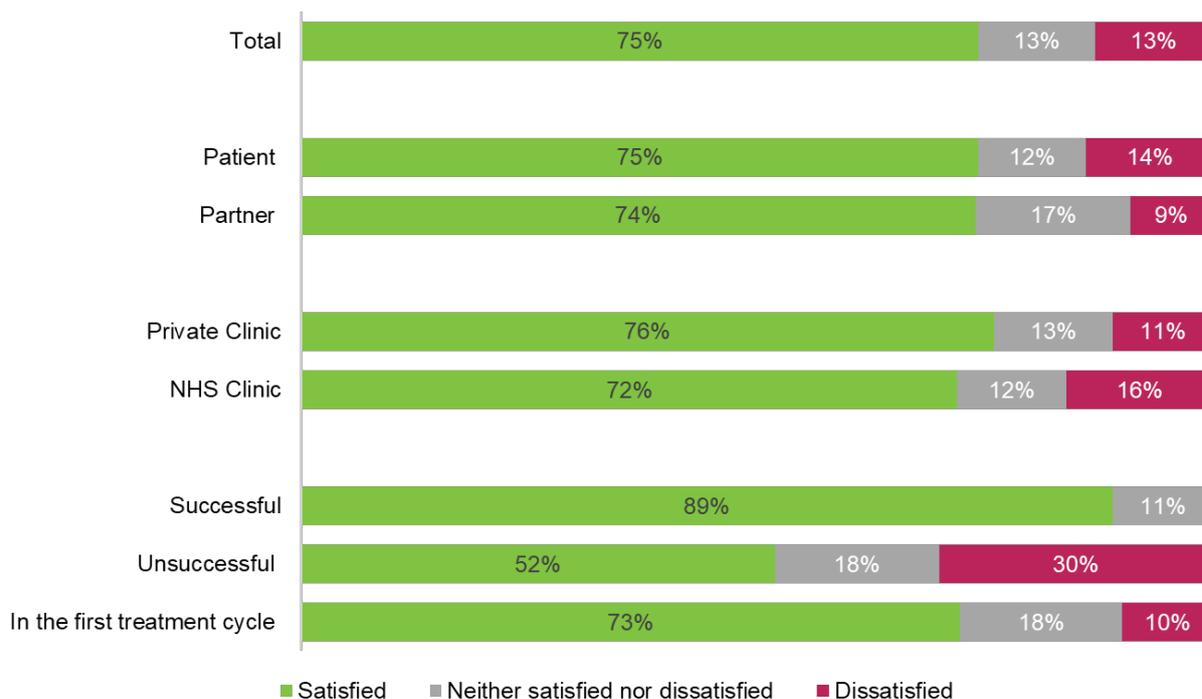
Summary of key findings

- For those that used a fertility clinic in the last two years, three in four (75%) say they were satisfied with the treatment overall.
- This is similar for those that used a fertility clinic in the last five years, with 74% saying they were satisfied with the treatment overall.

4.7.1 When thinking about their most recent fertility treatment as a whole, three in four (75%) of those that had treatment in the past two years say they were satisfied. Around one in eight (13%) were neither satisfied nor dissatisfied, and an equal number said they were dissatisfied.



Figure 26: Overall, how satisfied/dissatisfied were you with the most recent fertility treatment you had?



Base: All who used a UK fertility clinic within last two years (N=637)

- 4.7.2 Although earlier findings suggest that there are differences in satisfaction levels between those whose most recent treatment was in a private clinic and those who used an NHS clinic, this did not necessarily contribute to how they felt about the treatment overall. A similar proportion said they were satisfied, 76% of those who most recently used a private clinic and 72% of NHS clinic users.
- 4.7.3 There are also no significant differences in overall satisfaction between patients (75%) and partners (74%), nor between those that had undergone more or less cycles.
- 4.7.4 The outcome plays a role in determining overall satisfaction. Around nine in ten (89%) of those that were successful in treatment in the past two years say they are satisfied overall, with no one saying that they were dissatisfied.



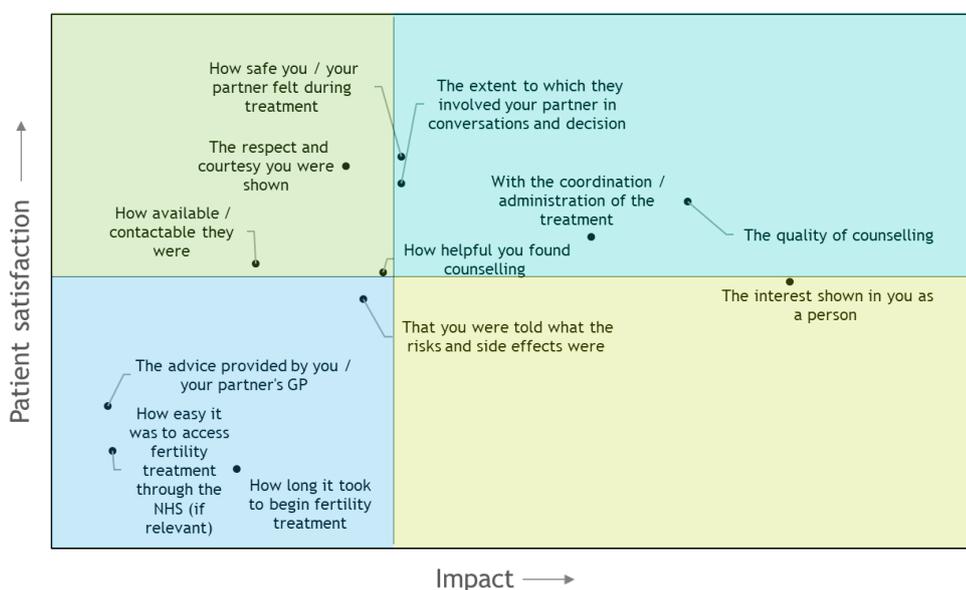
4.7.5 For those that were unsuccessful, three in ten (30%) say that they were dissatisfied. Yet even for those who were ultimately unsuccessful, for over half (52%), their view of the overall process was predominantly positive.

Key driver analysis

4.7.6 Key driver analysis is a statistical technique that identifies the impact that individual aspects of service have on a patient’s overall satisfaction. If we then plot the impact that each aspects has on overall satisfaction against the satisfaction rating for that aspect we can see that lower rated aspects with high impact are the most likely candidates for areas of improvement.

4.7.7 The first key driver model is the overall model, which includes all drivers of satisfaction. Twelve aspects of satisfaction sit within the model with an r squared value of (.40).

Figure 27: Key Driver Analysis: Model 1



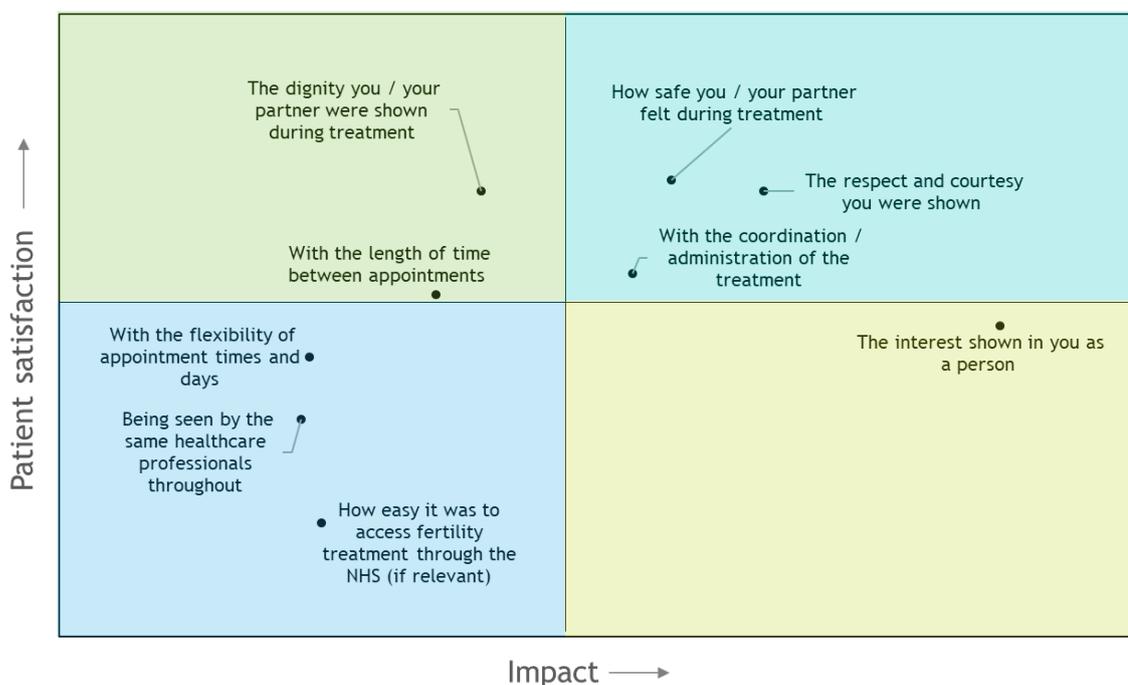
r squared value (0.43)



- 4.7.8 This model shows that the main drivers of satisfaction are the “interest shown in you as a person”, the quality of counselling and the coordination and administration of treatment. Relative to other high importance measures, the interest shown in you as a person is not highly rated.
- 4.7.9 Although slightly better performing measures of patient satisfaction, there is also room to improve the quality of counselling and the coordination and administration of treatment; in comparison to feeling safe during treatment and being involved in conversations and decisions, patients report lower levels of satisfaction.
- 4.7.10 The advice provided by GPs and the ease of access to fertility treatment are the lowest performing measures for patient satisfaction, however they do not have a significant impact on overall satisfaction perhaps because they are a short stage in the early part of the patient journey.
- 4.7.11 A limitation of this model at an overall level is that although the quality of counselling came out as the second most important driver of overall satisfaction, only one in five (20%) received it. Hence we created a second model which focuses on measures of satisfaction that are relevant to all fertility clinic users.



Figure 28: Key Driver Analysis: Model 2



r squared value (0.41)

4.7.12 As in the first model, the “interest shown in you as a person” comes out as top driver of overall satisfaction and the ease of accessing fertility treatment through the NHS one of the least important drivers.

4.7.13 The subsequent most important drivers are the respect and courtesy patients are shown and how safe they felt during treatment. These also have relatively high levels of patient satisfaction hence it is important to maintain these.



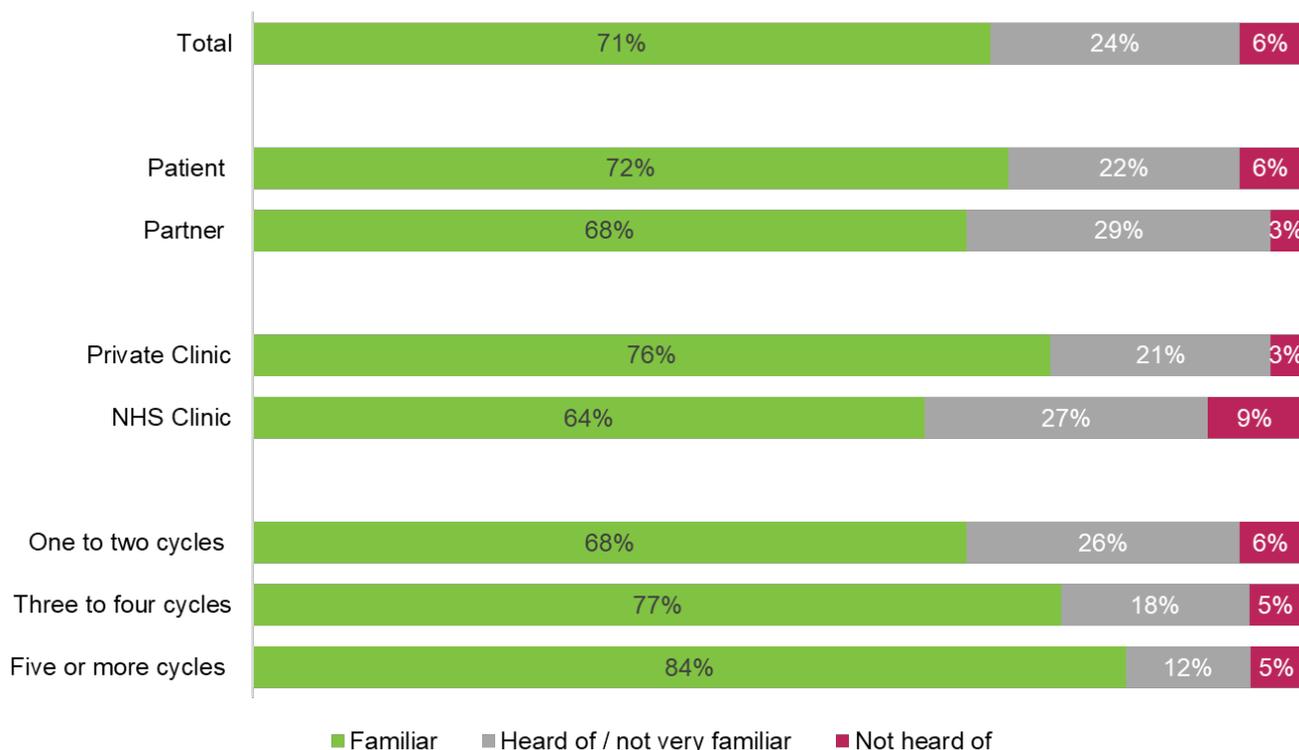
5 Knowledge of the HFEA

Summary of key findings

- Over two thirds (68%) of those that used a fertility clinic in the past five years say they were familiar with the HFEA before the survey.
- This has significantly increased to 71% of those that used a clinic in the last two years.

5.1.1 Around seven in ten (71%) of those that have had treatment in the past two years say they are very or quite familiar with the HFEA, significantly higher than for those who had treatment between two and five years ago.

Figure 29: Before this survey, how familiar were you with the Human Fertilisation and Embryology Authority (HFEA)?



Base: All who used a UK fertility clinic within last two years (N=637).



6 Recommendations

- An initial challenge is getting into the system itself. GPs play a key role in granting access to NHS funding and offering advice / guidance on accessing treatment, but of those that spoke to a GP, a quarter (25%) were dissatisfied with the advice provided. There is a need to improve the support for patients at this stage.
- Although the majority (82%) of those that visited a fertility clinic in the past two years felt comfortable asking questions, in the moment it can be hard to process information received during consultations. There is a desire for doctors' notes / audio recordings of the consultation to be shared post-consultation, wherever possible.
- While patients are not always actively involved in the treatment decision making process (and do not always want / need to be), it is important that they know about the range of options available to them upfront; transparency here is key.
- Throughout the process, information is available (whether formal documents or informal emails / phone contact), but the level of detail of them is varied. One in five (19%) feel there is too little treatment planning detail.
- Counselling is inconsistent as it stands – whilst three in four (75%) of fertility clinic users within the last two years say they were given information about it, one in five (20%) were not. There is a demand for a more robust offering, with one to one counselling, a degree of choice and availability at key points in the journey such as when treatment is not going to plan.
- Small changes could have a positive impact on the dignity / respect experienced by patients. Focusing on treatment and waiting areas, and better involving partners would be very positively received. As highlighted in the key driver analysis, the respect and courtesy patients are shown is a main driver of overall



satisfaction, therefore it is important to maintain high levels of patient satisfaction.

- In both key driver models, the interest shown in you as a person is shown to be the main driver of overall satisfaction. However, relative to other measures it is not as highly rated, suggesting that this is a key area to focus on. Improving satisfaction for this measure is likely to have the greatest impact on overall satisfaction with fertility treatment as a whole.
- Although not many receive counselling, for those that do the key driver analysis shows that the quality of that counselling is a significant factor in their overall experience of fertility treatment. This serves to highlight the impact that counselling can have and 80% are satisfied with the quality of counselling when received.



Appendix A: Breakdown of responses

Most recent treatment (timeframe)	Percentage	Count
Currently or in the last two years	63%	637
Between two and five years ago	29%	295
Between six and ten years ago	6%	57
More than 10 years ago	3%	28

Treatment type	Percentage	Count
IVF (In Vitro Fertilisation)	76%	773
DI (Donor Insemination)	6%	62
IUI (Intrauterine Insemination)	8%	84
Fertility preservation	4%	43

Partner / patient status	Percentage	Count
A woman receiving treatment with a male partner	63%	637
A man supporting a female partner	18%	178
A woman without a partner	8%	77
A woman receiving treatment with a female partner	1%	54
A woman supporting a female partner	2%	12
Other (receiving treatment)	2%	17
Other (partner)	4%	42



Age	Percentage	Count
Under 35	42%	430
35 to 37	25%	257
38 to 42	25%	256
Over 42	7%	68

Region	Percentage	Count
East Midlands	6%	59
East of England	5%	52
London	25%	250
North East England	5%	50
North West England	10%	103
Northern Ireland	3%	27
Scotland	8%	81
South East England	11%	107
South West England	9%	95
Wales	3%	29
West Midlands	8%	79
Yorkshire and the Humber	8%	78
Prefer not to say	1%	7



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